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Feasibility and acceptability of a multi-components intervention (PDConnect) to support physical activity in people living with Parkinson's: a mixed methods study.

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Julie Claire Jones

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A thesis submitted in partial fulfilment of the requirements of Robert Gordon University for the degree of Doctor of Philosophy

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ABSTRACT

Author: Julie Claire Jones

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Thesis Title

Feasibility and acceptability of a multi-component intervention (PDConnect) to support physical activity in people living with Parkinson's: a mixed methods study.

Introduction

The benefits of physical activity (PA) for people with Parkinson’s are widely acknowledged. To date research has focussed on the effectiveness of PA interventions, with limited research exploring the optimum means of supporting people living with Parkinson’s to change their PA behaviour.

Literature review

A narrative review was undertaken to provide context and underpin the development of a multi-component PA intervention (PDConnect) for people with Parkinson’s. PDConnect combines specialist Physiotherapy, group-based PA, and self-management with the aim of promoting increased PA and PA self-management. This study was undertaken to determine the feasibility and acceptability of the PDConnect intervention.

Methodology and methods

This study adopted a Pragmatist worldview and employed mixed methods. A convergent sequential mixed methods design was adopted and delivered online via Microsoft Teams. A convenience sample of 31 people with Parkinson’s were recruited and randomised into two groups: (i) the usual care group received standard Physiotherapy once a week for six-weeks. (ii) the PDConnect group received Physiotherapy once a week for six weeks which combined PA, education and behaviour change interventions delivered by a Parkinson’s specialist Physiotherapist. This was followed by 12 weekly sessions of group-based PA by a Fitness Instructor specially trained in Parkinson’s. Participants were then contacted by the Fitness Instructor once a month for three months to support PA engagement. Primary feasibility data was collected during the study, with acceptability assessed via semi-structured interviews. Secondary outcomes encompassing motor, non-motor, PA, and health and well-being measures were assessed at baseline, and at six, 18, and 30 weeks.

Results

PDConnect was shown to be feasible and safe. The sample was recruited in 12 weeks, and the retention rate was 74%. Outcome measure response and activity diary return rate was high (>95%, 84%respectively). PDConnect attendance was high: 100% for the Physiotherapy component and 83% for the group-based exercise component. Participants were very satisfied with PDConnect and perceived that participation increased exercise confidence and knowledge and understanding of Parkinson’s. Participation positively impacted Parkinson’s symptoms, with perceived improvements in flexibility, muscle strength, PA levels, and endurance. Fifty percent of participants receiving PDConnect reported that they were much improved compared to 10% in the usual care group. PDConnect study resources were deemed acceptable. Intervention fidelity was high, with 89% of the Physiotherapy and 88% of the group-based exercise delivered as planned. All progression criteria were met, except for participant retention which fell one percent below the a priori criterion.

Conclusions

PDConnect is feasible to deliver and rated as highly acceptable among people with Parkinson’s. A large-scale trial is required to fully evaluate the effectiveness of PDConnect.

Recommendations

Sampling within a future trial needs to include under-represented groups and broader cultural and ethical diversity. In addition, appropriate funding is required to minimise digital exclusion and optimise digital literacy. Minor modifications to the participant manual to support personalisation, and further consideration of type of PA monitor is also recommended. Further consultation with the Parkinson’s community is required to guide how to optimise social connection when delivering PA online and to inform the selection of future outcome measures.

Key Words:
Parkinson’s, physical activity, behaviour change, self-management, education, feasibility, and acceptability.

PUBLICATIONS AND PRESENTATIONS

Publications arising from this Thesis.

- JONES, J., et al. 2022. The development of a complex intervention to support exercise self-management for people with Parkinson's. *Physiotherapy*. 114:e199-e200.
- JONES, J., et al. 2021. A collaborative approach to exercise provision for people with Parkinson's: a feasibility and acceptability study of the PDConnect programme. *AMRC Open Research UK*. 2:29.

Conference presentations arising from this Thesis

- JONES, J. 2022. The Importance of Exercise for People with Parkinson's: Evidence, Empowerment and Enablement. Edinburgh Parkinson's Lecture. Royal College of Physicians, Edinburgh. (Oral presentation)
- JONES, J., et al. 2022. Feasibility and acceptability of PDConnect: a collaborative approach to physical activity for people with Parkinson's. Movement Disorders Society Conference, Madrid.
- JONES, J., et al. 2021. Development of a complex intervention to support exercise self-management for people with Parkinson's. Physiotherapy UK (Virtual Poster presentation)
- JONES, J., 2020. Development and delivery of the PDConnect study. Parkinson's Excellence Network Conference. Royal College of Physicians, Edinburgh. (Oral presentation)

Planned Publications arising from this Thesis:

The following manuscripts will be submitted to peer-review journals:

- Feasibility and acceptability of a multi-component intervention (PDConnect) to support physical activity in people living with Parkinson's: a mixed methods study.
- Barriers and motivators to online delivery of Physical Activity among people living with Parkinson's.
- Telehealth: challenges and opportunities for Physiotherapists
- Opinion paper: measurement and monitoring of Physical Activity: what should we be measuring?

Associated Publications during Fellowship

- ALUSHI et al., 2022. A Systematic Review on Physical Health Education Interventions for People with Parkinson’s Disease: Content, Impact, and Implementation Considerations Across the Parkinson’s Trajectory. *Journal of Parkinson's Disease.* 1389-1407.

- JONES, J., BAKER, K., and RAMASWANY, B. 2022. Physical activity and exercise for people with Parkinson’s. *Advances in Clinical Neuroscience Rehabilitation*.

- RAMASWAMY, B., BAKER, K., and JONES, J. 2021. Chapter 11: Exercise for Parkinson’s. In Parkinson's Disease: A multidisciplinary guide to management. Editor: Skelly, R., and Lindop, F. 1st Edition. Elsevier. 2021. ISBN: 9780702082610

- OLIVER, B., and JONES, J. 2021. Exercise and Parkinson’s update: are your patients getting the right dose? *PhysioFirst.* 174, pp. 4-12

- RAMASWAMY, B., et al., 2020. Methodology for exercise resources development for professional providing services for people with Parkinson’s: a technical report. *Physiotherapy*. 112, pp. 49-54.

ABBREVIATIONS

PA	Physical Activity
PLwP	People living with Parkinson’s
QoL	Quality of life
NMS	Non-motor symptoms
ADLs	Activities of daily living
WHO	World Health Organisation
NICE	National Institute of Health and Care Excellence
CSP	Chartered Society of Physiotherapy
AHP	Allied Health Professional
ACSM	American College of Sports Medicine

CHAPTER ONE – INTRODUCTION

1.1 CHAPTER OVERVIEW

This introductory chapter will provide an overview of Parkinson’s in relation to the epidemiology, aetiology, pathophysiology, symptoms, and the impact of living with Parkinson’s. This chapter will also explore the current medical and non-medical management of Parkinson’s including Physiotherapy and physical activity (PA). An overview of the PA habits of people living with Parkinson’s (PLwP) will be discussed, and the benefits of PA for PLwP will also be explored to provide context for the research and development of the research questions.

1.2 EPIDEMIOLOGY OF PARKINSON’S

Parkinson’s is the second most common neurodegenerative condition after Alzheimer’s (Pringsheim et al. 2014). The prevalence of Parkinson's is anticipated to rise by 50% in the next two decades, with global prevalence estimated to exceed 12 million by 2040, making Parkinson’s the fastest growing neurodegenerative condition worldwide (Dorsey et al. 2018a). The exponential rise in Parkinson’s is attributed in part to increased life expectancy, as prevalence of Parkinson’s increases with age (Pagano et al. 2016). Among 30 to 39-year-olds, prevalence of Parkinson’s is four to five per 100,000, however, this rises to 1,696 per 100,000 in those aged between 80 and 84 years (National Institute for Health and Care Excellence, [NICE] 2017). The life-time risk of developing Parkinson’s is estimated as one in 15 (Wanneveich et al. 2018), with 6.2 million people currently living with Parkinson’s globally (Dorsey et al. 2018). The global spread and burden associated with Parkinson's highlights the need for effective management approaches.

The risk of developing Parkinson’s is one and a half times higher among men than women (Wooten 2004). The experience of living with Parkinson’s differs between males and females. Males experience greater disability for longer (Deuschl et al. 2020), while the age of onset is typically older among females, females experience greater depression (Yoon et al. 2017) motor fluctuations and movement complications such as dyskinesia (Picillo et al. 2017). Parkinson’s is not limited by geography or socio-economic status, therefore with a growing ageing population, the burden of Parkinson's is predicted to rise substantially in future decades (Wanneveich et al. 2018). The escalation of the Parkinson’s population highlights the need for effective healthcare interventions to support PLwP to lead meaningful lives.

Living with Parkinson’s is associated with an increased personal and societal financial burden, (Gumber 2017). The annual cost to society has been reported to exceed £20,000 per PLwP per annum, with the global burden of Parkinson’s in terms of deaths and disability doubling in the last twenty years (Deuschl et al. 2020). Combining the increased global burden with the anticipated doubling of the number of PLwP by 2065, highlights a significant public health challenge and the urgent need for effective and sustainable management approaches for PLwP.

1.3 AETIOLOGY AND PATHOPHYSIOLOGY OF PARKINSON’S

The exact cause of Parkinson’s remains unknown. Increased age, lifestyle and a complex interaction of environmental and genetic factors are commonly implicated (Kalia and Lang 2015). Parkinson’s is characterised by the loss of dopaminergic neurones within the Substantia Nigra Pars Compacta, which is in the mid-brain. These dopaminergic neurones project to the Striatum, and their progressive loss results in a decrease in activity of the Nigrostriatal circuits leading to increased inhibition of the Basal Ganglia. Ultimately, this leads to a decrease, or poverty of movement, which is synonymous with Parkinson’s. The exact mechanism precipitating neuronal loss in Parkinson’s is unknown, however α-synuclein aggregation, dysfunction of mitochondria, lysosomes or vesicle transport, synaptic transport issues, and neuroinflammation are commonly cited (Kalia and Lang, 2015). Individually and cumulatively, these factors affect the integrity of individual and neighbouring neurons, causing accelerated neuronal loss. As illustrated in Figure 1.1 Braak et al. (2003) proposed that Parkinson’s commences in the Brainstem, before progressing through the Medulla, Midbrain, Forebrain and ultimately reaching the Cerebral Cortex giving rise to a wide symptom profile. Consequently, Parkinson’s is now recognised as a broad multi-system condition encompassing over 40 motor and non-motor symptoms (Chaudhuri and Naidu 2008).

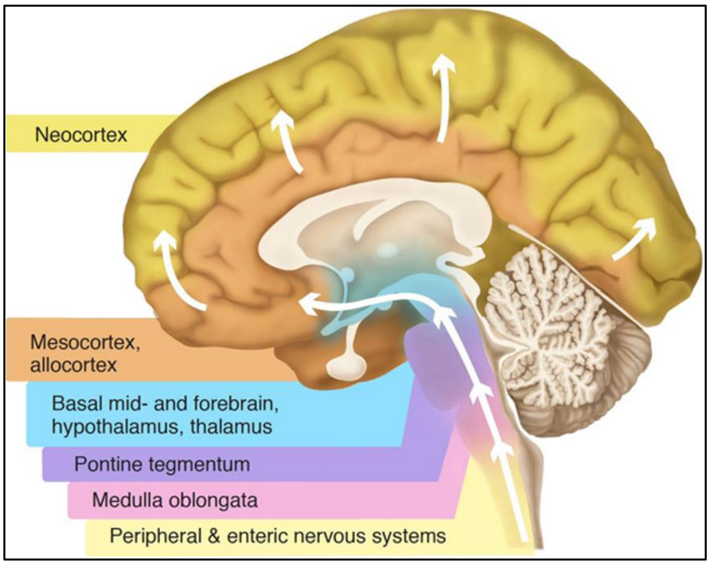


Figure 1.1 Illustration of progression of Parkinson's as proposed by Braak et al (2003)

Image used with kind Permission of Professor Anthony Lang.

1.3.1 Parkinson's motor symptoms

No definitive test for Parkinson's exists, therefore diagnosis is based on clinical criteria (Jankovic 2008). The Movement Disorders Societies clinical diagnostic criteria is based on the presence of bradykinesia. Bradykinesia is a slowness of movement combined with a reduction in frequency, or amplitude of movement in combination with either resting tremor, or rigidity, or both (Postuma et al. 2015). Other criteria, such as the UK Brain Bank Criteria also includes postural instability, not caused by primary visual, vestibular, cerebellar, or proprioceptive dysfunction as a cardinal symptom (Gibb and Lees 1988).

Bradykinesia arises due to the loss of dopamine within the Striatum, causing an imbalance between the direct and the indirect pathways through the Basal Ganglia. Normally, balance exists between the direct pathway which facilitates movement, and the indirect pathway which inhibits movement. In Parkinson's, the indirect pathway is hyperactive resulting in inhibition of voluntary movement. Bradykinesia typically manifests during functional tasks such as gait, causing a slow shuffling gait pattern and loss of arm swing (Morris et al. 1994). Progressive bradykinesia promotes muscle shortening, and reduced muscle strength and power (Paul et al. 2012).

Rigidity is characterised by increased muscle tone at rest. Lead-pipe rigidity presents as hypertonicity which can be felt throughout the range of motion (Xia et al. 2011). When combined with tremor, rigidity presents as cogwheel-rigidity (Rodriguez-Oroz et al. 2009) resulting in a jerky quality of movement. The underlying mechanisms of rigidity are poorly understood, but typically rigidity commences unilaterally affecting the limbs, spine, and face, before becoming bilateral over time. Long-term rigidity is associated with loss of range of motion, muscle strength, pain, and postural abnormalities (Jankovic et al. 2008), which negatively impacts on PA.

The underlying mechanism of Parkinson's resting tremor remains largely unknown. Parkinson's symptoms culminate in reduced socialisation, and subsequently QoL (Appleman, Stavitsky and Cronin-Golomb 2011; Hechtner et al. 2014; van Uem et al. 2018). The long-term sequela being that the body becomes deconditioned not only because of Parkinson's, but also due to inactivity. Supporting PLwP to be more active to this break this vicious cycle of decline, and deconditioning would seem both logical and pragmatic.

1.3.2 Parkinson's non-motor symptoms

Historically, Parkinson's was regarded solely as a movement disorder (Poewe 2009), however, non-motor symptoms (NMS) are now widely recognised as integral to Parkinson's. Parkinson's NMS are summarised in table 1.1, and include autonomic dysfunction, sleep disorders, cognitive decline, and neuropsychiatric symptoms (Martinez-Martin et al. 2011a). The onset of NMS pre-date motor symptoms (Fereshtehnejad et al. 2019) and progress with increasing age and condition duration (Siciliano et al. 2018). Non-motor symptoms are perceived to be more debilitating (Politis et al. 2010) and are associated with reduced QoL (Santos García et al. 2019), with the majority of NMS responding poorly to medication (Amara and Memon 2018).

Cognitive impairment is cited as the most frequent and disabling NMS (Fang et al. 2020) and is associated with reduced QoL (Lawson et al. 2016). At diagnosis a fifth of PLwP have mild cognitive impairment, with a quarter developing cognitive impairment over time (Aarsland et al. 2017). Cognitive impairment commonly results in executive dysfunction, affecting integration of sensory information and motor planning, required for maintaining balance during functional task such as walking. Cognitive impairment has been associated with postural instability, gait variability, increased falls risk (Rochester et al. 2014), and physical inactivity (David et al. 2015). Improved executive function, memory, and global cognitive function are higher among PLwP who are more active, suggesting that the benefit of PA is not restricted to physical function, but extends into cognition, further highlighting the need to support PLwP to be more active.

Table 1.1 Parkinson’s non-motor symptoms

Autonomic Dysfunction
Cardiovascular dysfunction: Postural hypotension and increased resting heart rate Gastrointestinal dysfunction: Sialorrhea, dysphagia, impaired gastric motility, constipation, and bowel incontinence Urinary dysfunction: Nocturia and increased urgency and frequency of micturition
Cognitive Dysfunction
Reduced executive dysfunction, bradyphrenia, memory deficits, language impairment, reduced visuospatial and visuo-constructive abilities, and mild cognitive impairment
Sleep Disorders
Sleep fragmentation, insomnia, rapid eye movement sleep behaviour disorder, excessive daytime sleepiness, periodic limb movements of sleep, and circadian rhythm dysregulation
Neuropsychiatric Disorders
Depression, anxiety, apathy, and psychosis

Depression is common from diagnosis (Schrag et al. 2015) and increases with Parkinson’s duration (van der Hoek et al. 2011). Prevalence of depression in Parkinson’s varies between 30 (van der Hoek et al. 2011) and 50% (Reijnders et al. 2008; Dissanayaka, Torbey and Pachana 2015), with similar findings reported for apathy (den Brok et al. 2015), anxiety (Broen et al. 2016; Dissanayaka, Torbey and Pachana 2015) and fatigue (Siciliano et al. 2018). High levels of depression among PLwP are associated with reduced PA (van Uem et al. 2018), while apathy and fatigue are commonly cited barriers to activity participation (Hunter et al. 2019; Afshari, Yang and Bega 2017)

A range of sleep disorders are synonymous with Parkinson's with 60-90% of PLwP reporting some form of sleep disorder (Suzuki et al. 2011). Sleep disorders are thought to arise due to neurodegeneration in the brainstem and are linked with accelerated progression of Parkinson’s, as well as reduced QoL and activities of daily living (ADL) (Poryazova et al. 2010). Overlap exists with cognitive impairment with sleep disorders synonymous with increased postural instability and falls risk (Bugalho and Viana-Baptista 2013).

In summary, Parkinson's is a heterogenous condition, involving a complex interplay of motor and NMS, which manifest alongside other pre-existing medical conditions associated with ageing. Collectively these symptoms have the potential to promote social isolation, constrain participation, PA and ultimately QoL (Hechtner et al. 2014; van Uem et al. 2016). The complex and progressive nature of Parkinson’s promotes physical inactivity, which initiates a viscous cycle of deconditioning, and accelerating an increase of symptoms (Nimwegen et al. 2011). Breaking this cycle through the provision of PA interventions is urgently needed to limit the rate of symptom decline and the physical inactivity it causes.

1.4 IMPACT OF LIVING WITH PARKINSON’S

Research has shown that the impact of living with Parkinson’s is influenced on several factors including severity of Parkinson’s, symptom profile, gender, age, social support, access to healthcare, and socio-economic status. Consequently, the impact and experience of living with Parkinson’s varies between individuals. Qualitative studies have highlighted the impact of living with Parkinson's, demonstrating a loss of independence, changes in identity, loss of control, stigma, and fear of the future (Maffoni et al. 2017; Valcarenghi et al. 2018; Ambrosio et al. 2019; Gardenhire, Mullet and Fife 2019; Haahr, Groos and Sørensen 2021). Consequently, poor emotional well-being often co-exists with Parkinson's. Owing to the progressive nature of Parkinson’s, factors such as identity must be redefined, and rebuilt over time, resulting in PLwP continually going through a process of acceptance, coping and adjustment (Ambrosio et al. 2019). The impact of living with Parkinson's is complicated further by the interplay of condition progression, symptomology, ageing and emergence of co-existing conditions.

Historically, the management of Parkinson's has been symptom-led (Ambrosio et al. 2019). However, more recent research suggests a strong desire for management to be skills focussed, enabling PLwP to live effectively with Parkinson’s, supporting autonomy, acceptance, independence, and adjustment as the condition progresses (Valcarenghi et al. 2018, Haahr et al. 2021, Maffoni et al. 2019). Adopting a skills-based approach requires a more dynamic approach to healthcare delivery, that is responsive to patients’ needs over time (Valcarenghi et al. 2018) with emphasis on active listening, understanding and enablement (Maffoni et al. 2019). Current research also advocates a personalised approach encompassing problem solving, information sharing, providing knowledge and skills to empower PLwP to effectively address their problems (Kessler and Liddy 2017; Kessler et al. 2019). Yet, a significant proportion of PLwP report feeling disempowered (Kessler et al. 2017, 2019) and unable to exert control over their Parkinson’s (Vlaanderen et al. 2019), suggesting a change in how services are delivered for PLwP is necessitated.

1.5 CURRENT MEDICAL MANAGEMENT OF PARKINSON'S

Currently, no cure exists for Parkinson's. The management of Parkinson's is complex, owing to its progressive nature, patient heterogeneity, and symptom diversity. Management is reliant upon medication, which targets dopamine imbalance through a variety of different mechanisms (Table 1.2). However, pharmacological management neither targets underlying pathological processes, nor limits the progression of the condition (Ferrazzoli et al. 2018). Moreover, medication efficacy is time limited, with Parkinson's progression necessitating different combinations of medications, taken at increasing dosages, due to wearing off. Long-term use of medication (> 5 years) induces debilitating motor fluctuations and dyskinesia's. Thus, with a growing Parkinson's population, and finite benefit from medication, the need to develop effective long-term health interventions are required.

Table 1.2 Medications commonly used to manage Parkinson's.

Medication Group	Generic drug name	Mode of Action
Levodopa	Co-beneldopa Co-careldopa	Levodopa crosses the brain-blood barrier, increasing the levels of dopamine available for use within the brain.
Dopamine Agonists	Pramipexole Ropinerole Rotigotine Apomorphine	Dopamine agonists mimic the way dopamine works. Prescribed early in isolation or in combination with levodopa
MAO-B Inhibitors (Monoamine oxidase inhibitors	Rasagiline Selegiline Safinamie	MAO-B inhibits the enzyme which breaks down dopamine. Used independently or in combination with other Parkinson's medication.
COMT Inhibitors (Catechol-o-methyl-transferase Inhibitors)	Entacopone Stelevo Tolcopone Opicapone	COMT inhibits block the enzyme which breaks down Levodopa medication. Taken alongside Levodopa

1.6 NON-MEDICAL MANAGEMENT OF PARKINSON'S

In addition to pharmacological management, several non-pharmacological approaches can be used in the management of Parkinson's. These include deep brain stimulation, cognitive behavioural therapy, and stem cell therapy. Deep brain stimulation (DBS) involves the insertion of a pulse generator under the skin like a heart pacemaker. Wires connected to the generator deliver electrical stimulation to specific areas within the brain which cause Parkinson's symptoms. DBS is commonly used to treat motor symptoms, primarily tremor (Parkinson's UK, 2023). Cognitive behavioural therapy (CBT) aims to improve PLwP psychological wellbeing, by helping people to identify and work through the barriers they face because of their condition. CBT has been shown to positively impact mood and build self-confidence (Parkinson's UK, 2023). Stem cell therapy involves implanting stem cells into body. Stem cells are versatile and have potential to develop into any kind of cells including dopamine cells. Current research is exploring the potential of developing stem cell replacement therapies for PLwP (Parkinson's UK, 2023). In recent years, interest into the potential value of physical activity (PA) for PLwP has grown. Physical activity is an umbrella term which encompasses bodily movements produced by skeletal muscles, which includes a wide range of behaviours including gardening, housework, and leisure related activities (World Health Organisation (WHO), 2022). Exercise is a subcategory of PA, defined as activities which are planned, structured, and purposeful, with the intention of improving and/or maintaining one or more components of physical fitness (Caspersen, Powell, and Christenson 1985). Within this thesis the term PA will be used as this captures all types of activity including exercise. Physical activity has been hailed as the new medicine for Parkinson's, no longer viewed as a complementary intervention, but of equal importance to medication (Hetchner et al. 2014). The interest in PA has been fuelled by the association between PA and reduced risk of developing Parkinson's (Chen et al. 2015) and the potential to attenuate symptom progression (Hirsch et al. 2018; Johansson et al. 2022). Systematic reviews highlight that PA results in improved, strength, balance, gait, and physical capacity (Yitayeh and Teshome 2016; Paolucci et al. 2020; de Almeida et al. 2022; Gamborg et al. 2022) as well as improved motor and NMS (Cusso, Donald and Khoo 2016; Ramazzina, Bernazzoli and Costantino 2017; Wu, Lee and Huang 2017; da Silva et al. 2018; Chen et al. 2020; Cristini et al. 2021; de Oliveira et al. 2021). High intensity PA is hypothesised to promote neurogenesis, synaptogenesis, dopamine turnover, and to reduce neuro-inflammation (Ahlskog 2011; Frazzitta et al. 2013; Petzinger et al. 2013) suggesting that PA may infer a neuro-restorative or protective function (Hirsch et al. 2018). Consequently, PA is currently regarded as the most positive avenue towards disease modification (Lauzé, Daneault and Duval 2016; Mak et al. 2017), and participation in PA endorsed by charities such as Parkinson's UK and the Michael J. Fox foundation. In addition, PLwP who participate in PA experience the same benefits as those without Parkinson's including reduced risk of cerebrovascular disease, stroke, diabetes, and some types of cancers (WHO, 2022), as well as improved QoL and well-being (Das and Horton 2012). Moreover, the benefits PA extend beyond maintaining strength, flexibility, balance, and aerobic capacity, with many studies reporting improvements which translate into improved functional ability, improved NMS, and QoL (Radder et al. 2020).

Prescription of PA is complex, akin to the prescription of medication, where careful consideration is required to establish ideal dosage with minimal side effects (Phillips and Kennedy 2012). Prescription needs to balance motor and NMS, in conjunction with co-existing health conditions, environmental, and psychosocial factors, and individual PA preferences. Over 50 PA systematic reviews have been published covering many different PA types, reflecting the variety of Parkinson's symptoms which may benefit from PA. However, the volume of literature, and variety of physical activities make drawing consensus to inform practice challenging. This is compounded further with diversity in research design, and methodological quality, small sample sizes, heterogeneity in measurement tools, and lack of clarity of intervention components. No one form of PA has been shown to be superior to another, reflecting the variety of physical activities suitable for PLwP, and the diversity of Parkinson's symptoms that benefit from PA. Therefore, current research advocates that PA should include a range of different PA types tailored to individual need (Ellis and Rochester 2018).

The Parkinson's UK Exercise Framework, and the Parkinson's Foundation's PA guidelines advocate five sessions of 30 minutes of PA per week, including strength, flexibility, and balance-based activities twice a week, aerobic-based activity five times a week, and daily participation in functional-based activities (Parkinson's UK, 2017; Parkinson's Foundation, 2022). Programmes incorporating more than one form of PA, which align with individual preferences are associated with better outcomes (Tillman et al. 2015).

Current guidelines also advocate that weekly PA programmes should be prescribed in a progressive manner, including strength, balance, aerobic, gait, and task specific training focussing on the upper and lower limb and spine, with emphasis placed on functional movement patterns and large amplitude movements (Radder et al. 2020).

1.7 OVERVIEW OF THE PHYSICAL ACTIVITY HABITS OF PEOPLE LIVING WITH PARKINSON'S

Recognising the value of PA, several studies have assessed PA levels in Parkinson's. Typically, these studies use accelerometers or activity trackers, for example wrist or waist mounted devices which count steps or self-administered PA questionnaires. People with Parkinson's have been shown to be 29% less active than age matched peers without Parkinson’s (van Nimwegen et al. 2011), with PA levels declining from diagnosis (Mantri et al. 2018). Typically, PLwP are sedentary for 75% of the time, walking on average 4,760 steps per day, spending only 18% of the day engaging in light intensity activity (Benka Wallén et al. 2015). Consequently, 75% of PLwP with mild to moderate Parkinson’s fail to achieve the American College of Sports Medicine (ACSM) activity guidelines of 150 minutes of moderate to vigorous PA per week (Pollock et al. 1998). Sedentary behaviour predisposes PLwP to other co-morbidities such as coronary heart disease, and promotes disuse muscle atrophy, negatively influencing functional capacity. In contrast, PLwP who are more active experience slower decline of Parkinson’s symptoms, and experience improved health outcomes (Paillard, Rolland and de Barreto 2015; Hirsch, Iyer and Sanjak 2016; Klamroth et al. 2016; Hirsch et al. 2018), improved QoL (Rafferty et al. 2017), and lower incidence of falls and fractures (Canning et al. 2015). Few PLwP achieve the recommended PA levels (Benka Wallen et al. 2015), despite many acknowledging the benefits (Hunter et al. 2019). This would imply that a disconnect exists preventing PLwP from participating in PA programmes. This disconnect could be attributed to interpersonal factors such as confidence, or environmental factors such as transportation or organisational factors where current services are not optimised to enable PLwP to effectively engage in PA. Acknowledging the benefits of PA on Parkinson's progression and positive impact on their wider health, emphasises the need for health interventions which aim to support PLwP to adopt long-term activity habits.

In addition to physical benefits, PA serves as a conduit for PLwP to enhance a sense of control, and an opportunity to help themselves (Hunter et al. 2019). Moreover, PA provides opportunity for social networking, and sharing experiences, which are highly valued by PLwP (Hunter et al. 2019). However, research also demonstrates that when PA interventions cease, PA levels decline, and PLwP commonly revert to prior sedentary levels (Lauze et al. 2016). Therefore, a sustainable means of maintaining activity, beyond the end of current interventions, is required. This will necessitate a different approach to support PLwP to be more active long-term, in the UK and beyond.

1.8 SUPPORTING PEOPLE LIVING WITH PARKINSON'S TO BE PHYSICALLY ACTIVE.

Physiotherapy is recommended by the National Institute for Clinical Excellence and Care (NICE) Parkinson's in Adults Guideline (NICE, 2017), and is advocated by the International Movement Disorders Society Evidence-based Review Panel (Fox et al. 2018). Physiotherapy for Parkinson's aims to restore and maximise quality of movement, functional independence, and physical capacity (Skelly and Lindop 2021). Through adopting a person-centred approach, Physiotherapists support self-management, optimising function and promoting well-being. Prescription of PA forms an integral component of Physiotherapy management of Parkinson's, encompassing a broad range of approaches including, aerobic, strength, balance, gait, and flexibility training, as well as strategies such as cueing, and falls-specific rehabilitation.

The positive impact of Physiotherapy for PLwP has been highlighted in several systematic reviews and meta-analyses (Fox et al. 2018; Bouça-Machado et al. 2020; Radder et al. 2020; Okada et al. 2021). The NICE Parkinson's in Adults Guideline (NG71, NICE, 2017) recommends that PLwP should see a Parkinson's specialist Physiotherapist from diagnosis. Specialist Physiotherapy is associated with improved cost effectiveness, as PLwP require fewer treatment sessions, and experience fewer Parkinson's related complications, when compared with usual care Physiotherapy (Ypinga et al. 2018). Similar findings have been reported in Australia where Parkinson's Physiotherapy was associated with optimised care (Canning et al. 2015). However, a national audit conducted by Parkinson's UK, highlighted that few PLwP have access to Parkinson's specialist Physiotherapists. Similar findings have been reported in Europe where more than 75% of Allied Health Professionals (n= 115, of which 89 were Physiotherapists) working with PLwP lacked Parkinson's specific expertise, with over 50% reporting having had no formal Parkinson's education (Nijkrake et al. 2009). This would suggest that while Physiotherapy is ideally placed to deliver PA interventions, insufficient Parkinson's specialist Physiotherapists exist to support delivery.

The European and American Physiotherapy Parkinson's guidelines both advocate the role of Physiotherapy in the management of PLwP (Keus, Munneke and Graziano 2013; Osborne et al. 2022). The American guideline published in2022, made several recommendations based upon 242 studies, and international expert opinion (Osborne et al. 2022). Osborne et al. (2022) recommended that Physiotherapy should involve external cueing, strength, aerobic, flexibility, balance, gait, and task specific training as part of a varied PA programme. Based on current research, no one form PA was regarded as superior to another, rather current research advocated that Physiotherapy should include a range of different PA types tailored to individual need (Ellis and Rochester, 2018). These recommendations provide guidance on what should be included in Physiotherapy-based PA interventions programmes; however, they give no indication of *how* PA interventions should be implemented to support changes in PA behaviour. Therefore, a gap exists between evidence advocating PA participation, and implementation.

Meta-analyses have reported the benefits of individual Physiotherapy approaches (Radder et al. 2021), however, Physiotherapy research has been subject to criticism. Due to the nature of Physiotherapy, current research is criticised for utilising small samples, different outcomes, inadequate active controls, and providing insufficient intervention description. Inconsistency between studies has hampered the ability to formally compare Physiotherapy interventions (Abbruzzese et al. 2016), and therefore, provide clear recommendations to guide delivery of Physiotherapy for PLwP (Radder et al. 2020). Therefore, evidence-based reviews such as Cochrane and the International Movement Disorders Task Force were unable to support or refute the benefit of Physiotherapy in the management of Parkinson's when compared with other treatment approaches (Tomlinson et al. 2014, Fox et al. 2018). In addition, research has also demonstrated that when Physiotherapy is withdrawn adherence declines and the effects on outcomes are diminished. This would suggest that current Physiotherapy approaches, while beneficial, the effects are short-lived, and are limited in their ability to influence long-term PA behaviour, and enable PLwP to self-manage their PA. Physiotherapists are an expensive resource, with limited capacity to support high intensity, or long-term PA interventions (Allen et al. 2012; Hulbert and Goodwin 2020). Consequently, Physiotherapy-based interventions are typically brief (up to eight weeks, Allen et al. 2012), falling short of the minimum time to promote physiological adaptation and develop self-confidence with exercise (Schenkman et al. 2018a) or support maintenance of changes in PA behaviour (Howlett et al. 2019). Therefore, there is a need to consider alternative models of PA delivery to promote the sustainable PA habits for PLwP (Collett et al. 2017).

A large body of evidence currently exists advocating the benefits of PA for PLwP, however relatively little research has focussed on the optimal means of delivering PA to support long-term changes in PA behaviour for PLwP. With a growing evidence base supporting PA as an effective means of managing symptom decline in Parkinson’s, future research needs to focus on how best to support PLwP to be physically active. Interventions designed to promote PA behaviour and enable people to actively self-manage activity are warranted. Physiotherapists are well-placed to support the delivery of PA, however, insufficient capacity exists in the UK healthcare system to support sustained high-intensity input (Hulbert and Goodwin, 2020). This lack of capacity is not unique to the UK, with other European and international studies drawing similar conclusions (Allen et al. 2012). This highlights that, in addition to bridging the gap between evidence supporting PA and implementation of PA. A further gap exists in interventions that are sustainable long-term, that support sustained changes in PA behaviour for PLwP.

In summary, while non-medical management approaches such as Physiotherapy appear promising, issues surrounding optimum dosage, cost, long-term effectiveness, and sustainability of delivery remain problematic. What is required are effective PA interventions that can be sustainably delivered within existing health services such as the National Health Service (NHS), that are accessible to PLwP.

1.9 CHAPTER SUMMARY

This chapter has provided an overview of Parkinson’s, encompassing the epidemiology, pathophysiology, clinical symptoms, and current management approaches. Additionally, this chapter has explored the impact of living with Parkinson's, in particular the impact of deconditioning, reduced participation, and functional decline. The term PA was defined, and the factors which need to be considered when prescribing PA were discussed.

This chapter also presented the benefits of PA for PLwP and its role in limiting the rate of symptom decline and minimising the impact of deconditioning. The potential of PA participation to attenuate the rate of progression, as well as to improve strength, balance, and mobility among PLwP was also highlighted. The benefits of PA beyond physical function were also discussed, with PA participation associated with improvement in NMS, sense of control and social belonging.

Despite the growing body of evidence highlighting the physical and psychosocial benefits of PA, a significant proportion of PLwP remain inactive. Moreover, maintaining PA participation is challenging in a condition where apathy, fatigue and low mood are prevalent. Challenges in relation to current Physiotherapy delivery of PA were discussed, and the mismatch between understanding the benefits of PA and actual engagement were raised. This would suggest that a different approach is required to support PLwP to be more active and to sustain activity levels in the longer-term.

The next chapter will present a review of the literature including the barriers and motivators to PA, factors that influence PA engagement and approaches that promote changes in PA behaviour for PLwP. This will provide further context for the research and development of the research questions. In particular, the literature will aim to address the following questions:

- What are the factors that prevent and enable PLwP to participate in PA?
- What are the key strategies that support changes in PA behaviour among PLwP?
- How can PLwP be best supported to self-manage their PA?

CHAPTER TWO – LITERATURE REVIEW

2.1 OVERVIEW

The introduction highlighted that the benefits of PA for PLwP are widely researched. However, limited research exists to support the optimum means of promoting changes in PA behaviour and enabling PLwP to self-manage their PA long-term. To provide an overview of the evidence underpinning the intervention presented in this thesis, a systematic search of the literature was conducted. A narrative review of the literature was undertaken to identify barriers and motivators to PA among PLwP as well as determine the key ingredients for supporting changes in PA behaviour and promoting long-term PA self-management.

This chapter is divided into six sections. This first section (2.1) provides an overview of the chapter. The second section (2.2) provides justification for the type of review adopted within this thesis. Sections 2.3 to 2.5, consist of a narrative review of the following literature:

- The barriers and motivators to physical activity for PLwP
- Behaviour change approaches for promoting PA
- Approaches to self-management for PLwP

Section 2.6 will provide a summary of the narrative review prior to section 3.0 which will set out the specific aim and objectives for the thesis.

2.2 NARRATIVE REVIEW JUSTIFICATION AND SEARCH STRATEGY

The introduction of evidence-based practice has resulted in an exponential rise in published research. This has created a need for reviews which synthesise research to facilitate transfer of knowledge into clinical practice. Several different types of reviews exist. All reviews aim to provide an overview, but distinction exists between methodology and subsequent rigour between approaches (Grant and Booth 2009).

A narrative review was selected to provide a critical overview of the evidence base to give context and underpin the development a multi-component PA intervention for PLwP. Conducting a narrative review allowed for consolidation of prior research, and offered scope to build upon existing work, promoting summation which is in-keeping with the requirements of this thesis. The requirements of this review were broad and exploratory, for example, to determine the factors which promote changes in PA behaviour among PLwP to inform the development of the intervention. Conducting a systematic review was considered, but dismissed, as systematic reviews focus on a well-defined research question, which was perceived as too restrictive for the purposes of this thesis. Greenhalgh, Thorne and Malterud (2018) argue that systematic and narrative reviews serve different purposes and should be seen as complementary. Systematic reviews use a priori methods, to search, screen, appraise and summarise the literature to answer a specific research question. Whereas MacLure (2005) describes a narrative review as one that utilises interpretation and critique to summarise research, which fits with the needs of this thesis.

Alternatively, conducting a scoping review was considered. Scoping reviews are broader in comparison to systematic reviews. Scoping reviews aim to identify types of evidence, clarify key concepts, and identify knowledge gaps, and are commonly used as a precursor to a systematic review (Munn et al. 2018). Davis, Drey and Gould (2009) suggested that scoping reviews are used "for reconnaissance" to enable researchers to clarify terms, concepts, definitions, and therefore are more suited when a body of literature is new, or unchartered. As the key concepts and knowledge gaps were already known in relation to this thesis as highlighted in section 1.8, conducting a scoping review was excluded as an option.

Selection of a narrative review meets the requirements of this thesis; however, they are not without their limitations. Narrative reviews can be regarded as lower quality, due to the potential for selection bias, that is, selecting only studies which align with a particular perspective (Greenhalgh et al. 2018). In addition, narrative reviews lack objectivity as findings are summarised which are subject to researcher bias. In contrast, systematic reviews are positioned at the top of the research hierarchy, owing to the rigour applied to literature searching, collation, and critical appraisal, resulting in a comprehensive synthesis of best available evidence (Aromataris and Pearson 2014). The merits of systematic reviews lie in the systematic approach adopted at each step, promoting transparency, replication, and potential to update when new research becomes available. In addition, systematic reviews which incorporate meta-analysis, statistically synthesising findings from two or more quantitative studies, allow pooling of findings to produce a strong estimate of effect.

Although systematic reviews provide the best evidence, due to heterogeneity in intervention delivery and variation in use of outcome measures within Physiotherapy and PA interventions, the ability to reliably compare studies and draw reliable conclusions from systematic reviews can be challenging (Fox et al. 2018). A recent Cochrane review exploring PA for PLwP highlighted that nearly 50% of studies included within the review had a high risk of bias, involved small samples, and were of low to medium methodological quality (Ernst et al. 2023), limiting the strength of the conclusions drawn from this review.

In recognition of the limitations associated with narrative reviews and to minimise selection bias, this narrative review followed the JBI three-step systematic literature search methodology (Lockwood and Oh 2017) and included both published and unpublished studies. For each section of the review, an initial limited search of MEDLINE and CINAHL was undertaken followed by analysis of the text words contained in the title and abstract, and of the index terms used to describe articles. A second search using all identified keywords and index terms was then undertaken across all included databases. Thirdly, the reference lists of all identified articles were searched for additional studies. Searched databases included: MEDLINE (EBSCOhost), CINAHL (EBSCOhost), AMED (EBSCOhost), SPORTDiscus (EBSCOhost), and the Cochrane Central Register. Key search terms were also utilised with Google Scholar and OpenDOAR to identify relevant unpublished literature. The search strategy was limited to articles published in English from 2000 to ensure currency in relation to clinical practice. No limitation was placed on study design. Specific search engine and related journal content alerts were set up to ensure that any new literature published after May 2020 could be included within the review. Search outputs were managed using Endnote™ (version 20). The search strategy is provided within each section of the literature review, alongside a PRISMA flowchart to provide transparency.

2.3 BARRIERS AND MOTIVATORS TO PHYSICAL ACTIVITY FOR PEOPLE LIVING WITH PARKINSON'S

The introduction highlighted that participation in PA is associated with slower rate of symptom decline in Parkinson's (Johansson et al. 2022). Emerging evidence also suggests that PA may have a neuroprotective or neurorestorative effect, with potential to slow the rate of Parkinson's progression (Johansson et al. 2022). The importance and benefits of PA are recognised by PLwP (Hunter et al. 2019), yet only 30% achieve the recommended weekly activity levels (Lord et al. 2013). Therefore, despite appreciating the need to be active, few PLwP are sufficiently active to reap the health benefits of PA.

An understanding of the barriers and motivators to taking part in PA, and how they interact is important, so that interventions designed to change PA behaviour can specifically target these factors (Bauman et al. 2012). Therefore, to provide context for the intervention examined in this thesis, this section aims to critically evaluate current literature on barriers and motivators to PA among PLwP.

2.3.1 Barriers and motivators search strategy

The literature was searched using the JBI 3-step search strategy discussed in section 2.2 using the key words detailed in detailed in table 2.1. Studies were included which explored barriers and motivators to taking part in PA among PLwP, with no restriction placed on study design.

Following full text screening, 23 articles were identified which explored the barriers and motivators to PA among PLwP. A PRISMA flowchart provides a summary of the screening process (Figure 2.1). The 23 studies included one qualitative systematic review (Hunter et al. 2019), one mixed-method narrative review (Schootemeijer et al. 2020), five qualitative studies (MacCosham et al. 2018, 2019; Johansson et al. 2019; Borrero, Miller and Hoffman 2022; Carroll et al. 2022), six mixed methods studies (Rossi et al. 2018; Lai et al. 2020; Spencer, Haub and Rockers 2020; Terrens, Soh and Morgan 2021; Atkins et al. 2022; and Bennett et al. 2022), and ten quantitative studies (Ellis et al. 2011, 2013; Afshari, Yang and Bega 2017; Mantri et al. 2019b; Garg et al. 2021; Krishnan Vasanthi et al. 2021; Paul et al. 2021; Prakash et al. 2021; Rosenfeldt et al. 2022; and Torriani-Pasin et al. 2022).

Of the 21 primary studies included in this narrative review, the majority were from the United States of America (n=12, 57%), but also included studies from Australia (n=3, 14%), Canada (n=2, 10%), Malaysia (n=1, 5%), India (n=1, 5%), Brazil (n=1, 5%), and Sweden (n=1, 5%). These studies provide a global perspective of the barriers and motivators associated with PA among PLwP. Significant diversity existed between the primary studies, with some exploring perceived barriers and motivators among PLwP who had participated in specific forms of PA such as Rock Steady Boxing (MacCosham et al. 2018, 2019; Borrero, Miller and Hoffman 2022), aquatic therapy (Terrens, Soh and Morgan 2021; and Carroll et al. 2022), cycling (Rosenfeldt et al. 2022) and balance training (Johansson et al. 2019). Whereas others had explored barriers and motivators among those who had participated in broader PA programmes developed for PLwP (Rossi et al. 2018; Mantri et al. 2019a; Spencer, Haub and Rockers 2020; Krishnan Vasanthi et al. 2021). Four studies explored barriers and motivators among PLwP who had attended PA delivered online (Lai et al. 2020; Garg et al. 2021; Bennett et al. 2022; Torriani-Pasin et al. 2022), highlighting the potential feasibility of using online means to support the management of PLwP (Dorsey, Bloem and Okun 2020). The remaining studies explored differences in reported barriers and motivators to PA among PLwP who were objectively defined or self-reported as physically active or not (Ellis et al. 2011; Ellis and Motl 2013; Paul et al. 2021).

Table 2.1 Search strategy for each data base

MEDLINE	
#1	MM parkinson’s disease OR TX Parkinson*
#2	MH "Exercise+" OR exercise* OR MH sedentary behaviour OR TX “physical activity” OR TX “physical fitness” OR TX “activity” OR AB “activity” or MH “physical therapy modalities”
#3	TX “barriers” OR AB “barriers” OR TX “challenges” OR TX “difficult*” OR TX “motivator*” OR TX “enable*” OR TX “facilitator” OR “TX “preference*” or TX “attitudes”
#4	#1 AND #2 AND #3
CINAHL	
#1	MM “Parkinson's disease OR TX “Parkinson*”
#2	(MM "Exercise") OR (MH "Resistance Training") OR TX “strength exercise” OR TX “strength training” OR (MH "Group Exercise") OR (MM "Aerobic Exercises") OR (MH "Aerobic Dancing") OR (MM "Balance Training”) OR TX “balance exercise” OR (MM "Rehabilitation") OR (MM "Therapeutic Exercise") OR TX “Physical Fitness”
#3	TX “barriers” OR AB “barriers” OR TX “challenges” OR TX “difficult*” OR TX “motivator*” OR TX “enable*” OR TX “facilitator” OR “TX “preference*” or TX “attitudes”
#4	#1 AND #2 AND #3
SPORTDiscus, AMED, and Web of Science	
#1	Parkinson’s disease OR Parkinson's Disease OR parkinson’s disease OR parkinsons disease OR PD or pd OR Parkinson's
#2	Physical activity OR activity OR exercise OR physical exercise OR physical fitness OR strength training OR resistance training OR weight Training OR balance exercise OR balance training OR balance training OR balance programme OR aerobic exercise OR Aerobic training OR Rehabilitation OR therapy OR treatment OR Intervention
#3	Experience OR Perceptions OR attitudes OR Barriers OR Obstacles OR challenges OR difficulties OR issues OR problems OR motivators OR facilitators
#4	#1 AND #2 AND #3

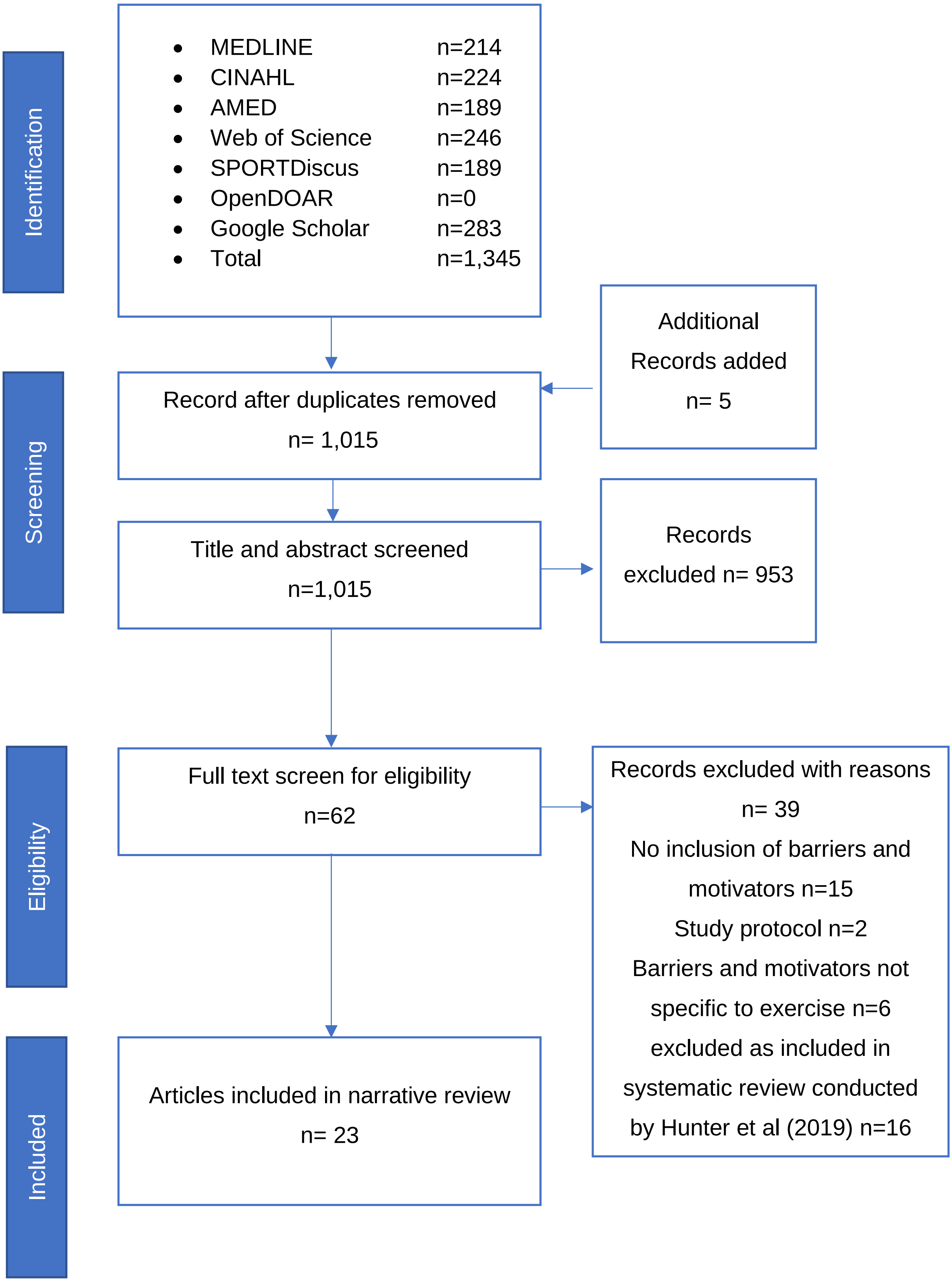


Figure 2.1 Physical activity barriers and motivators search history PRISMA Flowchart

2.3.2 Evaluation of the reviews identified from the search

The search of the literature identified two review articles (Shootemiejer et al. 2020; Hunter et al. 2019). The review by Shootemiejer et al. (2020) did not state any inclusion criteria, and the search strategy was restricted to PubMed only. No Prisma flowchart or detailed search strategy was included, and no quality assessment was conducted. Therefore, transparency in relation to identification of studies, rationale for inclusion, and the quality of the studies is unknown. Shootemiejer et al. (2020) used the International Classification of Functioning, Disability, and Health as a framework to map the barriers and motivators to PA identified from the 16 studies included in the review. Parkinson's motor and NMS, low exercise self-efficacy, lack of social support, and environmental factors such as transports were identified as key barriers for PLwP. Whereas personalised PA interventions, belief that PA was beneficial, and desire to maintain independence were key motivators to be active (Shootemiejer et al. 2020). While the Shootemiejer review does not have the rigour associated with a systematic review, the authors highlight many of the barriers identified were modifiable attitudes which Physiotherapists or exercise professionals are ideally placed to address. Staff were identified as having a pivotal role in motivating PLwP, to initiate and maintain PA, which was deemed necessary due to the fluctuating and progressive nature of Parkinson's symptoms.

Hunter et al. (2019) conducted a JBI qualitative systematic review, following a systematic methodological approach, and employed the JBI process of meta-aggregation to identify categories and synthesised findings. Using the JBI Checklist for systematic reviews (Aromataris and Pearson 2014), the review was assessed as high-quality scoring 10/11. The Hunter review was robustly conducted; however, the credibility and dependability of the primary studies were rated as low. Guba (1981) defines credibility as the confidence that can be placed on the truth of reported findings, whereas dependency is associated with whether the study findings are repeatable and consistent. Credibility was rated low to high based upon the congruency between the author's interpretation and the illustration (participant voice). A ConQual score was also generated for each synthesised finding. ConQual scores are rated low to high, based upon the dependability of the primary studies and the credibility of their research findings (Munn et al. 2014). Overall, the methodological quality of primary studies was low, with each synthesised finding rated as having low level of credibility and dependability. Therefore, owing to the quality of the primary articles, the findings of this review need to be interpreted with caution.

The Hunter review included 19 qualitative studies published between 2003 and 2017, and identified eight synthesised findings, which are illustrated in table 2.2. Overlap existed between the Shootemeijer and Hunter review findings. Both identifed the importance of personalisation of PA and a desire to maintain independence. In addition, Hunter et al (2019) highlighted that access to credible information, development of problem-solving skills and an understanding of the benefits of PA are vital. This would imply that PA interventions need to be delivered in conjunction with education, providing PLwP the necessary skills to enable them to be active. Similarly, both reviews highlighted that insufficient support, and environmental factors serve as key barriers to PA engagement.

In recognition of the quality of the systematic review conducted by Hunter et al. (2019), the synthesised findings have been used as subheadings to structure sections 2.3.3 and 2.3.4 of this narrative review. Each synthesised finding will be critically discussed in greater detail, and in conjunction with the 21 primary studies highlighted earlier. In addition, barriers, and motivators to online delivery of PA will be discussed in section 2.3.5, reflecting an emerging body of research which was not encompassed within the review conducted by Hunter et al. (2019).

Table 2.2 Synthesised qualitative findings adapted from Hunter et al. (2019)

Hunter et al. (2019) Review Synthesised Findings	
Motivators	Barriers
PA is perceived as positive experience. Belief that PA is beneficial and maintaining independence. PA prescription needs to be personalised to individual need. Information seeking, problem-solving and resilience are motivators to develop PA habit.	Parkinson's symptoms negatively impact of PA engagement. Lack of social and professional support is required to promote PA engagement. Variable accessibility of services and diversity and complexity of symptom limit PA engagement. Lack of family and friend support is crucial to initiate and sustain PA.

Table 2.3 Qualitative studies exploring the barriers and motivators to physical activity published after Hunter et al (2019)

Author, title, and aim	**Methods**	**Key findings in relation to physical activity barriers and motivators**
(Borrero, Miller and Hoffman 2022) To understand the meaning of regular participation in multiple types of vigorous-intensity PA for PLwP.	Qualitative phenomenological approach. Interviews. Inductive analysis process. Participants participated in Rock Steady Boxing regularly - (at least 120 min/week) for at least 6 months, and at least one other mode of PA. n=8 PLwP	**Motivational factors for participating in high intensity exercise** Social connections with other PLwP Provides a sense of purpose Determination and confidence. Feeling of hope, sense of self, and motivation Reduced isolation Feeling part of a community Giving back to community Self-efficacy
Carroll et al (2022) To explore the opinions of PLwP about access to and participation in community aquatic therapy.	Individual interviews and focus groups. Inductive Thematic analysis. N=34 PLwP from Ireland and Australia. Range of experience with aquatic therapy.	**Motivational factors for attending aquatic therapy:** Maintain abilities Motivation from peers Camaraderie and enjoyable Slow the rate of decline Benefit of aquatic therapy Credible instructor Personalisation of PA prescription **Barriers to attending aquatic therapy:** Fear of water, cultural views of aquatic therapy, and lack of confidence in the water Fear of falling Lack of information on aquatic therapy Timing of the class with medication, and transportation

Table 2.3 Qualitative studies exploring the barriers and motivators to physical activity published after Hunter et al (2019) (continued)

Author, title, and aim	Methods	Key findings in relation to physical activity barriers and motivators
(Johansson et al. 2019) To explore the meaning of balance for PLwP and the beliefs they hold regarding their ability to influence their balance in everyday life.	Qualitative study – Interviews, adopting an inductive analysis approach. n=19 PLwP. Content analysis.	**Motivators to engage in balance exercise:** Remaining in control over the body Adapting behaviour to deal with uncertainty PA enabled PLwP to temporarily take their mind off the disease Reinforced a sense of normality Belief in the benefits of exercise **Barriers:** Weather Stairs Crowds of people. Lack of progress with PA was demotivating Reduced sense of freedom and independence Fluctuating motor abilities
MacCosham et al. (2019) To explore the experiences of PLwP who are engaged in a boxing program.	A qualitative phenomenological study– semi structured interviews, analysed using thematic analysis. n=12 PLwP who had attended Rock steady Boxing.	**Motivation aspects of Boxing programme at attend and promoting long-term engagement** Perceived improvement in abilities Addressed individual need Coming out of isolation, relatedness, and coping mechanism Social support and sense of belonging Changes in psychological perspectives: escapism, perceptions of increased concentration, and gaining a sense of accomplishment Contextualised education alongside exercise

Table 2.3 Qualitative studies exploring the barriers and motivators to physical activity published after Hunter et al (2019) (continued)

Author, title, and aim	**Methods**	**Key findings in relation to physical activity barriers and motivators**
MacCosham et al. (2018) To identify the perceived constraints and facilitators to PA in each stage of behavioural change among PLwP.	A qualitative phenomenological research design. Semi-structured interviews among PLwP who attended Boxing4Health programme Thematic analysis n=12 PLwP	PA barriers and motivators change between pre-intention, intention, action, and maintenance phases. **Pre-intention phases**: Interpersonal factors were the largest constraints to PA including lack of confidence, motivation, knowledge on benefits, and decreased motor ability. Interpersonal factors such as lack of social support and stigma existed. Key facilitators: perception that PA is enjoyable. **Intention phases:** Interpersonal factors predominate -lack of social support, lack of guidance from HPCs Hearing about PA from others with Parkinson's, social support, access to information on benefits of PA, encouragement from others formed key motivators. **Action Phases:** Fewer barriers to PA Sustained motivation, decline in Parkinsons, and time to participate in PA were key barriers. Enjoyable PA, testimonials from other PLwP, accessibility of PA, ease of transportation all facilitators of PA **Maintenance Phase:** Very few barriers to PA. Barriers associated with cost, transportation, time, and weather. Facilitators for PA included: feelings of competence, confidence, experiencing the benefits of PA, actively managing symptoms, limiting rate of decline, feeling accepted by others, sense of community, shared experience, and knowledge. PA is personalised, challenging and simple.
Abbreviations: PA: Physical activity; PLwP: People living with Parkinson's		

Table 2.4 Quantitative studies exploring the barriers and motivators to physical activity.

Authors and aim	**Methods**	**Key findings in relation to physical activity barriers and motivators**
(Afshari, Yang and Bega 2017) To compare exercise habits, perceptions about exercise, and barriers to exercise in 'low' (<3 h/week) and 'high' (≥3 h/week) exercisers with PLwP.	Quantitative- Cross sectional survey. n=215 PLwP 48-item survey- multiple choice and Likert-scale-based questions regarding symptoms, exercise habits, perspectives on the benefit of PA, preferences, and perceived barriers to PA.	PA barriers and motivators differ between high and low exercisers High exercisers - significantly more likely to change their habits Exercising more following PD diagnosis (54.2% versus 27.8%, $p < 0.001$) Low exercisers were more likely to reduce their exercise following diagnosis (40.2% versus 15.9%, $p < 0.001$) Greater number of barriers in low exercise group **Key PA motivators among low exercisers:** Short duration of exercise Recommended to exercise by consultant Group-based PA Family support Knowledgeable instructor **Barriers to exercise among low exercisers (reported in >20% of sample)** Fear of falling Lack of someone to motivate them Parkinson's symptoms Access to facilities
Ellis et al (2011) To examine factors associated with PA behaviour in ambulatory PLwP	Cross sectional study n=264 PLwP Participants designated as exercisers" or "non-exercisers" based on responses to the Stages of Readiness to Exercise Questionnaire.	Lower UPDRS, GDS and PDQ-39 score, higher SEE score, education and income levels associated with higher PA levels PLwP with high self-efficacy were more than twice as likely to engage in exercise as those with low self-efficacy (adjusted OR 2.34, 95% CI 1.30–4.23) Level of disease severity did not modify the association between self-efficacy and exercise Self-efficacy, rather than disability, appears strongly associated with exercise habit

Table 2.4 Summary of quantitative studies exploring the barriers and motivators to physical activity (continued)

Author, and aim	**Methods**	**Key findings in relation to physical activity barriers and motivators**
(Krishnan Vasanthi et al. 2021) To explore the perceived barriers and motivators towards PA among people with Malaysian PLwP.	Cross-sectional survey including: 20 items of perceived barriers to exercise and 12 items represent the motivation to PA. n=47 PLwP	83% agreed that having an appropriate exercise instructor motivates them to exercise 81% encouragement from family and friends to exercise was important motivator 75% agreed improving mood as a motivator to exercise 72% sense of accomplishment was a motivator **Motivational factors for attending PA:** Improved mood, feeling more energised and healthy Taking control Having an exercise partner Credible Instructor Encouragement from HCPs, family, and friends Information about exercise **Barriers to attending PA:** Fatigue Fear of falling Lack of exercise information i.e., what is best for them Bad weather Transportation, costs Lack of exercise that meets their preferences
Ellis et al (2013) To identify perceived barriers to exercise among PLwP.	Cross sectional study. n=26-PLwP. Designated as exercisers" or "non-exercisers" using stages of Readiness to Exercise Questionnaire.	**Barriers in low exercise group:**Low outcome expectation, tightness in chest, lack of time, perceived health, discomfort with exercise, depression, bad weather, and fear of falling, significantly associated with the non-exercise group Non-exercisers had 3.93 times the odds of endorsing low outcome expectation as the exercise group, 3.36 times the odds of endorsing lack of time, and 2.35 times the odds of endorsing fear of falling as the exercise group.

Table 2.4 Summary of quantitative studies exploring the barriers and motivators to physical activity (continued)

Author, and aim	Methods	Key findings in relation to physical activity barriers and motivators
(Garg et al. 2021) To assess the feasibility of telerehabilitation among persons with PD.	Single-centre, prospective study. Attended 12-week structured online rehabilitation programme Survey prior to attending and satisfaction questionnaire on completion.	**Barriers to online PA:** Reservations regarding the potential of rehabilitation as an intervention Trepidation/lack of confidence/fear of falls in their personal ability to exercise Slow Internet speed Lack of access to smart phones Lack of rapport or sense of belonging to their treatment experienced during in-person visits
(Mantri et al. 2019b) To explore the activity habits, including barriers and motivators, in Veterans with parkinsons.	Cross sectional study. Questionnaire (EPQ), assessing knowledge, barriers, and motivators of activity and the Physical activity scale for the elderly to assess PA levels.	**Knowledge and attitudes about exercise** High levels of agreement that exercise was beneficial to motor (n=63, 100%) and NMS (n=62, 98.4%) Higher levels of exercise knowledge were moderately associated with PASE (r=0.28, p=0.03) The most common barriers were general health (44 agree or strongly agree, 71.0%) and aches/pains (40 agree or strongly agree, 63.5%) The most common motivators were feeling better after exercise (63 agree or strongly agree, 100%) and a desire to stay healthy (63 agree or strongly agree, 100%) To most frequently reported motivators: improve Parkinson's, and social engagement Most frequently reported barriers: depression/apathy and co-morbidities
Prakash et al (2021) To explore whether barriers and reports of participation differ depending on exercise type among PLwP.	Survey. Methods-poorly described.	86% of participants reported being encouraged to exercise and believing exercise was beneficial (90%) influenced participation Low energy (36%), physical symptoms (33%), and fear of falling (30%) were the most frequently reported barriers for all types of exercise. Those who referred to Physiotherapy were more likely to continue with exercise after the intervention compared with community programmes. Self-efficacy was a major barrier to PA

Table 2.4 Summary of quantitative studies exploring the barriers and motivators to physical activity (continued)

Author, and aim	Methods	Key findings in relation to physical activity barriers and motivators
Paul et al (2021) What specific attributes of exercise programs influence the preferences of PLwP for additional exercise compared with their current practice?	Discrete choice experiment. Participants were given a series of questions, asking them to choose whether they would add the presented exercise program to their current exercise regimen. Analysis: mixed logic model.	Preference, for not adding extra exercise to their current exercise regimens Participants were more willing to add additional exercise to their existing exercise routine when programs lead to physical (OR 1.85, 95% CI 1.61 to 2.13, p=0.0001) or psychological benefits (OR 1.45, 95% CI 1.26 to 1.67, p=0.0001) Participants preferred programs delivered by physiotherapists with expertise in Parkinson's (OR 1.51, 95% CI 1.08 to 2.11, p = 0.02) or qualified exercise instructors with expertise in Parkinson's (OR 1.91, 95% CI 1.18 to 3.09, p =0.009) compared with no supervision Preference for exercise that did not incur much travel (i.e., 10 minutes travel each way, ORs 1.50 to 2.02, p=0.001 to 0.03) Less likely to prefer programs with higher costs (OR 0.65 per AU$10 increase in cost, 95% CI 0.60 to 0.71, p=0.001) or a high frequency of sessions (i.e., four additional sessions: OR 0.41, 95% CI 0.30 to 0.55, p=0.001) Lower preference for group exercise compared with individual exercise (OR 0.72, 95% CI 0.54 to 0.96, p = 0.03)
(Rosenfeldt et al. 2021) To examine the personal beliefs, motivators, and barriers in PLwP following participation in a year-round community-based cycling programme.	Cross-sectional survey. n= 40 participating in pedalling for Parkinson's Programme. Surveys included 5-point Likert scale assessing of Personal Beliefs and Knowledge, Health and Disability, Program, and Fitness Environment following a 12-month exercise.	Mean subdomain scores were as follows: 4.37 (0.41) for Personal Beliefs and Knowledge, 4.25 (0.65) for Health and Disability, 4.11 (0.53) for Program, and 4.35 (0.44) for Fitness Environment PLwP are motivated to exercise due to their PD diagnosis and possess a general belief that exercise is beneficial to their physical and mental well-being PLwP Motivated by staff and peers to undertake cycling Goals planning and reward "cyclist of the month" maintained motivation Cost of the program, parking and transportation, proximity to residence, and ease of gym navigation are important to participants.

Table 2.4 Summary of quantitative studies exploring the barriers and motivators to physical activity (continued)

Author, and aim	**Methods**	**Key findings in relation to physical activity barriers and motivators**
(Torriani-Pasin et al. 2022) To evaluate the adherence rate, barriers to attend and safety of a telemonitoring programme for PLwP.	Phase 1 clinical trial, n=20. Asynchronous online PA programme. PA included videos personalised to level and skill. Participants were encouraged exercise every other day for 24 weeks.	**Barriers associated with the intervention:** Pain Lack of exercise capability Behavioural issues – motivation and fatigue Co-existing health conditions Communication difficulties Dual tasking Dependent on support of someone at home Lack of fitness, balance, and strength
Abbreviations: PA: Physical activity, PLwP: People living with Parkinson’s, OR: Odds ratio, CI: Confidence Interval, NMS: Non-motor symptom, UPDRS: unified Parkinson’s disease rating scale, PDQ-39: parkinsons disease questionnaire, SEE: self-efficacy exercise, GDS: Geriatric Depression Scale, HCPs: Health Care professionals.		

Table 2.5 Mixed methods studies exploring barriers and motivators to physical activity.

Author, and aim	Methods	Key findings in relation to physical activity barriers and motivators
(Atkins et al. 2022) To explore the subjective experience of apathy subtypes and how they influence engagement in PA among PD and HD.	Semi-structured interviews and quantitative of analysis LARS Purposeful sample of HD and Parkinson's. Video conferenced interviews. Used thematic analysis.	**PA Barriers:** Apathy and fatigue, especially initiating activity, and when activities have been discontinued and start up again **Strategies to overcome apathy:** Support and prompts from family and friends, community support, and personalisation of exercise Electronic reminders, established exercise routine Creating a safe environment

Table 2.5 Summary of mixed methods studies exploring the barriers and motivators to physical activity (continued)

Author, and aim	**Methods**	**Key findings in relation to physical activity barriers and motivators**
Bennett et al (2022) Explore experiences, perceptions, and perceived effect of participating in and transitioning from in-person to virtual PDEx in people with PLwP.	Cross-sectional mixed-methods design using an online survey and focus groups. n=26, completed online survey and participated in focus groups.	75% found using technology easy 50% preferred hybrid option to delivery **Motivators and benefits of PDEx:** Personalisation of PA Social support Safe and convenience environment **Barriers with PDEx:** Transportation Lack of referral Lacking education
(Lai et al. 2020) To explore the uptake and implementation of two common methods of Internet PA training in PLwP.	N=20 PLwP randomised to: telecoach-assisted exercise (TAE) or self-regulated exercise (SRE) groups. Both groups received the same eight-week exercise prescription. TAE was supervised and delivered via videoconferencing. SRE participants independently managed their PA. Quantitative data were described, and qualitative interview data underwent thematic analysis.	Improved attendance in TAE group 99.2% v 35.9%. SRE participants spent 48% less time exercising, and 74.5% less time exercising at moderate intensity. **Motivators for tele coach-assisted exercise:** Convenience Capacity for self-monitoring promoting accountability Personalisation of programme **Barriers for tele coach-assisted exercise**: Internet instability caused frequent disconnects Technology learning curve **Barriers for app-based self-regulated exercise** Technology frustration Lack of social contact Soreness, pain, or non-intervention related falls

Table 2.5 Summary of mixed methods studies exploring the barriers and motivators to physical activity (continued)

Author, and aim	Methods	Key findings in relation to physical activity barriers and motivators
(Rossi et al. 2018) To Identify key features of an enduring group exercise program for PLwP by exploring experiences of participants, student assistants and the exercise instructor.	Convergent mixed methods design. Fitness for Parkinson's Programme. n=14 PLwP. Physical Fitness and Exercise Activity Levels of Older Adults Scale. Interviews and written reflections, analysed via qualitative content analysis.	**Motivational factors:** Variation in exercise type Instructor who challenged abilities, and was supportive, caring and motivational Positive nature of staff Personalisation of PA Social interaction Recommendations by HCP to exercise Perceived benefits, improved mood, and energy **Barriers to PA:** Fatigue, other health issues Maintaining activity when programme ceased Transportation, weather
(Spencer, Haub and Rockers 2020) What are the reported benefits from participating in a PA programme? For PLwP who have not utilised the local PD community programmes, what are the barriers to participation?	Mixed methods study. Quantitive survey. Open questions in survey analysed using thematic approach. n=85. 64 participated in the PD program, and 21 did not.	**Perceived benefits of participating in community programme** A sense of community/belonging Increased knowledge and understanding about Parkinson's. Hope/improved outlook on life Physical improvements Exercise. Increased connection with staff and community Strategies to aid living with Parkinson's **Barriers to participating in the community exercise programme:** Lack of transportation, 75% had no transport Fear of seeing Parkinson's symptom progression

Table 2.5 Summary of mixed methods studies exploring the barriers and motivators to physical activity (continued)

Author, and aim	Methods	Key findings in relation to physical activity barriers and motivators
(Terrens, Soh and Morgan 2021) To describe the QoL in those with moderate Parkinson's and explore participant perceptions regarding barriers and enablers of aquatic Physiotherapy.	Nested in a pilot feasibility study of the Halliwick concept for PLwP. n=21. Hydrotherapy: 60 minutes, once a week for 12 weeks. Experience survey, PDQ-39 and focus groups.	**Survey of experience of aquatic therapy:** Exercises were adapted to suit their ability Enjoyed exercising with other people in a group environment. 95% found it beneficial, 81% felt safe **Enablers:** Functional movement Felling safe in changing rooms and in the water Exercising as a group **Barriers:** Fatigue Transport

Abbreviations: PLwP: people living with Parkinson's, PDQ-39: Parkinson disease questionnaire-39, HCP's: Healthcare Professionals, PD: Parkinson's Disease; HD: Huntington's disease, LARS: Lille Apathy rating scale.

2.3.3 Factors motivating participation in physical activity

Physical activity is perceived as a positive experience:

A key synthesised finding identified by Hunter et al. (2019) was that PA was regarded as a positive experience, based on 19 studies involving community-based PA programmes. Qualitative studies published since 2019 exploring barriers and motivators to PA reiterated Hunters findings that PA is a positive experience. In contrast, recent qualitative studies (see table 2.3) involved more intensive and diverse forms of PA such as Rock Steady Boxing™ (MacCosham et al. 2018, 2019; Borrero, Miller and Hoffman 2022), aquatic therapy (Carroll et al. 2022) and balance training (Joahnnsson et al. 2019). Pooling these more recent studies with the Hunter review suggests that positive experience associated with PA is independent of PA type.

Hunter et al. (2019) reported that PA provided PLwP with a sense of hope, purpose, and control, suggesting that the benefits of PA extend beyond the physical domain. More recent studies confirm Hunters' findings, but also add a sense of achievement and feeling good about oneself contributed to the positive experience associated with PA (MacCosham et al. 2018, 2019; Johansson et al. 2019; Borrero, Miller and Hoffman 2022; Carroll et al. 2022). The sense of achievement in these more recent qualitative studies could be attributed to the high intensity nature of Rock Steady Boxing™ where emphasis is based on personal challenge, and moderate to maximal effort reflecting the emerging evidence advocating high intensity PA (Johansson et al. 2022). Evidence advocating high intensity PA did not exist when a large proportion of the primary studies included in the Hunter review were published, which may explain the differences reported between studies. However, mixed methods studies identified in this narrative review highlighted that community PA programmes incorporating low intensity forms of PA such as yoga, and chair-based exercise also reported positive experiences such as improved outlook on life (Spencer et al. 2022) and feeling energised (Krishnan Vasanthi et al. 2021). This would suggest that the positive experience associated with PA may be independent of activity type and intensity.

Qualitative studies indicated that participation in PA was associated with improved physical capability, which fuelled a renewed focus on life. Interviews with PLwP who attended 120 minutes of Rock Steady Boxing™ a week reported that perceived physical improvements reinforced their commitment to PA, resulting in increased participation and determination to stay active (Borrero, Miller and Hoffman 2022). This would suggest that the positive experience of PA is self-perpetuating, with the positive experience of PA, further fuelling PA and promoting adherence. The findings reported by Borrero, Miller and Hoffman (2022) although positive, were based on a small sample of men, who had mild to moderate Parkinson's (Hoehn and Yahr stage II) and undertook 9.4 hours of self-reported PA per week, suggesting the findings are based on a highly motivated and active sample, thus limiting the generalisability of the findings. However, the study by Borrero, Miller and Hoffman (2022) would infer that motivation level may be key determinant of PA behaviour among PLwP. A qualitative study which mapped barriers and motivators to PA to the stages of behaviour change among PLwP (see table 2.3) highlighted that low confidence and motivation were key barriers among those contemplating starting PA (MacCosham et al. 2018). However, motivation and confidence were not reported as barriers among those who were in the maintenance phase of behaviour change (MacCosham et al. 2018). Similarly, cross-sectional survey data involving 243 PLwP, demonstrated that active PLwP were significantly more likely to increase their PA levels when diagnosed (54.2% versus 27.8%, $p < 0.001$), compared with those who were less active prior to diagnosis (Afshari, Yang and Bega 2017). In fact, less active PLwP were more likely to reduce their amount of PA following diagnosis (40.2% versus 15.9%, $p < 0.001$).

Drawing from these studies would suggest that motivation, confidence, and PA history maybe important factors influencing PA behaviour among PLwP, rather than PA type or intensity. PA interventions aiming to influence PA behaviour need to incorporate strategies to promote motivation to be active and provide strategies to enable development self-confidence with PA.

Belief that PA is beneficial and maintaining independence.

The perception that PA was beneficial, enabling the maintenance of independence and limiting the rate of decline associated with Parkinsons was a synthesised finding identified from the review by Hunter et al. (2019). Similar findings were reported in quantitative, and mixed methods studies (see table 2.4 and 2.5) which used surveys or questionnaires to explore barriers and motivators to PA (Ellis et al. 2011, 2013; Afshari, Yang and Bega 2017; Rossi et al. 2018; Mantri et al. 2019b; Spencer, Haub and Rockers 2020; Garg et al. 2021; Krishnan Vasanthi et al. 2021; Paul et al. 2021c; Prakash et al. 2021; Terrens, Soh and Morgan 2021; Bennett et al. 2022; Rosenfeldt et al. 2022; Torriani-Pasin et al. 2022) Typically, surveys involved Likert scales, with only three studies using a measure with established reliability and validity (Ellis and Motl 2013; Rossi et al. 2018; Mantri et al. 2019b), limiting direct comparisons between studies. Mantri et al (2019b) used the Exercise Perception Questionnaire (EPQ), which consists of 41, 4-point, forced-choice Likert scales encompassing physical fitness, barriers, motivators, and exercise frequency. The two other studies (Ellis and Motl 2013; Rossi et al. 2018), only used the barriers subsection of the EPQ. Using the EPQ, Mantri et al (2019b) demonstrated that the desire to stay healthy was a key motivational factor to be active. The use of a validated measure adds strength to the conclusions drawn by Mantri et al (2019). However, the EPQ, was developed for use in older adults and has not been validated for use among PLwP. Due to the complex nature of Parkinson's, encompassing motor and NMS, the EPQ may be limited in its capacity to address the breadth of factors which may impact PA barriers and motivators in Parkinson's.

The review by Hunter et al. (2019) also demonstrated that an understanding of the benefits of PA was a powerful motivator. However, all studies included within the Hunter review recruited participants who were currently active. This would suggest that an appreciation of the benefits is a strong motivator to maintain PA among those already active. However, what cannot be determined from the review by Hunter et al (2019) is whether an understanding of the benefits of PA serves as a motivator among those who are inactive. MacCosham et al (2018) mapped barriers and motivators to PA to the Transtheoretical model of behaviour change. A lack of knowledge of the benefits of PA was perceived as a barrier, among PLwP who were contemplating PA, but not during the action and maintain phases of behaviour change (MacCosham et al. 2018). Similarly, cross section study involving 270 PLwP (see table 2.4) reported that among Parkinson's non-exercisers (those exercising for 20 minutes less than three times a week), were 37.5% more likely to cite low expectation of the benefits of PA as a barrier (OR: 3.87, 95% CI: 2.10-7.13) compared with those who exercised for 20 minutes three or more times a week. Higher levels of PA knowledge were moderately associated within increased levels of PA as measured by the Physical Activity Scale for the Elderly (r =0.28, p=0.03) within a sample of Parkinson's veterans (Mantri et al. 2019b). This suggests that lack of knowledge serves as a barrier to PA engagement. These studies in combination indicate that PA education is a powerful motivator to support both the initiation of PA but also maintain PA and suggests that education is an important factor in shaping PA behaviour among PLwP.

A recent "voice of the customer" study conducted in 2019, highlighted that receiving PA information from Parkinson's specialists was an unmet need cited by PLwP (Vlaanderen et al. 2019). Providing education from diagnosis may be a practical solution to modify PA behaviour and mitigate the initiation of the vicious cycle of decline and deconditioning commonly seen among sedentary PLwP. The value of receiving education on the benefits of PA was demonstrated in several qualitative studies (MacCosham et al. 2018, 2019; Johansson et al. 2019; Carroll et al. 2022, table 2.3). Provision of education in tandem with PA prescription was perceived to motivate PA participation (MacCosham et al. 2019), with quantitative studies adding that delivery of education by a credible instructor was also a motivational factor in shaping PA behaviour (Afshari, Yang and Bega 2017; Krishnan Vasanthi et al. 2021). This would suggest that who and how education is delivered are important considerations when delivering education to support changes in behaviour. However, a recent systematic review exploring educational interventions to support PA, has highlighted that a lack of consensus exists to guide content of education to effectively shape PA behaviour among PLwP (Alushi et al. 2022).

Synthesised findings from the Hunter review also identified that maintaining independence was a key motivational factor for participating in PA (Hunter et al. 2019). Among those with mild symptoms, PA was an approach used to minimise medication intake and exert control over their condition (Ravenek and Schneider 2009). Possessing a sense of control of one's own life has been associated with successfully living with Parkinson's (Kang and Ellis-Hill 2015). Attending "Dance with Parkinson's" once a week for six months was associated with perceptions of taking back control of Parkinson's symptoms both physically and emotionally (Bognar et al. 2017). This sense of regaining control was not restricted to dance but was also reported in studies which recruited PLwP who had participated in group-based exercise (Sheehy, McDonough and Zauber 2017), strength training (O'Brien, Dodd and Bilney 2008), aquatic therapy (Carroll et al. 2022) and balance training (Johansson et al. 2019), which could suggest being active is key to motivation, as opposed to activity type.

Self-efficacy was a key determinant of PA reported in all studies, regardless of methodological approach. Cross-sectional studies demonstrate that self-efficacy, rather than disability, was a key determinant for initiating and maintaining PA, as well as influencing the type of PA and intensity of engagement (Ellis et al. 2011, 2013; Stevens, Stanton, and Rebar 2020). Self-efficacy is central to Bandura's Social Cognitive Theory, which, when applied within a PA context is defined as the individual's belief that they have capacity to engage in PA (Stevens, Stanton, and Rebar 2020). Hunter et al. (2019) highlighted that self-efficacy was a powerful motivator but an equally powerful barrier to PA. Lack of self-confidence was fuelled by Parkinson's continually requiring people to reframe their identity. Therefore, due the progressive and fluctuating nature of Parkinson's posed as a barrier to PA participation (Hunter et al. 2019). Combined with the lack of education mentioned previously, MacCosham et al (2018), indicated that uncertainty surrounding what type of PA PLwP should be engaging in or what was best for their Parkinson's was a barrier to engagement among those considering taking up PA. In contrast, studies which explored barriers and motivators among those who were involved in regular PA, self-efficacy and low confidence were less frequently cited as barriers to PA (Hunter et al. 2019). This would suggest that barriers associated low confidence and self-efficacy are modifiable when appropriate support is put in place.

Supervised PA which promoted the development of knowledge and skills were perceived as integral to improvements in self-efficacy (Hunter et al. 2019). Supervised PA programmes were reported to provide opportunity for goal setting, developing problem-solving and decision-making skills that were seen as instrumental to promote self-efficacy (Hunter et al. 2019). The association between supervision and self-efficacy has been reiterated in a more recent mixed methods study comparing tele-coach-assisted exercise (TAE) or self-regulated exercise (SRE) (Lai et al. 2020). Those in the unsupervised SRE group had 35.9% lower attendance and 48% less time exercising compared with the supervised TAE group. Qualitatively, supervised PA was also associated with a more positive experience and greater enhanced PA confidence compared to the SRE group. Similarly, in the PDSafe study, supervision was associated with greater effort and commitment to participating in PA (Rowsell et al. 2022). The value of supervised PA is not unique to Parkinson's, with a prior systematic review concluding that supervised PA is more superior to non-supervised PA (Lacroix et al. 2017). The development of self-efficacy, and problem-solving skills form the bedrock of self-management. Collectively these studies suggest that the provision of PA in isolation may be insufficient to modify PA behaviour. Rather, PA interventions need to be knowledge and skills based, so that PLwP develop the capacity and capability needed to influence their own PA behaviour (Stevens, Stanton and Rebar 2020; Urell et al. 2021) such that they are equipped to exert control of their own future (Kang and Ellis-Hill 2015; Ambrosio et al. 2019).

PA prescription needs to be personalised to individual need

The personalisation of PA interventions was identified as a key motivational factor by Hunter et al. (2019) and was reiterated by more recently published studies (Rossi et al. 2018; Johansson et al. 2019; Lai et al. 2020; Krishnan Vasanthi et al. 2021; Bennett et al. 2022; Borrero, Miller and Hoffman 2022). These studies were conducted in a variety of countries and prescribing different types of PA, suggesting that personalisation is a key motivation factor regardless of culture and activity type.

NHS England define personalised care as a holistic approach to management, involving conversations between healthcare professionals and patients to explore their management of their health and well-being (NHS England, 2022). Delivery of a personalised approach to care is recommended by NICE (NICE 2017) and the Physiotherapy guidelines for Parkinson's (Osborne et al. 2021). Titova and Chaudhuri (2017) argue that a personalised approach is necessitated in Parkinson's owing to the heterogeneity in symptoms, and the variation in condition progression. Qualitative findings in the current review highlight that the ability of exercise professionals to tailor PA prescription to accommodate their Parkinson's and co-existing conditions motivated PA adherence and promoted PA confidence (Hunter et al. 2019).

Personalisation was perceived to be optimised when delivered by professionals who were knowledgeable about Parkinson's (Hunter et al. 2019; Schootemeijer et al. 2020; Carroll et al. 2022), and when PA was supervised, enabling provision of feedback on performance (Hunter et al. 2019; Shootemeijer et al. 2020). Qualitative findings also suggested that among those new to PA, that personalisation of PA was important to develop PA confidence and skills. whereas frequent exercises valued the use of goals to maintain PA challenge, and shared discussion in relation to PA choice (MacCosham et al. 2018, 2019), suggesting that personalisation needs to be responsive to the changing needs of PLwP as they develop PA confidence.

The finding of this review would suggest that tailored PA intervention delivered by healthcare professionals motivate PLwP to be more physically active as well as support the development of confidence in PA engagement. However, these conclusions are drawn from qualitative studies, involving physically active samples. No qualitative studies have explored the views of PLwP who are sedentary. In addition, few studies have explored objectively the impact of personalised PA interventions on long-term PA behaviour and self-management, with most studies lasting 12 weeks or less. A recent study demonstrated that a large proportion (42%) of PLwP who completed the Patient Activation Measure (measure of a person’s level of knowledge, skills, and confidence to manage their condition) felt disengaged and overwhelmed, suggesting scope for improving personalised care for PLwP. While personalisation of care is advocated, little guidance exists on how to deliver it (Tenison et al. 2020). This section of the review would suggest personalisation is more than tailoring of PA prescription, but should also include skills, and strategy-based training to develop individual PA confidence.

2.3.4 Barriers to physical activity among people with Parkinson's

Hunter et al. (2019) identified several key barriers to PA including Parkinson's symptoms, lack of family or social support, access to Parkinson’s specialists, and barriers associated with PA environments. The wider literature in relation to each of these barriers is discussed below.

Negative impact of Parkinson’s on PA engagement

Co-existing health conditions and the progressive nature of Parkinson’s were widely reported barriers to PA (Hunter et al. 2019). Synthesised findings indicated that the complex, progressive, and fluctuating nature of Parkinson’s presented a substantial barrier to PA (Hunter et al. 2019), despite many of the primary studies included in the Hunter review recruiting people with mild to moderate Parkinson's. The implications of this are twofold; i) even in early stages of Parkinson’s, where physical symptoms are classified as mild, Parkinson’s negatively impacts PA engagement, and ii) the barriers to PA in the later stages of the condition are under-researched, therefore, the barriers during mid to late-stage Parkinson’s are unknown. However, it could be hypothesised that the barriers become greater with Parkinson's progression, recognising that motor complications and cognitive decline are more prominent in the later stages of Parkinson’s (Kalia and Lang 2015)

The presence of NMS which typically predate the motor symptoms of Parkinson's were also highlighted as barriers to PA. Fatigue, apathy, and reduced motivation were widely reported as barriers to PA in several studies involving different forms of PA (MacCosham et al. 2018, 2019; Rossi et al. 2018; Hunter et al. 2019; Terrens, Soh and Morgan 2021), suggesting fatigue is an independent barrier regardless of activity type or intensity. Non-motor symptoms, in particular fatigue, were cited as a key barrier to starting, and committing to regular PA. A recent prevalence study indicated that 46.8% of PLwP report fatigue compared to 3.5% in aged-matched controls (Siciliano et al. 2018), illustrating that fatigue is a PA barrier which may affect a significant proportion of PLwP. As fatigue predates development of Parkinson's motor symptoms (Schrag et al. 2015), inactivity caused by fatigue could be an established behaviour prior to diagnosis, highlighting the importance of addressing PA behaviour from diagnosis. Prior PA history has been shown to be a determinant of PA later in life among PLwP (Chen et al. 2016). Therefore, interventions which aim to promote PA should not be restricted to those with motor symptoms but should be commenced at diagnosis to support changes in PA behaviour.

Fatigue, and low energy have been reported as barriers to PA particularly among PLwP contemplating or starting PA but were not reported among those with an established PA routine (MacCosham et al. 2018). A recent study involving 1,029 PLwP demonstrated that PLwP who reported higher PA using the Physical Activity Scale for the Elderly (PASE) reported less fatigue (Lin et al. 2021), implying that PA may influence fatigue levels. The underlying mechanism of how PA may positively influence fatigue is undetermined (Lin et al. 2021). MacCosham et al (2018) demonstrated that when PLwP are supported to be active, and develop a regular PA routine, fatigue no longer presents itself as a barrier to PA engagement. It could therefore be suggested that the provision of education may be pivotal to shape beliefs, and behaviours in relation to PA among those with NMS such as fatigue.

Lack of social support to initiate and sustain physical activity

Social support from family and friends were reported as instrumental to commencing and maintaining of PA (Hunter et al. 2019). In the absence of support, many PLwP reported that they would not have attended PA interventions (Hunter et al. 2019). Lack of social support was perceived as a barrier for all types of PA, and regardless of mode of delivery, i.e., one-to-one, or group-based PA.

MacCosham et al (2018) mapped PA barriers to a four-stage model of behaviour change based on the Transtheoretical model of behaviour change described by (Prochaska and Velicer 1997). During the pre-intention phase when PLwP were considering being active, PA was perceived as intimidating, and PLwP expressed reluctance to socialise, and avoided social environments, yet many PLwP reported feeling isolated (MacCosham et al. 2018). These barriers were shown to persist until PLwP commenced a PA programme. When developing a PA intervention, providing 1:1 PA sessions may therefore be preferable to group-based PA initially, enabling people to develop PA confidence, and self-efficacy prior to participating in group-based activity. Although the study by MacCosham et al (2018) was small (n=12), it suggests that PA barriers and motivators may change over time. Intra and interpersonal factors predominated during the pre-intention and intention phases, whereas environmental factors were more predominant during the maintenance phase. This would imply that PA is a modifiable behaviour when PLwP are adequately supported and enabled to overcome barriers. Some evidence exists to support this from the review conducted by Hunter et al. (2019). All the studies included in the Hunter review used samples who were active or had just completed a PA programme. Synthesised findings highlighted that social support provided opportunity for shared experience, peer support, camaraderie, and sense of community, which were perceived as key motivational factors (Hunter et al. 2019). This may infer that once PLwP are supported to be active, social environments are perceived as motivational factors not barriers to PA.

Both mixed method and qualitative study designs reported that the benefits of social support extended beyond physical benefits, providing holistic benefits including social, physical, and emotional support (MacCosham et al. 2018, 2019; Rossi et al. 2018; Johansson et al. 2019; Mantri et al. 2019b; Spencer, Haub and Rockers 2020; Krishnan Vasanthi et al. 2021; Atkins et al. 2022; Bennett et al. 2022; Borrero, Miller and Hoffman 2022; Carroll et al. 2022). Synthesised findings from the Hunter review demonstrated that shared experience combined with the sense of belonging and mutual support in group-based PA provided a safe and supportive environment, which may also attribute to the positive experience associated with

PA identified earlier. This would suggest while the lack of social support is a barrier to commence activity, it is also key for long-term maintenance of PA as well as well-being.

Social and professional support is required to promote physical activity engagement.

The NICE Guidelines for Parkinson's recommend that PLwP should see a Parkinson’s specialist (NICE, 2017), however, access to specialists is frequently cited as an unmet need by the Parkinson's community (Vlaanderen et al. 2019). The lack of referral and guidance from healthcare professionals (HCPs) was highlighted as a key barrier by Hunter et al. (2019). Insufficient access to Parkinson's specialist HCP’s is reiterated by more recent studies published after the Hunter review (MacCosham et al. 2018; Bennett et al. 2022; Carroll et al. 2022). The 2017 Parkinson’s UK audit identified that only 16.8% of PLwP were referred with Physiotherapy at diagnosis, with half of patients completing the audit seeing a Physiotherapist within two years from diagnosis. Seeing a Parkinson’s specialist is associated with improved health outcomes (Ypinga et al. 2018), yet the 2019 Parkinson’s UK audit highlighted that nearly half of Physiotherapists completing the audit did not work as part of a Parkinson’s multi-disciplinary team, and only a third (30%) of Physiotherapists had access to a Parkinson's specialist team for support. In addition, 2019 Parkinson's UK audit highlighted limited access to training for existing and staff new to working with Parkinson’s (Parkinson’s UK, 2019). Therefore, while clinical guidelines may advocate seeing a specialist Physiotherapist (NICE 2017; Osborne et al. 2022), in practice few PLwP get referred to a Parkinson’s specialist Physiotherapist. Limited access or referral to specialist Physiotherapy could be attributed to insufficient provision of post-registration training/education or a lack of clarity in what constitutes a Parkinson’s specialist Physiotherapist.

Clinical competencies for Allied Health Professionals including Physiotherapists were published in 2018, co-produced by Neurological Charities and clinical experts (Allied Health Professions Competency Framework for Progressive Neurological Conditions 2018). This framework details key knowledge and competencies for specialist and highlight specialist Physiotherapists working with PLwP. However, to date no training had been developed to support the attainment of these competencies. A Dutch study demonstrated that 75% of HCP’s lacked expertise in Parkinson’s despite having a large Parkinson’s case load, and 50% had undertaken no post registration Parkinson's Training (Nijkrake et al. 2009). HCPs who regarded themselves as "Parkinson’s Specialists” saw more PLwP per year compared to self-reported non-experts (7±7.4 compared with 3.3±2.7) and were more likely to have had Parkinson's training (35% compared with 6%) and had a greater awareness of other treatment options for example Occupational Therapy compared to non specialists. The lack of post-registration training to develop specialist Parkinson’s skills may explain why large RCT’s such as the ParkFit (van Nimwegen et al. 2011, 2013) and ParkSafe (Chivers Seymour et al. 2019), both included Parkinson's specific training to all staff delivering the exercise components within these studies.

A retrospective observational study that analysed health insurance claims in the Netherlands demonstrated that Parkinson’s care was optimised when delivered by professionals with dedicated Parkinson’s training, leading to enhanced quality of care and improved cost-effectiveness (Ypinga et al. 2018). Cross-sectional studies (table 2.4) highlighted that Parkinson’s specialist instructors were integral to motivate and maintain PA among PLwP (Krishnan Vasanthi et al. 2021), even among highly motivated and physically active PLwP (Afshari, Yang and Bega 2017). The ability of Parkinson’s specialists to personalise and modify prescription to address individual needs were frequently cited as motivational factors within mixed methods studies (Alberts and Rosenfeldt 2020; Spencer, Haub and Rockers 2020; Krishnan Vasanthi et al. 2021; Prakash et al. 2021); table 2.5. Qualitative studies have also demonstrated that access to a Parkinson’s specialist was a “*big attraction*” to commence and continue with PA (Carroll et al. 2022). The ability of Parkinson's specialists to educate, motivate, personalise, and adapt interventions was widely perceived as a motivational factor (Carroll et al. 2022). Other studies highlighted that the ability of specialist staff to prescribe fun, enjoyable and varied programmes was also regarded as a key motivational factor (Rossi et al. 2018). Therefore, current evidence would suggest that access to Parkinson's specialists optimises PA delivery, promotes PA adherence, and is associated with enhanced cost-effectiveness. However, limited access to such professionals serves as a significant PA barrier for the Parkinson’s community. While access to Parkinson's specialists is advocated in clinical guidelines (NICE 2017; World Health Organisation 2021), current evidence would suggest that a gap exists in current service provision, which may be attributed to limited training opportunities for staff (Armstrong et al. 2021).

Accessibility and environmental barriers to physical activity

Traditionally, PA has been delivered in clinical settings, at home or community leisure facilities. However, environmental factors, in particular transportation have been identified as key barriers to PA (MacCosham et al. 2018, 2019; Hunter et al. 2019; Krishnan Vasanthi et al. 2021; Terrens, Soh and Morgan 2021; Carroll et al. 2022). Access to public transport, or anxieties associated with parking were highlighted, as well as a sense of burden by those who were dependent on others for transportation. Even when PLwP had an established PA routine, environmental factors remain a persistent barrier due to costs associated with gym memberships and transportation (MacCosham et al. 2018). Alternatives such as use of telehealth via online video conferencing may be a potential solution, particularly in Scotland where a large proportion of PLwP live rurally, where distance and transport links are often limited. Barriers and motivators to online delivery of PA are discussed in section 2.3.5.

Hunter et al. (2019) also highlighted that the PA environment serves as both a barrier and a motivator to PA, with some barriers being site specific. For example, two studies exploring hydrotherapy reported water-based anxieties and barriers associated with accessibility of changing facilities (Terrens, Soh and Morgan 2022, and Carroll et al. 2022). In addition, clinically delivered PA interventions, although perceived as beneficial, were typically brief, after which PLwP reported it was difficult to maintain PA independently, which promoted deconditioning (Rossi et al. 2018). A Phase II randomised controlled trial (RCT) demonstrated that community-based PA delivered by fitness instructors were safe and led to potential long-term benefits (Collett et al. 2017). The study by Collet et al (2017) would suggest that PA delivered within leisure facilities offers a de-medicalised environment, may be a sustainable long-term alternative to the clinical environment, which would be advantageous due to finite healthcare resources. Section 2.3.3 highlighted that access to Parkinson's specialists was a key motivational factor. A discrete choice experiment involving over 400 PLwP highlighted preferences existed for PA programmes delivered by Physiotherapists with expertise in Parkinson's disease (OR 1.51, 95% CI 1.08 to 2.11, $p = 0.02$) or qualified exercise instructors with expertise in Parkinson's disease (OR 1.91, 95% CI 1.18 to 3.09, $p = 0.009$). This would imply that it is the Parkinson's knowledge and expertise which is valued, with greater preference for Fitness Instructor led PA programmes.

The findings from a focus group study highlighted a willingness to attend leisure facilities, however clear caveats on accessibility were expressed (Elsworth et al. 2009). PA interventions delivered in leisure facilities presented barriers associated with membership costs (Paul et al. 2021), accessibility and self-confidence (Bognar et al. 2016). A report commissioned by Parkinson's UK reported that PLwP perceive gyms as *"daunting places… full of young… lithe… beautiful people…in Lycra!" (*Parkinson's UK, 2019b, Power report). It is unclear whether participants in the Parkinson's UK report were gym users or not, therefore, the views expressed may simply reflect their perceptions of gyms rather than their experiences. Environmental barriers associated with leisure facility-based studies are not universally expressed (Rossi et al. 2018). Semi-structured interviews conducted among PLwP who had participated in a 16 month Staying Active Programme, suggested that motivators of long-term PA were less dependent on the environment (Rossi et al. 2018). Ene, McRae and Schenkman (2011) highlighted that appropriate facilities and programs that were tailored to individual needs, which were suitably challenging, enjoyable, affordable, easily accessible and delivered by motivational and knowledgeable staff, were the key motivators to supporting long-term PA engagement. The literature suggests mixed views exist in relation to environmental barriers. While practical barriers such as transport cannot always be overcome, the studies included in this review would also suggest that some environmental barriers are sometimes assumed, and when adequately supported, PLwP can be enabled to participate in PA run within leisure facilities.

2.3.5 Barriers and motivators use of telehealth to delivery physical activity

Traditionally, PA interventions have been delivered within the clinical environment or within the community. More recently, telehealth has been used to deliver PA. The WHO define telehealth as healthcare services delivered by HCP's, using information and communication technologies, such as online video-conferencing (WHO, 2022). The search strategy identified four studies (Lai et al. 2020; Garg et al. 2021; Bennett et al. 2022; Torriani-Pasin et al. 2022) which explored barriers and motivators to PA interventions for PLwP delivered via telehealth which are summarised in table 2.5. Three studies adopted a mixed methods approach, two combined a survey with focus groups (Torriani-Pasin et al. 2022; Bennett et al. 2022) and the other, used quantitative Parkinson's measures pre- and post-intervention combined with semi structured interviews (Lia et al. 2022). The fourth study used a satisfaction survey to gauge perceptions of online delivery of PA (Garg et al. 2021). Prior research has indicated that uptake of technology is low in older people (Turner and McGee-Lennon 2013), however, none of the four studies reported that telehealth-based technology was a barrier for PLwP. Rather, telehealth delivered PA was perceived as convenient, mitigating the barriers of transport, parking, and the anxiety this causes (Lai et al. 2020; Garg et al. 2021; Bennett et al. 2022; Torriani-Pasin et al. 2022). Using technology such as Zoom was not perceived as a barrier, however, internet stability, and connectivity was a potential barrier causing frustration (Lai et al. 2020, Garg et al. 2021). These findings align with recent systematic review findings which have reported that online delivery of PA is effective for chronic conditions (Brown et al. 2022), and among older people (Lilian Solis-Navarro 2022).

Prior sections have highlighted that personalisation of PA is a key PA motivator (Hunter et al. 2019). This ability to personalise PA was also shown to be feasible during online delivery (Lai et al. 2020; Garg et al. 2021; Bennett et al. 2020; Torriani-Pasin et al. 2022). However, fostering social cohesion during online delivery was inconsistently reported. Limited capacity for social interaction was reported by participants who received PA tele-coaching using videoconferencing (Lai et al. 2020). Conversely, this was not reported in the PDEx study (Bennett et al. 2022). This difference could be explained by the mode of delivery, as the PDEx delivered Parkinson's specific exercise (Parkinson’s Wellness Recover) as a group, via telehealth, whereas PA was delivered one-to-one in the study reported by Lai et al (2020). Therefore, lack of social cohesion reported by Lai et al (2020) may also had occurred had it been delivered face-to-face, rather than attributed to the online delivery.

Exercising with others was identified as a key motivator in the systematic reviews conducted by Hunter et al (2019), providing a “safe” exercise environment, offering potential for shared experience and learning. The PDEx study was converted to online delivery in response to COVID-19, therefore participants may have established strong social connection prior to meeting online which may also explain why they did not perceive online as a limitation to social engagement.

While telehealth was perceived as convenient (Lai et al. 2020), practical barriers were reported. Telehealth offered no capacity for hands-on feedback from the instructor (Bennett et al. 2022). Limited fine motor skills and technical skills were also reported as barriers with using smart devices (Garg et al. 2021). All four studies reported that telehealth-based PA was feasible, however preference existed for face-to-face delivery (Garg et al. 2021; Torriani-Pasin et al. 2022), or a hybrid approach to delivery, combining face-to-face and online delivery (Lia et al. 2020, Bennett et al. 2022). As all four studies were conducted prior to, or during the early stages of COVID-19, the views captured in these studies may no longer accurately reflect this approach to delivery. Therefore, further research may be required as social distancing rules are now either relaxed or non-existent, to ascertain whether this preference for hybrid or face-to-face is still valid.

2.3.6 Section summary

This section of the narrative review has highlighted that multiple factors influence PA among PLwP, and that these barriers change over time. PA is influenced by a complex interaction of factors related to the individual, and their beliefs, as well as access to PA support.

The principal methodological limitation of the studies exploring the barriers and motivators to PA is that most studies have recruited PLwP who are currently active, therefore the barriers to PA among those who are not active is not known. While participants may not always have been active, the potential for recall bias is high in the studies included in this review. The review conducted by Hunter et al. (2019) also highlighted the methodological quality of many of the studies included were of low, limiting the reliability of the conclusions drawn from this review. A large proportion of the primary studies included in this narrative review adopted convenience or purposeful sampling, involving small numbers of PLwP. In addition, the majority of studies recruited people in early to mid-stages of Parkinson's therefore the barriers and motivators among newly diagnosed and those in later stages of Parkinson's remains unknown. No studies explored whether differences existed between males and females. A recent Australian study involving 1845 people aged between 60-67 demonstrated motivational factors associated with PA differed between genders (Lindsay Smith et al. 2017). Women were more motivated by social factors and were less motivated by vigorous forms of PA or PA undertaken alone, compared to men (Lindsay Smith et al. 2017). The Parkinson's symptom profile differs between males and females (Cerri, Mus and Blandini 2019), with Parkinson's progressing at a faster rate in females (Dahodwala et al. 2018), and females also experience greater levo-dopa motor complications (Colombo et al. 2015), which may also influence perceived barriers and motivators to PA.

While methodological limitations are evident within both quantitative and qualitative studies, consistent themes arose which highlight factors which may enable and optimise PA engagement as well as inhibit PA and these are summarised in table 2.6. Barriers and motivators need careful consideration when developing PA interventions aimed at shaping PA behaviour among PLwP. On an intrapersonal level, self-efficacy was identified as a key determinant of PA. Development of self-efficacy was enabled through the provision of education, supported by healthcare professionals with expertise in Parkinson's. Personalised prescription of PA, which was enjoyable and delivered in tandem with education on the benefits of PA also facilitated PA adherence. However, this review also highlighted that Parkinson's symptoms, in particular NMS, were a significant barrier to commencing and maintaining PA. Due to inconsistent access to HCP's, lack of awareness of the benefits of PA was also a significant PA barrier, reiterating the importance of education to influence PA behaviour.

On an interpersonal level, social support was widely reported as a motivating factor to engage in PA, with those lacking in social support reporting this as a significant barrier to commencing PA. Once active, social support from the wider Parkinson's community facilitated adherence and provided a conduit for peer support, shared learning, and camaraderie. Social support was widely perceived as a motivational factor, due to low self-confidence, perceptions of self-identity, fear of seeing one's future self. This emphasises the need for PLwP to be adequately supported to participate in PA interventions.

Looking more broadly, PA which incorporates opportunities for social engagement, which are accessible long-term, delivered locally and are affordable are desirable factors. Interventions aimed at increasing PA need to consider these factors to ensure optimal participant engagement. Parkinson’s specialist staff were valued by PLwP, however brief interventions or lack of access to professionals were perceived as significant barriers. This would suggest there is a need for more sustainable approaches to PA intervention in the future.

Finally, environmental factors had a pivotal role in long term PA behaviour. Transportation and/or dependency on others for transportation was a widely reported barrier. Equally the accessibility of the PA environment resulted in significant challenges to PA participation. This narrative review also highlighted the challenges of traditional clinical PA environments and proposes that leisure facilities may provide a more sustainable long-term alternative. However, both options are challenged by dependency on transportation. Alternatively, the use of online videoconferencing negates the dependency on transportation and subsequently reduces health inequalities. The convenience of exercising at home was highlighted as a feasible option to support PA for PLwP. While online delivery of PA offers many advantages, this needs to be balanced with potential for widening health inequalities, owing to lack of access and competency using digital technology.

Table 2.6 Summary of facilitators and barriers to physical activity among PLwP

	Facilitators	**Barriers**
Intrapersonal Factors	Exercise self-efficacy Sense of empowerment Capacity and capability to be active Knowledge, beliefs, and attitudes in relation to PA Guidance from Parkinson's specialists Enjoyment Prior history of being PA	Non-motor Parkinson's symptoms in particular fatigue, apathy, and depression Co-existing morbidities Disempowered Lack of knowledge of benefits of PA Lack of professional support History of sedentary behaviour
Interpersonal Factors	Social support Guidance and support from Parkinson's specialists Development of social network Group based PA Development of camaraderie	Lack of access to social support Lack of professional support Lack of signposting to PA opportunities Social stigma and social isolation Reluctance to socialise
Environmental Factors	Enjoyment Parkinson's specific classes Specialist Professionals, who are motivated and passionate Variation in PA types Variety of PA setting	Cost Transportation, and PA environments Activities pitched too low or high Inability of professional to adapt PA to meet individual needs Short duration of classes

2.4 CHANGES IN PHYSICAL ACTIVITY BEHAVIOUR

The previous section of this review highlighted the key barriers and motivators to PA participation. Specifically addressing these factors within PA interventions may help improve PA engagement. However, enabling increased PA and PA self-management among PLwP requires a change in PA behaviour. The need to identify ways of promoting sustained changes to PA behaviour is widely recognised within published literature (Ellis and Motl 2013; Speelman et al. 2014; Aktar, Balci and Donmez Colakoglu 2020). The focus of this section of the review is to explore current literature on how best to support behaviour change among PLwP. The NICE public health guidance on behaviour change (Abrahams et al. 2017) highlights that supporting people to change from a sedentary lifestyle is complex. In their "future of exercise" paper Ellis and Rochester (2018) highlighted that simply prescribing PA is insufficient to change PA behaviour. Similarly, informing people of the benefits of PA, likewise does not lead to sustained changes in PA behaviour (Abraham et al. 2009). Currently, PA interventions typically provide short-term benefit. However, when these interventions cease, PA levels decline, and PLwP return to prior sedentary levels of activity (Lauzé, Daneault and Duval 2016). This would suggest that current interventions are missing a vital ingredient to support PLwP to develop a long-term PA activity habit.

2.4.1 Behaviour change models

Many behaviour change models and theories exist (Davis et al. 2015), although no one model dominates health research and practice (Michie et al. 2013). No guidance exists to inform theory selection, leading to researchers selecting specific aspects of one theory or basing intervention design on one or more models (Cane, O'Connor and Michie 2012), limiting replication, implementation, and evaluation (Michie, van Stralen and West 2011). An umbrella review conducted by the ACSM PA Guideline Advisory Committee highlighted five key behaviour change theories which are commonly applied in relation to PA (King et al. 2019). The key principles of each model are provided in table 2.7. These five behaviour change theories guided the search strategy adopted in this section of the narrative review.

This section of the review critically discusses the theoretical models of behaviour change in relation to PA. In addition, it will explore and discuss the current use of behaviour change interventions/approaches/techniques to promote behaviour change among PLwP. This section will finish by summarising the literature, highlighting the optimal approaches and ingredients to enable change in PA behaviour.

Table 2.7 Overview of the five key behaviour change theoretical models commonly applied to physical activity

Theoretical Model	**Guiding principles**
Theory of planned behaviour (TPB) (Fishbein and Ajzen 1975)	TPB evolved from the Theory of Reasoned Actions Change in behaviour is dependent upon intention and ability Intent is influenced by attitudes associated with the behaviour to changed and the perceived risks and benefits associated with the change
Self-Determination Theory (SDT) (Deci and Ryan 2008)	Proposes that behaviour is governed by motivation (intrinsic and extrinsic), which shape who we are and how we behave Extrinsic motivation is behaviour that is influenced by external sources and is associated with reward Intrinsic motivation comes from within, influenced by values, morality and ethics The guiding principles include autonomy, competency, relatedness
Trans theoretical model of Behaviour Change (TTM) (Prochaska and Velicer 1997)	TTM is a model of intention change, which focusses on the decision making of individuals Individuals move through six stages of change: pre-contemplation contemplation, preparation, action, maintenance, and termination
Social Cognitive Theory (SCT). (Bandura 2004)	Learning occurs within a social context arising from interactions with others Behaviour, cognitive, personal, and environmental factors interacting with each other to determine behaviour Development of self-efficacy is central to changing behaviour Five constructs: Reciprocal determinism, behavioural capability, observational learning, reinforcement, expectations
Theoretical domains framework (Michie et al. 2005)	Summation of 33 behaviour change theories Consists of 14 domains: 1) knowledge; 2) skills; 3) social role and identity; 4) beliefs about capabilities; 5) optimism; 6) beliefs about consequences; 7) reinforcement; 8) intentions; 9) goals; 10) memory, attention, and decision processes; 11) environmental context and resources; 12) social influences; 13) emotion; and 14) behaviour regulation

2.4.2 Behaviour change search strategy

A search of the literature was undertaken to explore the use of behaviour change theory and techniques in relation to PA interventions for PLwP. As with the prior section, the JBI three-step systematic search strategy was employed (Lockwood and Oh 2017) prior to conducting a narrative review.

The key MeSH terms, subject headings and text words used within each database are illustrated in table 2.8. In addition, the five models identified in table 2.7 were used as key search headings. No limitation was placed on study design, stage of Parkinson's or PA type. Studies were excluded if no reference to a behaviour change model, theory, or technique were made within the study. The definition of a behaviour change model proposed by Michie et al (2011) was used for the purposes of this narrative review – "*a model designed to help us understand behaviour and identify the underlying factors that influence it*". Behaviour change techniques (BCTs) are defined as *"an observable, replicable component of an intervention designed to alter or redirect causal processes that regulate behaviour*" (Michie et al. 2013). The terms behaviour change theory and model were searched as both are used within the literature. Models of behaviour aim to promote understanding of factors which explain behaviour, whereas theories of behavioural changes are more practically focussed, which can be applied to influence or change behaviour. The PRISMA flowchart (Figure 2.2) summarises the screening process of identified articles, highlighting the number of articles located and reasons for exclusion. Table 2.9 provides a summary of all articles which are included within this section of the narrative review.

Table 2.8 Behaviour change search strategy

	MEDLINE
#1	MM parkinson’s disease OR TX parkinson’s OR Tx Parkinson*
#2	MH "Exercise+" OR exercise* OR MH sedentary behaviour OR TX “physical activity” OR TX “physical fitness” OR TX “activity” OR AB “activity” or MH “physical therapy modalities”
#3	(MH "Behavior Therapy+") OR "behaviour change" OR (MH "Change Management") OR (MH "Health Behavior") OR (MH "Sedentary Behavior") OR (MH "Behavior") OR "Theory of planned behaviour" OR "self determination theory" OR (MH "Psychological Theory") OR (MH "Social Theory") OR (MH "Transtheoretical Model") OR "Transtheoretical model" OR MH "Psychological Theory") OR "social cognitive theory" OR (MH "Models, Theoretical") OR "Theoretical domains theory” OR (MH "Cognitive Behavioral Therapy") OR (MH "Behavior Therapy") OR (MH "Health Behavior") OR (MH "Behavior Therapy+") OR (MH "Health Belief Model") OR (MH "Health Behavior") OR "health belief" OR (MH "Health Education") OR (MH "Motivation") OR (MH "Motivational Interviewing") OR (MH "Change Management") OR (MH "Behavior Therapy") OR (MH "Self-Management") OR "behaviour management" OR (MH "Behavior Observation Techniques") OR (MH "Behavior Therapy") OR "behaviour change techniques" OR TX (com-b model or com-b or com b or com-b framework)
#4	#1 AND #2 AND #3
	CINAHL
#1	(MH "Parkinson Disease") OR "parkinsons disease" OR parkinson's disease or parkinson disease or parkinsons disease or pd or parkinsons or parkinsonism
#2	(MM "Exercise") OR (MH "Resistance Training") OR TX “strength exercise” OR TX “strength training” OR (MH "Group Exercise") OR (MM "Aerobic Exercises") OR (MH "Aerobic Dancing") OR (MM "Balance Training”) OR TX “balance exercise” OR (MM "Rehabilitation") OR (MM "Therapeutic Exercise") OR TX “Physical Fitness” OR TX physical activity or exercise or fitness or physical exercise OR TX strength training or resistance training or weight training or resistance exercise OR TX aerobic exercise or aerobic training or physical activity or exercise or physical exercise OR TX Physiotherapy or physical therapy or physiotherapist or physical therapist
#3	(MH "Behavioral Changes") OR (MH "Transtheoretical Stages of Change Model") OR "behaviour change" OR (MH "Behavior Therapy") OR (MH "Cognitive Therapy") OR "behaviour therapy" OR (MH "Health Behavior") OR (MH "Health Belief Model") OR "health belief model" OR (MH "Health Beliefs") OR (MH "Transtheoretical Stages of Change Model") OR "Transtheoretical model" OR "Theory of planned behaviour" OR (MH "Ajzen's Theory of Planned Behavior") OR "self-determination theory" OR (MH "Bandura's Social Cognitive Theory") OR (MH "Social Learning Theory") OR (MH "Change Management") OR (MH "Behavioral Changes" OR (MH "Behavioral Changes") OR TX com-b model or com-b or com b or com-b framework OR TX behavior change techniques OR TX behaviour change techniques OR TX behaviour change or lifestyle change or behaviour modification
#4	#1 AND #2 AND #3

Table 2.8 Behaviour change search strategy (continued)

SPORTDiscus, AMED and Web of Science search strategy	
#1	Parkinson’s disease OR Parkinson's Disease OR parkinson’s disease OR parkinsons disease OR PD or pd OR Parkinson's
#2	TX Physical activity OR activity OR TX exercise OR physical exercise OR physical fitness OR TX strength training OR resistance training OR weight Training OR balance exercise OR TX balance training OR balance training OR balance programme OR aerobic exercise OR TX Aerobic training OR Rehabilitation OR therapy OR treatment OR Intervention
#3	TX behaviour change OR TX behavior change or behavior modification OR TX behavior change or behavior modification or lifestyle change or behavior change techniques OR health behaviour change OR health behavior change interventions OR health belief model or health belief theory or hbm OR theory of planned behavior or theory of planned behaviour or tpb OR self determination theory or sdt or self-determination theory OR transtheoretical model of change or stages of change or tmc OR social cognitive theory or sct or social-cognitive theory OR theoretical domains framework OR com-b model or com-b or com b or com-b framework
#4	#1 AND #2 AND #3

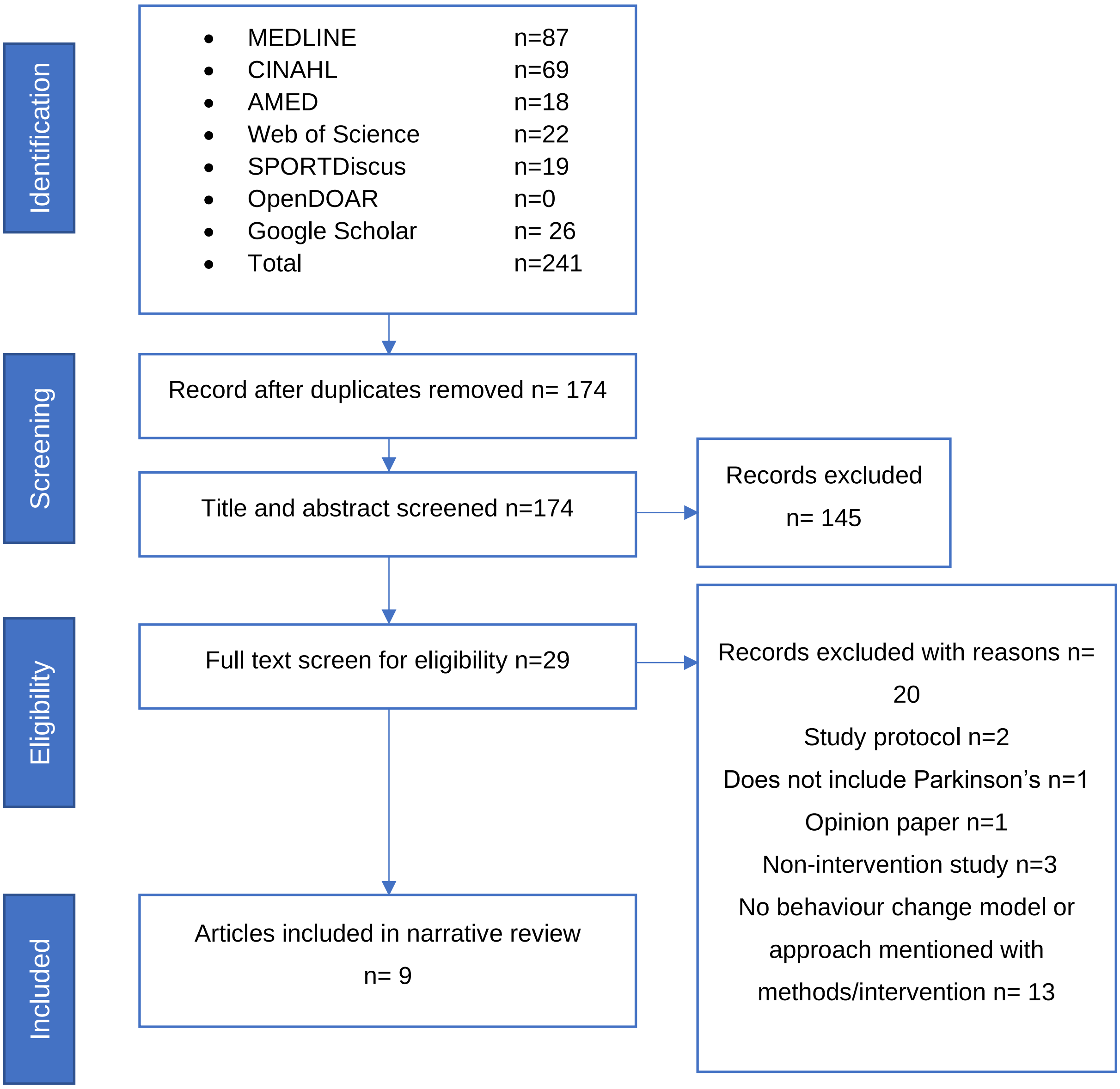


Figure 2.2 PRISMA flowchart of behaviour change models

2.4.3 Critical review of behaviour change models and theories

The Medical Research Council (MRC) Guidelines for the development of complex interventions recommend that interventions should be grounded in theory (Skivington et al. 2021). Therefore, an understanding of behaviour change models and theories was essential to underpin the intervention being explored in this Thesis. Overlap exists between behaviour change models and theories. All share the same ideology that individuals are agents of their actions, with ability to exert control over their affairs, through either the development of self-efficacy, ability, or autonomy. The use of behaviour change approaches are advocated in the American Physical Therapy Parkinson's Disease guidelines (Osborne et al. 2022), and it is widely regarded that behaviour change interventions should form an integral part of PA interventions (Ellis et al. 2019; Aktar, Balci and Donmez Colakoglu 2020; Ahern et al. 2022). However, only nine studies were identified from the literature search. This small number could be attributed to inadequate reporting or how behaviour change approaches are reported within PA interventions. A recent analysis of the Clinical Trials Registry highlighted that few Parkinson’s PA trials studies complied with the SPIRIT guidelines (Silva et al. 2019), and historically, PA interventions have been largely atheoretical (Buchan et al. 2012). Consequently, many PA studies may have employed recognised behaviour change techniques (BCT’s), such as self-monitoring, or feedback, however, the studies themselves may not be grounded in any theoretical model or reported these as BCT’s. Michie et al (2013) define BCTs as “an observable, replicable component of an intervention designed to alter or redirect causal processes that regulate behaviour”.

Studies identified from the search were published between 2012 and 2022, with the majority conducted in the United States of America (Chang, 2012; Long, 2019; Ellis et al. 2019; Lai et al. 2020; Quinn et al. 2020; Shih et al. 2022). The remainder were conducted in the Netherlands (van Nimwegen et al. 2013; Speelman et al. 2014), and Korea (Chang et al. 2019). No studies were identified from the United Kingdom. All studies recruited ambulatory people with mild to moderate Parkinson’s. Five studies involved interventions delivered using telehealth (Ellis et al. 2019; Lee et al, 2019; Lai et al. 2020; Quinn et al. 2020; Shih et al. 2022) reflecting the potential of telehealth-based interventions to promote behaviour change due to their capacity to increase participant reach, and potential for scalability (Vassilev et al. 2015).

An overview and key findings of the nine studies are presented table 2.9. Two studies were doctoral theses with no associated journal publications (Long et al. 2019 and Chang et al. 2012). Study design varied and included two RCT’s reporting of differing aspects of the same intervention (van Nimewegen et al. 2013; Speelman et al. 2014), one pilot RCT (Ellis et al.

2019), two feasibility and acceptability studies (Long et al. 2019; Shih et al. 2022), two quasi-experimental studies (Lai et al. 2020, Lee et al. 2019), a single cohort study (Chang et al. 2012) and a case report (Quinn et al. 2020). Three studies related to 'Engage-PD', a PA intervention grounded in self-determination theory (SDT), designed to increase PA through a coaching programme supported by a Parkinson's specific workbook. Participants were encouraged to exercise three times a week for a total of 150 minutes supported by five 1:1 tele-coaching session over three months (Shih et al. 2022). Long et al. (2019) explored the feasibility of Engage-PD among six PLwP, which was later explored by Shih et al (2022) in a larger cohort (n=62 PLwP). A case report by Quinn et al. (2020) described the delivery of Engage-PD online during COVID-19. Two studies related to the 'ParkFit' intervention, which drew from the Transtheoretical Model of Health Behaviour Change and Social Cognitive Theory (SCT). Participants received 35, thirty-minute Physiotherapy sessions over the course of the year. Like Engage-PD, delivery of ParkFit adopted a coaching approach supported by a workbook. Van Nimewegen et al. (2013) evaluated the impact of a multifaceted behavioural change programme (ParkFit) on PA among PLwP whereas, Speelman et al. (2014) explored participants' and Physiotherapists' experiences of ParkFit. Of the remaining four studies, one explored the use of SDT to increase motivation within an eight-week Physiotherapy Intervention (Chang et al. 2012). The remaining three studies were all grounded in SCT. Ellis et al. (2019) explored an individually tailored home exercise and walking program enhanced with mHealth technology (Ellis et al. 2019). Lai et al. (2020) compared tele-coach-assisted PA (TAE) delivered over eight weeks with self-regulated exercise (SRE). Finally, Lee et al. (2021) explored the effectiveness of PA delivered twice a week, for 12 weeks, supported by fortnightly telephone motivational counselling.

No studies were underpinned by the Theory of Planned Behaviour (TPB) or the Theoretical Domains Framework (TDF). The TPB model has been used extensively in health behaviour and PA literature, although it is also subject to criticism (Buchan et al. 2012). The strengths of TPB lie with predicting behaviour, however, as a framework to inform the intervention development, it is regarded by some as ineffective (Sniehotta et al. 2014), which may explain why no studies reported its use. The following sections will explore the applications of these models and theories within PA and Parkinson's.

Table 2.9 Summary of behaviour change studies

Author and aims	**Behaviour change model or theory**	**Study design**	**Intervention**	**Outcome measure**	**Key findings**
Chang et al. (2012) To determine the effectiveness of SDT increase motivation in PLwP.	Self-determination Theory.	Quantitative within-subject design. n=10	8-week personalised PA programme. Motivational interviewing used in each session.	TUAG Tinetti gait and balance measure PDQ-8 Exercise Self-Regulated Questionnaire SRQ-E	No significant change in motivation measured by SRQ-E PDQ-8 average improvement 0.118. Changes in Tinetti and PDQ-8 (p=.0007 and p=.008 respectively) 60% continued Physiotherapy at end of study suggesting increased motivation to be active
Ellis et al. (2019) To explore the effectiveness, safety, and acceptability of a mobile health exercise program designed to promote PA in PLwP.	No model of behaviour change model identified.	12-month single-blind, pilot RCT. n=51	**Intervention group:** Walking with a pedometer plus engagement in planned exercise supported by the mobile Health app. **Control group**: Walking with a pedometer and exercise with no mobile technology. **Behaviour change components:** Goal setting. Personalised PA and feedback via activity tracker.	Step count PDQ-39 6MWT UPDRS III	Both groups increased daily steps, moderate-intensity minutes, and 6-MWT No statistically significant differences between-groups (steps −56 steps, 95% CI =−1494 to 1382; *P* =.94) PDQ-39 mobility improved for the mHealth group The behavioural change elements in the mHealth app benefits more active participants less Future studies: self-monitoring, and PT follow-up assessments to increase accountability, and sustain engagement

Table 2.9 Summary of behaviour change studies (continued)

Author and aims	Behaviour change model or theory	Study design	Intervention	Outcome measure	Key Findings
Lai et al. (2020) 1. Compare impact of TAE and SRE on the adoption of exercise behaviour 2. Explore participants' perceptions of intervention	Social Cognitive Theory	Mixed methods pilot study. n=20 PLwP	3 sessions a week for 8 weeks either supervised - TAE group or unsupervised SRE group. Behaviour change components of TAE: Real-time feedback and monitoring Behavioural coaching including goal setting	Attendance Time spent exercising per week Semi structured interviews	**Quantitative Findings** TAE: higher attendance (99.2% v 63.8%) SRE: 36% fewer sessions, 48% less total time exercising **Qualitative findings** convenience and monitoring capability of the telehealth system, increased sense of accountable Tele-coach, increased motivation, and confidence to exercise
Lee et al. (2019). To explore impacts of an PA Program and Motivational Telephone Counselling on HRQoL in PLwP.	Social Cognitive Theory	Mixed methods study. n=20 PLwP	**Intervention Group: PA** and telephone counselling for 12 weeks. Delivered by specialist nurses. **Control group**: usual care. **Behaviour change element:** Personalised information, exercise skills, motivational interviewing.	Short form IPAQ PDQ-39 Schwab and England ADL measure GDS-8 Functional fitness	**Quantitative Findings** Improved HRQoL No significant differences were found in ADL, depression, and functional fitness **Qualitative findings** Positive feedback about the exercise program, enjoyable, and increased PA.

Table 2.9 Summary of behaviour change studies (continued)

Author and aims	Behaviour change model or theory	Study design	Intervention	Outcome measure	Key Findings
Long et al. (2019) To evaluate feasibility and acceptability of Engage-PD	Self-determination Theory.	Single arm cohort, feasibility study. n=13 PLwP	6, 1:1 Physio sessions Behaviour change elements: Participant/therapist interaction PD-specific PA workbook Fitbit PA monitor with online monitoring platform. Therapist coaching manual Education, exercise plan, goal planning, self-monitoring	Montreal Cognitive Assessment. Readiness to change exercise behaviour.	Improved self-efficacy (*MD* = 5.55; 95% *CI* -1.74-12.74; *d* = 0.33) Improved regulation of motivation (*MD* = 0.21; 95% CI -0.14-0.55; *d* = 0.48) Increased planned PA (*MD* =; 95% *CI* -0.28-0.98; *d* = 0.45); Improvement in perceptions of performance (*MD* =3.09; 95% *CI* 2.12-4.06; *d* = 1.63) and satisfaction (*MD* = .58; 95% *CI* 1.72-4.06; *d* =1.63) Feasible and acceptable for PLwP
Quinn et al. (2020) To describe a PA coaching programme, *Engage-PD*, for newly diagnosed PLwP.	Self-determination Theory.	Single-cohort feasibility study. n=27 PLwP	**Intervention:** Coaching intervention for newly diagnosed PLwP, using BCTs to promote self-efficacy and motivation for PA. 3x weekly exercise.	TUAG 10-minute walk test 30-second chair stand test Brunel Lifestyle Physical Activity Questionnaire Norman Self-Efficacy Scale	Feasible to deliver online 4 participants experienced technology difficulties that took longer than 15 minutes to address, 12 participants had a carer or partner present during the sessions to assist with technology Quantitative data not provided within publication

Table 2.9 Summary of behaviour change studies (continued)

Author and aims	Behaviour change model or theory	Study design	Intervention	Outcome measure	Key Findings
Shih et al. (2022) To determine the feasibility and preliminary efficacy of *Engage-PD.*	Self-determination Theory.	A single cohort study. n=62 PLwP	Engage-PD: 3 months, including 5, 1:1 coaching sessions delivered on Zoom. 3 times per week PA and a total of 150 minutes. **Behaviour change element:** Focus on autonomy, relatedness, competence Included goal setting, shared decision making, feedback, and encouragement.	Brunel Lifestyle Inventory Exercise Self-Efficacy Scale ESE, COPM, Survey to explore participants perspectives	Recruitment and retention rate 62% and 85% High intervention acceptability Improvement in Brunel planned PA scores (*d* = 0.33), ESE (*d* = 1.20), and individualized goal performance (*d* = 1.63) and satisfaction (*d* = 1.70). Participants with lower baseline planned PA experienced greater improvements in planned PA, and those with lower baseline ESE experienced greater improvements in ESE.
Speelman et al. (2014) To explore experiences of therapists and patients with the ParkFit.	Transtheoretical model of behaviour change and Social Cognitive Theory.	Multicentre RCT. n=299	**ParkFit:** designed to increase PA includes BCTs **BCTS:** Health contract Self-monitoring Workbooks Activity coach Goal setting Physiotherapy	Therapists and patients completed questionnaire:	**Therapists:** 96% felt competent delivering ParkFit 78% ParkFit as planned Most frequent tools: Education (94%) and coaching (93%) **Participants:** 90% reported benefits 73% would recommend ParkFit 83% activity monitor as very useful

Table 2.9 Summary of behaviour change studies (continued)

Author and aims	Behaviour change model or theory	Study design	Intervention	Outcome measure	Key Findings
van Nimwegen et al. (2013) To evaluate whether a multifaceted behavioural change programme increases PA in PLwP.	Transtheoretical model of behaviour change and Social Cognitive Theory.	Multicentre RCT, 32 sites in the Netherlands. n= 586 PLwP	**Intervention arm:** ParkFit – programme to increase PA. **ParkFit workbook** Education about the benefits of PA Advice about suitable PA act Identifying and overcoming PA barriers Goals setting Health contract ParkFit Coaching Education Self-monitoring **Control arm**: matched Physiotherapy Both arms 35 sessions of 30 minutes a year.	LAPAQ, 6MWT, PDQ-39, time spent active per week, level of PA with diary, mUPDRS, TUAG, HADS, Fatigue severity scale, Åstrand-Ryhming test, falls and adverse events	No difference in PA levels as measured by LAPAQ (adjusted group difference 7%, 95% CI−3 to 17%; P=0.19) Increased PA as measured by PA diary (difference 30%; P<0.001), and activity tracker (difference 12%; P<0.001), and 6MWT ParkFit participants spent almost 1.5 hours a week extra on PA compared with controls No difference in PDQ-39 or falls rate between groups 12.8% did not complete the intervention

Abbreviations: TUAG: Timed up and go; PDQ-8: Parkinson’s Disease Questionnaire 8, SLUMS: St. Louis University Mental Status Examination, H&Y: Hoehn and Yahr Test, SRQ-E: The Exercise Self-Regulated Questionnaire, PT: Physical Therapist, TAE: telecoach-assisted exercise, SQRE: self-regulated exercise, RCT: Randomised controlled trial, 6MWT: six minute walk test, HADS: Hospital Anxiety and Depression Score; LAPAQ: LASA Physical Activity Questionnaire, mUPDRS: motor subsection of the Unified Parkinson’s Disease Rating Scale

2.4.4 Application of Self-Determination Theory

As shown in table 2.9, four studies used Self-Determination Theory (SDT) as a framework for intervention development and delivery (Chang et al. 2012; Long 2019; Quinn et al. 2020; Shih et al. 2022). Central to SDT is that people are motivated or self-determined to change (Ryan and Deci 2008). The guiding principles of SDT include autonomy, relatedness, and competency. Autonomy reflects an ability to make independent choices, which can be enabled through provision of education to enable informed decision-making. Relatedness is associated with feelings of connection, and belonging within a community, that is enhanced or facilitated through the development of a supportive environment. Competency is associated with the ability to do something successfully or effectively and is promoted by providing challenge and positive feedback. Chang et al. (2012) reported no change in motivation levels, as assessed by the Exercise Self-Regulated Questionnaire, following the eight-week PA programme which was delivered in parallel with motivational interviewing. The lack of effect could be attributed to the weekly format of the motivational interviewing. Emphasis was placed on reflecting on the prior week's exercise engagement. Interviewing focussed on exploring choices and autonomy with less emphasis upon relatedness and competency, which may have attributed to the lack of change in motivation reported by Chang et al. (2012). Equally, the short duration of the intervention (eight weeks) may have been insufficient to promote change. Application of several BCTs has been shown to be more effective (Howlett et al. 2019), therefore the dependency on one strategy or BCT, i.e., motivational interviewing, may also explain the non-significant findings reported by Chang et al (2012).

Conversely, the Engage-PD intervention which was informed by SDT demonstrated improved PA self-efficacy and increased planned PA (Long 2019; Shih et al. 2022). Using the Brunel Lifestyle Inventory, Shih reported small and medium effects sizes in relation to planned (Cohen's *d* 0.33, 95% CI: -0.058) and unplanned PA (*d*= 0.52, 95% CI: 0.12, 0.91 respectively). Large effect sizes were demonstrated in relation to self-efficacy as measured by the Exercise Self-Efficacy Scale (Cohen's *d* 1.20 95% CI: 0.78, 1.63). Engage-PD is an adapted form of Engage-HD, a PA coaching programme designed and shown to improve PA levels in people with Huntington's Disease (Busse et al. 2014). The positive findings associated with Engage-PD could be attributed to the number and variation of strategies which targeted the development of autonomy, relatedness, and competency. The ethos of Engage-PD was to promote a shift away from "passive patient", to "exercise participant" with the therapist adopting a coaching approach to communication with the aim of promoting autonomy and facilitating competency. Study specific workbooks provided education on awareness of barriers and motivators, goal planning, self-monitoring, and knowledge of Parkinson's, all delivered in tandem with five sessions of PA led by a study specific trained Physical or Occupational Therapist. Engage-PD was shown to be feasible and acceptable when delivered face-to-face (Long 2019) or online (Quinn et al. 2020; Shih et al. 2022). It is not possible, from the Engage-PD studies, to identify which component is the "active ingredient" facilitating changes in PA behaviour. However, in comparison to Chang et al (2012), the Engage-PD studies would indicate that a range of approaches or strategies is required to successfully support changes in PA behaviour.

The focus of the Engage-PD studies was intervention development and methodology testing, aligning with the MRC guidance which advocate robust evaluation of intervention feasibility testing prior to exploring effectiveness (Skivington et al. 2021). Due to the study design (feasibility and acceptability and single cohort study), none of the Engage-PD studies were designed, nor powered to demonstrate effectiveness, therefore this remains to be explored. Secondly, the Engage-PD studies recruited a single cohort of PLwP in Hoehn and Yahr stages I-III, therefore the impact of Engage-PD compared to control group and those in later stages of Parkinson's also requires to be explored. The promising findings of the Engage-PD study need to be explored further by means of a larger randomised study that is adequately powered to demonstrate potential short and long-term effectiveness of this approach.

2.4.5 Application of Social Cognitive Theory

Social-Cognitive Theory (SCT) is one of the most frequently applied theories of health behaviour (Baranowski, Perry and Parcel 2002) and was used in five of the studies identified from the literature search (van Nimewegen et al. 2013; Speelman et al. 2014; Lee et al. 2019; Ellis et al. 2019; Lai et al. 2020). Despite the popularity of SCT, it is widely criticised as it is a theory, and therefore does not provide a framework for application to practice, leading to a lack of standardisation in implementation within interventions. Within SCT, new behaviour is attributed to an individual's belief in their ability to succeed (Bandura 2004). Integral to SCT is self-efficacy, which is defined as the confidence individuals have in their capability to develop and meet planned goals, and is recognised as a powerful predictor of PA, among PLwP (Ellis et al. 2013).

Within the five studies adopting SCT, overlap existed in the strategies employed to influence PA behaviour. All studies used activity trackers allowing participants to self-monitor their PA. A recent meta-analysis demonstrated that self-monitoring of PA is an effective means of supporting behaviour change among sedentary adults (Compernolle et al. 2019). In a pilot RCT, Ellis et al. (2019) compared exercise supported using a mobile health app, with a control group who were provided with a Fitbit to measure step count. The app allowed remote monitoring of PA by staff and provided a platform to amend home exercise programmes (HEPs) to ensure that the programmes remained challenging. The app also monitored PA adherence and had the facility for two-way text messaging between Physiotherapists and participants, promoting timely communication and collaboration between both parties. Both groups increased step count and time spent undertaking moderate intensity PA, however no difference was reported between groups. This study demonstrated the positive role of self-monitoring to promote changes in PA behaviour, however the additional strategies such as the ability to communicate with staff did not appear to influence behaviour in this study. This is contrary to prior research which suggests that a greater number of BCTs are more effective (Howlett et al. 2019). These opposing findings could be attributed to the sample, who were very active at baseline, creating a ceiling effect where, regardless of implementation of BCTs, no further enhancement to PA levels were achievable. Alternatively, the ability of text-based communication to deliver motivational coaching, set goals, and provide feedback as used in the study by Ellis et al. (2019) may not be as effective as face-to-face delivery. The authors concluded that self-monitoring was a powerful means of supporting PA among PLwP but highlighted that selection of BCTs need to be tailored to individual need, recognising that less active PLwP may benefit from different BCTs compared to those who are more active (Ellis et al. 2019).

Like Ellis et al. (2019), the development of a tele-coach-assisted exercise (TAE) PA intervention was underpinned by SCT (Lai et al. 2020). TAE participants received one-to-one behavioural coaching aimed at promoting mastery of exercise technique, goal setting, answering questions, and providing encouragement and feedback (see table 2.9). The self-regulated exercise group (SRE) only used the telehealth system to access their HEP. Over the eight-week study, the SRE group spent 48% less time being active, and 74.5% less time performing moderate aerobic exercise compared to the TAE group. In addition, they were less compliant with their HEP. This RCT pilot study concluded that the inclusion of behaviour coaching, and self-monitoring positively influenced intensity and duration of PA (Lai et al. 2020). Similar conclusions were drawn by Lee et al. (2019) who conducted a quasi-experimental pre-test–post-test design, where the primary outcome was QoL. Significant improvements in QoL (p=0.012) were reported in the intervention group, who received 12 weeks of group-based PA combined with fortnightly tele-coaching, compared to the usual care group which received medication and routine medical appointments. A theme arising from the studies conducted by Lai et al. (2020), and Lee et al. (2019), suggests that in addition to the type and range of BCTs used, the frequency of BCT delivery may be crucial in influencing changes in behaviour. The fortnightly motivational coaching delivered in the study by (Lee et al. 2019) may have served to reinforce key messages in relation to PA, resulting in the statistically significant improvement in QoL reported by Lee et al. Supervised PA interventions for PLwP have consistently demonstrated better outcomes compared with those which are unsupervised (Flynn et al. 2021). Drawing from educational literature, delivery of regular feedback to “learners” encourages the focussing of thoughts and behaviours and promotes reflection and analysis and as such self-awareness (Selvaraj et al. 2020), supporting the notion that the frequency of supervision may be instrumental.

None of the studies to date have explored the perceived impact of the BCTs employed. Regardless of behaviour change theory, self-monitoring, use of workbooks and motivational coaching were the most frequent BCTs adopted. Motivational coaching, although widely adopted, varied in implementation and delivery. In some studies, motivational coaching was well described, including provision of real-time feedback on PA performance, discussing PA barriers and motivators, goal setting, providing encouragement, providing education, and discussing benefits of PA for Parkinson's (Lai et al. 2020). In contrast, others simply stated that a motivational approach was adopted (Chang et al. 2012). Variation in intervention reporting limits the capacity to identify the active ingredients within an intervention which are positively impacting on PA, and therefore the ability to draw valid conclusions. Influencing behaviour change is complex, and therefore it is likely that the intervention will need to encompass many co-operating BCTs. Currently the effectiveness of which BCTs either individually or collectively positively influence PA in PLwP is unknown. Further studies are therefore required to determine the effectiveness of BCTs, and which BCTs in combination optimise PA engagement.

The studies evaluating the ParkFit intervention employed a range of BCT’s (van Nimwegen et al. 2013 and Speelman et al. 2014). See table 2.9. The BCT’s were similar to those of Ellis et al. (2019) which included: educational workbooks, self-monitoring through use of an activity tracker, activity coach, goal setting, supervised Physiotherapy, coach style of delivery, and a health contract embedded within a year-long PA intervention. In contrast to prior studies, ParkFit was delivered face-to-face and not online, where participants received 35, thirty-minute sessions of Physiotherapy. The primary outcome (Longitudinal Aging Study Amsterdam Physical Activity Questionnaire-LAPAQ) in the ParkFit studies demonstrated no statistically significant improvement in PA levels (adjusted group difference 7%, 95% CI−3 to 17%; P=0.19, van Nimewegen et al. 2013). Conversely, the activity diaries indicated that the intervention group spent almost 1.5 hours per week extra on PA compared to controls. The negative trial finding could be attributed to the LAPAQ which measures all activity, whereas the diaries only recorded strenuous activity, suggesting that participation in ParkFit may not have increased

PA, but has shaped the intensity of PA which PLwP participate in. With a growing body of evidence advocating high intensity PA, this can only be seen as positive. In parallel with the findings of Ellis et al (2019), the ParkFit study also suggests that the selection of BCTs may need to differ depending on an individual's PA behaviour at baseline, as those most inactive at baseline demonstrated most improvement. Of interest, coaching approaches and the workbooks were perceived by Physiotherapists as the most valuable BCTs, whereas for participants it was the activity tracker. This difference in perspective reinforces the need for a personalised approach, to ensure that BCT are tailored to meet individual needs. A recent systematic review concluded that a greater range of BCTs are associated with greater improvements in PA levels (Kunstler et al. 2018), and this narrative review would also suggest that tailoring of BCTs to individual need is also required to successfully support changes in PA behaviour.

Behavioural change training was provided to all staff delivering ParkFit, enhancing consistency of delivery. However, the follow-up ParkFit study which explored perceptions of Physiotherapists who delivered ParkFit identified that many Physiotherapists perceived that further BCT training was needed. Physiotherapists are regarded as ideally placed to deliver BCTs (Nilsson et al. 2015; Hulbert and Goodwin 2020), however, little is known about use of behaviour change strategies in practice (Kunstler et al. 2018). A systematic review demonstrated that Physiotherapists utilise a limited range of BCTs (Kunstler et al. 2018), with lack of time, knowledge, and confidence cited as barriers to implementation (Kunstler et al. 2019). Therefore, while Physiotherapists may be ideally placed to deliver BCTs, interventions aiming to influence physical activity should include staff training on application of BCTs to optimise delivery (Donkers et al. 2018).

All studies discussed above, employed a range of different BCTs within their intervention delivery, apart from Chang et al. (2012) who adopted only motivational interviewing. Regardless of the theoretical underpinning adopted amongst the studies included in this narrative review, the type of BCTs did not differ significantly. However, the delivery of BCTs lacked detail. None of the studies included a fidelity assessment, therefore it is unclear whether the BCTs were delivered as planned. This is particularly pertinent in the ParkFit studies which involved over 100 Physiotherapists who treated between one and 13 participants each (mean 2.4), therefore the consistency of delivery is unknown. Shih et al. (2022) provided an overview of what was provided in each session, enhancing reproducibility. However, as no fidelity assessment was conducted, the time spent delivering BCTs or the intensity with which they were delivered remains unknown, which negatively impacts on the reliability of the findings. Moreover, no consensus can be drawn on which BCTs or combination of BCTs are superior at promoting PA behaviour change. Systematic reviews which have explored BCTs application among sedentary adults, and those with Dementia. These reviews identified that problem solving, goal setting, social support, credible source, and information on health consequences were the most frequently used (Nyman, Adamczewska and Howlett 2018; Howlett et al. 2019). These BCTs were broadly included in the studies incorporated into this review, and social support was not included in all studies. Social support is widely recognised as a key motivator to PA as discussed in section 2.3.3 (Hunter et al. 2019), and its absence as a BCT in many studies may reflect that the majority were delivered online or delivered on a 1:1 basis. Lack of a social element may explain in part the inconsistent findings reported in the studies included in this narrative review.

While no firm conclusion can be drawn from the nine studies discussed within this narrative review, this review has highlighted that a greater number and frequent of delivery of BCT's is linked with improved outcome. Equally, tailoring of BCTs may be required, for example: sedentary individuals may require BCTs which focus on health consequences to spark motivation, whereas those engaging in PA may benefit from goal planning to maintain motivation or BCTs which focus on shaping knowledge so to refine their PA capacity. In addition to personalisation of BCTs, their use and combination may change over time. Finally, staff training was also highlighted to optimise delivery of BCTs within practice.

2.4.6 COM-B model of behaviour change

Significant overlap exists between behaviour change theories, therefore justifying one theory over another is challenging. Moreover, Social Cognitive Theory, Self-Determination Theory, and the Transtheoretical Model of behaviour change theory are widely criticised for being theoretical frameworks, limiting application into practice. To ameliorate this, "super-theories" have been developed which amalgamate several theories (Prestwich, Kenworthy and Conner 2017). The Theoretical Domains Framework (TDF) and the Behaviour Change Wheel (BCW) are two super-theory examples. The TDF was primarily developed for implementation research, to shape health professionals' behaviour (Cane, O'Connor and Michie 2012). The BCW, also widely recognised as the COM-B model is a variant of the TDF, and is the summation of nineteen frameworks, which provides a comprehensive model of behaviour applicable across a variety contexts and settings (Barker et al. 2016). Crucially, the BCW is both an evidence-based framework and method to support the design and implementation of behaviour change interventions (Truelove et al. 2020), therefore providing a framework to support application to practice. The BCW supports a systematic approach to the implementation of behaviour change interventions, and in doing so aligns with the MRC guidance on the development and evaluation of complex interventions (Skivington et al. 2021). To date no studies have used the BCW nor have specifically explored frequency or effectiveness of BCTs among PLwP (Ahern et al. 2022).

The BCW is made up of three layers, with the COM-B model at the centre. The COM-B model (Figure 2.3) dictates that effectiveness of behaviour change interventions are dependent upon the person having the capability (C), and opportunity (O) to engage in the behaviour and that they are motivated (M) to undertake that behaviour (B) (Michie et al. 2011). Change in one or more of these factors is required for sustained behaviour change (Michie et al. 2013).

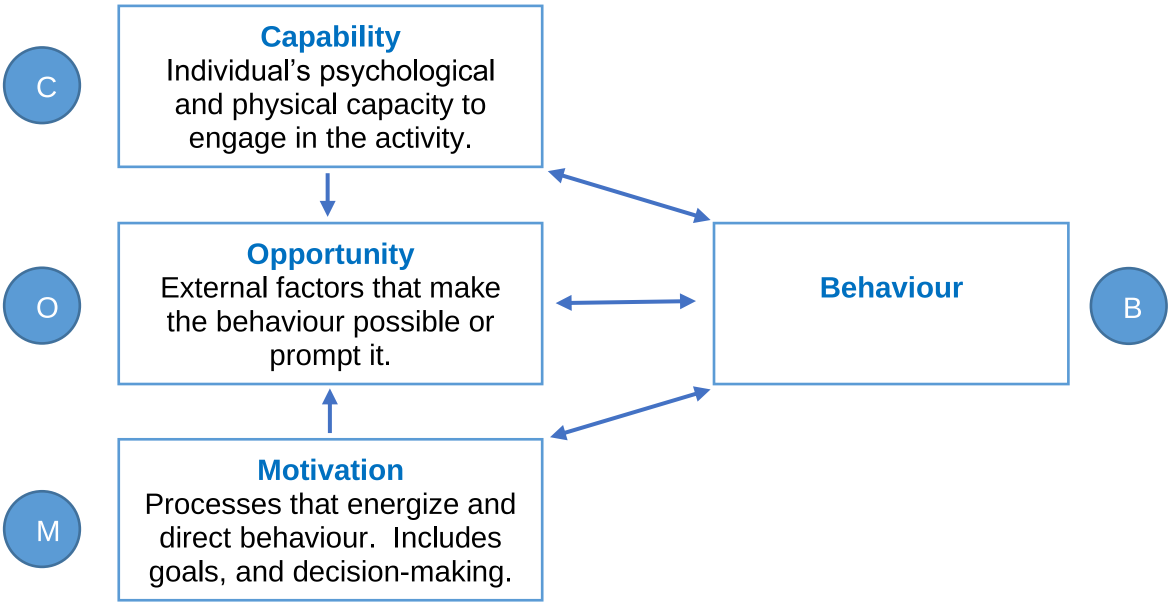


Figure 2.3 The COM-B model, adapted from Michie et al. 2011

The BCW framework encompasses a taxonomy of 93 internationally agreed and validated BCTs (the Behaviour Change Technique Taxonomy version 1, BCTTv1, Michie et al. 2013), which are clustered into 16 groups of BCTs. The groups of BCTs are broad for example comparison of behaviour, and within this group three BCTs are recommended: demonstration of behaviour, social comparisons and information about others approval are suggested. The taxonomy provides transparency for selecting BCTs and implementing these within clinical and research practice (Michie, van Stralen and West 2011; Michie et al. 2013). The taxonomy supports the use of a common language, facilitating the comparison of BCTs between studies (Kunstler et al. 2018). Therefore, adopting the BCW provides potential to select and map the use of BCTs to an evidence-based taxonomy ensuring consistency in application and promotes compliance with the Consolidated Standards of Reporting Trials (CONSORT Guidelines, Schulz et al. 2010), MRC (Skivington et al. 2021) and Template for Intervention Description and Replication guidelines (TIDieR) (Hoffman et al. 2014), therefore addressing some of the reliability and validity issues highlighted in current studies which have used BCTs.

2.4.7 Section summary

This section of the narrative review has highlighted the important role BCTs have in shaping PA activity among PLwP. Despite identifying few studies which were underpinned by theories behaviour change, this narrative review highlighted the following:

i. The use of BCT's appear to positively influence PA among PLwP.
ii. The adoption of a coaching style of delivery which focusses on motivation, and problem-solving appear to be preferrable.
iii. The use of self-monitoring of PA, through use of an activity tracker, which can be shared with HCPs can be a powerful tool to promote participant autonomy and allows HCPs to provide feedback and adaption of PA programmes based on individual need.
iv. The use of education in the form of workbooks encompassing the benefits of PA, and strategies to overcome common barriers can be useful to support behaviour change.
v. The type of BCTs need to be personalised depending on the stage of behaviour change and baseline PA levels.
vi. Staff training in the theory of behaviour change and delivery of BCTs appears to be required to ensure optimal delivery.

Determining the optimal combination of BCTs would require multiple studies and would not be feasible. However, additional research is required to determine the effectiveness of BCT's encompassed within PA interventions compared to PA alone (Osborne et al. 2022). Research from other fields (Dementia, and sedentary population, musculoskeletal conditions) would suggest that use of a greater number of BCTs is associated with greater improvements, although whether this is applicable to PLwP is unknown. Implementation of behaviour change within PA interventions requires further justification and transparency to aid reproducibility, transferability, and reliability. Interventions using BCTs need to align with the TIDieR Guidelines, and further research is required to establish the most effective BCTs (e.g., goal planning, self-monitoring, education) to influence PA behaviour (Osborne et al. 2022). This narrative review proposed that the BCW and COM-B model may be preferable to identify other determinants of behaviour and select appropriate BCTs to use within PA interventions. Use of the BCTTv1 promotes transparency in selection and implementation of BCTs into clinical research practice (Michie et al. 2013), and supports the use of a common language, facilitating the comparison of BCTs between studies (Kunstler et al. 2018).

2.5 SELF-MANAGEMENT

Thus far, this narrative review has evaluated the research exploring the factors which prevent and enable PLwP to participate in PA and explored the current evidence-base in relation to strategies to support changes in PA behaviour. This final section focusses on self-management of PA. The introduction highlighted that the number of PLwP is increasing. In addition, the introduction highlighted the positive impact of PA on Parkinson's symptoms, and the potential to attenuate the rate of decline of Parkinson’s. In conjunction with supporting PLwP to be more physically active, enablement of PLwP to self-manage their PA as part of their lifestyle is also required. Self-management is widely advocated in healthcare policy (Scottish Government 2022; NHS England 2019) and is the proposed mechanism to effectively manage long-term conditions, with the aim of promoting independence and maintaining QoL (Scottish Government 2008). Yet, an NHS survey highlighted that up to 40% of patients have low self-management knowledge, skills, and confidence (Hibbard and Gilbert 2014), with this figure rising to over 50% among PLwP (Kessler et al. 2021). The Parkinson’s NICE guidelines recommend that PLwP should have ‘access to education and advice about PA’, (NICE 2017) yet the ability to successfully self-manage has been voiced as the biggest unmet need among the Parkinson’s community (Vlaanderen et al. 2019).

Self-management has evolved from the Chronic Care Model proposed by Wagner in 1998 and aims to provide individuals with the capacity to take responsibility for their own behaviour and well-being (Lorig and Holman 2003). Self-management aims to promote problem-solving and decision-making and is built on the foundation of empowerment and partnership between patients and healthcare professionals (Peek et al. 2016). Lorig and Holman (2003) proposed a skills-based approach to self-management including; problem-solving, decision-making, resource utilisation, partnership and enabling people to act.

Despite the value placed on self-management, the optimum content and means of delivery remains unknown. There is a need therefore for evidence-based recommendations on the content of self-management interventions so that PLwP are effectively supported to self-manage their PA (Alushi et al. 2022). For the purposes of this review, the definition of self-management as defined by Lorig (2003, pp11) was used: “*the knowledge and skills required* *to maintain an active and emotionally satisfying life in the face of a chronic condition*", to guide article selection. The literature search was undertaken to establish the key components of self-management programmes to provide the context for the intervention explored in this thesis. Table 2.10 details the MeSH and subject headings used within various databases that were used to conduct this review. Figure 2.4 provides a PRISMA flowchart detailing the search process, and the outcome. As shown in the PRISMA flowchart, many publications were excluded at full text screening, as several primary studies were incorporated into either a quantitative or qualitative review which had been recently published (Tuijt et al. 2020; Pigott et al. 2022). Therefore, this narrative review consists of a total of seven studies, including two systematic reviews, and five primary studies which were published after the systematic reviews. This narrative review will first discuss the findings of the systematic reviews, prior to considering the more recent literature that has been published. This section will finish by summarising current self-management literature and the implications for research and clinical practice**.**

Table 2.10 Self-management search strategy

MEDLINE	
#1	(MH "Parkinson Disease") OR "parkinsons disease" OR TX parkinson's disease or parkinson disease or parkinsons disease or pd or parkinsons or parkinsonism
#2	MH "Exercise") OR "exercise" OR (MH "Exercise Therapy") OR (MH "Resistance Training") OR (MH "Exercise") OR (MH "Muscle Strength") OR "strength exercise" OR "Physical activity" OR TX physical activity or exercise or fitness or physical exercise
#3	(MH "Self-Management") OR "self-management" OR (MH "Self Care") OR "self-care" OR (MH "Patient Education as Topic") OR "patient education" OR TX self management OR TX (self-management or self-care or self-regulation or self-monitoring)
#4	#1 AND #2 AND #3
CINAHL	
#1	(MH "Parkinson Disease") OR "parkinsons disease" OR TX parkinson's disease or parkinson disease or parkinsons disease or pd or parkinsons or parkinsonism
#2	(MH "Physical Activity") OR "Physical activity" OR (MH "Exercise") OR "exercise" OR (MH "Resistance Training") OR (MH "Therapeutic Exercise") OR TX exercise or physical activity
#3	(MH "Self-Management") OR "self-management" OR (MH "Self Care") OR "self-management" OR (MH "Self Care") OR "self-care" OR (MH "Patient Education as Topic") OR "patient education" OR TX self management OR TX (self-management or self-care or self-regulation or self-monitoring)
#4	#1 AND #2 AND #3
SPORTDiscus, AMED, and Web of Science	
#1	Parkinson’s disease OR Parkinson's Disease OR parkinson’s disease OR parkinsons disease OR PD or pd OR Parkinson's
#2	TX Physical activity OR activity OR TX exercise OR physical exercise OR physical fitness OR TX strength training OR resistance training OR weight Training OR balance exercise OR TX balance training OR balance training OR balance programme OR aerobic exercise OR TX Aerobic training OR Rehabilitation OR therapy OR treatment OR Intervention
#3	"Self-Management" OR "self-management" OR "Self Care" OR "self-management" OR "self-care" OR "Patient Education” OR "patient education" OR TX self management OR TX (self-management or self-care or self-regulation or self-monitoring)
#4	#1 AND #2 AND #3

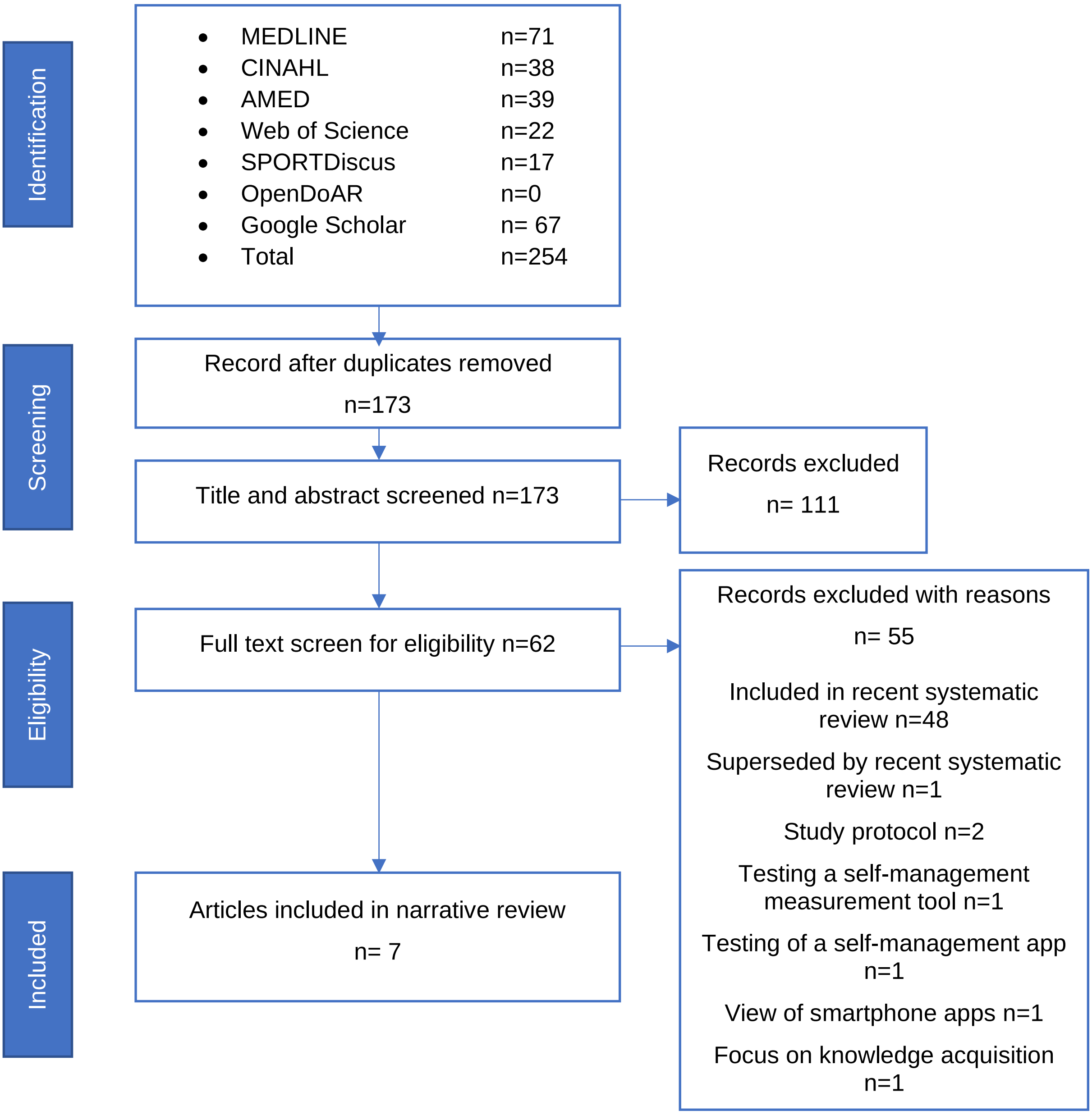


Figure 2.4 PRISMA flowchart illustrating self-management search outcome

2.5.1 Systematic review findings on Parkinson's self-management

Two systematic reviews were identified from the search; one quantitative review (Pigott et al. 2022) and one qualitative review (Tuijt et al. 2020), which are summarised in Table 2.11. Reflecting the rise in self-management research, the Pigott review updated the prior review conducted by Kessler and Liddy (2017), considering data published since 2017, and adopted a broader definition of self-management. Each review was evaluated using the JBI Checklist for systematic reviews (Aromataris et al. 2014). As seen in Table 2.11, the quantitative and qualitative reviews scored highly (10/11 and 9/11 respectively) indicating robust and comprehensive reviews.

The quantitative review focussed on the effectiveness of self-management for PLwP, whereas the qualitative reviews explored PLwP, and their carers' perspectives of participating in self-management programmes. The search also identified a further two quantitative (Lyons et al. 2021; Park et al. 2022), and three qualitative studies (Armstrong et al. 2021; Kessler et al. 2021; Shah et al. 2022) that were published after the systematic reviews. Therefore, this narrative review will discuss the findings of these reviews, in conjunction with the recently published primary studies, prior to synthesising the findings and considering the impact of the findings within the section summary.

Table 2.11 Key findings from self-management systematic reviews

Author and Aim	Study type	Method to assess quality	Key findings	Limitations
Piggott et al. 2022 To evaluate the clinical effectiveness of self-management interventions for PLwP, considering effects on QoL, wellbeing and function.	Systematic review and meta-analysis. n=36 studies (19 RCTs) n=2884 PLwP	Cochrane Risk of Bias tool 2 or ROBIN-I tool. GRADE Score for systematic reviews.	Insufficient high quality RCT's to show effectiveness of self-management interventions for PLwP. No significant difference in ability to self-manage self-management and the control groups -SMD (Hedges g) of − 0.17 (− 0.56, 0.21) p = 0.38. • Self-management components associated with improved in QoL, wellbeing or function: • Information on Parkinson's and its management • Information of available resources • Exercise plans and regular clinical review • Monitoring of condition with feedback • Training in communication with HCPs • Training in practical self-management strategies • Training or rehearsing psychological strategies • Social support and lifestyle advice and support.	Approaches and outcomes to self-management interventions in Parkinson's are heterogenous. Due to study heterogeneity meta-analyses based on 4 RCTs (n = 478).
Tuijt et al 2020 To review the components of self-management	Qualitative systematic review. n= 6 studies n=147	CASP tool.	7 themes around self-management valued by PLwP: Medication management, physical exercise, self-monitoring, psychological strategies, maintaining independence, social engagement, and knowledge and information	High methodological quality of primary studies.
Abbreviations: PA: Physical activity, RCT: randomised controlled trial, SMD: Standard mean difference, ADL: Activities of daily living, HCP: Health care practitioner, CASP tool: Critical Appraisal Skills Programme tool				

2.5.2 Quantitative self-management systematic review findings

The systematic review and meta-analysis review by Pigott et al. (2022) included 36 studies which explored the effectiveness of self-management for PLwP on QoL, well-being and function. Over half of the primary studies were RCT's, and a third were pre and post-test intervention comparisons. Most studies were from North America (n=14), and Europe (n=14), including a total of 2884 PLwP. Overlap existed between some studies, with multiple reports on the same study using the same sample with differing outcomes. The Stanford Chronic Disease Self-Management Programme (CDSMP) (Lorig et al. 2001), the Patient Education Program Parkinson (Macht et al. 2007), the Swedish National Parkinson's School, Strive to Thrive (Lyons et al. 2021), and the CDSMP with an additional Parkinson's specific week, were the most frequently researched self-management programmes. An overview of these programmes is provided in Appendix 1. Significant heterogeneity existed between studies in relation to the content of self-management interventions, the mode of delivery, intensity of delivery, the HCPs involved, and the measures used to assess effectiveness (Pigott et al. 2022). Programmes were delivered: in isolation or, in combination with exercise or cognitive behavioural therapy, via telehealth, in groups or individually. Heterogeneity could be attributed to a lack of a standardised definition of self-management, or poor intervention reporting (Tuijit et al. 2020). Hulbert and Goodwin (2020) highlighted poor intervention reporting particularly when self-management was combined with PA, as emphasis was placed on describing the PA intervention, with limited discussion pertaining to the self-management component.

Many authors have reported that the variation in self-management programmes limits potential to draw conclusions to inform practice (Pigott et al. 2022; Kessler and Liddy 2017; Hulbert and Goodwin 2020; Tennigkeit et al. 2020; Alushi et al. 2022; Milne-Ives, Carroll and Meinert 2022). This variation was reflected in the Pigott review, where only four of the possible 19 RCT's were included within the meta-analysis. The standard mean difference (Hedges g) suggested a small QoL benefit (− 0.17, − 0.56, 0.21), although this was not statistically significant ($p = 0.38$), and the heterogeneity between studies was high (I_2= 68%). The sample sizes of the primary studies were small, and of low methodological quality, and were associated with a high risk of bias using the Cochrane risk of bias tool (Pigott et al. 2022). Consequently, Pigott et al. (2022) concluded that there were insufficient high quality RCT's to demonstrate effectiveness of self-management interventions for PLwP. However, the Pigott et al. (2022) review did highlight components of self-management programmes which may be effective, however, these results need to be interpreted in the context of the low methodological quality.

Within the 36 studies included in the Pigott et al. (2022) review, typically self-management was combined with education, or additional therapies, or self-monitoring. When combined with education, this included provision of information as part of a group training programmes. Therapies typically combined with self-management included PA, cognitive behavioural therapy, multi-disciplinary co-ordination, or mindfulness. Self-monitoring included Parkinson's symptom monitoring or PA. Self-management programmes which included multiple components were associated with improved outcomes compared with those that delivered fewer components such as education and PA (Pigott et al. 2022). Tennigkeit et al. (2020) proposed that self-management represents a complex cognitive-behavioural challenge, requiring the individual to adapt their behaviour to their symptoms, and be able to cope productively. This complexity perhaps explains why unidimensional approaches that simply provide education on the benefits of PA are ineffective. Suggesting therefore that self-management may be optimised when knowledge, skills training, and problem solving are delivered in combination allowing PLwP to develop functional strategies to self-manage their own condition (Kessler et al. 2017).

Pigott et al (2020) reported that self-management programmes frequently included information about Parkinson's, communities, relationships, social and financial support, and lifestyle issues. These topics arguably sit under a traditional health promotion or health education paradigm, rather than self-management where emphasis is placed on contextualised education, self-tailoring, and skills-based training. According to Corbin and Strauss Chronic Illness trajectory framework, effective self-management needs to incorporate medical management with behavioural, role and emotional management (Corbin 1998). Focussing solely on medical management provides people with knowledge but fails to provide people with skills to apply that knowledge to behaviours such as PA (Corbin 1998). This may explain the limited effect of many of the primary studies included in the Pigott review, as education was consistently delivered within primary studies but psychological aspects of living with Parkinson's and skills or strategy-based training were less consistently reported.

The components of self-management associated with improved QoL, and function highlighted within the Pigott review included skill acquisition incorporating the following: exercise planning, training in communication, self-management strategies, rehearsal of psychological strategies, condition monitoring with feedback, problem solving, and signposting to relevant information. These factors are in keeping with the five key self-management skills identified by Lorig and Holman (2003). Lorig and Holman (2003) state that problem-solving is central to self-management. Promoting problem-solving requires a coaching approach to delivery, where people are encouraged to find solutions, and think through how these can be implemented, rather than depending on traditional didactic approaches where people are given solutions. The second key skill is decision-making. While PLwP may be supported by a multi-disciplinary team, typically they will see a consultant once a year, a nurse twice a year and they may see other HCPs depending on their individual needs. Consequently, PLwP spend a significant proportion of time on their own, and therefore the ability to make decisions independently is paramount. Making decisions requires access to information which Lorig and Holman (2003) identify is the third skill, allowing people to make informed decisions about their own health. The fourth skill centres upon partnership with HCPs. Partnership and shared decision making are widely supported in healthcare policy (NHS England, 2019). Partnership implies shared responsibility, respecting the expertise of each party. However, partnership is dependent upon PLwP being knowledgeable about their condition, and confident to articulate their views and make decisions. The fifth skill is taking action, which is dependent on skill acquisition on rehearsal, repetition, feedback and action planning. Combining the findings from Pigott et al’s review with prior self-management research would infer that successful self-management is a combination of education and skills-based training. Therefore, successful self-management is dependent on how self-management is supported and delivered as well as ensuring PLwP have the appropriate skills to actively self-manage themselves (Maffoni et al. 2019).

2.5.3 Qualitative self-management review findings

Six qualitative studies were included in the review by Tuijit et al. (2020). Two studies explored perceptions of the Swedish National Parkinson's School, one involved the CDSMP, and one study explored PLwP experiences of the Living Well with Parkinson’s programme. A further study was also included which involved the Parkinson’s care network. Within these six studies, data was captured via interviews, group discussions or observations and were analysed using thematic or content analysis. In contrast to the quantitative studies, the methodological quality of qualitative studies included within the Tuijt et al. (2020) review were rated as high, using the Critical Appraisal Skill Programme tool (Critical Appraisal Skills Programme 2022). The Tuijt review was robustly conducted, however, the review conclusions were based on only six studies compared with 36 within the quantitative review conducted by Pigott et al. (2022). This would infer that a greater emphasis has been placed on determining the effectiveness of self-management, with less importance placed on exploring PLwP perceptions of self-management programmes. This may also explain the inconclusive findings reported by Pigott et al. (2022) as to date little research has focussed on exploring which components of self-management intervention are valued by PLwP. Synthesised qualitative findings from the Tuijt et al. (2020) review identified seven key components of self-management valued by PLwP which included medical management, PA, self-monitoring, psychological strategies, maintaining independence, social engagement, and knowledge. Delivery of each of these components were perceived as more effective by PLwP when specific skills and strategies were provided alongside information. This reiterates the findings highlighted from the quantitative studies that self-management is more than health education, rather it is giving people the "know how", to develop capability to actively self-manage their Parkinson's. Rather than solely information giving, a toolkit approach which enables PLwP to be knowledgeable about what to do, how to do it and why it is important, is needed (Shah et al. 2022). For example, in relation to PA, education needs to be delivered alongside PA, so PLwP understand why a specific exercise is being prescribed, and why it is beneficial for their Parkinson's. Similarly, with psychological strategies, identifying barriers, promoting problem solving, and developing practical strategies to overcome barriers were cited as valued by PLwP (Tuijt et al. 2020). While the quantitative review highlighted components of self-management which may promote effectiveness, the findings of the quantitative review provide clarity on how delivery and content of self-management could be optimised.

The value of shared decision making and partnership in self-management were also highlighted by the Tuijt et al. (2020) study, reiterating the findings of Lorig and Holman (2003). Shared decision making and a partnership approach are central to person-centred care (NHS England 2022). A qualitative study published after the Tuijt review reported that over half of HCPs recognised the need to adopt a person-centred approach when working with PLwP (Armstrong et al. 2021). Armstrong et al. (2021) also demonstrated that HCPs recognised that delivery of person-centred care necessitated a shift away from fixing PLwP's problems, to working in partnership, amalgamating the lived expertise of PLwP, with their own professional expertise (Armstrong et al. 2021). Motivational interviewing was reported as the optimum approach to facilitate delivery of a partnership approach (Armstrong et al. 2021). However, Armstrong et al. (2021) reported that motivational interviewing was poorly defined by HCPs, and few HCPs interviewed were able to articulate how motivational interviewing was implemented in practice. The use of motivational interviewing in a PA context has been shown to improve PA adherence, (SMD: 0.33, 95% CI −0.03 to 0.68, I2 62%) and positively impact on long-term PA behaviour and self-efficacy (SMD: 0.71, 95% CI: 0.55 to 0.87, I2 41%) (McGrane et al. 2015). However, these systematic review findings reported by McGrane were not specific to Parkinson's. Current research would indicate that motivational interviewing is widely used as a self-management tool. However, how it is used, and to what effect remains unknown, as limited research exists on the application of motivational interviewing among HCPs (Fortune et al. 2019). Moreover, Armstrong et al. (2021) highlighted that staff confidence and training in using motivational interviewing is needed to motivate PLwP to overcome the barriers they face.

The qualitative review by Tuijt et al. (2020) also highlighted that staff were perceived as integral to the success of self-management, which has been reiterated by more recent qualitative studies (Shah et al. 2022; Kessler et al. 2021). HCPs who were motivational, supportive, and understood Parkinson's, enabling a personalised approach to self-management, were highly valued. Working in partnership with HCPs and making shared decisions about current and future management, was associated with enhanced self-efficacy. The ability of staff to personalise the self-management, in particular the education, was also highly valued (Kessler et al. 2021). Personalisation, motivation, and Parkinson’s informed staff are themes which have previously emerged in this narrative review (section 2.3.3) in relation to supporting behaviour change, adding further credence that these are key active ingredients in supporting PLwP.

Tuijt et al. (2020) highlighted that social engagement was a valued component of self-management. Group-based self-management sessions with individuals experiencing similar emotional or physical challenges provided a conduit for peer support and sharing of experiences. Social networks supported the development of emotional reliance, and a sense of connection and cooperation. Social opportunities provided a “safe space” where PLwP did not feel that they had to explain themselves or apologise for any challenges which arise because of their Parkinson’s. The opportunity to talk with a Parkinson's specialist or someone with Parkinson’s was associated with reducing the emotional burden associated with the condition (Shah et al. 2022) for those PLwP and their carers (Armstrong et al. 2021). Taking a broader perspective, overlap exists between the benefits of self-management for PLwP reported by Tuijt et al. (2020), with the benefits associated with social support discussed in section 2.3.3. Moreover, the key self-management skills of problem-solving, decision-making and action planning for example, align with BCTs identified in section 2.4.4, and 2.4.5 which are known to promote changes in PA behaviour. This would suggest that merit lies in combining PA prescription within a broader self-management programme.

2.5.4 Discussion of research published after the systematic reviews

Two quantitative (Lyons et al. 2020 and Park et al. 2022) and three qualitative studies (Armstrong et al. 2021; Kessler et al. 2021; Shah et al. 2022) were published following the reviews previously discussed and are summarised in table 2.12. These studies broadly reiterate the findings of the previously discussed systematic reviews, but they also highlight the potential role of self-management delivered via telehealth, the perspectives of the carers, the role of self-efficacy and the potential barriers to self-management delivery, which will be discussed in the sections below.

Table 2.12 Summary of quantitative studies published after Pigott et al. (2022)

Author and aim	Study design	Intervention	Outcome measure	Key findings
Park et al. (2022) To evaluate the effect of mobile health intervention for self-management for PLwP.	RCT. n=43, 20 intervention group.	**Intervention group:** Mobile health intervention and telephone counselling for 16 weeks. Self-management information Parkinson's diary PA alarm PA self-monitoring HEP provision **Control group:** monthly text messages and telephone counselling for 16 weeks.	Self-Efficacy for Managing Chronic Disease, mUPDRS, NMS Scale, Korean PDQ-39.	Significant improvement in self-efficacy in the intervention group compared to control (t=2.33, p=.025) No significant improvement in the mUPDRS between groups (t=0.82, p=.419) Significant improvement in NMS score in intervention v control (t=-2.04, p=.048) No significant improvement in self-management score or PDQ-39 High satisfaction with the mHealth intervention and technology
Lyons et al. (2022) To explore the benefits of a Self-Management programme for the couples Living with Parkinson's.	Quasi-experimental study Compared *Strive to Thrive* programme to waitlisted controls.	*Strive to Thrive: Self-Management programme* - follows the CDSMP including monitoring, taking action, problem-solving, decision-making, and evaluating results. A 7th session added with Parkinson's specific content.	Physical Score of the SF-36. MCSI. CES-D. Likert scale for time spent exercising.	PLwP in the *Strive to Thrive* group improved physical health (d = 0.31), aerobic activity (d = 0.44) and mental relaxation (d = 0.24), compared with the control group, but experienced declines in self-efficacy compared to the control Spouses: improved depressive symptoms (d = 0.29). Significant improvement in mental relaxation compared with control group spouses (d = 1.12) Small increases in positive self-management behaviours by PLwP and spouses. Spouses reported increased confidence to support their partner with PD

Abbreviations: RCT: Randomised controlled trial, ADL, Activities of daily living, NMS: Non-motor symptoms, FAQs: Frequently asked questions, HEP: Home exercise programme, mUPDRS: Motor subsection of the UPDRS, PDQ-39: Parkinson's disease questionnaire-39, CDSMP: Chronic Disease self-management Programme, MCSI: Multidimensional Caregiver Strain Index, CES-D: Centre for Epidemiologic Studies Depression scale, SF-36: Short-Form Health Survey

Table 2.13 Summary of qualitative studies published after Tuijt et al (2020)

Author and aim	Study design	Methods	Data collection and analysis	Key findings
Shah et al. (2022) To explore PLwP perspectives and experiences of self-management.	Qualitative design. Semi structured interviews. n= 22	**Interview topics**: barriers to self-management, techniques to self-manage.	**Analysis:** constructionist thematic analysis.	**Valued components of self-management:** Information about Parkinson's; and medication, emotional support, and exercise. **Barriers to self-management:** Lack of information provided by HCP's Overwhelming amount of information Lack of signposting to help Stigma and negative attitudes of Parkinson's Lack of public awareness of Parkinson's Acceptance of diagnosis Levels of self-esteem and self-efficacy.
Armstrong et al. (2021) To explore HCPs perspectives on self-management for PLwP.	Qualitative design. Focus groups and interviews. N=42 HCPs.	**Interview topics:** How do you facilitate the self-management for PLwP? Key components of self-management. Barriers and motivators to implementing self-management.	Thematic analysis.	**Self-management should** Empower PLwP Be patient centred, personalised and involve carers Delivered in partnership with HCPs Develop self-efficacy Increasing motivation, and capability to self-manage **Barriers to self-management** Inflexibility of healthcare system Lack skills in motivating PLwP Lack of sharing data sharing and training

Table 2.13 Summary of qualitative studies published after the Tuijt et al (2020) review (continued)

Author and aim	Study design	Methods	Data collection and analysis	Key findings
Kessler et al. (2021) To explore acceptability of the Integrated Parkinson's disease Care Network (IPCN) among PLwP.	Descriptive qualitative approach. Semi-structured interviews and focus groups.	Purposive sampling of PLwP who participated in the pilot study of the IPCN n=15 PLwP.	Content analysis.	**Valued aspect of self-management** Motivated and caring staff Personalised delivery Signposting to community help Provision of psychosocial support Empathic communication style of staff Need to personalised education Help to identify goal identification and achievement. Staff were pivotal in setting goals
Abbreviations: HCP: Health care professionals, PA: Physical activity, IPCN: Integrated Parkinson's disease Care Network				

2.5.4.1 The use of telehealth to promote self-management.

A Korean study explored the effectiveness of a mobile intervention to promote self-management, self-efficacy, QoL and Parkinson's symptoms (Park et al. 2022). Those randomised to the intervention received a smart watch to measure PA, and access to an app. The app provided information on Parkinson’s and had a diary function providing opportunity to document reflections on PA and Parkinson's symptoms. The intervention was supported by texts and monthly telephone calls delivered over the 16-week study period. The control group received one text and telephone call per month. Statistically significant improvements in self-efficacy and NMS were demonstrated (p=0.24, and p=0.048 respectively), however no improvement in the self-management score or motor symptoms were reported (Park et al. 2022). Lim et al. (2020) highlighted that to self-manage, PLwP need to have good self-efficacy. In the study by Park et al. (2022), self-efficacy was shown to improve, yet perceived ability to self-manage did not. This may be attributed to several factors. Methodologically the study was based on a small sample (n=20 PLwP), who experienced motor fluctuations which may have confounded the findings. In addition, the study was supported via an app, text messages, and monthly phone calls. This remote delivery approach may have limited the interventions’ potential to support the development of self-management skills such as problem solving. While telehealth-based self-management has potential for scalability, further consideration is needed to ensure the intervention provides the key skills and experience to allow the development of self-management skills.

2.5.4.2 Carer involvement in self-management

Lyons et al. (2021) explored the benefits of self-management for PLwP and their spouses. Participants were randomised to receive ‘Strive to Thrive’, which is a Parkinson’s adapted version of the Chronic Disease Self-Management Programme described by Lorig et al. (2001). Large effect sizes were reported in favour of the intervention group, with spouses better enabled to engage in relaxation techniques (d =1.12), improved ability to support their partner manage their Parkinson’s (d = 0.27) and reduced depressive symptoms (d=0.29). Those with Parkinson’s had greater improvements in aerobic activity (d = 0.44) and mental relaxation (d = 0.24) compared with the control group, but the effect sizes were small. Self-efficacy was shown to decline among those with Parkinson's (d = 0.33). A decline in self-efficacy (confidence in one’s abilities) would suggest that the ability to self-management worsened because of attending. Reduced self-efficacy could be attributed to discussions and information provided during the intervention which may have increased awareness of the impact of Parkinson’s has had on thier life. A decline in self-efficacy was not reported in any other studies, however the variety of measures used to assess self-efficacy limits capacity to make reliable comparisons between studies.

The quasi-experimental study conducted by Lyons et al. (2021) involved a small sample, however, the preliminary data indicates the potential benefits extend beyond the individual with Parkinson's. Current evidence suggests that carers' strain negatively impacts on carers' well-being (Hand et al. 2022) and higher strain is associated with increased hospital admission (Klaptocz et al. 2019), highlighting potential wider health and cost benefits of self-management programmes. The study by Lyons et al. (2021) supports the inclusion of carers within self-management programmes, however a qualitative study exploring the views of HCPs on self-management programmes demonstrated divided opinion (Armstrong et al. 2021). Interviews with 42 UK-based Parkinson's HCPs suggested that some perceived that carers are instrumental in motivating PLwP, others thought carers themselves needed support, and therefore should attend self-management programmes. Conversely, some HCPs expressed concern that attending self-management added to a carers burden (Armstrong et al. 2021). Conflicting themes arising from these studies would suggest that self-management programmes should be flexible and provide choice to PLwP and their carers offering flexibility depending on preference.

2.5.4.3 Self efficacy as a key component of self-management

This narrative review has highlighted that self-efficacy is a key determinant of PA behaviour among PLwP (Ellis and Motl 2013). A UK based study exploring PLwP's perceptions of self-management (Table 2.12), highlighted that low self-esteem and self-efficacy were key barriers to self-management (Shah et al. 2022). This suggests that self-efficacy may be pivotal within self-management also. In contrast, semi-structured interviews involving HCPs delivering self-management, indicated that HCPs perceived that empowerment and self-efficacy was paramount to enable PLwP to self-management (Armstrong et al. 2021). Rappaport (1987) defines empowerment as having the knowledge, and capability to do or make decisions for oneself, whereas Bandura (2004) defines self-efficacy is the belief in their own capability. This difference in perspective between PLwP and HCPs may be of potential importance and may explain why many self-management programmes have not been shown to be effective to date (Pigott et al. 2022). Rawlett (2014) states that self-efficacy and empowerment are mutually exclusive, as empowerment is a consequence of achieving self-efficacy. Bandura states that self-efficacy is promoted by four factors: i) mastery experiences, ii) vicarious experiences, iii) social persuasion, and iv) emotional state (Bandura 2004). Bandura goes on to state that mastery experiences is the most influential factor, as this provides individuals with genuine evidence of whether they can do what they need to succeed (Bandura 2004). Mastery is achieved through repetitive practice, which may involve breaking the task down into its component parts, before being able to compete the task in its entirety. Vicarious experiences involve observing others successfully completing a task, which reinforces the belief that the task can be achieved. Self-belief is further reinforced by social persuasion or receiving positive feedback while practicing or undertaking a task. Finally, Bandura (2004) highlights the emotional state of an individual can influence how they feel about their personal abilities, which is pertinent within Parkinson's where the incidence of depression, and apathy are common. Combining findings from the qualitative research with Bandura’s model of self-efficacy would imply that effective self-management programmes need to:

- be tailored to individual need
- focus of developing self-efficacy and empowerment
- be delivered as part of a group, to promote socialisation, and vicarious experiences
- encompass skill-based training in parallel with contextualised education
- provide opportunity to practice skills to achieve mastery
- provide feedback on skill development
- delivered by HCPs who understand Parkinson's, who can motivate and support PLwP, and are sensitive to the complexity of Parkinson's and the impact this has emotionally
- promote shared decision-making and a partnership approach to delivery

2.5.4.4 Perceived barriers to the delivery of self-management programmes for people living with Parkinson's

Recent qualitative studies indicate that self-management needs to be personalised, with clear lines of communication and collaboration between health providers and service users (Kessler et al. 2020). However, inflexibility of the healthcare system, and challenges associated with information sharing between primary and community healthcare settings were cited as key barriers to delivering self-management in a qualitative study involving 42 UK-based HCPs (Armstrong et al. 2021). These findings suggest that organisational barriers need to be overcome to ensure effective delivery of self-management. Similarly, a lack of information or signposting to information by HCPs for PLwP, especially when newly diagnosed, was a key theme arising from a UK qualitative study involving 20 PLwP (Shah et al. 2022). Lack of signposting may be a consequence of insufficient staff training on self-management, motivational interventions, and Parkinson's which has been reported by Armstrong et al. (2021) or simply lack of time and resources. The qualitive study conducted by Armstrong et al. (2021) involved a diverse group of HCPs, suggesting a knowledge and skills gap exists across the multidisciplinary team. Moreover, the HCPs were purposively sampled from community and hospital-based teams who were currently supporting PLwP, highlighting the skills gap in the current workforce who regularly manage PLwP. Acknowledging the limitations of these small qualitative studies, these more recent studies would suggest that staff development and operational changes may be required to facilitate effective delivery of self-management for PLwP.

2.5.5 Self-management section summary

Due to the heterogeneity of self-management programmes, their delivery, content, and outcomes used, insufficient evidence exists to draw conclusions on the effectiveness of self-management for PLwP. Furthermore, no reliable conclusions can be drawn to inform the optimal means of delivering self-management. However, this narrative review of the available research has highlighted several components of self-management that hold promise, and these are summarised in Figure 2.5. Review of the qualitative literature clearly highlighted the components of self-management which are valued by PLwP and gave insight into how these could be optimally delivered. Both the qualitative and quantitative research published to date would appear to support that self- management should be a multi-component intervention encompassing strategies to support changes in behaviour, skill-based training, and contextualised education. Self-management needs to foster a partnership approach between the person with Parkinson’s and HCPs, which centres upon an ethos of problem solving, shared decision making, promoting development of self-efficacy and mastery of skills. The benefits of self-management are optimised when delivered by HCPs who understand Parkinson's, and creates as social environment, that build individual self-efficacy and empowerment.

2.6 NARRATIVE REVIEW SUMMARY

This narrative review aimed to explore the current evidence base to underpin an intervention which aims to increase PA levels among PLwP and enable PA self-management. Many studies have explored the barriers and motivators to PA among PLwP. Current research would suggest that an understanding of the benefits of PA, seeing staff who are informed about Parkinson’s, and social support are key motivators for getting started and maintaining PA for PLwP. Barriers identified included lack of support, the motor and NMS associated with Parkinson’s, as well as a lack of knowledge and environmental factors such as transportation. A small number of studies have explored the use of BCT to shape PA behaviour among PLwP.

The current evidence base suggests that are larger number of BCTs optimises changes in behaviour. The use of education, goal setting, feedback, and self-monitoring were used most frequently in the studies included in this narrative review commonly delivered in tandem with PA.

The current evidence based has be unable to demonstrate the effectiveness of self-management for PLwP. However, drawing from both qualitative and quantitative studies included in this narrative review has shown what the knowledge, and skills which are required to enable self-management, as well as highlight how interventions could be configured to enable PLwP to develop self-management skills as illustrated in Figure 2.5.

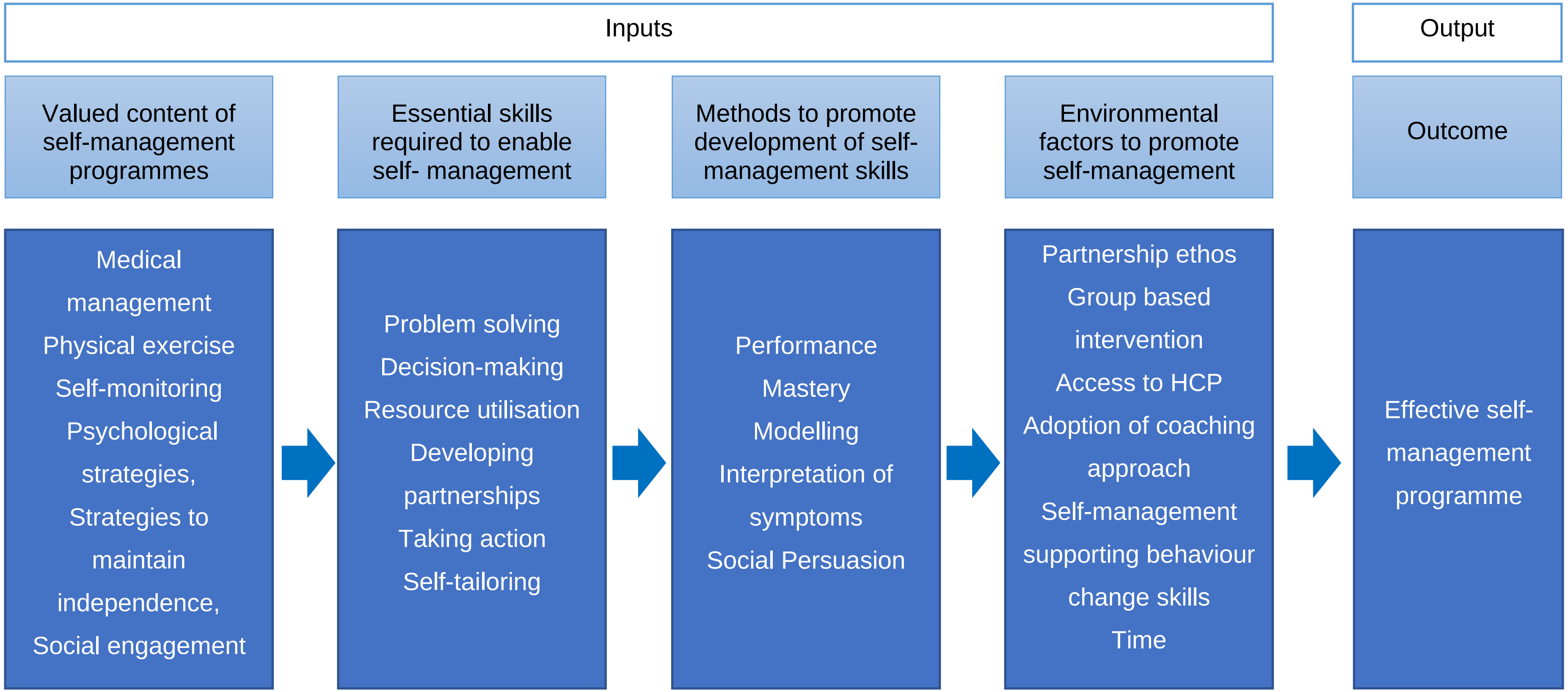


Figure 2.5 Key components of self-management programme

2.7 DEVELOPMENT OF THE PDCONNECT INTERVENTION

PDConnect is a multi-component intervention aimed at increasing PA participation and PA self-management for PLwP. This following section will detail how this intervention was developed.

2.71 Development of the PDConnect intervention

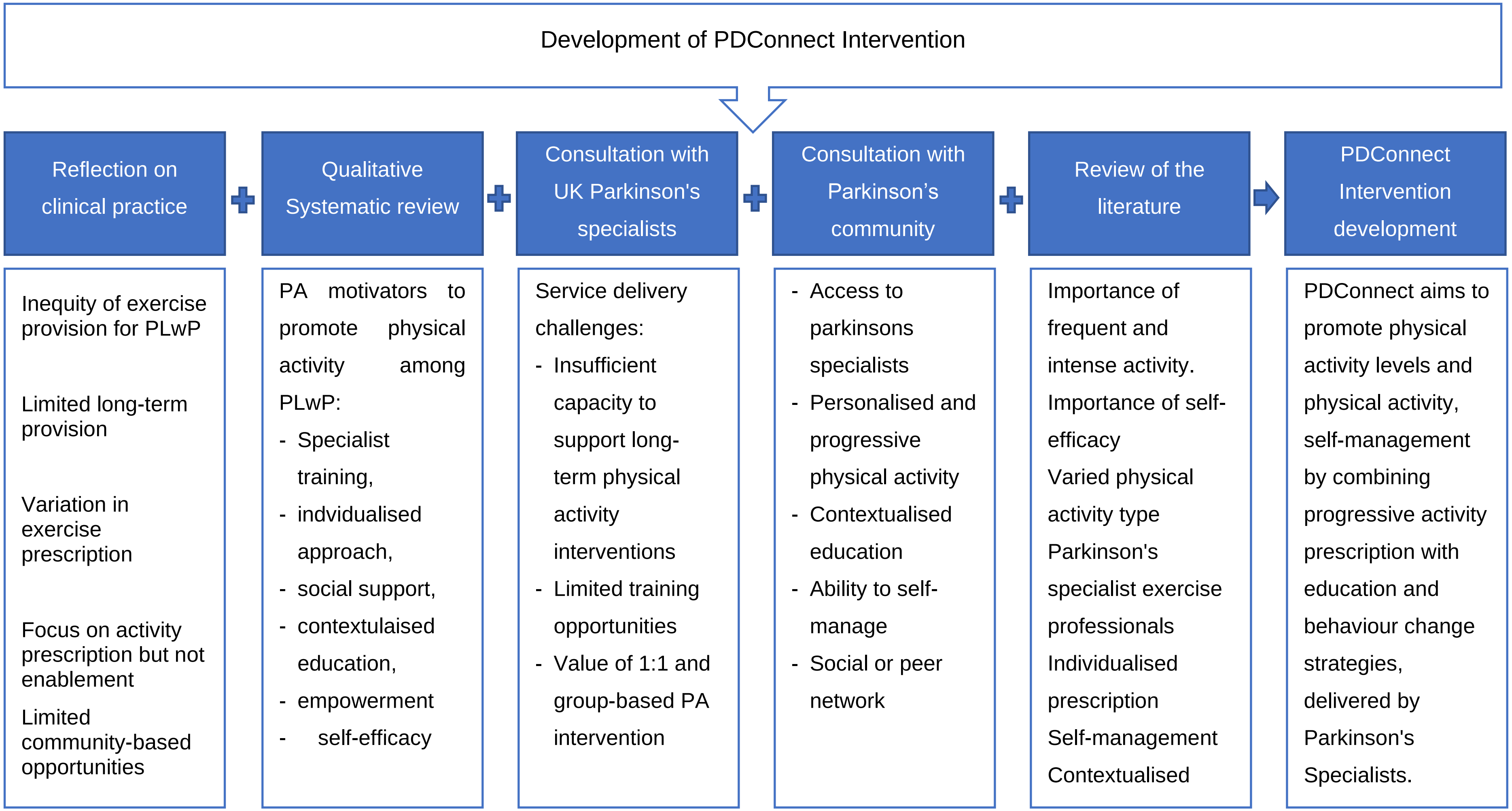
The development of the PDConnect Intervention was an iterative process evolving from the researcher's clinical reflections, which were subsequently shaped by consultation with Parkinson's specialist professionals, the Parkinson's community, and current research, as illustrated in Figure 2.5. The researcher was actively involved in several national Parkinson's community and professional groups, providing the researcher with a unique insight into the challenges faced by those living and working with Parkinson's.

The PDConnect intervention was robustly developed combining clinical and patient group consultation and informed by the current evidence base. Following the MRC Complex intervention guidelines, the aim of this research is the explore the feasibility and acceptability of the PDConnect Intervention. The development of PDConnect intervention pre-dated the Clinical Academic Fellowship awarded to the researcher, and therefore does not form part of this thesis. Sections 2.7.1.1 to 2.7.1.5 provide background context on the development and content of the PDConnect Intervention.

2.7.1.1 Reflections from clinical practice

Reflecting on working clinically with PLwP and working with professional networks associated with Parkinson's highlighted the following key issues:

- Large variation in PA levels and understanding of the benefits of PA.
- Inequity in accessibility to exercise professionals who had specialist knowledge of Parkinson's.
- Perceived lack of confidence among exercise professionals to manage PLwP.
- Lack of long-term PA interventions to support long-term participation.



Reflection on clinical practice	Qualitative Systematic review	Consultation with UK Parkinson's specialists	Consultation with Parkinson’s community	Review of the literature	PDConnect Intervention development
Inequity of exercise provision for PLwP Limited long-term provision Variation in exercise prescription Focus on activity prescription but not enablement Limited community-based opportunities	PA motivators to promote physical activity among PLwP: - Specialist training, - indvidualised approach, - social support, - contextulaised education, - empowerment - self-efficacy	Service delivery challenges: - Insufficient capacity to support long-term physical activity interventions - Limited training opportunities - Value of 1:1 and group-based PA intervention	- Access to parkinsons specialists - Personalised and progressive physical activity - Contextualised education - Ability to self-manage - Social or peer network	Importance of frequent and intense activity. Importance of self-efficacy Varied physical activity type Parkinson's specialist exercise professionals Individualised prescription Self-management Contextualised	PDConnect aims to promote physical activity levels and physical activity, self-management by combining progressive activity prescription with education and behaviour change strategies, delivered by Parkinson's Specialists.

Figure 2.5 Iterative development of PDConnect Intervention

2.7.1.2 Systematic review

The researcher undertook a qualitative systematic review guided by an a-priori protocol (PROSPERO CRD42017068705) to explore the barriers and motivators related to the PA participation of community-dwelling PLwP and were presented at the World Physiotherapy Congress in 2019. The findings of this systematic review combined with barriers and motivators to PA highlighted in the literature review chapter (section 2.3) resulted in an improved understanding of barriers and motivators to participation to PA which informed the intervention design, in particular the:

- Value of contextualised education on PA.
- Need to develop PA self-efficacy.
- Need for staff training to develop understanding of Parkinson's.
- Importance of peer support to promote long-term PA adherence.
- Value of group-based PA.
- Need to develop of a supportive PA environment.

2.7.1.3 Consultation with exercise professionals

Two consultation events (May 2018 and November 2018) were undertaken involving Parkinson's specialist exercise professionals who were members of the UK Parkinson's Excellence Network Exercise Hub. These consultation events were part of a larger piece of work being undertaken by the Parkinson's Excellence Network Exercise Hub, exploring how to improve services for PLwP in the UK, which were disseminated nationally (Oliver and Ramaswamy 2020; Ramaswamy et al. 2021), and led to the development of the Parkinson's UK, Exercise Framework. This consultation highlighted:

- The need for post-registration training on Parkinson's, exercise prescription of PLwP, and strategies to support long-term PA adherence,
- Developing an awareness of the benefits of PA among PLwP and supporting and enabling changes in PA levels among PLwP
- The need to provide long-term sustainable PA provision for PLwP.

2.7.1.4 Consultation with people living with Parkinson's

Informal consultation was undertaken by the researcher through attending local branches, research interest groups, and Scotland-wide Parkinson's UK events to explore PLwP perceptions of how services could be best configured to support PA engagement. The key findings from these informal consultations aligned with the findings identified in section 2.3 literature review. PLwP valued PA interventions, delivered by Parkinson's specialists, who enable an understanding of the value of activity in relation to their Parkinson’s symptoms. It is recognised that those attending Parkinson’s UK events and Branch meetings may not be reflective of the wider Parkinson’s population resulting in potential for bias. However, those attending were self-described urban and rural residents with a mixture of those who self-reported that they were active or not.

2.7.1.5 Literature review conclusions and recommendations

The introduction of this thesis (section 1.6) highlighted that a substantive body of evidence exists supporting PA prescription. To date, research has focussed on the effectiveness of types of PA, or the impact on motor or NMS, or QoL. Comparatively little research has explored the optimal means of delivering PA, with the aim of influencing PA behaviour and supporting long-term PA, which may explain why PLwP are aware of the benefits of PA yet remain inactive.

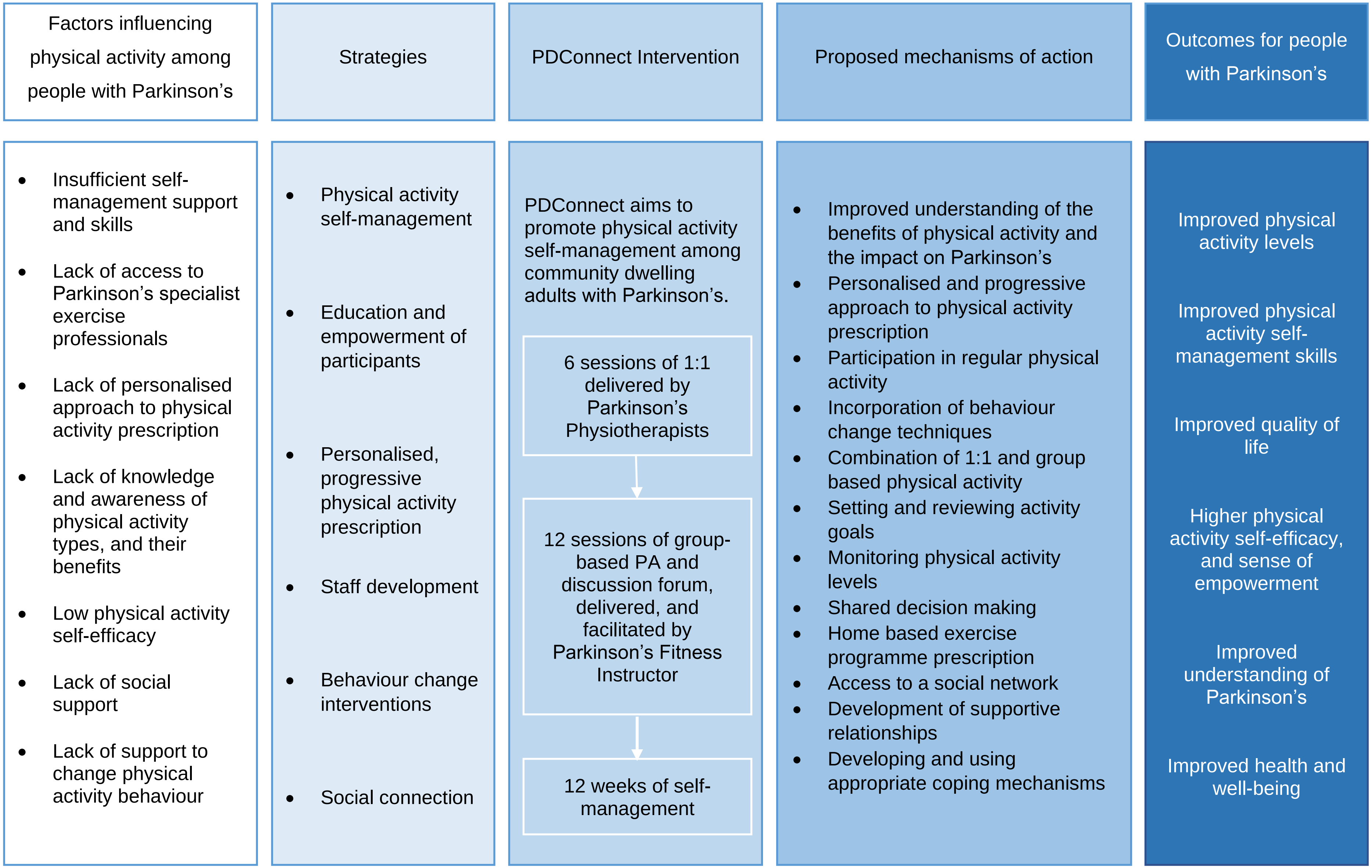
Simply providing PLwP with a PA programme is recognised as ineffective (Ellis and Rochester 2018). Rather, the narrative review highlighted that PA needs to be delivered as part of a package. Section 2.4 and 2.5 of the review identified several key ingredients which were shown to positively influence PA behaviour and support PLwP to be able to self-manage their PA. Key ingredients included personalised PA prescription, access to Parkinson's specialists, education, development of self-efficacy, and empowerment. In addition, the narrative review (section 2.4) highlighted those interventions which adopted a coaching style of delivery, and incorporated BCT’s and self-management skills positively influenced PA behaviour among PLwP.

The combined findings from the consultations and the narrative review of the literature informed the development of the PDConnect intervention, its scope, sequence, and mode of delivery. The researcher devised the PDConnect intervention which is an evidence informed multi-component intervention which aims to increase PA, providing PLwP the skills and strategies to change thier PA behaviour. PDConnect aims to support PLwP to develop a “physical activity habit”, providing them with the skills required to effectively self-manage their PA. PDConnect is a 30 week intervention which combines individualised and group-based progressive PA prescription and consists of: i) six sessions of one-to-one specialist Physiotherapy; ii) 12 weekly sessions of group-based PA; and iii) 12 weeks of supported self-management, where participants were contacted monthly, delivered exclusively online via Microsoft Teams by a Fitness Instructor. Key features of PDConnect include evidence informed progressive PA prescription delivered by Staff with expertise in Parkinson's, delivered in parallel with BCTs and self-management skills such as education, decision-making, problem-solving, to promote PA self-efficacy, and empowerment. Figure 2.6 presents a logic model of the intervention, including the proposed mechanisms of action. The following sub-sections will discuss in greater detail the individual components of the PDConnect intervention.

2.8 CHAPTER SUMMARY

This chapter has highlighted that many barriers to participation in PA exist, which may explain why a large proportion of PLwP are classified as sedentary. However, this review also highlighted that Parkinson's informed staff, education, personalisation of PA prescription, and support are key motivation factors which enable PLwP to participate in PA The current review also highlighted that incorporating BCTs into interventions optimises the impact on behavioural change, with a greater number of BCTs associated with enhance behavioural outcomes. In addition, the use of self-management strategies such as problem solving, education, self-monitor delivered in conjunction with PA support changes in PA behaviour.

This chapter also introduced PDConnect and explored the processes which had lead to the development of of this multicomponent intervention which aims to support PLwP to increase their levels of PA and be able to self-manage this PA long term.



Factors influencing physical activity among people with Parkinson’s

- Insufficient self-management support and skills
- Lack of access to Parkinson’s specialist exercise professionals
- Lack of personalised approach to physical activity prescription
- Lack of knowledge and awareness of physical activity types, and their benefits
- Low physical activity self-efficacy
- Lack of social support
- Lack of support to change physical activity behaviour

Strategies

- Physical activity self-management
- Education and empowerment of participants
- Personalised, progressive physical activity prescription
- Staff development
- Behaviour change interventions
- Social connection

PDConnect Intervention

PDConnect aims to promote physical activity self-management among community dwelling adults with Parkinson’s.

6 sessions of 1:1 delivered by Parkinson’s Physiotherapists

12 sessions of group-based PA and discussion forum, delivered, and facilitated by Parkinson’s Fitness Instructor

12 weeks of self-management

Proposed mechanisms of action

- Improved understanding of the benefits of physical activity and the impact on Parkinson’s
- Personalised and progressive approach to physical activity prescription
- Participation in regular physical activity
- Incorporation of behaviour change techniques
- Combination of 1:1 and group based physical activity
- Setting and reviewing activity goals
- Monitoring physical activity levels
- Shared decision making
- Home based exercise programme prescription
- Access to a social network
- Development of supportive relationships
- Developing and using appropriate coping mechanisms

Outcomes for people with Parkinson’s

Improved physical activity levels

Improved physical activity self-management skills

Improved quality of life

Higher physical activity self-efficacy, and sense of empowerment

Improved understanding of Parkinson’s

Improved health and well-being

Figure 2.6 **PDConnect Logic Model**

CHAPTER THREE – STUDY AIMS AND OBJECTIVES

Aim

To determine the feasibility and acceptability of a multi-component intervention (PDConnect) aimed at promoting physical activity and self-management in community dwelling adults with Parkinson’s.

Feasibility Objectives

1. To estimate the recruitment rate to the study.
2. To determine the required duration to recruit the target sample size.
3. To estimate the recruitment rate of Physiotherapists and Fitness Instructors to deliver the PDConnect intervention.
4. To estimate participant retention rate during the study.
5. To explore the proportion of participants who withdraw, and the rationale for withdrawal.
6. To estimate participant attendance to the PDConnect intervention.
7. To estimate outcome measure completion rates.
8. To explore completion and return rate of activity diaries.
9. To explore whether the intervention is associated with any adverse events.

Acceptability Objectives

1. To explore acceptability among participants with Parkinson’s
2. To explore experiences of participating in the intervention.
3. To explore perceptions of the study and intervention resources.
4. To explore satisfaction with the intervention.
5. To explore acceptability among those delivering the intervention
6. To explore perceptions and experiences of intervention training.
7. To explore perceptions of delivering the intervention.
8. To explore perceptions of the study resources.

Fidelity Objectives

1. To explore whether the intervention can be delivered as planned.

2. To explore what proportion of sessions adhere to ≥75% of the PDConnect intended content.

Secondary Objectives

1. Explore which outcome measure should be the primary measure in a future RCT to evaluate effectiveness, and to perform sample size calculation.
2. To estimate effect sizes for secondary measures to enable sample size calculation for a full-scale trial.

CHAPTER FOUR – METHODOLOGY AND METHODS

This chapter will consider the relevant research worldviews and explore the theoretical perspectives that underpinned this research. Key methodological concepts are defined, described, and appraised in relation to the proposed study. The aim and the nature of the study required the collection of objective data combined with an exploration of the perceptions of those involved within the research. Consequently, a single research method was insufficient, therefore a mixed methods approach was selected, more specifically a fixed convergent parallel design (Creswell and Plano Clark 2011). The following sections will provide the rationale for selecting this approach.

4.1 WORLDVIEWS AND METHODOLOGICAL CONCEPTS

Distinction exists between research methodology and methods. The former relates to the beliefs and processes which guide selection of specific research methods (Glogowska 2010), whereas the latter is a series of techniques and procedures applied during a research study. Creswell (2014) argues that research methodology should be framed within a worldview to add credibility, context, boundaries and meaning to the proposed research. A worldview creates a foundation for conducting research, which is shaped by the assumptions and values of the researcher, creating a framework to guide methodological choices (Crotty 1998). In this thesis, informed by Creswell and Plano Clark (2011 pp 39), the term worldview is used and is defined as “a set of beliefs that guide actions”. Selection of a particular worldview is informed by a range of factors including ontology, epistemology, and axiology (Guba and Lincoln 2005). Ontology refers to nature of reality, what exists and what can be known (Richards 2003). Epistemology is defined by Creswell and Plano Clark (2011) as the nature of knowledge, and the mechanism by which knowledge is gained. Axiology is a branch of philosophy focussing on judgements and values (Saunders 2009). In the research context, axiology encompasses ethics, spirituality, and morality, which influence how researchers generate knowledge (Lincoln 2011). Therefore, different worldviews are based on different ontological and epistemological perspectives and beliefs, which provide the foundation of a research study from which the research is built upon. Due to the variation in ontological and epistemological perspectives, several differing worldviews, and approaches to selecting worldviews exist. Positivism is associated with empirical research, which involves the use of objective measurement and observation. Positivists believe in one reality, where results are drawn solely from observation (Creswell and Plano-Clark 2011). In contrast, Interpretivism embraces peoples views, and the researcher plays an active role in the interpretation of the participants’ views to formulate meaning (Howe 1992). Therefore, Positivism and Interpretivism represent two extremes of the spectrum. Authors such as Guba and Lincoln (1983), identify four worldviews, with differing ontological and epistemological stances; Positivism, Post-positivism, Critical Theory, and Constructivism, whereas other authors such as Crotty (1998), dictated that Worldviews are influenced solely by epistemological perspectives. Creswell and Plano-Clark (2011) have identified four Worldviews, which include: Post-Positivism, Constructivism, Participatory, and Pragmatism (Creswell and Plano-Clark 2011), which will now be explored in relation to this study.

The ontological perspectives differ between the four worldviews postulated by Creswell (2014). Post-positivism and Constructivism are at opposing ends of the ontology spectrum. Central to Post-positivism is objectivity, with assumptions that human behaviour is governed by fact. Post-positivism emerged from Positivism, with the latter grounded in the principle that the researcher and the researched person are independent of each other. Post-positivists, however, accept that the theories, background, knowledge, and values of the researcher can influence what is observed. In contrast, Constructivism acknowledges multiple realities, where knowledge is generated by social interaction informed by views and opinions (Creswell and Plano-Clark, 2011). Arguably, adopting a post-positivist approach allows for robust and statistical verification that a health intervention resulted in change. However, it is limited in its ability to determine why the results occurred, what the underlying mechanisms were, or to draw any inference on participants' views of the intervention. Conversely, Constructivism centres upon exploring the lived experience, enables inferences to be drawn on participants’ views and experiences (Creswell and Plano-Clark, 2011), as well as highlighting factors which may explain why an intervention was beneficial. However, conclusions only reflect the subjective views of those involved, and therefore are not directly applicable to the wider community (Bowling 2014).

Establishing efficacy and effectiveness of health interventions is essential (Clarke et al. 2019). Efficacy is the extent to which an intervention produces the intended result under ideal or controlled conditions, whereas effectiveness is the extent to which an intervention produces the intended result under usual care circumstances (Haynes 1999). Efficacy and effectiveness studies sit within the Post-positivist Worldview, and while of value they are potentially restrictive. Prior to interventions being adopted, there is a need to ascertain the participants’ perceived value of the intervention and whether the intervention meet participants’ needs, as failure to do so could result in services failing to meet demand. This would infer that a hybrid Worldview which combines objectivity and values gained from social interaction may be preferable for this study, which aims to explore feasibility and acceptability of PDConnect.

Epistemology relates to the nature of knowledge, and the mechanism by which knowledge is gained (Creswell and Plano Clark, 2011). Epistemology aligns with ontology, and therefore the epistemological stance differs between worldviews (Guba and Lincoln 2000). Within the Post-positivist worldview, knowledge is gained through a scientific approach, involving hypothesis testing, to establish causation or association between variables (Creswell and Plano Clark, 2011). Post-positivist approaches therefore adopt quantitative methods, employing inductive or deductive process to inform reliable and systematic conclusions. Conversely knowledge generated through a Constructivist approach posits that multiple realities exist, which are socially constructed, and therefore lend themselves to qualitative methods (Creswell and Plano Clark, 2011).

Axiology focusses upon values, and influences how research is conducted, and the role of the researcher. Within the Post-positivist worldview, the researcher is independent to the research process, involved in data collection and objective data interpretation. Consequently, the phenomenon of interest is unaffected by the views and values of the researcher (Andrew and Halcombe 2009). Conversely, when adopting a Constructivist approach, the researchers are integral to the research; therefore, the views, perceptions, and values may shape the direction of the research, and thus influence the conclusions that are drawn (Creswell 2014).

The Participatory worldview is an extension of Constructivism (Heron and Reason 1997), aligning with a qualitative approach. However, the Participatory worldview is broader in nature, and commonly influenced by political concerns (Creswell and Plano Clark, 2011). Participatory research concentrates on reform that may change participants' lives, the institutions where they work, or live, and the researcher's life. Accordingly, the focus of this Worldview is to incur changes with an emphasis on targeting marginalised groups. The Participatory worldview is self-reflexive, drawing parallels from adult educational theory; knowing is richer when learning is grounded in experience, reinforced by narratives, explored through theories and applied to real life (Creswell and Plano Clark, 2011). While this approach is broader than Constructivism, this doctoral researcher is not motivated by a political agenda, and while health interventions commonly aim to instil change and empower patients, this researcher does not seek to do this through a political lens therefore this worldview was not considered appropriate.

Pragmatism arose from many researchers rejecting Post-positivism, which posits that truth can only be reached through one scientific method (Creswell and Plano Clark, 2011). In contrast to Constructivism and Post-positivism, Pragmatism dictates that research design should be influenced by the research question, not dictated by epistemology and ontology (Creswell and Plano Clark, 2011). Pragmatic research commences with a problem, with the goal of establishing practically guided solutions which can inform change, behaviours, or practice. Pragmatism is based on the proposition that researchers should adopt whichever methodological approach best addresses the area being researched (Creswell and Plano Clark, 2011). Therefore, the ontological stance within the Pragmatist Worldview accepts that both singular and multiple realities can exist, with potential to combine hypothesis testing with gaining multiple perspectives. The pluralistic ontological stance within the Pragmatic Worldview shapes the epistemological perspective in that reality can be captured through multiple tools. As such, Pragmatic research is associated with plurality of methods (Tashakkori and Teddlie 2003), whereby emphasis is placed upon the research question as opposed to methods, and where multiple methods of data collection are acceptable to understand the problem. Pragmatism, therefore, offers flexibility, utilising and valuing a combination of quantitative and qualitative data collection methods. In summary, worldviews provide a foundation for conducting research, which are shaped by the assumptions and values of the researcher (Denzin and Lincoln 1998). The adopted worldview of Pragmatism, therefore, reflects the ontological, epistemological, and axiological stance of the researcher, which serves to inform the subsequent choice of research methodology and methods.

4.1.1 Application of worldview

Current healthcare systems place emphasis on quality, effectiveness, and efficiency (NHS England, The NHS Long Term Plan, 2019). Central to healthcare policy is the need to ensure that health interventions meet the needs of the population they serve. This has necessitated a shift away from a medical approach to care delivery, to one which is based upon partnership and shared values. Consequently, when developing healthcare interventions, consideration needs to be given to whether the intervention can be delivered (feasibility), and whether it is acceptable by patients and staff. The Medical Research Council (MRC) advocates that ascertaining whether an intervention can be delivered, and whether the target community deem it acceptable, should be determined prior to establishing effectiveness (Skivington et al. 2021). This doctoral research has arisen from a real-world, practice-orientated problem, and has led to the development of a health intervention which is hoped will inform change in individual’s behaviour, and/or practice. Central to this programme of research is to explore whether the health intervention can be delivered and whether this intervention is acceptable to both those receiving and delivering it. Therefore, this research is dependent upon multiple viewpoints, requiring multiple data collection techniques, and analysis procedures. Adopting a post-positivist stance would limit the generation of new knowledge, serving only to quantify participation, while failing to explore why people attended, or adhered, or gauge perceptions of the intervention itself. Conversely, adopting a constructivist stance, while providing rich data on perceptions of, and attitudes towards the health intervention, would be limited in its capacity to quantify engagement or feasibility. This programme of research therefore sits comfortably within the Pragmatist worldview, bringing together quantitative and qualitative approaches, exploring connections between the two, and thus mitigating the limitations of other worldviews (Bishop 2015), allowing for a more comprehensive exploration of the area of interest. Critically, it facilitates an approach in which both quantitative and qualitative approaches are valued.

By underpinning this doctoral research within the Pragmatist worldview, the researcher's ontological perspectives are pluralistic, acknowledging that singular or multiple realities can exist (Figure 4.1). The subsequent epistemological belief is that reality can be captured through multiple tools encompassing the combination of qualitative and quantitative approaches in the study methodology. Therefore, this doctoral research has adopted a practical and applied research stance to guide its methodological choices, adopting a mixed methodological approach. Adopting a mixed methodological approach allows inclusion of quantifiable measures of feasibility and acceptability combined with collection of qualitative data to gauge the perceptions and experiences of those involved in the research. The combination of quantitative and qualitative approaches allows rounded and informed conclusions to be drawn based upon multiple perspectives, allowing confidence that the research conclusions are representative of those who participated.

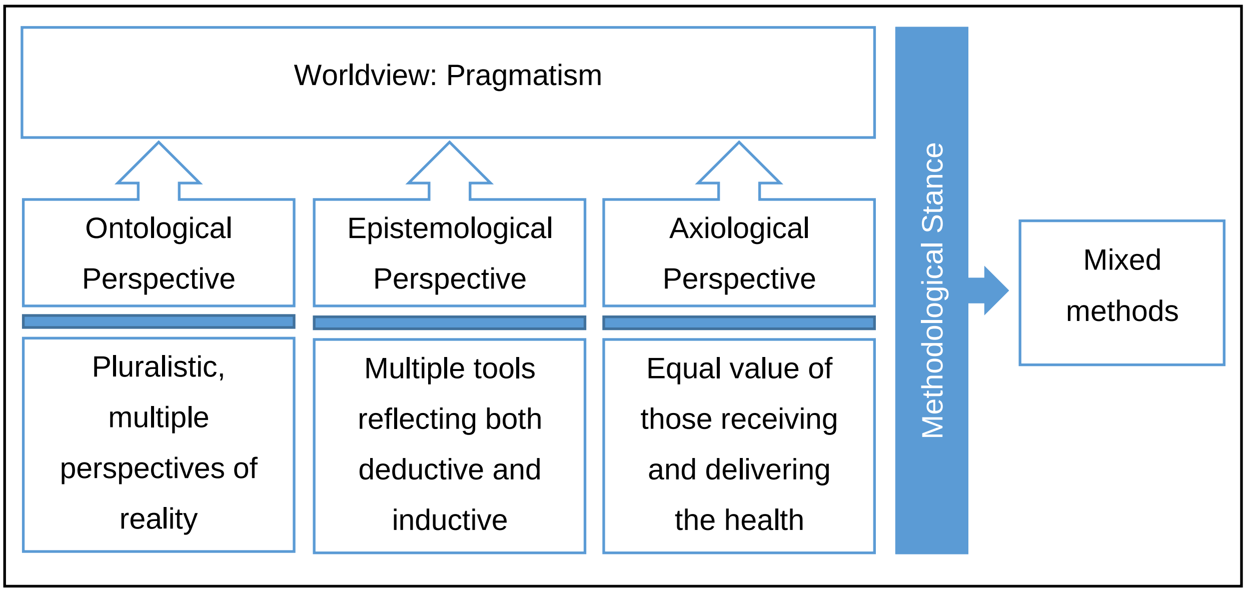


Figure 4.1 **Summary of the Worldview adopted within this doctoral research.**

4.2 MIXED METHODOLOGY RESEARCH

Mixed methodology studies combine the collection of quantitative and qualitative data within a single study, which are integrated at one or more stages in the process of research (Tashakkori and Teddlie 2003). The use of mixed methodology has risen exponentially within health research (Tariq and Woodman, 2013), reflecting their ability to capture the complexity of human interaction within healthcare interventions. Debate exists whether mixed methods are a methodological approach or a method of inquiry (Creswell 2007, pp5). As a methodology, it is based on the philosophical assumptions that inform the collection and analysis of quantitative and qualitative data within a single study. Proponents of mixed methodology perceive it as a “best of both worlds” approach combining the merits of quantitative and qualitative data collection (Shorten and Smith 2017). Therefore, adopting a mixed methodological approach results in a better understanding of research problems than would be achieved by using either approach alone (Creswell and Plano Clark, 2011). The core characteristics of mixed methodology research have been summarised by Creswell and Plano Clark (2011) and are illustrated in table 4.1. This study adopted a mixed methodological approach as this sits comfortably in the Pragmatic worldview, which acknowledges the importance of using the best approach to investigate a phenomenon.

Table 4.1 Characteristics of mixed methods research

Core characteristics of Mixed Methodology research	
1	Collects and analyses rigorously both qualitative and quantitative data.
2	Mixes two forms of data either concurrently or sequentially
3	Gives priority to one form or both forms of data
4	Conducted during a single study or in multiple phases of a study
5	Procedures are framed within a philosophical Worldview
6	Combines procedures into specific research designs that direct the plan for conducting the study.

Adapted from Creswell and Plano-Clark 2011

4.2.1 Rationale for adopting a mixed methodology

Health interventions are commonly complex (Skivington et al. 2021) encompassing several interacting components, which necessitates a nuanced approach to appropriately deal with this complexity. Adopting a mixed methodological approach enables researchers to comprehensively evaluate health interventions by combining quantitative and qualitative approaches. Moreover, Parkinson's is a heterogeneous condition, with a broad symptom profile (Bloem, Okun and Klein 2021). Bowling (2014, pp.364) wrote "*when capturing both complexity and diversity, these cannot be adequately addressed by one approach, evidencing the need to combine methods within this doctoral research*".

A mixed methodological approach was selected for this doctoral research for several reasons. Firstly, to address the study aims, one form of data source would be insufficient. In this study the quantitative and qualitative strands are interdependent, yet complementary. The objectives of the study include recruitment and retention rates to the health intervention (which requires a quantitative approach) but also critically developing an understanding of the factors which influence retention and participation in the health intervention which requires a qualitative approach. Secondly, use of mixed methodology allows for a greater understanding of the mechanisms that underpin the quantitative findings. Simply collecting quantitative data on retention rates limits our understanding of participant behaviour, and the factors which influence retention. The collection of qualitative data can be used to explain the quantitative findings, leading to deeper understanding of the issues. Thirdly, mixed methodology allows the offsetting of the limitations of both quantitative and qualitative approaches, thus allowing the researcher to draw on the strengths of both, and thus enhancing the greater credibility of the research programme. Finally, the combination of both quantitative and qualitative data allows both a detailed and general understanding of the health intervention. Having explored and justified the need to adopt a mixed method approach, the following section will identify and evaluate the specific qualitative and quantitative approaches that were used within the programme of research.

4.2.2 Qualitative approaches

Despite the relative infancy of qualitative research, many approaches exist. Creswell (2007) proposes four key qualitative approaches: Narrative Research, Phenomenology, Grounded Theory, and Ethnography. Appreciation of the merits of each of these approaches needs to be undertaken, as selection will influence research design, and thus data collection methods. The following sections will explore each of these, justifying the approach taken within this study.

Narrative Research centres upon individuals lived experiences and stories, encompassing a single or series of events, which are chronologically connected (Czarniawska 2004). Narrative Research generates a large volume of rich data, collected via interviews, observations, documents, and photographs (Creswell, 2007). Narrative Research was discounted as it focusses upon capturing life experiences, whereas the focus of this study is to capture the experiences and perceptions of a specific health intervention. Therefore, a Narrative approach is too broad, and does not align with the research objectives of this study.

Like Narrative Research, Phenomenological research focusses on the exploration and understanding of the lived experience. However, Phenomenology draws people together that have experienced the same phenomenon (e.g., diagnosis of Parkinson's), from which the researchers construct a universal understanding of their experience (Creswell 2014). Phenomenology is commonly used within health research (Nieswiadomy 1989), including those with neurological conditions (Greenfield and Jensen 2012). However, this approach was discounted as the focus of Phenomenological research is to produce in-depth descriptions of the phenomenon, which in isolation would be insufficient to address the aims and objectives of this study.

In contrast to the prior to approaches, Grounded Theory aims to produce new theory, generated, and developed from participant engagement. This approach assumes an iterative approach collected via semi-structured interviews or focus groups to generate new theory (Noble and Mitchell 2016). Grounded Theory, like the prior approaches are subject to bias, owing to the role of the person conducting the research, and their role, within data collection, and analysis. Moreover, this approach was discounted as the development of theory is not the focus of this study, rather the emphasis of this doctoral research is to explore participants experience of a health intervention.

Ethnographic research aims to explore the beliefs, values, and behaviours of a "culture sharing group" (Creswell, 2007). Ethnographic studies capture a true picture of participant experience, documenting highs and lows, as opposed to a snapshot in time, which by their nature, could induce the Hawthorne effect. The Hawthorne effect occurs when participants behaviour changes due to their awareness of being studied, not as a direct consequence of the intervention (Bowling 2014). While exploration of the beliefs, and perceptions of participants is central to the objectives of this study, adopting an ethnographic approach was discounted as it dependent upon the researcher being immersed within the group which would have prevented the researcher remaining blind to participant group allocation. Moreover, ethnography is resource heavy, where emphasis is placed upon capturing social interactions, and identifying behavioural patterns. The focus of this study is to capture individual perceptions of a health intervention, as opposed to exploring the interactions between and within the group, thus it was not considered.

4.2.3 Qualitative descriptive approaches

The qualitative approaches discussed in section 4.2.2, all have their merits, however, in their purest sense, none are a good fit with the objectives of this research. This predicament is commonplace (Bradshaw, Atkinson, and Doody 2017), resulting in the need to develop more pragmatic approaches. Qualitative descriptive methodologies are commonly used in health-based research, with over half of the published qualitative studies adopting this methodology (Polit and Beck 2014). Qualitative descriptive approaches offer a pragmatic approach, that "simply seeks to discover and understand a phenomenon, a process, or the perspectives and worldviews of the people involved" (Merriam 1998, pp11). The Qualitative Descriptive approach encompasses some of the key elements of the main qualitative approaches already discussed, using them in combination, to explore experiences of novel and unknown phenomena (Kim, Sefcik and Bradway 2017). Recognising the flexibility of this approach, Qualitative Description has become the approach of choice by researchers wishing to explore views and perceptions of participants, and to develop and refine new interventions (Neergaard et al. 2009). As the researcher wishes to capture participants' views on a new health intervention, the flexibility and freedom that Qualitative Description offers seems more fitting, than the restrictions imposed by the other qualitative approaches.

Despite the popularity of the Qualitative Descriptive approach, few publications exist to guide researchers on its application (Kim, Sefcik and Bradway 2017). Qualitative Descriptive research is not wedded to a particular theory or framework, encouraging a pragmatic approach dependent on the phenomena being studied (Sandelowski, Barroso and Viols 2007). This flexibility extends to the choice of data collection (Neergaard et al. 2009), and sampling, permitting the use of purposeful sampling to promote sample diversity, and therefore enhancing richness of data obtained. Therefore, this approach is pragmatic in nature, allowing flexibility in approach guided by the researcher's Worldview and was adopted for use in this research.

4.2.4 Quantitative approaches

Quantitative approaches have an established history (Bowling 2014), following an experimental approach, and sit firmly in the Positivist worldview (Tanner 2018). Experimental research is deductive in nature, encompassing hypothesis testing explored within a logical framework, adhering to defined, and controlled conditions, to minimise the effects of systematic and random error. At a basic level, quantitative research encompasses an experimental group, who receive the intervention. Randomised controlled trials (RCT's) are regarded as the gold standard in quantitative research, involving randomisation of participants to an intervention or control group (Bowling 2014). Pre and post-test assessments allow conclusions to be drawn on the effect of the intervention (Bowling 2014). Within true experimental studies, participants are randomly allocated to either group, with all variables kept constant between the two groups except for the exposure to the intervention. The use of valid and reliable measures is fundamental in quantitative research. Reliability is associated with the consistency of a measure whereas, validity is the measurement tool's ability to measure what it is required to measure (Bowling 2014). Several different forms of reliability and validity exists as illustrated in table 4.2, each of which needs careful consideration during the design phase of research, so that the results can be generalised to the population with confidence. Quantitative approaches were deemed relevant to the scope of this study to allow accurate assessment of recruitment procedures, intervention adherence, outcome measure completion rates and quantify satisfaction.

Table 4.2 Types of reliability and validity

Concept	Description
Internal validity	Confidence with which the results obtained are because of the independent variable, and not other factors or variables
External validity	Is the ability to generalise the findings to the wider population
Internal consistency	Used to assess the consistency of results across items within a test. The degree of interrelationship among the items within a test, such that they are consistent with one another and measuring the same thing
Inter-rater reliability	Is the extent to which two or more raters agree when using the same measure
Intra-rater reliability	Is the degree of agreement among repeated administrations of a test by a single rater
Test-retest reliability	The degree of agreement between the results of successive measurements of the same measure, when carried out under the same conditions over time

Adapted from Bowling 2014

Quantitative experimental research is often regarded as the gold standard for assessing the effectiveness of interventions (Concato, Shah and Horwitz 2000). That said, the rigour in which experimental research is conducted is also subject to much criticism, as the high levels of controls do not reflect real life (Bowling 2014). Consequently, experimental research is associated with low external validity despite having high internal validity. Experimental studies through their scientific approach allow researchers to draw relationships between cause and effect. Owing to judicious control of variables, the results are specific, and regarded as reliable. Within a laboratory, variables can be controlled for, however within healthcare this is more challenging. Among a given population such as Parkinson's, there is marked variation in symptom profile, age, gender, and co-existing conditions. Therefore, isolation of variables and/or excluding all confounding variables is challenging, with potential to impact on the overall reliability of the study. Careful balance is therefore required so that this research can draw casual relationships, while being able to generalise finding to the wider population. The need to ensure balance further support the adoption of a mixed methods approach combining the merits of both quantitative and qualitative approaches.

4.3 SECTION SUMMARY

Healthcare interventions need to be effective and meet the needs of those who receive them. Therefore, the foundation of this research is embedded within the Pragmatist worldview, which combines both Interpretivist and Positivist values. The epistemological and ontological perspective of Pragmatism recognises that diversity exists within a population, and subsequently accepts that multiple realities exist, which cannot be researched by a single approach. As this study is interested in the implementation of a health intervention, the use of a mixed methods approach allows the researcher to explore the impact of the intervention on participants in a quantitative manner, as well as to explore the perceptions of those engaging and delivering with the intervention. Combining the strengths of qualitative and qualitative methods will allow the researcher to draw contextually driven holistic conclusions encompassing diverse perceptions and unveiling relationships that exists, and hence a mixed methods approach was selected.

4.4 METHODS

This section will consider research methods adopted within this research. Key concepts are defined, described, and appraised in relation to the proposed study. The aim and the nature of this programme of research, is to establish the feasibility, acceptability, and fidelity of a health intervention for people with Parkinson's, using a fixed convergent parallel design. The methods section aligns with the CONSORT extension for feasibility studies (Thabane et al.

2016) and TIDieR guidelines (Hoffmann et al. 2014). Completed CONSORT and TIDieR checklists are available in Appendix 2.

4.4.1 Ethical Approval

The study was reviewed by the RGU School of Health Sciences Research Ethics Committee (REC) (SHSREC 20/21) and sponsor approval was obtained (RGU). Full ethical approval was granted by the Liverpool Central REC on the 30th of June 2020 to deliver the PDConnect intervention face-to-face (IRAS Number 280159). Due to the COVID-19 pandemic, and the impact this had on the face-to-face delivery of health interventions, a major amendment was submitted in August 2020. The major amendment reflected the need to change the mode of delivery from face-to-face to exclusive online delivery to adhere to Government social distancing, and research governance guidelines at that time. Appendix 3 summaries the IRAS amendments which were sought during the study.

Transferring to online delivery involved some minor changes to the mode of recruitment and inclusion criteria. Changes to the inclusion criteria, and use of certain outcome measures were made to ensure participant safety during online PA and are detailed in Appendix 4. No changes were required to the content of the intervention, only the mode of delivery. Full ethical approval was granted by the Liverpool Central REC Centre on the 11th of November 2020 (IRAS Number 280159) to deliver the online version of PDConnect. This study was also approved by NHS Grampian Research and Development department on the 1st of December 2020 (2020RG001E). The study was registered on ISRCTN (ref: 11672329) and on the Open Science framework (DOI10.17605/OSF.IO/TY9XE). The study protocol was published in AMRC Open Research Journal (Jones et al. 2021).

The following sections will provide rationale for the selection of the approaches taken in this study in addition to other key aspects of research methods including sampling, intervention development, data collection, and analysis. For clarity the term intervention will be used throughout this Thesis to denote the PDConnect Intervention.

4.4.2 Feasibility and acceptability studies

The MRC guide to complex interventions suggests that research should be undertaken in four phases: development, feasibility, evaluation, and implementation (Skivington et al. 2021). As the intervention had been developed prior to the awarding of the clinical academic fellowship that funded this doctoral research, aligning with the MRC complex intervention guidance, this study is a feasibility and acceptability study of an online multi-component intervention (PDConnect) aimed at promoting PA self-management for PLwP. The researchers ultimate aim is to investigate the long-term effectiveness of the intervention by way of a future definitive RCT. However, embarking on a RCT would be premature, due to several unknown factors. Thus, this design was selected to build the foundations for the future large-scale study (Tickle-Degnen 2013). Adopting this approach allows the generation of knowledge on several aspects: feasibility, acceptability, fidelity, perceptions, adherence and attitudes to the intervention and its processes to inform future research.

The MRC define complex interventions as those which contain several interacting components involving a range of possible outcomes, employed among a varied target population (Skivington et al. 2021). The intervention fulfils these criteria, as it is being delivered to PLwP which is a heterogeneous population, and encompasses many components and outcomes that can be positively influenced by PA. Moreover, the online intervention incorporates tailored PA delivered individually and as part of a group.

Feasibility studies are vital prior to evaluation and implementation of an intervention, allowing for the exploration of processes, procedures, and intervention perceptions, to inform refinements prior to full scale evaluation (Eldridge et al. 2016a). If omitted, inconclusive or negative evaluations can occur, due to issues with intervention delivery and recruitment, which could be mitigated, had feasibility studies been undertaken (Thabane et al. 2016). Much debate exists in relation to feasibility studies, fuelled by the lack of consensus on what constitutes a feasibility study (Eldridge et al. 2016b). The terms “feasibility and pilot studies” are commonly used interchangeably (Eldridge et al. 2016b), with some authors arguing that they are synonymous. Both are regarded as essential for the planning of larger RCT’s, with a clear purpose of ensuring future RCT’s are well-designed (Eldridge et al. 2016a). Pilot studies are a small-scale version of the full trial, whereas feasibility studies are an essential step which focus on whether interventions can be delivered as planned, to ensure smooth transfer and adoption within the healthcare setting. Fundamentally, feasibility studies do not test treatment effect (Lancaster et al. 2015), but focus on the suitability of the chosen design, to generate and inform sample size for the definitive full-scale study to ensure that it is adequately powered. Adopting the National Institute for Health Research (NIHR) definition, this study is a feasibility study, which is the precursor to a large-scale study, with the principal aim of establishing whether a study can be done, with the goal of establishing essential parameters that need to be incorporated into the main study. The intended outcome of the proposed study therefore will be a protocol for a robust and adequately powered RCT to evaluate the clinical and cost-effectiveness of the intervention.

The MRC state that acceptability should be evaluated alongside feasibility (Skivington et al. 2021). Solely conducting a feasibility study will not inform whether an intervention is acceptable from the perspective of those receiving or delivering it. Moreover, while feasibility may encompass recruitment and retention rates, lower than expected recruitment could be attributed to perceived intervention acceptability, highlighting the need to consider both feasibility and acceptability. Sekhon, Cartwright and Francis (2017, pp8) define acceptability as "*a multifaceted construct, which is formed based on anticipated or experienced cognitive or emotional responses to an intervention*", inferring that acceptability is broader than satisfaction. Adopting this definition, acceptability will be explored through both quantitative and qualitative means, to inform the design, development, and implementation of a future trial.

The MRC also advocate that fidelity assessment should be embedded within study design (Skivington et al. 2021). Health interventions targeting PA have been criticised for lacking intervention fidelity (Toomey et al. 2020). Gearing et al. (2011) defined fidelity as the degree to which an intervention is delivered as intended. Without intervention fidelity, uncertainty exists as to whether observed effects are attributable to the intervention or not (Borrelli 2011). In the event of a negative trial, low impact could be attributed to variability in intervention delivery rather than intervention ineffectiveness. Moreover, fidelity assessment provides opportunity to highlight low fidelity aspects of the intervention, which can be addressed prior to conducting a definitive trial (Hankonen et al. 2017). The MRC advocate that complex multicomponent interventions such as PDConnect which aim to shape participant behaviour, should encompass fidelity planning and assessment as part of intervention development. However, assessment of fidelity is poorly addressed, particularly among behaviour change interventions (Toomey et al. 2020). The National Institute of Health Behaviour Change Consortium particularly emphasise the importance intervention delivery fidelity, by assessing both the strategies used to enhance delivery fidelity as well as methods that assess delivery (Bellg et al. 2004). Adopting a study design incorporating feasibility, acceptability, and fidelity allows the researcher to triangulate findings to gain deeper insight into the delivery and the experience of the health intervention, as illustrated in Figure 4.2.

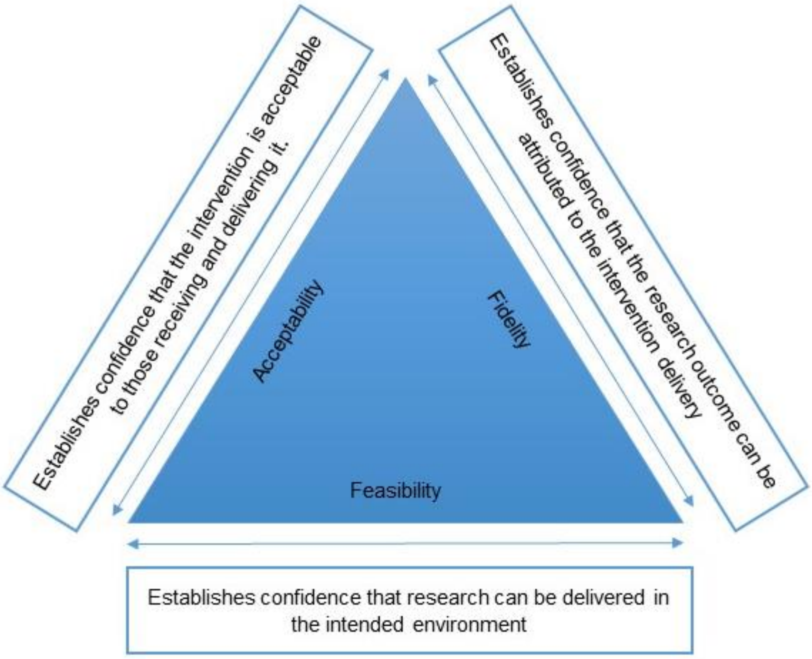


Figure 4.2 Combined benefit of feasibility, acceptability, and fidelity studies

Owing to the interdependent relationships between feasibility, acceptability and fidelity, the study design will henceforth be referred to as a feasibility study. The MRC complex intervention guidance advocates that both qualitative and quantitative methods are needed to assess feasibility studies (Skivington et al. 2021). This allows a complete picture to be drawn by combining information from complementary sources (Denscombe 2008), allowing triangulation of data, adding credibility to the study findings (Bryman 2006). Table 4.3 summaries the feasibility, acceptability, and fidelity aspects of the PDConnect study, and the methods used to explore these factors.

Table 4.3 Approaches used to assess feasibility, acceptability, and fidelity of the PDConnect study.

	Quantitative	**Qualitative**
Feasibility		
Recruitment and retention rates	✓	
Time to recruit sample	✓	
Delivery of intervention as planned	✓	
Intervention attendance	✓	
Reasons for withdrawal	✓	✓
Time to complete outcome measures	✓	
Intervention adverse events	✓	
Acceptability		
Experiences of participating in the intervention and its evaluation		✓
Intervention satisfaction	✓	
The perceptions and experiences of intervention training		✓
Fidelity		
Intervention can be delivered as planned.	✓	✓

4.4.3 Mixed methodology design

In contrast to long established quantitative paradigms, mixed methodology approaches have evolved rapidly (Tashakkori and Teddlie 2003). Rapid evolution has promoted an abundance of mixed methods designs, and thus heterogeneity in approach, making comparisons between studies challenging. To enable clarity, Creswell, and Plano-Clark (2011) developed a typology to guide selection of mixed methods design, based on four dimensions, namely:

- The level of interaction between the quantitative and qualitative strands
- The relative priority of the strands
- Timing of collecting quantitative and qualitative strands i.e., concurrent, or sequential
- Level of mixing of the quantitative and qualitative data i.e., fully, or partially

Applying this typology, this study employed a fixed convergent parallel mixed methods design as detailed in table 4.4. This approach sits comfortably within the Pragmatist Worldview, amalgamating two approaches to achieve a deeper understanding (Creswell, and Plano-Clark, 2011, pp78). It is problem and solution focussed, acknowledging the equal value of qualitative and quantitative data to address the problem. This approach offers capacity for triangulation, bringing together two different but complementary data sources.

Table 4.4 Application of Creswell and Plano-Clark's Mixed methodological framework to the study.

Prototypical Characteristics	Research Study
Worldview	Pragmatism
Research methodology	Mixed methodology
Mixed methods design	Convergent parallel design
Research strands	Quantitative and Qualitative
Interaction between qualitative and quantitative strands	Independent
Priority of the qualitative and quantitative strands	Equal
Timing of the qualitative and quantitative strands	Concurrent
When and how qualitative and quantitative strands are mixed	Mixing during interpretation

To address the study aims, the use of quantitative and qualitative methods was predetermined and planned therefore a fixed mixed methodology was adopted. The opposing approach – the emergent design is more iterative in nature, where the use of mixed methods evolves during the research, normally in response to inadequacy of one single approach (Morse 2009). An emergent design was discounted, as it did not align with the aims of the study. This study placed equal priority on qualitative and quantitative strands, therefore explanatory and exploratory sequential designs were dismissed as they prioritise quantitative or qualitative data collection respectively. The interaction between quantitative and qualitative strands were distinct, and therefore according to Creswell and Plano-Clark (2011) are classed as independent. In the current study, qualitative and quantitative data collection and analysis were collected concurrently, combined only at the end of the study, providing potential for triangulation. This approach allowed the researcher to synthesise results and draw conclusions to produce a comprehensive account of the study on aspects associated with feasibility, acceptability, and fidelity. This ability to triangulate data aids corroboration and validation of study findings which is essential as part of this feasibility study.

4.4.4 Population

A pragmatic approach to participant inclusion was adopted with a focus on ensuring diagnosis of idiopathic Parkinson's, and participants' ability to safely engage in PA. Inclusion criteria are presented in table 4.5. Several different types of Parkinsonism exist, although they share a degree of similarity, distinct variation in symptoms, prognosis and management exist. In the absence of a diagnostic test (Postuma et al. 2015), or accurate clinical biomarkers (Miller and O'Callaghan 2015) to diagnose Parkinson's, Specialist Consultants were involved in recruitment to confirm the diagnosis of idiopathic Parkinson's. Use of specialist consultants are associated with higher diagnostic accuracy when compared to non-experts (Rizzo et al. 2016) and are recommended within the NICE Parkinson's disease in Adults Guideline (NICE, 2017).

Table 4.5 Study Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
Confirmed diagnosis of Parkinson's Stage I-III Hoehn and Yahr Scale Mild to severe gait disturbance with a score of ≤2 on the Unified Parkinson's disease Rating Scale (UPDRS) item 29 Able to walk independently with or without a walking aid further than 100m Stable medication for more than 3 weeks Able to speak and understand English without assistance. Access to a laptop or tablet	Secondary or atypical Parkinsonism Severe, unpredictable episodes of motor fluctuation Use of medications known to interfere with cognitive function History of neurological diseases other than Parkinson's Any unstable mental or physical condition that prevent consenting and participating in exercise. Unstable or uncontrolled medical conditions

As Parkinson's affects a broad age range, no restriction was placed upon participant age, reflecting normal societal distribution. To ensure participant safety in relation to PA engagement, only those with mild to moderate Parkinson's (Stages I-III Hoehn and Yahr Scale, table 4.6), without significant gait impairment (≤2 item 29, Unified Parkinson Disease Rating Scale, see table 4.7) were eligible to participate. These measures are commonly used in clinical practice and are advocated by the Movement Disorders Task Force to define inclusion and exclusion criteria (Friedman et al. 2010). Applying these criteria ensured that participants could mobilise independently and were able to safely participate in online PA within their own home.

Table 4.6 Modified Hoehn and Yahr Scale (Goetz et al. 2004)

Modified Hoehn and Yahr Scale	
Stage	**Description**
0	No signs of disease
1	Symptoms on one side only (unilateral)
1.5	Symptoms unilateral and also involving the neck and spine
2.0	Symptoms on both sides but no impairment of balance
2.5	Mild symptoms on both sides, with recovery when the ‘pull’ test is given
3.0	Balance impairment, mild to moderate disease, physically independent
4.0	Severe disability, but still able to walk or stand unassisted
5.0	Needing a wheelchair or bedridden unless assisted.

Table 4.7 Unified Parkinson’s Disease Rating Scale, item 29 (Goetz 2003)

Unified Parkinson’s Disease Rating Scale, item 29	
Score	**Descriptor**
0	Normal
1	Walks slowly, may shuffle with short steps, but no festination (hastening steps) or propulsion.
2	Walks with difficulty, but requires little or no assistance; may have some festination, short steps, or propulsion
3	Severe disturbance of gait, requiring assistance.
4	Cannot walk at all, even with assistance.

The requirement to have access to a laptop or tablet was necessitated due to the COVID-19 imposed changes to the mode of delivery from face-to-face to online delivery. Additional funding was obtained from the research funder to purchase Wi-Fi enabled tablets including Wi-Fi capability for up to 10 participants should this have been required, to limit sample bias and minimise potential for digital exclusion. However, all participants who expressed an interest in participating in the research already had their own Wi-Fi enabled laptop or tablet device, therefore the additional funds were not required.

Medication is the principal means of managing symptoms for many PLwP, which periodically needs adapted as Parkinson’s progresses. Medication was recorded at baseline, with any subsequent changes documented throughout the study. Minor changes to medication did not affect ability to participate in the study. Participants who required substantial changes in medication which resulted in unpredictable movement dysfunction, or sudden and/or frequent "off periods" which compromised their safety to participate in PA were withdrawn. A record of all withdrawals was maintained throughout the study.

The study exclusion criteria (Table 4.5), encompassed standard precautions to ensure safety during PA, including cardiovascular and respiratory disease, and cognitive dysfunction. The presence of other neurological conditions was also excluded; for example, hemiplegia, which may impact on ability to participate in PA, and thus would compromise the reliability of the study.

4.4.5 Sampling

A variety of different sampling approaches exist. Convenience sampling was selected within this research as a non-random method, focussing on recruiting individuals with a similar characteristic i.e., community dwelling PLwP who met a specific inclusion criterion (Bowling 2014). Purposeful sampling was discounted, as this approach samples a group of people with a defined characteristic (Bowling, 2014, p209). While purposeful sampling offers potential to provide rich data on PA participation, due to the heterogenic nature of Parkinson's, selecting a particular characteristic was seen as too restrictive. Convenience sampling is applicable in either qualitative and or quantitative studies (Etikan 2016), aligning with the mixed methods approach adopted within this study. Convenience sampling was selected as it offers a pragmatic and economically efficient means of recruitment that is commonly adopted within clinical research (Etikan et al. 2016) and within evaluation of complex interventions (Bowling 2014, pp 209). With convenience sampling participants are enrolled owing to their availability and accessibility to the population (Elfil and Negida 2017), providing a simple and efficient approach to sampling. Convenience sampling has been criticised for being vulnerable to bias, making population generalisations potentially unreliable (Bowling, 2014, pp 209). Potential for bias was mitigated in part in this study, with all participants randomly allocated to the intervention or control arm, with each participant having equal chance of being randomised to the intervention arm.

4.4.5.1 Identification of participants

Potential participants living with Parkinson's within the NHS Grampian Health board area were identified through a multi-level process involving: NHS Grampian Consultant Geriatricians and Neurologists, Parkinson's UK Research Take Part Hub, and Research Support Network and Self-referral from the Parkinson's community. Participant identification processes are illustrated in Figure 4.3, which will be discussed in detail in sections 4.4.5.2-.4.4.5.4.

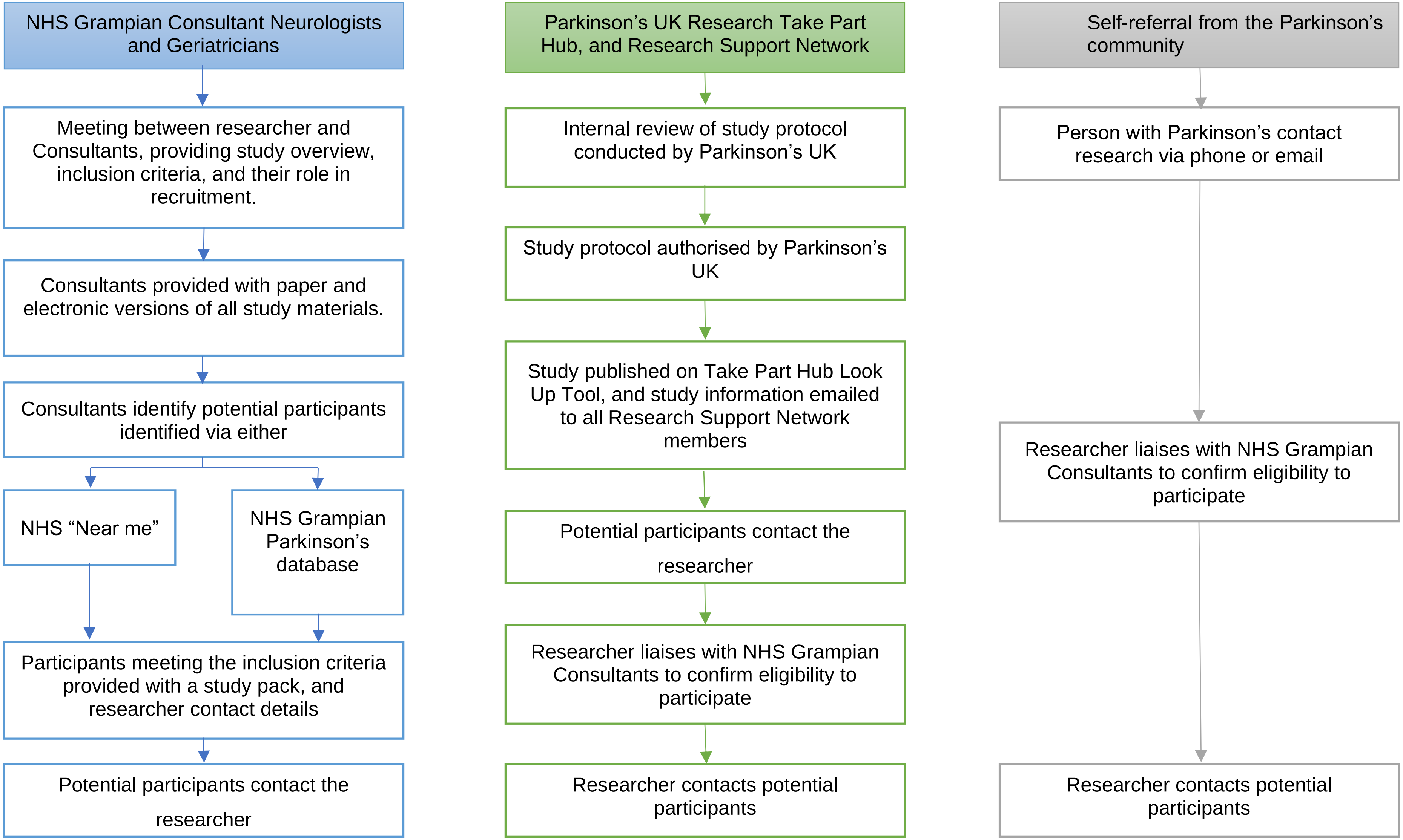


Figure 4.3 Approach to participant recruitment

4.4.5.2 NHS Grampian Consultants

All NHS Grampian Consultant Neurologists and Geriatricians were invited to a Microsoft Teams meeting arranged by the researcher. The purpose of this meeting was to outline the study, discuss the inclusion criteria, and provide resources to support participant recruitment. Both Consultant Geriatricians and Neurologists were invited to maximise recruitment and achieve a varied sample of PLwP in respect to age, time since diagnosis, severity, and gender. Involvement of both Geriatricians and Neurologists reflects current practice, with those of younger onset typically seen by a Neurologist, and those older typically seen by Geriatricians (Parkinson's UK, 2019a). The inclusion criteria placed no restriction on age, therefore involvement of both Consultant types was deemed appropriate. All Consultants were provided with a recruitment study pack (Appendix 5) which consisted of:

- PowerPoint slide deck including outline of the study
- Confirmation of the study ethical approval
- Participant information sheet
- Letter of invitation
- Researcher's contact details for participants

The study pack was provided in an electronic form to all Consultants. In addition, paper copies of the participant information sheet, consultant invitation letter, and researcher contact details were provided which could be given or posted to eligible participants as required. Due to the COVID-19 pandemic, normal face-to-face clinical appointments were significantly disrupted at the time of participant recruitment (December 2020-February 2021). Therefore, potential participants were identified via a combination of face-to-face appointments, the NHS online consultation platform "Near Me", and through the NHS Grampian Parkinson's database. All participants deemed eligible to participate by the Consultants as illustrated in Figure 4.3 were posted or emailed a participant pack including a letter of invitation, the participant information sheet and the researcher's contact details. Those wishing to participate were instructed to contact the researcher via phone or email. PLwP contacting the researcher were given a phone appointment. During this appointment, opportunity was provided to ask further questions in relation to study participation. Additional telephone appointments were offered for those who wished further time to consider participation. For those who wished to proceed, a standardised screening assessment (Appendix 6) was conducted by the researcher to ensure eligibility in relation to health and well-being, and safe participation in PA. Eligible participants were then sent a Microsoft Teams appointment, to conduct taking of consent, and complete baseline physical measures (Figure 4.4). Any PLwP who were deemed not eligible at screening, were notified of the reason(s), and if required, participants were referred to their

General Practitioner and or healthcare professional for further investigation and management as appropriate. All reasons for ineligibility were recorded.

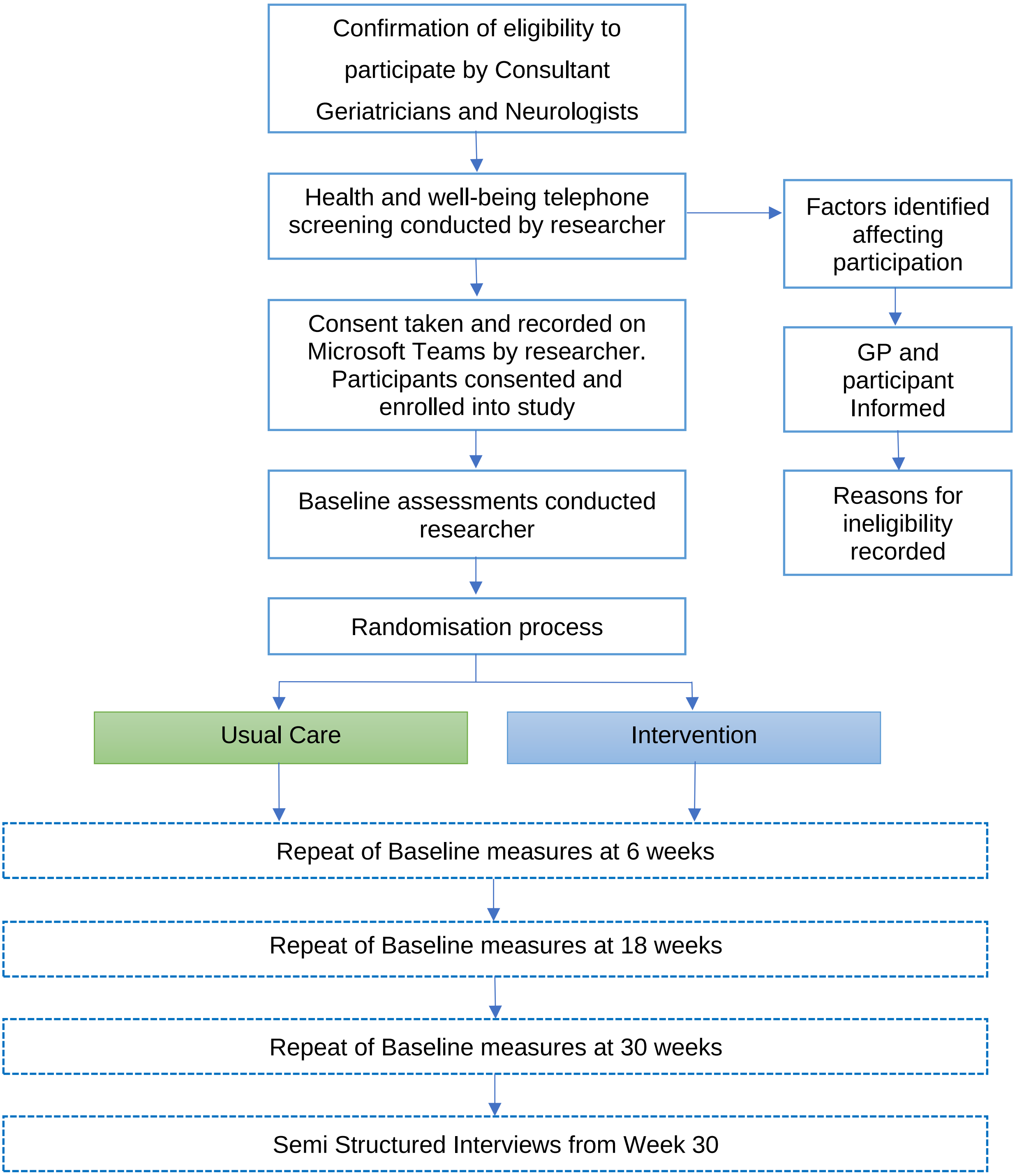
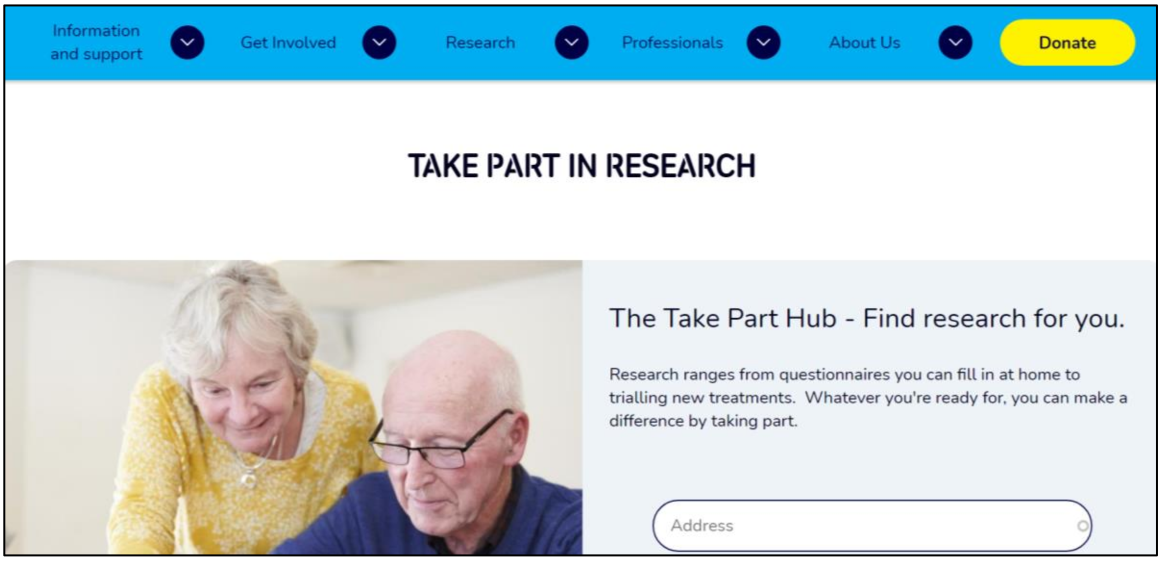


Figure 4.4 Recruitment process after participant identification

4.4.5.3 Parkinson's UK Take Part Hub

The Take Part Hub was developed by Parkinson's UK to support greater involvement of the Parkinson's Community within research. The Take Part Hub is part of the Parkinson's UK Research Support Network which has over 5500 members nationally. The Take Part hub is available through the Parkinson's UK webpages and allows PLwP to identify research opportunities using the look up tool (Figure 4.5). Members of the Research Support Network also receive email notifications of up-and-coming research opportunities.



TAKE PART IN RESEARCH

The Take Part Hub - Find research for you.

Research ranges from questionnaires you can fill in at home to trialling new treatments. Whatever you're ready for, you can make a difference by taking part.

Figure 4.5 Parkinson's UK Take part landing page

IRAS approval was granted to use the Take Part Hub within recruitment. The researcher applied to the Take Part Hub, to promote the study through the look up tool and to circulate study information to the Research Support Network membership. Application involved the provision of confirmation of consent, and copies of the consent and participant information sheet. The study went live on the Take Part Hub and was circulated to the Research Support Network in January 2021 (Appendix 7). The Take Part Hub is accessible nationally therefore criterion of living in NHS Grampian health board area was stipulated, aligning with the study inclusion criteria.

PLwP contacting the researcher via the Research Support Network, and or the Take Part Hub were asked to provide the name of their Parkinson's Consultant. The researcher contacted the Consultant to confirm Parkinson's diagnosis, and that participants met study inclusion criteria. Following the confirmation of diagnosis and eligibility, standardised screening was conducted as previously described.

4.4.5.4 Self-referral from the Parkinson’s community

This study was jointly funded by the Chief Scientist Office and Parkinson’s UK. This was the first jointly funded Clinical Academic Fellowship between these two funding bodies, and consequently, the Fellowship was widely promoted via social media channels, and local and national press. Consequently, PLwP directly contacted the researcher expressing interest in participating in the research study. Management of these direct enquires mirrored that of those who contacted the researcher following promotion through the Research Support Network, as illustrated in Figure 4.3.

4.4.6 Sample size

Despite wide recognition of the need and value of feasibility studies, little consensus exists to guide appropriate sample size (Lewis et al. 2021). The target sample size for this study was 30 PLwP, with 15 PLwP randomised to each of the intervention and control groups. Billingham, Whitehead and Julious (2013) stated that feasibility studies do not require a power calculation, rather they advocate the use of a target sample. This reflects the focus of feasibility studies where emphasis is placed upon whether an intervention is appropriate for further investigation rather than exploring the effectiveness of the intervention. Recently published feasibility studies exploring PA and PLwP used varying samples between ten and 20 (Conradsson et al. 2017, Harvey et al. 2018), suggesting that the proposed sample of 30 was appropriate, accommodating any potential drop out which may occur during the study. At the time of conducting the study it was estimated that 1000 people were living with Parkinson’s within NHS Grampian (Personal Communication, Scotland Service Improvement Manager, Parkinson’s UK), therefore a sample of 30 was also deemed feasible.

Recruitment to non-pharmacological interventions is widely recognised as challenging (Vaswani, Tropea and Dahodwala 2020). The heterogeneous nature of Parkinson’s, and the combination of motor and NMS are frequently cited to negatively impact on recruitment (Picillo et al. 2015). Picollio et al. (2015) identified several factors which have been shown to be influential in Parkinson’s recruitment: infrastructure, nature of the research, recruiter characteristics, and participant characteristics. Application of Picillio’s recommendations within this research programme are illustrated in table 4.8.

Table 4.8 Optimisation of recruitment applied to this study

Domains	**Approach used within PDConnect study**
Infrastructure	Research meetings were held prior to the recruitment phase involving the research team, the consultants and staff involved in recruitment Follow up 1:1 communication was provided as required Regular communication between researcher and consultants to review: - The number of participants packs issued - Number of participants who had contacted the researcher - Recruitment milestones.
Nature of research	The design of the study and development of study resources involved PLwP. The researcher met with recruiting consultants prior to the study commencing, which included study background, study design, inclusion and exclusion criteria, and goal recruitment All participants were recruited prior to randomisation therefore participants had an equal chance of randomisation to control or intervention groups. The intervention and measurements were all delivered and undertaken online using Microsoft Teams, therefore anxiety associated with travel and unknown environment was mitigated. All study resources were posted to participants, and where required freepost return envelopes were provided for use by participants
Recruiter characteristics	Use of specialist Parkinson's Neurologists and Geriatricians to recruit potential Participants. Use of unique project email address to streamline point of contact for participants All staff delivering the intervention have specialist training in Parkinson's
Participant characteristics	The health benefits of PA are endorsed widely by Parkinson's charities and within healthcare policy

Adapted from Picillo et al. 2015

4.4.7 Consent

Following screening, and verbal agreement to participate in the study, all participants were formally consented. Owing to COVID-19 restrictions this could not be completed face-to-face. This research study gained Ethical and local Research and Development approval to obtain informed verbal consent using Microsoft Teams. Consent was conducted by the researcher, whereby each participant was sent a Microsoft Teams video call appointment. During this video call, the consent form (Appendix 8), was read out to the participants, and they were asked to confirm, or not, whether they consented to each of the items within the consent for form for this research study. This video call was recorded as MP4 file, and saved by the researcher, and stored within the site file on the university password protected server.

Many online video-conferencing platforms exist. Microsoft Teams was selected for use in this study as it complies with General Data Protection Regulations (Microsoft Cooperation, 2023, UK Government 2023), and at the time of the study was endorsed by the NHS as a secure means of conducting telemedicine. Microsoft Teams allows the use of audio and visual conferencing and sharing of documents (e.g., home exercise programmes) both privately and with a group, meeting the needs of this study. Other platforms such as Zoom were considered; however, were dismissed, as it not GDPR compliant, and consequently was not supported on NHS computing systems and lacked capacity for document sharing. FaceTime™ were excluded as this is an Apple™ based platform and would exclude potential participants with Android devices. What's App© was excluded as this is not GDPR compliant, and is principally a phone-based app, where the screen would be too small to engage within the PA intervention. All participants received a Microsoft Teams induction prior to commencing the study, supported by a paper-based guide (Appendix 9), and a mock Microsoft Teams appointment.

4.4.8 Randomisation

Randomisation procedures were conducted by an independent Chartered Statistician, based within the School of Health Sciences. A stratified random sampling method by Hoehn and Yahr stage, PA level, and gender were used to ensure comparability at baseline. Using computer-generated random number sequencing (Excel, Microsoft Corporation) in a ratio of 1:1, a random number was placed in a sealed, sequentially numbered, opaque envelope. Participants were randomly allocated to the intervention or usual care by extracting the random number from the envelope. The randomisation list was stored on a secure server held by a research assistant based within the School of Health Sciences. The research assistant notified physiotherapists and participants of the randomisation outcome via email. The researcher conducting measures was blinded to the group allocation until the end of the study, following completion of all data analysis. Owing to the nature of the intervention, blinding of participants was not possible.

4.4.9 Staff Recruitment – Physiotherapists and Fitness Instructors

Convenience sampling was adopted to identify Physiotherapists and Fitness Instructors to deliver the study intervention. Purposeful sampling which involves identifying and selecting individuals that are knowledgeable or experienced with a phenomenon of interest, was dismissed due to the clinical and professional challenges imposed by COVID-19 at the time of recruitment. Convenience sampling was adopted whereby the NHS Grampian Lead Physiotherapist circulated a recruitment email and participant information sheet (Appendix 10) to all Physiotherapists employed within NHS Grampian providing an overview of the study, and the researchers contact details. Due to COVID-19, this email was also extended to include all physiotherapists on the NHS Grampian Physiotherapy Bank and local private Physiotherapists to ensure recruitment of eligible Physiotherapist to deliver the intervention. Adopting a convenience approach allowed all Physiotherapists to consider being involved thereby not restricting to those with expertise in movement disorders and Parkinson's. Four Physiotherapists were required, one to deliver each arm of the study (intervention and control arm) and a backup Physiotherapist per arm to cover any leave during the study.

Eligible Physiotherapists were required to be Band 6 or above, with a minimum of two years clinical experience, possessing a broad range of experience encompassing Neurology and Geriatrics. Band 6 Physiotherapists were deemed appropriate as they are independent and autonomous practitioners, with an ability to modify assessments and treatments to meet individual need, with established communication skills (Chartered Society of Physiotherapy, 2018), meeting the requirements of this study.

Physiotherapists contacting the researcher were provided with an opportunity to ask questions prior to consenting to participate. Consent was conducted following the same process as described for participants via Microsoft Teams. Following obtaining consent, recruited Physiotherapists were randomly allocated using sealed envelopes provided by the research assistant to deliver the intervention or usual care.

The RGU:Sport Facility Manager purposively recruited two Fitness Instructors from RGU:Sport, based on availability, interest, and experience. Instructors were required to possess a level three personal training qualification or above, which is Register of Exercise Professionals (REPS) accredited or equivalent. Level three or above reflects normal practice within local leisure facilities (personal communication, Head of RGU Sport), and ensured instructors had broad skills and experience in tailoring training sessions out with athletic populations. As with the Physiotherapists, Fitness Instructors were provided with a participant information sheet and consent form (Appendices 11, and 12). Verbal consent was obtained by the researcher via Microsoft Teams as described earlier. The Physiotherapist randomly allocated to deliver the intervention and the Fitness Instructor were provided Parkinson's and intervention specific training by the researcher, as described in section 4.4.14.5. This training was delivered by the researcher therefore, the researcher was not blinded to staff allocation.

4.4.10 Setting

Traditionally, PA interventions are delivered face-to-face within health and leisure facilities. Delivery of PDConnect was originally planned to be delivered face-to-face, however the emergence of the COVID-19 pandemic necessitated a change to delivery via telehealth. The terms telehealth, telemedicine, or digital health are used interchangeably. The World Health Organisation define telehealth as healthcare services delivered by HCP's, using information and communication technologies for the exchange of valid and correct information (WHO, 2022). Telemedicine is advocated in the Scottish Government's digital healthcare delivery plans (Scottish Government: Digital Health and Care Strategy, 2021) and is perceived as a key mechanism to support monitoring of PLwP, (Pappa et al. 2017; Schirinzi et al. 2020). The role of telemedicine, using online means to deliver PA interventions for example, offers a practical solution to the evolving challenges of delivering health interventions during the COVID-19 pandemic and beyond. Telemedicine has potential to reduce health inequalities, allowing timely access to specialist care (Duncan and Macleod 2020), making it an attractive and affordable option (Mehrotra et al. 2016) to rural communities within Scotland. PLwP have reported high satisfaction with healthcare delivered online (Wilkinson et al. 2016). Online approaches offer flexibility, allowing PA interventions to be delivered within the home, removing environmental barriers, and mitigating interpersonal barriers, providing care in a de-medicalised environment, reducing participant anxiety and costs for providers (Simpson et al. 2020). As such online delivery has potential to improve access and adherence to PA, as well as provide a more cost and time efficient mode of delivery. Selection of Microsoft Teams for use in the current study was guided by security, and encryption, and alignment with UK GDPR guidelines (UK Government, 2018).

The COVID-19 pandemic necessitated a change to how face-to-face health interventions were delivered, including PA, however, online delivery is not without its limitations. Technical and quality issues are commonly cited, as well as issues associated with patient safety, digital literacy, privacy, and accountability (Greenhalgh et al. 2020). Despite two thirds (62.8%) of people aged between 55 and 74 being connected to the internet (Office for National Statistics, 2020), digital skills, and literacy among this population group have been reported as limited (Martínez-Alcalá et al. 2018). To negate potential barriers associated with Microsoft Teams and to optimise participation, each participant received a live 1:1 Microsoft Teams induction conducted by the researcher. The live induction covered the functionality of Microsoft Teams promoting familiarity with using Microsoft Teams, including audio-video set up, and alignment, icons, tabs, channels, chat forums, making and receiving video calls, and accessing files. All participants were provided a minimum of one mock appointment in addition to the induction prior to commencing the study, so they were familiar with how to attend and participate within an appointment.

Patient safety during PA is paramount. As this intervention was delivered exclusively online in the absence of in-person supervision, several measures were put in place to optimise participant's safety during all phases of the study.

Recruitment: Eligibility to participate in this study required Consultants to confirm that participants to be able to walk independently up to 100 metres, with no significant gait impairment. Those with significant cognitive impairment or other co-morbidities which may compromise safe participation in PA were excluded.

Prior to consenting to participate: All participants underwent a telephone health and well-being screening, conducted by the researcher. The screening tool (Appendix 6) was based upon the Physical Activity Readiness Questionnaire (Thomas, Reading and Shephard 1992). Any participants who were flagged at this point and did not meet the study inclusion criteria were referred to their GP for further advice and management.

Following consenting to participate: A Home Risk Assessment Form (Appendix 13) was completed jointly by the researcher and the participants in a Microsoft Teams video conferencing call. This call included viewing and discussion of optimal places within their home to participate in PA, as well as identify any risks such as rugs and loose-fitting carpets. All participants were asked to complete a participation statement (Appendix 14), which required participants to provide two emergency contact details, who could be contacted should an emergency arise when participating in the online intervention. This information was stored securely on a restricted channel within Microsoft Teams accessible only to the research team and those delivering the intervention.

During the study: All participants, regardless of randomisation and where possible, were requested to have a family member present when participating in PA online and were advised to have a telephone within the room where they were exercising. All participants were asked to report any falls with the researcher and note falls within their activity diary. A priori, more than five people reporting falls during the intervention delivery would trigger referral to the study steering group. Participant manuals provided to both groups clearly highlighted researchers, staff, and participant health and safety responsibilities (Appendix 15). At the beginning of each appointment, a health and safety check was conducted by staff to ensure safety. Study manuals also provided information on safe engagement in PA and the importance of hydration.

4.4.11 Intervention

Participants were randomly allocated to receive either usual care or PDConnect as detailed in section 4.4.8.

4.4.12 Usual care/control arm

Usual care for this study was defined as Physiotherapy delivered online via Microsoft Teams by a Band 6 or above Physiotherapist without post-registration Parkinson's training. The term usual care reflected current service provision at the time of the study, whereby many Physiotherapists lacked specialist Parkinson's training (Nijkrake et al. 2009; Clarke et al. 2016) and were not undertaking face-to-face visits due to COVID-19. Participants randomised to usual care received six one-to-one Physiotherapy sessions lasting up to an hour as illustrated in Figure 4.6. Each session included assessment, treatment, goal setting and intervention delivery reflecting usual care within NHS Grampian (personal communication with Physiotherapy Service Lead). Central to this research was clinical applicability, and hence adhering to normal practice allowed this research to be reflective of clinical practice. Following professional practice standards, treatment choices were guided by participant need (Chartered Society of Physiotherapy, 2013), and supplemented by a home exercise programme (HEP). Reflecting normal and ethical practice, no confines were placed on what should be prescribed, thus no intervention(s) were withheld. While this has the potential to create heterogeneity and confound findings, it is reflective of person-centred care, based on individual need as opposed to a one-size-fits-all approach. Prior to commencing usual care, all participants were mailed a study manual (Appendix 16) which contained the following:

- Study overview
- Microsoft Teams user guide
- Safe exercise at home guidance
- Physical activity tracker guide
- Activity and falls diary

On completion of the six Physiotherapy sessions, participants were advised to continue with their HEP, and signposted to local and online PA opportunities to meet their needs. Usual care participants were provided with a PA tracker – Mi band, to wear for the duration of the study (30 weeks). Participants were asked to document their daily step count recorded by the Mi band within the activity diary provided. Usual care participants were also asked to notify the researcher and document any falls which occurred during the study within their diary. Usual care participants underwent measurements at baseline, which were repeated at six, 18 and 30 weeks. The approaches taken to maintain blinding of the researcher are discussed in section 4.15.1.

Prior to the commencement of the study the Physiotherapist delivering the usual care arm received an induction into the use of Microsoft Teams by the researcher. The Physiotherapist was also given access to the Usual Care Microsoft Teams area which allowed access to usual care participant manual, Mi band and Microsoft Teams guide, and safe exercise at home guidance (Appendices 16, 9 and 13 respectively). Within this Microsoft Teams area, a channel was created where access was restricted to the Physiotherapist and the research team which provided professional access to the following:

- Completed home risk assessment forms (Appendix 13)
- Completed participant statement which included emergency contact details (Appendix 14)
- Handover sheet completed by the researcher, which included participant's details, past medical history, and medication. (Appendix 17)
- Attendance record sheets (Appendix 18)
- Physiotherapy session documentation records (Appendix 19)

4.4.13 PDConnect intervention

The development of PDConnect was discussed in section 2.7. Key features of PDConnect include evidence informed progressive PA prescription delivered by Staff with expertise in Parkinson's, delivered in parallel with BCTs and self-management skills such as education, decision-making, problem-solving, to promote PA self-efficacy, and empowerment. The following sub-sections will discuss in greater detail the individual components of the PDConnect intervention.

4.4.14 Key components of the PDConnect intervention

4.4.14.1 Supporting change in physical activity behaviour

PDConnect is an evidence-informed PA multicomponent intervention underpinned by the Behaviour Change Wheel and the COM-B model and therefore aims to promote capability, opportunity, and motivation to positively influence PA behaviour and provide PLwP with strategies to self-manage their PA. The BCW framework described by (Michie, van Stralen and West 2011) discussed in section 2.4 was selected for use in this study as it provided an evidenced-based framework enhancing the quality of research reporting in the current study. Application of the COM-B model to the PDConnect intervention is illustrated in table 4.9.

Table 4.9 Application of the COM-B model to the PDConnect Intervention.

	COM-B Model	Application to PDConnect
Capability	Physical capability	Having the physical skill, strength, balance, and endurance to participate in PA.
	Psychological capability	Understanding impact of inactivity on Parkinson's and wider health and well-being Having self-confidence and efficacy to participate in PA Having to required cognitive reserves to follow a PA programme Ability to regulate behaviour Ability to recognise the impact of Parkinson's on motor and NMS
Opportunity	Physical Opportunity	Able to access safe and available spaces to be active at home and in local community. Availability of long-term PA provision Time within daily routine to participate in PA
	Social Opportunity	Accessibility to specialist HCP's Access to family, and peer support network Opportunity to develop self-confidence with PA and exercise engagement
Motivation	Reflective motivation	Understand the benefits of PA and the impact this has on Parkinson's Intention to adopt physically active lifestyle and participate in regular exercise
	Automatic motivation	Feel in control, be independent Re-establishment of identity Be part of a wider community
Behaviour diagnosis from the COM-B components		Physical and psychological capability, physical and social opportunity and automatic motivation need to change to achieve the target behaviour – Increased PA participation

Central to PDConnect was influencing PA behaviour. The literature review (Section 2.4) highlighted that interventions which encompass behaviour change techniques (BCT's) are perceived as critical to influence PA behaviour in the short and long-term (Kunstler et al. 2019). Michie et al (2011) defined behaviour change interventions "as coordinated sets of activities designed to change specified behaviour patterns". In relation to PA, BCTs are a set of techniques aimed at influencing PA, to support development of a "physical activity habit". Therefore, the inclusion of BCTs were seen as central to the success of the PDConnect programme. Reporting of behaviour change interventions within research and practice has been widely criticised due to a lack of detail, limiting replicability (Donkers et al. 2018). To enhance clarity, the Behaviour change Technique Taxonomy Version 1 (BCTTv1) was used in the current study. This taxonomy categorises BCTs into 16 broad interventions, providing transparency of BCT selection within clinical and research practice (Michie et al. 2013), enhancing reproducibility of the intervention.

The effectiveness of BCTs on PA self-efficacy or long-term PA participation is unknown (Ahern et al. 2022). The literature review (section 2.5.6) highlighted that education, feedback, self-monitoring, goal setting, social support, credible sources, instruction on performance, feedback were key BCTs valued by PLwP. Recognising that self-efficacy is a key determinant of PA (Ellis et al. 2013) a developmental approach to BCT selection was adopted. BCTs used early in the intervention focussed on development of confidence with activity participation. Whereas later BCTs centred upon preparing participants for exercising with others and techniques geared to promote confidence, and independence with PA, in preparation for self-management. BCT's such as a health contract, activity planner, goal setting, activity diary and daily and weekly step targets were implemented throughout the PDConnect programme. Key categories of the BCTTv1 used in the study are highlighted in blue in table 4.10. The specific BCTs that were employed during specific PDConnect sessions are provided in table 4.11 and 4.12.

Table 4.10 BCT Taxonomy (v1) applied within in the PDConnect intervention

Those highlighted blue were used during the study.

1. Goal Planning	2. Feedback and monitoring	3. Social support	4. Shaping knowledge	5. Natural consequences
1.1. Goal setting (behaviour) 1.2. Problem solving 1.3. Goal setting (outcome) 1.4. Action planning 1.5. Review behaviour goal(s) 1.6. Discrepancy between current behaviour and goal 1.7. Review outcome goal(s) 1.8. Behavioural contract 1.9. Commitment	2.1. Monitoring of behaviour by others without feedback 2.2. Feedback on behaviour 2.3. Self-monitoring of behaviour 2.4. Self-monitoring of outcome(s) of behaviour 2.5. Monitoring of outcome(s) of behaviour without feedback 2.6. Biofeedback 2.7. Feedback on outcome(s) of behaviour	3.1. Social support (unspecified) 3.2. Social support (practical) 3.3. Social support (emotional)	4.1. Instruction on how to perform the behaviour 4.2. Information about Antecedents 4.3. Re-attribution 4.4. Behavioural experiments	5.1. Information about health consequences 5.2. Salience of consequences 5.3. Information about social and environmental consequences 5.4. Monitoring of emotional consequences 5.5. Anticipated regret 5.6. Emotional consequences

Table 4.10 BCT Taxonomy (v1) applied within in the PDConnect intervention (continued)

Those highlighted blue were used during the study.

6. Comparisons of behaviour	7. Associations	8. Repetition and substitution	9. Comparison of outcomes	10 Reward and threat
6.1. Demonstration of the behaviour 6.2. Social comparison 6.3. Information about others' approval	7.1. Prompts/cues 7.2. Cue signalling reward 7.3. Reduce prompts/cues 7.4. Remove access to the reward 7.5. Remove aversive stimulus 7.6. Satiation 7.7. Exposure 7.8. Associative learning	8.1. Behavioural practice/rehearsal 8.2. Behaviour substitution 8.3. Habit formation 8.4. Habit reversal 8.5. Overcorrection 8.6. Generalisation of target behaviour 8.7. Graded tasks	9.1. Credible source 9.2. Pros and cons 9.3. Comparative imagining of future outcomes	10.1. Material incentive 10.2. Material reward 10.3. Non-specific reward 10.4. Social reward 10.5. Social incentive 10.6. Non-specific incentive 10.7. Self-incentive 10.8. Incentive (outcome) 10.9. Self-reward 10.10. Reward (outcome) 10.11. Future punishment

Table 4.10 BCT Taxonomy (v1) applied within in the PDConnect intervention **(continued)**

Those highlighted blue were used during the study.

11 Regulation	12 Antecedents	13 Identity	14 Scheduled consequences	15 Self-belief
11.1. Pharmacological support 11.2. Reduce negative emotions 11.3. Conserving mental resources 11.4. Paradoxical instructions	12.1. Restructuring the physical environment 12.2. Restructuring the social environment 12.3. Avoidance/reducing exposure to cues for the behaviour 12.4. Distraction 12.5. Adding objects to the environment 12.6. Body changes	13.1. Identification of self as role model 13.2. Framing/reframing 13.3. Incompatible beliefs 13.4. Valued self-identify 13.5. Identity associated with changed behaviour	14.1. Behaviour cost 14.2. Punishment 14.3. Remove reward 14.4. Reward approximation 14.5. Rewarding completion 14.6. Situation-specific reward 14.7. Reward incompatible behaviour 14.8. Reward alternative behaviour 14.9. Reduce reward frequency 14.10. Remove punishment	15.1. Verbal persuasion about capability 15.2. Mental rehearsal of successful performance 15.3. Focus on past success 15.4. Self-talk
16 Covert learning				
16.1. Imaginary punishment 16.2. Imaginary reward 16.3. Vicarious consequences				

Table 4.11 Mapping of BCTs to individual PDConnect Physiotherapy sessions

Physiotherapy Sessions							
BCTTv1 categories	1	2	3	4	5	6	Examples of BCTs used in sessions
1. Goals and planning	✓	✓	✓	✓	✓	✓	Setting of SMART goals and the formulation of a health contract Discussion to identify barriers to PA and potential solutions Discuss and plan of weekly activity planner/schedule Review goals and Mi Band output Review prior week activity and planner, adjust as required Examine engagement with HEP, and modify prescription of goals Examine how participants performance corresponds with agreed goals. Increase number of outdoor walks and training intensity as able Review and set joint long-term goals Discuss and explore potential challenges about group PA Explore with participants perceived challenges and barriers and discuss solutions
2. Feedback and monitoring	✓	✓	✓	✓	✓	✓	Issue participants with a Mi band to measure daily and weekly step count Provision of an activity diary Provide feedback on performance to date, the impact this is having, and what needs done next Feedback from participant, and carer to discus thoughts, attributing factors and potential barriers Feedback to participants of any improvement in measured outcomes Review activity on Mi band and reset goals
3. Social Support				✓		✓	Provide information about locally available social support networks for PLwP. Discuss the use of an exercise buddy to exercise with participant Re-affirm benefit of have a buddy to exercise with, advise carer on exercise

Table 4.11 Mapping of BCTs to individual PDConnect Physiotherapy sessions (continued)

Physiotherapy Sessions							
BCTTv1 categories	1	2	3	4	5	6	Examples of BCTs used in sessions
4. Shaping knowledge	✓	✓	✓	✓			Provision of an exercise programme, providing advice on how to perform this and the benefits to the participant With exercise programme – provide instruction on how to do the exercise- i.e. skills training. To ensure correct technique. Provide written, and visual aids via REHABGuru
5. Natural consequences		✓				✓	Provide health education about to consequences of inactivity for general health as well as Parkinson's. Discuss in immediate and long-term effect. Reiterate message of the benefits of exercise, the need to ensure this is continued, effect of discontinuing exercise, reiterate gains that have been made to date, to ensure longer term adherence
6. Comparisons of behaviour	✓	✓	✓	✓	✓	✓	Add any further exercise to REHABGuru as appropriate, ensure technique is safe and effective
7. Associations			✓		✓	✓	Introduce the use of environmental cues to promote physical activity engagement Introduce further prompts. E.g., walking and maintaining pace, using lampposts as a guide. Walking and talking while maintaining step quality
8. Repetition and substitutions	✓		✓	✓			Suggest within weekly activity planner where physical activity and or exercise can be substituted for sedentary activities Prompt participant to walk with larger step length, and normalise step count Provide prompts on dual tasking for example within the home, providing strategies to maintain quality of movements when combining cognitive and physical tasks.

Table 4.11 Mapping of BCTs to individual PDConnect Physiotherapy sessions (continued)

Physiotherapy Sessions							
BCTTv1 categories	1	2	3	4	5	6	Examples of BCTs used in sessions
9. Comparison of outcomes		✓	✓	✓	✓	✓	Discuss with the participants their thoughts on the pros and cons of exercising in relation to their Parkinson's and general health and well being Complete intervention manual on challenges and motivators Revisit any pros and cons of exercise and identify barriers and facilitate problem solving strategies Provide education from credible sources ie intervention manual, conference or journal, to deepen understanding on theoretical principles, and information related to living with Parkinson's Develop further knowledge and understanding of theory of exercise, self-management theory
10. Reward and threat			✓	✓	✓	✓	Congratulate participants on achievements to date Encourage participants to reward self because of changed behaviour.
11 Regulation		✓					Advise on strategies to reduce anxiety, reduced motivation and apathy
12 Antecedents	✓	✓	✓				Provide advice of how to alter physical environment to promote greater activity, ie walking to shops instead of using the car Advise participant, discuss solutions to promote greater physical activity engagement Introduce concept of exercise buddy and social network to support exercise and physical activity involvement

Table 4.11 Mapping of BCTs to individual PDConnect Physiotherapy sessions (continued)

Physiotherapy Sessions							
BCTv1 categories	1	2	3	4	5	6	Examples of BCTs used in sessions
13 Identity				✓	✓	✓	Discuss with participants their thoughts on additional exercise choice of interest, how they could develop exercise and physical activity involvements, and their thoughts as exercising as part of a group Explore with the participants how their change in behaviour may be positive to family and friends, ie promote self-efficacy Reflect on session one, with an emphasis on how their abilities, perceptions and capabilities have changed in that time
15 Self-belief	✓	✓				✓	Discuss and demonstrate to the participants that they can still engage in exercise even though they have Parkinson's. Use of intervention manual exercise testimonial video materials Discuss strategies to support socialisation within social environment. Encourage the person to talk about how they see how they will continue to maintain exercise engagements in the forthcoming weeks

Table 4.12 Mapping of BCTs to PDConnect group-based exercise sessions

Group-based Exercise sessions													
BCTv1 categories	1	2	3	4	5	6	7	8	9	10	11	12	**Examples of BCTs used in sessions**
1. Goals and planning			✓			✓			✓			✓	Goal setting and review Problem solving and strategy development Activity planning Evaluate performance versus goals
2. Feedback and monitoring	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	Provision of feedback on performance in class and prior week Feedback on activity diary content Discuss improvement of regressions and problems solve strategies to address. Continue to review activity on Mi output and reset goals, encouraging higher intensity workouts, ensure participant are fully independent with the device.
3. Social Support			✓			✓			✓	✓	✓	✓	Provide information about locally available social support networks Discuss the use of an exercise buddy Advise carer on exercise as appropriate
4. Shaping knowledge	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	Provide information of the benefits/purpose of each exercise (weekly) Refresh HEP, every 3-4 weeks Provide exercise instruction- i.e. skills training. Provide written, and visual aids via REHABGuru

Table 4.12 Mapping of BCTs to PDConnect group-based exercise sessions (continued)

Group-based Exercise sessions													
BCTv1 categories	1	2	3	4	5	6	7	8	9	10	11	12	**Examples of BCTs used in sessions**
5. Natural consequences			✓			✓			✓			✓	Reiterate message of the benefits of exercise, the need to ensure this is continued, effect of discontinuing exercise, reiterate gains that have been made to date, to ensure longer term adherence
6. Comparisons of behaviour			✓			✓			✓			✓	Promote reflection of changes Reflect of goals achieved
7. Associations			✓			✓			✓			✓	Introduce the use of environmental cues to promote physical activity engagement Introduce further prompts. E.g. walking and maintaining pace, using lampposts as a guide. Walking and talking while maintaining step quality. Support development of exercise routine
8. Repetition and substitutions		✓		✓		✓				✓		✓	Refine HEP Refine and revisit weekly activity planner Challenge participants to change routine eg walking further and or focus of gait quality Provide prompts on dual tasking for example within the home, providing strategies to maintain quality of movements when combining cognitive and physical tasks.

Table 4.12 Mapping of BCTs to PDConnect group-based exercise sessions (continued)

Group-based Exercise sessions													
BCTv1 categories	1	2	3	4	5	6	7	8	9	10	11	12	**Examples of BCTs used in sessions**
9. Comparison of outcomes			✓			✓				✓	✓	✓	Reflect on exercise journey in PDConnect Discuss perceived health impact of participating in PDConnect Revisit any pros and cons of exercise and identify barriers and facilitate problem solving strategies Provide education from credible sources to support maintenance of exercise behaviour Develop further knowledge and understanding of theory of exercise, self-management theory
10. Reward and threat		✓		✓		✓				✓	✓	✓	Congratulate on achievements to date Encourage participants to reward self because of changed behaviour.
11 Regulation				✓				✓				✓	Advise on ways to address stress, anxiety, and fatigue
12 Antecedents				✓				✓				✓	Group discussion on solutions to promote greater PA engagement Introduce concept of exercise buddy and social network to support exercise and involvement

Table 4.12 Mapping of BCTs to PDConnect group-based exercise sessions (continued)

Group-based Exercise sessions													
BCTv1 categories	1	2	3	4	5	6	7	8	9	10	11	12	**Examples of BCTs used in sessions**
13 Identity			✓			✓			✓			✓	Group discussion on solutions to promote greater PA engagement Group discussion on thoughts of activities to undertake following PDConnect Explore with the group how their change in behaviour may be positive to family and friends, ie promote self-efficacy Reflect as a group how their abilities, perceptions and capabilities have changed in that time Discuss next PA challenge Introduce concept of exercise buddy and social network to support exercise and involvement
15 Self-belief							✓			✓	✓	✓	Share in group experiences of perception of exercise Discuss strategies to support socialisation and confidence within social environment. Encourage the person to talk about how they see how they will continue to maintain exercise engagements in the forthcoming weeks

Several tools which are illustrated in Figure 4.6 were used to deliver BCTs throughout the PDConnect intervention. A health contract was introduced as a written agreement between staff delivering the intervention and participants, to support initiation and maintenance of PA within the study and beyond. Health contracts were used successfully in the ParkFit study (Speelman et al. 2014), and were used in the current study in conjunction with goal setting. Goal setting is associated with higher patient motivation and enhanced self-efficacy (Levack et al. 2015), and therefore was initiated at the beginning of the programme and revisited regularly throughout the programme. Information on goal setting was incorporated in the participant manual to support participant involvement and was encompassed in staff training to promote application. Goals were mutually agreed between staff and participants to promote participant involvement and were reviewed every three weeks during the intervention. Participants were encouraged to set specific, measurable, achievable, realistic, and timely goals (SMART Goals) that were of importance to them. Setting SMART goals was intended to promote active involvement in treatment choices and shared decision-making, both of which are associated with improved satisfaction (Turner-Stokes et al. 2015), a greater sense of ownership and perceived sense of control (Rose, Rosewilliam and Soundy 2017), all of which align with the central aim of the PDConnect intervention.

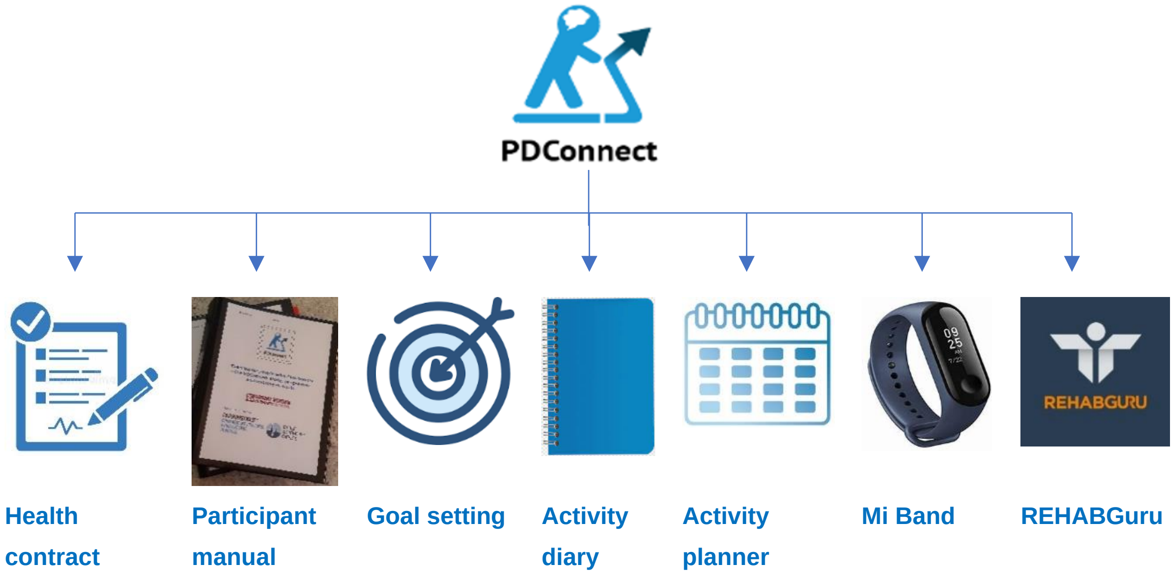


Figure 4.6 Tools used during the PDConnect intervention to support delivery of BCT's

All participants were provided with an intervention manual, which included an activity diary and activity planner (Appendix 20). The activity diary required participants to record their daily step count as measured by Mi band activity tracker and PA engagement. Activity diaries are a low cost means of monitoring and evaluating PA patterns (Vanroy et al. 2014), while also serving as a behaviour change tool. Activity diaries were reviewed in supervised sessions to support completion of diaries and promote reflection on their activity levels in the prior week. Participants were supported to complete an individualised activity planner. The planner provided a timetable for participants to support the development of a daily PA routine, these were reviewed regularly in parallel with goal setting. Completed diaries were returned to the researcher at the end of the study using freepost envelopes.

4.4.12.2 Supporting the development of physical activity self-efficacy.

The literature review (section 2.2) highlighted that PLwP who are empowered and had high levels of self-efficacy are more like to start and stay physically active (Ellis et al. 2013). Therefore, promoting the belief in PA capability and providing the necessary knowledge and skills to enable PA engagement were integral components of the PDConnect intervention. Development of empowerment was promoted through the inclusion of evidence-based behaviour change techniques (BCT's), contextualised education, faciliatated by a coaching style of delivery by staff. Rooted in empowerment, PDConnect was delivered in a collaborative manner, with staff working with participants to personalise knowledge, skills, and strategies to influence their PA behaviour. Adopting a collaborative approach is integral to Physiotherapy practice (Chartered Society of Physiotherapy, 2013), therefore cannot be regarded as novel. However, few PLwP (11.6%) report that they feel involved in decisions related to their treatment (Bloem and Stocchi 2015), with a lack of information and emotional support from professions perceived as a key unmet need (van der Eijk et al. 2011; Vlaanderen et al. 2019).

Section 2.4 of the literature review demonstrated that studies adopting a coaching approach to delivery were associated with enhanced outcomes and supported changes in PA behaviour (Shih et al. 2022). Physiotherapists and Fitness instructors delivering PDConnect adopted a coaching role to promote changes in PA behaviour. This approach was selected for a variety of reasons: i) coaching is a person-centred approach, based upon behaviour change theory aimed at developing capacity among participants to become partners in their own care (NHS England 2020), ii) coaching aligns with adult learning theory, whereby participants are encouraged to find their own answers, promoting problem-solving, skill acquisition, leading to optimising learning (Knowles, 1984), and iii) coaching aligns closely with a partnership approach which is associated with improved self-management outcomes (Lorig and Holman 2003), as well as improved behavioural, physiological, social, and psychological outcomes, including PA (Kivelä et al. 2014). Coaching is commonly adopted in the management of long-term conditions (Benzo et al. 2021) and was successfully used in the ParkFit study (van

Nimwegen et al. 2013). In the ParkFit study, Physiotherapists and participants reported that coaching had a positive impact on influencing PLwP PA behaviour (93 and 71% respectively) (van Nimwegen et al. 2013; Speelman et al. 2014). Therefore, drawing from this research, staff delivering PDConnect adopted a coaching style, with the aim of promoting partnership, shared decision-making and problem-solving.

4.4.14.3 Education

The literature review (section 2.3.3) highlighted that an understanding the benefits of PA was pivotal in shaping PA behaviour among PLwP. Education was threaded throughout PDConnect, supported by a participant manual (Appendix 20). The manual reinforced key components of the intervention and served as an educational resource. The content and scope of the manual was guided by the current evidence-base, and by PLwP, with subsequent drafts reviewed by PLwP to ensure relevancy and readability. Key topics included: pathophysiology, benefits of activity, types of PA, behaviour change, health and safety, and tips for getting started and staying active. The manual encompassed a variety of resources including embedded links to podcasts, videos, research blogs and articles, and tasks for participants to complete during the programme. Space was allocated within the manual to allow participants to note any questions, which could be addressed in subsequent supervised sessions. Education was delivered in an applied, and contextualised manner, alongside PA prescription; for example, promoting the understanding of the value of a specific activity has on their Parkinson’s symptoms rather than solely focussing on how to do the activity.

Education was also embedded within the group-based element of the PDConnect intervention. Group sessions lasted 90 minutes of which 30 minutes was given over to group discussion. Education sessions were facilitated by the Fitness Instructor, the first six sessions were guided by the instructor and included topics such as the benefits of strength training, with the remaining six sessions guided by the participants.

4.4.14.4 Development of social support network

The importance of social connection was highlighted within section 2.3.3 of the literature review. Socialisation was shown to provide opportunity for shared learning, shared experience, and peer support. PDConnect combined one-to-one and group-based PA. This combination was purposefully selected recognising the combined benefits of both approaches. One-to-one delivery allows development of self-confidence and reduces the potential for anxiety associated with personal ability and exercising with others. However, this approach is not sustainable long-term (Allen et al. 2012), nor does it foster the development of independence and address social isolation commonly reported among PLwP (Perepezko et al. 2019). Conversely, group-based PA has potential to address the physical, emotional, and social needs of PLwP, creating a positive environment promoting camaraderie, and social integration (Claesson, Ståhle and Johansson 2020). Group-based activity has been shown to improve participation and long-term PA adherence (Hunter et al. 2019), leading to enhanced QoL among PLwP (Soundy et al. 2019). Group-based PA also offers a more sustainable long-term approach to PA delivery (Allen et al. 2012).

Arguably however, group exercise can be off-putting for PLwP. Low self-confidence and anxiety associated with Parkinson’s can be intensified within a group environment (Hunter et al. 2019). Group-based interventions provides potential for PLwP to glance into what their future may hold, which may act as a barrier to participation (Parkinson’s UK, 2019b). However, research has also demonstrated that when PLwP are supported to overcome initial anxieties they report improved acceptance, and are better equipped to cope, and manage their Parkinson’s (Hellqvist et al. 2018; Andrejack and Mathur 2020), leading to improved health status (Hellqvist et al. 2020), even when delivered online (Attard and Coulson 2012). Therefore, the PDConnect combines the merits of both 1:1 and group-based PA, with the aim of supporting long-term PA behaviour.

4.4.14.5 Access to Parkinson’s specialist professionals

Informal consultation with the Parkinson's community and the literature review (sections 2.3.3) highlighted that staff with specialist Parkinson's knowledge were valued by PLwP. The literature review highlighted those services delivered by Parkinson’s specialist staff result in improved health outcomes, and enhanced cost-effectiveness (Ypinga et al. 2018, Canning et al. 2013). Access to Parkinson’s specialists is regarded as essential, nationally (NICE, 2017) and internationally (Cheng et al. 2010), and by the Parkinson’s community (Hunter et al. 2019). However, no formalised post-registration Parkinson’s training exists in the UK for healthcare professionals. To address this gap, Physiotherapists and Fitness Instructors delivering PDConnect received specialist training developed by the researcher prior to delivery. Training content was informed by current frameworks (Allied Health Professions Competency Framework for Neurological Conditions, 2018), Physiotherapy guidelines (Keus, Munneke and Graziano 2013; Osborne et al. 2022) and stakeholder consultation. Content was also guided by the researcher who is a clinical academic with over 15 years of working in higher education developing learning resources, as well as working with the Parkinson’s community as a Physiotherapist. Training provided knowledge and skills to confidently prescribe PA and deliver BCTs to develop self-confidence with long-term PA participation, to promote self-management for PLwP. Table 4.13 illustrates the staff training learning objectives. Manuals were reviewed by senior academics in relation to educational content as well as reviewed by PLwP.

Table 4.13 Learning outcomes for Physiotherapists and Fitness Instructors

PDConnect Training Package Learning Objectives	
1.	**PDConnect** To articulate the aims, values, and ethos of PDConnect, and apply these to practice. To apply the PDConnect model to PLwP.
2.	**Pathophysiology** To critically discuss the pathophysiology of Parkinson's and be able to relate and evaluate the impact this has on PLwP and their wider support network. To critically discuss the impact of motor and non-motor Parkinsonian symptoms on movement and function amongst PLwP. To critically discuss and justify core treatment and assessment approaches and safely, effectively, and professionally apply selected techniques. To independently select and apply appropriate assessment techniques to meet individual patient needs.
3.	**Symptom Management** To critically discuss the medical management of Parkinson's. To select, plan, justify and apply appropriate treatment approaches and techniques for PLwP. To critically discuss and justify a range of outcome measures suitable for the use in the management of PLwP.
4	**Exercise Prescription** To critically justify the benefits of exercise for PLwP. To critically evaluate the barriers and motivators to exercises for PLwP. To critically discuss the evidence-base in relation to exercise prescription for PLwP. To select, plan, justify and apply appropriate exercise interventions for PLwP
5.	**Self-Management Theory and Approaches** To critically discuss self-management and empowerment theory in relation to practice.
6.	**Behaviour Change Theory and Strategies** To critically discuss behaviour change theory and application to the Parkinson population. To critically evaluate different behaviour change strategies. To select, plan and justify appropriate behaviour change strategies for PLwP.
7.	**Developing Effective Patient Partnerships** To critically discuss empowerment theory and the application to the management of PLwP. To apply motivational interviewing within management of PLwP. To critically discuss collaborative practice and reflect on delivery within practice.

All staff were provided with a training and development manual (Appendix 21) which included specified learning outcomes to guide study, supplemented by a variety of learning resources including videos, research articles, presentations, testimonials, and discussion forums, taking approximately 12-hours to complete. Learning materials covered:

- Introduction to the training manual, and preparing to study guide
- Understanding Parkinson’s
- Medical management of Parkinson’s
- The assessment of PLwP
- Prescribing PA for PLwP
- Promoting self-management
- Supporting behaviour change
- Developing effective patient relationships
- The PDConnect Intervention
- Using RehabGuru™, Microsoft Teams and Mi bands

Each section of the manual commenced with learning objectives to guide personal study and finished with a learning checklist. Directed study was supported by the delivery of a 1-day course by the researcher to enable practical application of learning delivered on Microsoft Teams. Adopting a blended approach was selected to allow flexibility and convenience allowing studying to fit around work commitments (Choules 2007). Combining directed learning with online workshops have been successfully implemented in other Physiotherapy courses such as LSVTBig® and PD Warrior® and was the mode of choice following consultation with local Physiotherapists (Personal communication with Operational Community Lead Physiotherapist, NHS Grampian). The online workshop included interactive demonstrations to aid contextualisation of learning gained from the manual. Evaluation of the training was conducted at the end of the intervention to explore training satisfaction and acceptability and whether staff felt that the training adequately prepared them to deliver the intervention. The training evaluation is described in more detail in section 4.15.3.

Professionals were also provided access to PDConnect Microsoft Teams area. This allowed staff to view the participant intervention manual, Mi band and Microsoft Teams guide, and safe exercise at home guidance. A restricted channel was also created within the Microsoft Teams area, for communication between staff delivering the intervention and the research team and the sharing of information including:

- Handover sheet completed by the researcher, which included participant’s details, past medical history, and medication. (Appendix 17)

- Completed home risk assessment forms (Appendix 13)
- Completed participant statement which included emergency contact details (Appendix 14)
- Attendance record sheets (Appendix 18)
- Physiotherapy and fitness instructors' session documentation records (Appendix 19, 22)
- Handover sheet for use between physiotherapists and fitness instructors. (Appendix 23)

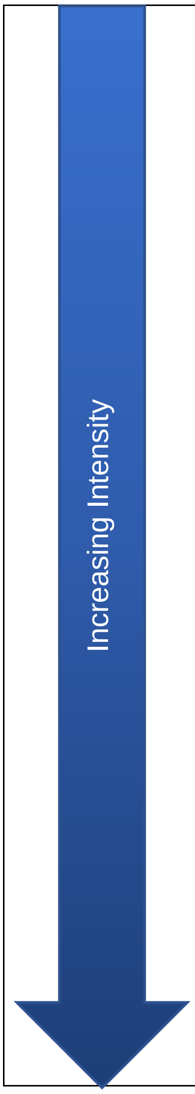
To ensure that the researcher remained blind to participant allocation, the researcher had no access to the Microsoft channels for the duration of the study.

4.4.14.6 Personalised and progressive physical activity prescription

The benefits of PA for PLwP are widely reported (Mak et al. 2017). However, the optimum type or dosage of activity remains undetermined (Ellis and Rochester 2018). Recognising diversity of Parkinson's symptoms and the potential for co-existing pathologies, an individualised approach to PA prescription was adopted. Selection of PA was informed by evidence, current guidelines, and participant's preference. Following the European Physiotherapy Guideline for Parkinson's, PA programmes encompassed strength, flexibility, balance, gait, amplitude, and functional-based exercise (Keus et al. 2013). PA prescription was guided by the FITT principles (Frequency, Intensity, Type and Time), with all participants receiving weekly supervised sessions for a total of 18 weeks (6 weeks of one-to-one Physiotherapy and 12 weeks of group-based exercise) supplemented by an individualised home exercise programme, undertaken independently up to five times a week, aligning with national and international PA guidelines (Chief Medical Officer 2019). Activity was prescribed in a progressive manner by increasing repetitions, speed, load, and/or task complexity (Keus et al. 2013). Prior to participating, participants were sent an equipment bundle for use during the study (Figure 4.7). This bundle included resistance bands of various strengths, a ball, spot mats, cue cards, a scarf, and safety information (Appendix 24).

Figure 4.7 Exercise equipment bundle sent to all PDConnect participants

Current research advocates the prescription of high intensity activity for PLwP (Alberts and Rosenfeldt 2020), therefore a progressive approach to activity intensity was adopted throughout PDConnect. Delivery of high intensity home-based activity has been shown to be safe and feasible (Schenkman et al. 2018b; van der Kolk et al. 2018). However, a significant proportion of PLwP are known to be sedentary (Lord et al. 2013), worsened further by the imposed COVID-19 restrictions negatively impacting on PA levels (Song et al. 2020). Therefore, participants were encouraged to work at moderate intensity initially prior to progressing towards higher intensities. Activity intensity was guided by the Borg Rating of Perceived Exertion (RPE) scale, which is commonly used in practice to monitor and gauge activity intensity, and perceptions of perceived effort (Borg 1982). The Borg Scale (Figure 4.8) allows participants to gauge how hard their body is working and thus their perceived exertion on a 6-20 scale. The Borg Scale has been shown to be valid and reliable for PLwP (Penko et al. 2017), and was selected for ease of use over absolute ranges of heart rate during online delivery. Initially, participants were encouraged to work at moderate levels –RPE 8-10 progressing to RPE 14-17, which equates to 70-85 % of maximum heart rate which is classed as high intensity (Alberts et al. 2020), during all sessions. Copies of the RPE scale were available within the intervention manual to guide intensity of HEP engagement, and participants were reminded of the activity effort throughout supervised sessions.



Number Rating	**Verbal Rating**	**Example**
6		No effort at all. Sitting and doing nothing
7	Very, very light	Your effort is just noticeable.
8		
9	Very light	Walking slowly at your own pace.
10		Light effort.
11	Fairly light	Still feels like you have enough energy to continue exercising.
12		
13	Somewhat hard	
14		Strong effort needed
15	Hard	
16		Very strong effort needed.
17	Very Hard	You can still go on, but you really have to push yourself. It feels very heavy, and you are very tired.
18		
19	Very, very hard	For most people, this is the most strenuous exercise they have ever done. Almost maximal effort.
20		Absolute maximal effort (highest possible). Exhaustion.

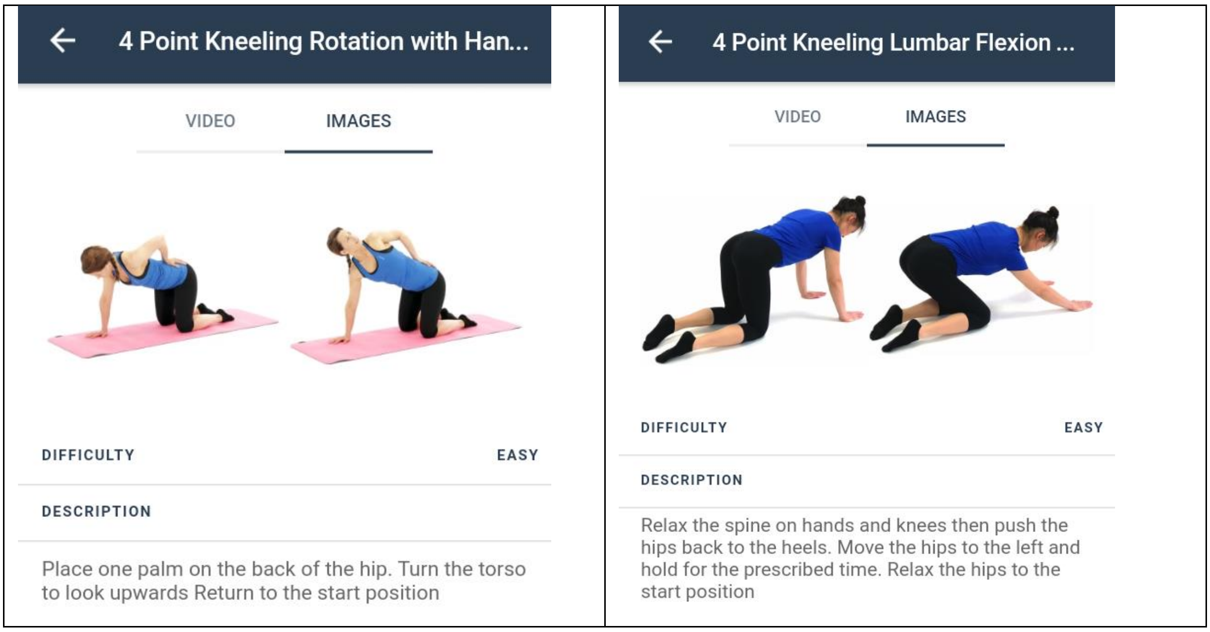
Figure 4.8 Borg Rating of Perceived Exertion (RPE) Scale

4.4.14.7 One-to-one specialist Physiotherapy

Participants received six, one-to-one, hour-long, weekly Physiotherapy sessions, mirroring that of usual care delivered over Microsoft Teams. Weekly sessions were selected to promote: Continuity of treatment, and development of a sound foundation whereby behaviour change could be developed in a supportive environment. Weekly session were also selected to promote self-confidence with PA, and effective self-management strategies, prior to progressing to the group phase of the intervention.

The Physiotherapist was provided with session plans to standardise delivery of PA, education and BCT’s (Appendix 25). Each session encompassed a minimum of 35 minutes of exercise, including warm up and cool down, and a minimum of 10 minutes to develop a HEP. A shared decision-making approach to activity selection was adopted to promote motivation and adherence (Zizzo et al. 2017). Education on the purpose and rationale of each exercise was embedded within each session, along with practical demonstration and real time feedback on performance to ensure appropriate, and safe technique. Where appropriate participants were also signposted to their intervention manual, to support education provided within one-to-one sessions.

Physiotherapy sessions were supplemented by a HEP selected from the REHABGuru® exercise library, aligning with the participant's goals. REHABGuru® was selected as it offers colour images and videos, with clear instructions to guide exercise participation out with Physiotherapy as illustrated in Figure 4.9. HEPs were emailed to participants as a link or a PDF file depending on participant preference. Participants were encouraged to undertake their HEP five times a week, with each session lasting a minimum of 30 minutes.



4 Point Kneeling Rotation with Han...

DIFFICULTY EASY

DESCRIPTION

Place one palm on the back of the hip. Turn the torso to look upwards Return to the start position

4 Point Kneeling Lumbar Flexion ...

DIFFICULTY EASY

DESCRIPTION

Relax the spine on hands and knees then push the hips back to the heels. Move the hips to the left and hold for the prescribed time. Relax the hips to the start position

Figure 4.9 Example of REHABGuru® Exercise prescription resource

BCT's and education were delivered in tandem with PA prescription to ensure relevancy. A coaching style of delivery was adopted to promote participant autonomy, decision-making, problem-solving and self-awareness. Coaching was also used to develop individual PA confidence, to prepare participants for the group-based component of PDConnect.

Each 1:1 Physiotherapy session was recorded (video and audio) with participant consent and saved on the university password protected server. These videos were stored only for the purposes of assessing intervention fidelity on completion of the study, and were only accessible by the Physiotherapist, and research team. Fidelity assessment was conducted at the end of the study when the researcher was unblinded. Following each intervention, the Physiotherapist made notes on the session, aligning with professional note keeping standards (The Chartered Society of Physiotherapy, 2013). These notes were stored on the restricted channel within Microsoft teams. The same Physiotherapist provided all sessions promoting a standardised and consistent approach to delivery.

On completion of the six Physiotherapy sessions, participants were given a choice to attend either a Monday or Thursday morning group-based class delivered on Microsoft teams. Two groups were run, allowing a maximum of eight participants per group, to ensure participant safety and aligning with best practice guidelines (The Chartered Institute for the Management of Sport and Physical Activity 2018). The Physiotherapist completed a standardised handover sheet (Appendix 23) to share with the Fitness Instructor detailing; progress to date, current goals and HEP, and any other information deemed relevant to support smooth transition from 1:1 to group-based components of the intervention. Prior to the commencement of the group-based component, the Fitness Instructor contacted all participants individually via email to confirm the date and time of their first group session and clarify how to join the session on Microsoft Teams. In addition, the fitness instructor provided participants with an introductory video.

4.4.16.8 Group exercise classes.

Following completion of 1:1 Physiotherapy, participants commenced a 12-week group-based exercise class, with the aim of consolidating PA self-efficacy and promoting strategies to encourage independence with PA. The aim was to promote a life-long PA habit, and PA self-management. All sessions were delivered by a Fitness Instructor who had completed the PDConnect training discussed in section 4.4.14.5. The same Fitness Instructor provided all sessions, limiting variation in delivery, and ensured a standardisation between the two classes. Sessions lasted 90 minutes with a minimum 60 minutes of PA, and 30 minutes for group education discussion. The optimum duration of PA interventions is undetermined (Ellis and Rochester, 2018). Twelve weeks was selected for use in this study, recognising that physiological adaptation to PA occurs after eight weeks (Folland and Williams 2007); however, in the presence of Parkinson’s this is reported to take up to 12 weeks (Schenkman et al. 2018). Selecting 12 weeks was also deemed an appropriate time to facilitate the development of group rapport.

Recognising heterogeneity in Parkinson's presentation, a circuit-based approach to PA was selected. Circuit training consists of rotating around different exercise stations, permitting participants to work at their own intensity. Whilst the virtual environment does not permit rotation, adoption of this approach allowed everyone to do the same exercise at the same time, while allowing individual adaptation. Based on current research, the class ran for a minimum of 60-minutes, encompassing ten exercise stations, with participants spending four minutes at each station (Klika and Jordan 2013). Four minutes was selected to allow sufficient time for participants to optimise performance within each station, recognising that cognitive processing and motor learning can be slower among PLwP (Pang et al. 2019). Each station had four levels of difficulty, allowing tailoring to individual participant ability. Difficulty was progressed by the inclusion of a dual task or a cognitive challenge. Following European Physiotherapy Parkinson's Guidelines (Keus et al. 2014), PA included mobility, strengthening, aerobic, balance, cognitive, and goal-oriented components, with an emphasis on large amplitude movements and intensity of effort. All participants received an introduction to each PA, encompassing key teaching points, practical demonstration, proposed benefits, and purpose of the activity. Videos of each PA and individual levels were available on Microsoft Teams area prior to and following classes to aid participation. Fitness Instructors were provided with session plans to standardise delivery of PA, education and BCTs. Building on the foundations developed within 1:1 Physiotherapy, PA was prescribed in a progressive manner, promoting participants to work consistently at moderate to high intensities (RPE 14-16). Sessions plans were used to guide which BCTs should be incorporated into each session (Appendix 26), with emphasis on developing problem solving, autonomy and decision making, and refinement of knowledge.

Falls risk among PLwP is higher than that of age-matched controls (Allen, Schwarzel and Canning 2013). Prior to commencing sessions, participants were reminded to check the safety of their activity area and ensure that they had access to a phone and water. To minimise distractions, and reduce falls risk while exercising, participants were required to have their laptop or tablet screen set at speaker view, allowing them to see only themselves and the Fitness Instructor. When providing individual feedback during the class the "spotlight" feature within Microsoft Teams was utilised so only the participant and the Fitness Instructor were visible on screen.

The remaining 30-minutes of the class was dedicated to group discussion facilitated by the Fitness Instructor. The first six sessions were predetermined (Appendix 30), with participants encouraged to make suggestion of topics they would like to discuss in the later six weeks. During this time participants were able to see and interact with each other and the instructor on screen. The purpose of the discussions was to promote shared learning which has been reported as highly valued by PLwP (Hunter et al. 2019). Participants were encouraged to continue with their HEP out with the weekly class, and record PA and daily step count in the activity diary. HEP's and goals were reviewed on an individual basis every three weeks and progressed as required by the Instructor. Reviews were conducted at the end of group-based session. Participants were made aware of their review session in advance via email. Participants were sent updated HEPs by email, with all new goals documented within the activity diary. Following completion of the 12-week programme, participants were encouraged to attend community-led exercise opportunities highlighted within the intervention manual and to continue to complete their activity planners and diaries.

As with the 1:1 Physiotherapy sessions, all group sessions were recorded with participant consent and saved on the university password protected servers for the purposes of assessing intervention fidelity on completion of the study. The Fitness Instructor also kept an attendance log of attendees.

4.4.14.9 Self-management

During this 12-week component, participants self-managed their PA regime. Participants were encouraged to access and engage with the videos of each exercise station as well as follow their HEP developed during the programme. Participants were asked to record all activities and daily step count within their activity diaries. Participants received a 20-minute audio or video call every month, from the Fitness Instructor, to review and adapt the exercise regime and goals and to support problem solving as required. Monthly calls were selected as prior studies have shown that adherence declines after one month (Allen et al. 2012). The monthly calls were not recorded and therefore were not assessed for fidelity.

4.15 DATA COLLECTION

The aim of this study was to explore the feasibility, acceptability, and fidelity of the PDConnect intervention, therefore primary data collection addressed these domains. Although this study was not powered to detect statistically significant changes in clinical outcome measures, secondary outcomes (measured at baseline, at six, 18 and 30 weeks) were collected on outcomes such as PA, motor and NMS, depression and anxiety, fatigue, function, self-efficacy and QoL to inform future sample size calculations. A suite of outcome measures were employed in order to inform selection of the most appropriate measures for use in a future effectiveness study. Both primary and secondary data collection will be discussed and justified in the subsequent sections. Self-reported measures are provided in Appendix 27.

4.15.1 Blinding and bias limitation procedures

Double blinding of both participants and the researcher was not possible owing to the nature of the intervention, as participants were inevitably aware of the arm they had been randomised too. Randomisation and notification of group allocation was undertaken by researchers independent to the study, so that the principal researcher remained blind to participant group allocation. Participants were asked not to disclose at any point during the study their group allocation or participant ID. A study specific email address was created, and monitored by a researcher independent to the study, to reduce risk of potential unblinding of the researcher during the study. The researcher conducted the eligibility screening, and all physical outcome measures on Microsoft Teams at each time point. During data analysis a coded data set (Group A and B) was used to maintain blinding. Only when data analysis was complete was the group allocation unblinded.

To limit potential for researcher or participant bias, the semi-structured interviews were conducted by a member of the research team who had not previously met the study participants or staff and who was not involved in the intervention delivery or outcome measurement. The same researcher conducted all interviews (staff and participants) and used a standardised topic guide (Appendices 28 and 29) to limit potential for researcher bias and ensure standardisation of approach. All interviews were conducted within two months of participants completing the study to limit potential recall bias. All qualitative data was intelligently transcribed by the researcher when all quantitative data analysis was complete to avoid bias during transcription or the undertaking of the framework analysis. Various types of transcription exist including edited, verbatim, and intelligent. Edited transcription was not considered as it involves removing sentences or phrases which are deemed unnecessary. While the essence of the text is maintained, some of the meaning can be lost, and is open to bias due selectivity of the person who deems what material should be removed. Intelligent transcription was selected over verbatim transcription as it adopts a light touch approach to editing, removing ums, ah’s and stammers expressed during the interview. McMullin (2021), argues that using intelligent transcription allows the research to document what the participant wished to stay and therefore the final transcript remains true to the participant. Adopting intelligent transcription, therefore, allows the final transcript to be more concise, while maintaining the original meaning and language.

4.15.2 Feasibility

As a feasibility study, the focus of this study was to examine whether the study can be done, with an emphasis upon the assessment of the research and intervention processes. Feasibility was assessed by collecting data on the following:

- Recruitment and retention rates in both the intervention and control arms
- Number of eligible participants required to recruit target sample size
- Number of participants who completed each aspect of PDConnect Intervention
- Intervention attendance rates
- Feasibility of testing procedures and data collection methods, including return and completion rates of outcome measures

Data on recruitment procedures was essential to inform a future large-scale study to ensure that it is adequately powered. Data was collected throughout the study by the researcher to determine recruitment and retention rates as illustrated in Figure 4.10. In a review of Parkinson's clinical trials, Allen et al (2012) reported that 69% of interventions retained 85% or more of their participants, therefore a-priori the retention rate was set at 85%, allowing five participants to withdraw. A retention rate below this figure was deemed as a criterion for not progressing to a full trial. Attendance and adherence is poorly reported in Parkinson's PA trials (Allen et al. 2012), with the majority only reporting PA adherence for those who completed the intervention, which introduces significant reporting bias. The number of sessions attended in both arms of the study was recorded, as well as self-reported activity, and daily step count was recorded within the activity diary. The target attendance for this study was set at 77% allowing participants to miss one Physiotherapy session (5/6 sessions), and a maximum of three out of 12 weeks of group-based exercise. The 77% attendance level was based upon two factors. Firstly, prior research has indicated that a minimum of 12 weeks is required for PLwP to experience benefit from exercise (Schenkman et al. 2018). Secondly, low dose (less than 4 sessions) Physiotherapy has been shown to be ineffective (Clarke et al. 2016).

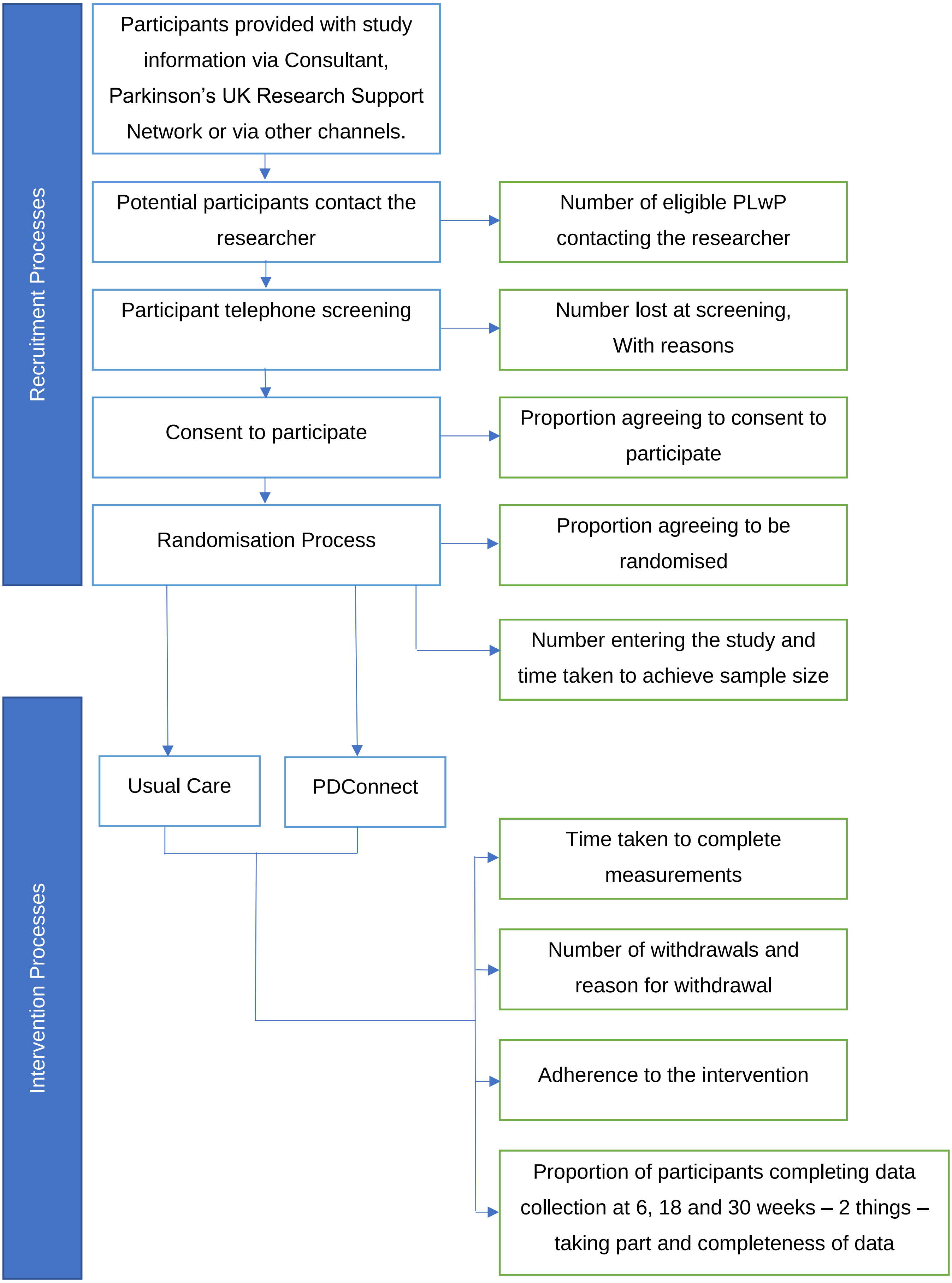


Figure 4.10 Recruitment and retention data collection during the study

Time is limited in healthcare, therefore recording the time required to deliver the intervention, and measures was an essential aspect of feasibility to inform the future study and applicability to practice. Specifically, time taken to complete the following tasks was recorded:

- Recruit to target sample size
- Conduct individual telephone screening
- Conduct Microsoft Teams, and Mi band induction for participants, and staff delivering the intervention
- Completion of staff training
- Complete baseline physical assessment via Microsoft teams
- Complete self-administered outcome measurement tools at baseline, 6, 18, and 30 weeks
- Complete repeat baseline physical assessments at 6, 18 and 30 weeks
- Complete semi-structured interviews with participants, and staff.

4.15.3 Acceptability

Establishing the acceptability from the perspective of those delivering and receiving an intervention is essential (Diepeveen et al. 2013). Acceptability was explored through both quantitative and qualitative means, to inform the design, development, and implementation of a future trial. At the final data collection point, all PDConnect participants were sent a satisfaction survey (Appendix 29), which consisted of a mixture of open and closed questions, visual analogue scales, and Likert scales. Participants were given the choice to complete this survey either in paper format or online. This survey explored participants' views on the following aspects of the study:

- Delivery of the PDConnect Intervention
- The staff delivering the intervention
- Intervention resources

Semi-structured interviews were conducted to explore perceptions of PDConnect and were conducted and recorded using Microsoft Teams. Interviews were selected as they are commonly used in health research (Kallio et al. 2016) to explore consumers' thoughts, beliefs, and experiences (DeJonckheere and Vaughn 2019). The use of focus groups was rejected to allow the capture of individual views, free from the influence of others within a group-based format. As Parkinson's is a heterogeneous condition, it was anticipated that experiences may differ between participants, therefore interviews allowed for the capture of this diversity.

Interviews followed a standardised topic guide schedule (Appendices 27 and 28). The interview domains of interest are illustrated in table 4.14. Interviews were analysed using the five-step qualitative framework analysis described by Ritchie and Lewis 2003. Framework analysis was undertaken by the researcher and a member of the research supervisory team with experience in qualitative analysis, and who had not been directly involved in recruitment, intervention delivery or measurement. The researcher maintained a fieldwork journal when undertaking the interviews to note additional relevant details that arose.

Table 4.14 Domains of interest within Interviews

Participants with Parkinson's	**Physiotherapists and Fitness Instructors**
Satisfaction with and experiences and perceptions of: Physiotherapy sessions. 12-week group-based circuit classes 12-week self-management session, exploring motivators and barriers	Views, experiences and perceptions of the training and development package
Perceptions of the staff delivering the PDConnect programme	Perceptions of the use of the study documentation – assessment sheets, data collection forms, study information
Perceptions of the use of the study resources – joint goal setting, BCTs, weekly diary and exercise planner, REHABGuru, and activity monitor	Perceptions of the use of the study resources – joint goal setting, BCTs, weekly diary and exercise planner, REHABGuru, and activity monitor
Perceptions and views on the use of and experience of using Microsoft teams	Perceptions and experience of delivering the PDConnect programme using Microsoft teams
Perceptions of the impact participation has had.	Perceptions of the impact of the intervention on PLwP
Other views and comments that they wish to share	Other views and comments that they wish to share

4.15.4 Intervention Fidelity

Assessment of intervention fidelity was undertaken to assess the degree to which the intervention was delivered as intended by the Physiotherapists and Fitness Instructors. Fidelity assessment was also conducted to highlight any areas of potential low fidelity for consideration for future trial development. The absence of intervention fidelity assessment can result in an inability to ascertain whether changes in study outcomes are due to the influence of the independent variable (PDConnect intervention) or due to variation in approach to implementation. The MRC complex intervention guidance advocates that fidelity assessment is warranted when researching complex interventions such as PDConnect, which has several components with potential to influence outcomes (Skivington et al. 2021).

This study employed a mixed methods approach to fidelity assessment, as advocated by the guidelines for fidelity assessment of behaviour change interventions developed by the National Institute of Health Behaviour Change Consortium (Bellg et al. 2004). A mixed methods approach allowed a more comprehensive overview of fidelity. Semi structured interviews as discussed in section 4.14.3 were conducted to explore staff perceptions of intervention fidelity and explore factors which may have influenced fidelity guided by a topic guide. Scripts were shared with the Physiotherapist and Fitness Instructor, to check for accuracy, and provide opportunity to add any further comments prior to analysis.

Intervention fidelity was also explored quantitatively using checklists. All PDConnect sessions were recorded using Microsoft Teams. Fidelity assessment was conducted by the researcher following completion of the study, after researcher un-blinding had occurred. Retrospective video fidelity assessment was selected over self-reported checklists, due to the potential for responder, and recall bias (Bowling, 2014), with self-reported assessment. Real time fidelity assessment was excluded, due to un-blinding of the researcher, and the potential Hawthorne effect arising during live observations (Bowling 2014). A total of 96 Physiotherapy sessions (6 Physiotherapy sessions x 16 PLwP), and 24 group exercise sessions (2 groups each receiving 12 sessions) were delivered as part of the PDConnect intervention. A random sample of nine Physiotherapy interventions representing 10% of delivery, were used to assess intervention fidelity. Sessions were identified using random number generator using Microsoft Excel conducted by a Chartered Statistician independent to the study. At the time the study, Microsoft Teams video recordings expired after two weeks if they were not downloaded. This was unknown at the time. When this issue was identified, all group-based sessions were immediately downloaded after the delivery of class. However, this resulted in only four recordings per group being available for fidelity assessment, therefore it was only possible to complete a limited intervention fidelity assessment of the group-based component. All eight sessions were assessed for fidelity, using a standardised template (Appendix 30). The focus of the fidelity assessment was to establish whether the intervention was delivered as planned, specifically content, delivery, and duration. Fidelity assessment was conducted by the researcher using a checklist (Appendix 30) mapped to the individual session plan provided to the Physiotherapists and Fitness Instructors. The checklist contained tick boxes to confirm whether content was delivered as planned, and the time spent conducting PA. Any deviation from the session plans were noted.

4.15.5 Secondary measures

A suite of Parkinson's specific outcome measures with established psychometric properties were preferentially selected with the aim of establishing which outcomes may provide meaningful data for a future RCT. Table 4.15 and 4.16 illustrate the measures used in this study which reflects the breadth of motor and NMS associated with Parkinson's and the number of variables potentially affected by PA.

Due to restrictions imposed by COVID-19, several outcome measures originally planned for inclusion in this study had to be omitted to maintain participant safety. These included balance measures (Timed up and Go, MiniBESTest), functional gait assessments (Functional Gait Assessment tool, 10 metre walk test) and endurance measures (6-minute walk test), which were not feasible to undertake online in the absence of supervision. In addition, the assessment of rigidity and the pull test which form part of the motor section of the UPDRS were also omitted.

Regardless of participant randomisation, all secondary measures were completed at baseline, and again at six, eighteen and thirty weeks. The Lille Apathy rating scale and section I, II, and IV of the UPDRS were conducted by the researcher via Microsoft teams. To limit potential for bias and confounding, the same researcher completed these measures at each time point. The researcher used a standardised measurement pack, colour coded for each measurement timeframe, which detailed the standardised protocol for each measurement tool to ensure consistency (Appendix 31). Participants were given a Microsoft Teams appointment in advance of the session and were reminded via email not to disclose their allocation to preserve researcher blinding. These appointments were scheduled within an hour of participants taking their medication to ensure all measurements were taken during the participants on phase. At each appointment, any changes to health status and medication, and time taken to complete the assessment were recorded. Participants were sent self-administered questionnaires in the post or online depending upon individual preference at the same 6-, 18-, and 30-week timeframes by the researcher and asked to return these within two weeks. Non-responders were emailed and given a further two weeks to return their responses. Failure to return them after this period resulted in recording them as a non-responder. Due to the range of Parkinson's symptoms, a range of measures were employed within the PDConnect study. The selection of outcome measures used are discussed and justified in the following sections.

Table 4.15 Domains assessed within the PDConnect study

Measurement Tool	Motor symptoms	Non-Motor Symptoms	Function	Physical activity	Endurance	Health and well-being	QoL	ADL
Unified Parkinson's Disease Rating Scale (UPDRS)	✓	✓	✓					✓
Activities-specific Balance Confidence scale (ABC)			✓					
Mi Band	✓		✓	✓	✓			
Physical Activity Scale for the Elderly (PASE).	✓			✓				
Physical Activity Scale for individuals with Physical disabilities (PASIPD).	✓			✓				
Self-Efficacy for Exercise Scale						✓		
Schwab and England Activities of Daily Living Scale				✓				✓
Lille Apathy Scale (LAS)		✓						
Parkinson's Fatigue Scale (PFS)		✓						
Parkinson's Anxiety Scale (PAS)		✓						
Geriatric Depression Scale (GDS)		✓						
Parkinson's Disease Questionnaire PDQ-39							✓	
Nottingham Health Profile (NHP)			✓			✓		✓
Warwick Edinburgh Mental Well-Being Scale (WEMWBS)		✓				✓		

Table 4.16 Overview of measurement tools used within the study.

Measurement Tool	MDTF recommended	EPGP recommended	Psychometric properties for PLwP	Self-administered
Unified Parkinson's Disease Rating Scale (UPDRS)	✓	n/a	✓	
Activities-specific Balance Confidence scale (ABC)	✓	✓	✓	✓
Mi Band	n/a		Adults only	✓
Physical Activity Scale for the Elderly (PASE).	n/a		Older people only	✓
Physical Activity Scale for individuals with Physical disabilities (PASIPD)	n/a		Neurological population only	✓
Self-Efficacy for Exercise Scale	n/a	n/a		✓
Schwab and England Activities of Daily Living Scale	✓	n/a	✓	✓
Lille Apathy Scale (LAS)	✓	n/a	✓	
Parkinson's Fatigue Scale (PFS)	✓	n/a	✓	✓
Parkinson's Anxiety Scale (PAS)	Suggested	n/a	✓	✓
Geriatric Depression Scale (GDS)	✓	n/a	✓	✓
Parkinson's Disease Questionnaire PDQ-39	✓	n/a	✓	✓
Nottingham Health Profile (NHP)	✓	n/a	✓	✓
Warwick Edinburgh Mental Well-Being Scale		n/a	Adult population only	✓

Abbreviations: MDTF: Movement Disorders task Force. EPGP: European Physiotherapy Guideline for Parkinson's disease.

4.15.6 Motor symptom measures

Measures which assess the primary motor symptoms of Parkinson’s such as bradykinesia, and motor symptoms which arise because of Parkinson's such as balance, and function were used within this study. As illustrated in table 4.16, most of the measures selected for use in the current study are recommended by the Movement Disorder Task Force (MDTF) and had an established reliability and validity. Bowling (2014) defines reliability as the extent to which a measure can be replicated. Intra-class correlation coefficients (ICCS) are commonly used in test-retest, intra and inter-tester reliability analysis. In mathematical terms, reliability values range between 0 and 1, with values closer to one indicative of stronger reliability. When interpreting ICCs, (Koo and Li 2016, pp161) stated that “values less than 0.5 are indicative of poor reliability, values between 0.5 and 0.75 indicate moderate reliability, values between 0.75 and 0.9 indicate good reliability, and values greater than 0.90 indicate excellent reliability”. The following discussion will apply these values when commenting on measurement tool reliability.

Unified Parkinson’s Disease Rating Scale (UPDRS)

The UPDRS assesses motor and NMS of Parkinson’s and is widely used in clinical and research practice (Ramaker et al. 2002) and is considered the gold standard measurement tool (Goetz et al. 2008). The UPDRS is internationally validated (Goetz 2003; Martinez-Martin et al. 2013), with excellent test-retest reliability (ICC 0.92, Siderowf et al. 2002) and is recommended for use by MDTF (Bloem et al. 2016). The UPDRS consists of four subsections: i) NMS experience of daily living, ii) Motor experience of daily living, iii) Motor examination, and iv) Motor complications. Each question is rated on a 0-4 scale, with 0 representing normal and 4 representing severe. Each subsection can be individually analysed and summed to form a total composite score, with higher score representing worsening symptoms.

Balance – Activities-Specific Balance Confidence scale (ABC)

Postural instability is a cardinal feature of Parkinson’s, with over a third of PLwP classified as recurrent fallers (Allen, Schwarzel and Canning 2013), therefore balance measures were included. Owing to the COVID-19 restrictions physical assessment of balance was not possible. Clinical balance measures such as the miniBESTest, that involve the incline and decline walking and response to anterior perturbation, were not safe to conduct without direct clinician supervision. Therefore, self-perceived measures of balance were used. The ABC scale is a self-report confidence with balance scale that is recommended by the MDTF (Bloem et al. 2016) and the European Physiotherapy Guideline for Parkinson’s disease (Keus, Munneke and Graziano 2013). Participants score their perceived level of balance confidence performing 16 common indoor and outdoor activities. Each item is scored from 0% (no confidence) to 100% (full confidence); with the total ABC score being calculated as the mean value of the individual items (Huang and Wang 2009). Internal consistency (Peretz et al. 2006) and test-retest reliability (Steffen and Seney 2008) are excellent (>0.90) with an ability to discriminate between fallers and non-fallers among PLwP. Construct validity is reported as moderate to strong when compared with the dynamic gait index (Herman et al. 2009).

Physical Activity– Mi Band

Influencing PA behaviour among PLwP was central to the PDConnect intervention. Therefore, PA participation was measured objectively using an activity monitor (Mi band), and self-reported using self-administered questionnaires such as the Physical Activity Scale for the Elderly (PASE). The use of wearable technology within clinical and research practice has revolutionising patient care, due to the ability to generate comprehensive personalised data (del Din et al. 2021). Wearable technology such as wrist worn activity monitors allow continuous patient monitoring of PA habits, providing HCP a more realistic picture of how Parkinson’s effects everyday lives (del Din et al. 2016). Activity monitors contain accelerometers, allowing capturing variation and intensity of PA, which may have potential track or monitor progression of Parkinson’s (Patel et al. 2021).

Activity monitors complement existing clinical scales with potential to improve clinical decision making and long-term management (Morgan et al. 2020). However, much debate exists in the literature on the accuracy of activity monitors, with conflicting conclusions on reliability and validity (Pradhan and Kelly 2019). Waist worn activity monitors have been shown to be more reliable than wrist mounted devices (Wendel et al. 2018), however the latter are more acceptable with consumers. Activity monitor adherence is high among PLwP (Pradhan and Kelly 2019), suggesting user acceptability, leading to the use of monitors being advocated to promote PA participation among PLwP (Lamont et al. 2018). All participants, regardless of randomisation, were provided with an activity monitor (Figure 4.11), to recorded daily and weekly step count. The purpose of the monitor was threefold: i) to provide an objective means to measure daily activity, ii) to serve as a motivational tool to promote PA, iii) to provide means to set daily and weekly activity goals. Participants were asked to record their daily step counts within an activity diary.

The Mi band Version 5.0 was used in this study as an objective means of measuring daily PA levels. While many activity monitors are available, the Mi band was selected as it is an affordable (£25 per device) and has good internal consistency during the six-minute walk test and stairs climb [ICC: 0.83] (Paradiso, Colino and Liu 2020). A recent study which compared six different commercially available monitors (Fitbit Blaze®, GFitbit Flex®, Jawbone™, Pebble

Smartwatch 2014, and 2016 version) including the Mi band (Version 3.0), reported that none of the devices were superior in any domains including comfort and ease of use. In the current study, all participants were sent a Mi band and user guide (Appendix 9) a minimum of one week prior to the commencement of the study. The manual included information on how to set up the Mi band, charging, device functionality, maintenance, and synchronisation with a smartphone or tablet. Any participants who did not own a blue tooth enabled smart device were provided one by the researcher. All participants had a scheduled appointment via Microsoft Teams with the researcher to address any issues associated with setting up the device prior to commencing the study. All participants were asked to wear the Mi band for the duration of the study (30 weeks) recording daily step count within their activity diary.

Figure 4.11 The Mi band activity tracker

Physical Activity - Physical Activity Scale for the Elderly (PASE)

Insufficient evidence exists to support the reliability and validity of any one PA measure (Doma et al. 2017; Smitha et al. 2017). Currently, no PA measures have been validated for PLwP (Jimenez-Pardo et al. 2015). As Parkinson’s is typically diagnosed in the mid 60’s (Pringsheim et al. 2014), PA measures applicable to older adults were selected. The PASE is a self-report measure, encompassing a range of physical activities typically chosen by older adults. The ten questions require participants to rate their PA over the prior week. Total PASE scores range from 0-500, with higher scores indicative of increased PA. The PASE has been used with PLwP, (Amara et al. 2019; Mantri et al. 2019a), and has been validated among the older adults (Washburn et al. 2002), with a test-retest reliability coefficient (Pearson's) of 0.997 (Loland 2002).

Physical Activity- Physical Activity Scale for Individuals with Physical Disabilities (PASIPD).

This measure is an iteration of the PASE but updated in recognition of lack of PA measures for those with disabilities (Washburn et al. 2002), with three additional self-report questions. The PASIPD has good test-retest reliability (r=0.77, van der Ploeg et al. 2007), and criterion validity when compared with accelerometery (Sallis and Saelens 2000). This measure has been used with PLwP (Jimenez-Pardo et al. 2015). Although overlap exists between the PASE and PASiPD, as this is a feasibility study, both were included to allow for evaluation of which measure could be included in a future RCT.

Function - Schwab and England Activities of Daily Living Scale

The combined impact of motor and NMS, impacts PLwP ability to engage in functional tasks, therefore a measure of function and participation was deemed appropriate to include within this study. The Schwab and England Activities of Daily Living Scale is a self-administered questionnaire capturing perceptions of functional ability during activities of daily living. This measure is recommended for use for PLwP by the MDTF (Shulman et al. 2016). Among PLwP, this measure has good test-retest reliability (ICC=0.70, Dal Bello-Haas et al. 2011), and moderate inter and intra-tester reliability (0.65, 0.60 respectively, McRae et al. 2002).

4.15.7 Non-motor symptoms measurement tools

Non-motor symptoms (NMS) are a key feature of Parkinson’s (Goldman and Postuma 2014), which negatively affect QoL (Tibar et al. 2018). While several NMS exist in Parkinson’s, PA has been shown to have a positive impact upon apathy (Subramanian 2017), fatigue, apathy, and depression (Dashtipour et al. 2015). Therefore, tools which measure NMS were included within this study, and are discussed below. Cognitive impairment, and autonomic dysfunction are further key NMS recognised by the researcher, however these were omitted as they were perceived to be out with the scope of the research and the competencies of the research team.

Lille Apathy Scale (LAS)

Apathy in Parkinson occurs in over 40% of PLwP (Sousa et al. 2018) and is thought to be a direct consequence of the physiological changes which occur in Parkinson’s rather than a behavioural response to the condition (Pluck 2002). Several measures exist that assess apathy in Parkinson’s; however, the LAS was selected as it is recommended by the MDTF (Leentjens et al. 2008a). The LAS originally described by Sockeel (2006) is a structured interview conducted by the researcher, which contains 33 questions, incorporating different facets of apathy including cognitive, behavioural, and affective features, which are not addressed in other measures such as the Apathy Scale (Weintraut et al. 2016). The LAS is quick and easy to administer taking a maximum of 10 minutes (Dujardin et al. 2008). Systematic reviews report strong psychometric properties (Intra-tester reliability, ICC= 0.966, Dujardin et al 2008) and validity as a diagnostic tool for apathy amongst PLwP (Radakovic et al. 2015; Carrozzino 2019).

Parkinson’s Fatigue Scale (PFS)

The prevalence of fatigue in Parkinson’s is estimated between 33 and 58% (Friedman et al. 2007). Fatigue levels are higher among PLwP compared with age matched controls (Beiske et al. 2010), and is commonly cited by PLwP as one of the most disabling symptoms (Barone et al. 2009). The PFS is specifically designed for evaluating fatigue in PLwP, and is endorsed by the MDTF (Friedman et al. 2010) for use in clinical practice and research. The PFS is a 16-question self-administered questionnaire assessing fatigue levels and their impact on everyday function. The PFS has a strong reliability and test re-test reliability (Cronbach's α = 0.97–0.98; test–retest = 0.82 using the total score), and high internal validity (Friedman et al. 2010).

Parkinson’s Anxiety Scale (PAS)

Anxiety is reported to occur in up to 57 % of PLwP (Dissanayaka et al. 2014) although estimates vary hugely between studies. Insufficient evidence existed for the MDTF to recommend any anxiety measurement for use in Parkinson’s (Leentjens et al. 2008b). More recent reviews have recommended the PAS in PLwP without dementia (Dissanayaka, Torbey and Pachana 2015), making it applicable for use in this study. The PAS is a 12-item self-rated instrument, which incorporates persistent, episodic anxiety and behaviour avoidance, taking up a maximum of 5 minutes to complete. Each item is scored on a 5-point Likert scale ranging from zero- not or never to four - severe or almost always. The PAS is considered superior to the Beck Anxiety Inventory and the Hamilton Anxiety rating Scale, with excellent test–retest (ICC = 0.89 ± 0.51), and inter-rater reliability [ICC = 0.92 ± 0.46] (Leentjens et al. 2014) therefore was selected for use in this study.

Geriatric Depression Scale (GDS-30)

Depression is one of the most frequently reported NMS in Parkinson’s, and prevalence is known to rise with condition duration (van der Hoek et al. 2011). Conservative estimates suggest that 17% of PLwP report depression (Reijnders et al. 2008), with more recent studies reporting up to 36.3% having minor depression, with a further 12.9% having major depression (van der Hoek et al. 2011). Several depression measures exist, however the GDS was selected as it is validated for older adults (Krishnamoorthy, Rajaa and Rehman 2020), which encompasses the largest proportion of PLwP (Pringsheim et al. 2014). The GDS is a simple, economic, and clinically relevant measure of depression, which includes a 30-question self-administered questionnaire. The GDS is recommended by the MDTF (Schrag et al. 2007); with meta-analysis demonstrating that the GDS has greater sensitivity and specificity than the Beck Depression Inventory, and the Montgomery-Åsberg Depression Rating Scale. The GDS-30 measure takes less than 10 minutes to complete reducing participant burden.

Self-Efficacy for Exercise Scale

This measure was included as it aligns with the study's aim of promoting self-efficacy with PA participation. This self-report scale encompasses nine domains which are known to impact activity participation: weather, boredom, pain, exercising alone, not pleasurable, too busy, feeling tired, stress, and depression (Resnick and Jenkins 2000). Good internal consistency (a=0.92), and reliability (R^2 ranged from 0.38 to 0.76) has been demonstrated among older adults (Resnick and Jenkins 2000). Although not validated for PLwP; an extensive literature search identified no validated self-efficacy tools for PLwP or other neurological conditions, therefore this tool was selected.

Quality of Life - Parkinson's Disease Questionnaire PDQ-39

Recent systematic reviews highlight that PLwP have significantly lower QoL compared to those without Parkinson's (Zhao et al. 2021). The PDQ39 is commonly used in practice (Marinus 2002) and research (Hagell and Nygren 2007). This self-report questionnaire encompasses 39 questions addressing eight domains of daily living allowing the capturing of perceived health status, and quality of life including mobility, activities of daily living, emotional well-being, stigma, social support, cognition, communication, and bodily discomfort (Peto et al. 1995) . Each question is scored between zero and four with higher total scores signifying worse QoL. The PDQ39 has an established reliability (Cronbach's alpha 0.72–0.95; test–retest 0.76–0.93, Hagell and Nygren, 2007) and discriminant validity (Tan et al. 2004).

Health Status - Nottingham Health Profile (NHP)

The NHP (Hunt, McEwen and McKenna 1985) measures perceived health status. It consists of 38 items covering eight domains pain, energy, sleep, mobility, emotional reaction and social isolation, and impact on everyday life. The self-administered questionnaire is quick to complete, requiring participants to respond with a yes/no to each question. High scores are indicative of greater number and severity of perceived health problems. The NHP, is recommended for use by the MDTF (Martinez-Martin et al. 2011b).

Warwick Edinburgh Mental Well-Being Scale (WEMWBS)

The WEMWBS is a measure of mental wellbeing, used globally to monitor and evaluate intervention programmes. The WEMWBS is a 14-item self-administered tool, addressing feeling and functional aspects of mental well-being. The reliability and validity have not been confirmed among PLwP, however, good content validity, and high-test re-test reliability (0.83) has been reported among a broad adult population (Tennant et al. 2007). In the absence of any validated mental well-being tool for PLWP this tool was selected based upon its established reliability and international adoption involving long-term conditions.

4.16 DATA ANALYSIS PLAN

A data analysis plan was developed and agreed a-priori which detailed the qualitative and qualitative data cleaning, processing, analysis, and storage protocols. The main quantitative outcomes of interest were feasibility outcomes which included rates of participant recruitment and retention and intervention acceptability. As this is a feasibility trial, involving a small sample, it is underpowered to detect statistically significant improvements in the non-feasibility outcomes (e.g., PA, motor symptoms, QoL, well-being) and so these are reported descriptively (mean, standard deviation, range etc). Qualitative data collected at the end of the study via online semi structured interviews were analysed using Framework analysis as described by Ritchie and Lewis (2003).

Baseline characteristics of study participants were described using simple descriptive statistics appropriate to data type (median and inter-quartile range for ordinal data and mean and standard deviation for continuous variables). The characteristics of interest included: sample demographics (gender, age, disease duration), clinical characteristics (medication) and Parkinson's symptoms (Unified Parkinson's disease rating scale and Parkinson's severity (Hoehn and Yahr), and PA level (Physical Activity Scale for the Elderly PASE). The following section details how the quantitative data was processed, cleaned, and analysed in relation to feasibility objectives and secondary outcomes.

4.16.1 Quantitative Measures

Feasibility objectives:

Determine the required recruitment duration to recruit target sample size: An excel spreadsheet was used to record the date and name of all potential participants who contacted the researcher expressing interest in participating in the study. In addition, how they heard about the study was also recorded (e.g., via their consultant, the Take Part Hub or word of mouth). The number of potential participants who consented to a telephone screening appointment and were subsequently deemed eligible to participate in the study were also recorded and are reported as frequencies. The reason(s) for ineligibility were also recorded.

Establish participant and staff recruitment and retention rates: Following the CONSORT guidelines, participant withdrawals were recorded throughout the study. The proportion of withdrawals per arm of the study (i.e., Intervention or Usual care) were reported and the rationale for withdrawal. Any differences in recruitment and retention between groups was explored, via frequencies and descriptive statistics.

Explore whether the intervention can be delivered as planned: Staff delivering PDConnect were provided with detailed session plans (see Appendices 25 and 26). A standardised data collection sheet (see Appendix 30) was developed to record whether individual elements of each session were delivered as per the protocol, and to report the number and rationale of any deviations. This data was used to report the proportion of sessions that were delivered as planned. This data was categorised as follows:

- Number of sessions which delivered ≥75 of the protocol
- Number of sessions which delivered between 50 and 74 per cent of the protocol
- Number of sessions which delivered ≤ to 49 percent of the protocol.

Explore whether participants attend the intervention: Attendance was recorded for participants receiving either usual Care or PDConnect. The proportion of absences and the rationale for absence were also recorded, allowing direct comparisons to be made between the two groups, and were summarised using descriptive statistics.

Ascertain the time required to complete outcome measures and establish completion rates: Outcome measures were recorded at baseline, with the same measures repeated at 6, 18, and 30 weeks. Outcome measures consisted of a battery of self-completion measures and physical measures conducted online by the researcher. Participants were asked to document the time taken to complete the self-administered outcomes, and the researcher recorded the time taken to complete the physical measures at each assessment time point. Time taken to complete both sets of outcomes at each time point for all participants are reported as a mean and standard deviation. The physical and self-administered outcomes measures response rate was recorded at each time point, allowing reporting of percentage response rate, and any differences between groups.

Explore whether the intervention is associated with any adverse events: Any adverse events were recorded throughout the study. These are reported aligning with local Research and Development standard operating policies.

Acceptability objectives

Satisfaction with the intervention: Those randomised to the PDConnect intervention received a satisfaction survey embedded within the self-administered outcomes measures pack (see Appendix 29). Questions consisted of a mixture of Likert and VAS scales, and open questions. Simple descriptive statistics appropriate to data type (median, inter-quartile range) for ordinal data and mean and standard deviation for continuous variables) were employed to explore participant satisfaction. Satisfaction and perception of PDConnect were also explored through qualitative semi structured interviews as discussed in section 4.15.3.

Secondary measures

Physical and self-administered measures were collected during this study from all participants. Data was collected at baseline, six, 18 and 30 weeks. All data was inputted in Excel and processed and cleaned prior to conducting data analysis using IBM SPSS Statistics, V24. The approach to dealing with missing data is summarised in table 4.17.

Table 4.17 Missing data protocol

Type of missing data	Protocol of analysis
Participants withdrawing from the study	Participants were asked to consent to their data which had been collected prior to withdrawal to be used for analysis. Only data from the completed data collection points were included. E.g., participants who withdrew at week 10 of the study, data was only included for analysis from 6 weeks and baseline but excluded for all other time points.
Incomplete data entry	The last observation carried forward imputation approach was adopted for any incomplete data entry, paper based self-administered outcome measures and activities diaries.

4.16.2 Quantitative Data analysis

An overview of data analysis processes employed within this study are presented in Figure 4.12. Step one involved processing of data and cleaning. Physical measures were conducted by the researcher via Microsoft Teams (Lille Apathy Scale, and items I, III and IV of the UPDRS), and recorded in a standardised paper-based booklet which were colour co-ordinated with each specific time point (Baseline: pink, 6 weeks: yellow, 18 weeks: blue, 30 weeks: green). After data collection, data was inputted into excel by the researcher. The data was then processed and cleaned allowing calculation of total score for the LAS, and the total score for each component of the UPDRS for each participant at each timepoint, following the standardised scoring methods for these measures. To preserve researcher blinding, the final cleaned excel document was shared with a research assistant independent to the study, who replaced participants names with participant IDs. The same research assistant divided the data into groups A and B, so that the researcher conducting the analysis was blind both to participants and intervention received. Depending on participant preference self-administered outcome measures were completed either online using JISC online survey (https://www.jisc.ac.uk/), or in paper format. Participant preference for online or paper was recorded as part of this feasibility study. Returned paper responses were inputted directly into the JISC online platform by the researcher at each time point, so that all data from each timeframe could be exported as one excel document.

Step one: data cleaning. Raw data was then processed and cleaned so that outcome-specific domains and total scores could be calculated for each measure for each participant following the standardised protocols for each measure. Data cleaning involved checking the data for any errors or inconsistencies. Data cleaning also involved coding data of non-numerical data from Likert scales for example, so that uniformity existed within the data set. Final cleaned data for each data collection point was collated into one excel document. This file was shared with the independent research assistant who returned the excel sheet back to the researcher, with participants assigned to group A or B to reflect their group allocation at randomisation. This ensured that the research remained blind to group allocation.

Regardless of randomisation, all participants kept a paper-based PA diary for the duration of the study documenting daily step count. Activity diaries were returned to the researcher at the end of the study in a provided pre-paid envelope. The response rate was recorded, and all daily step counts were inputted into excel by the researcher. The weekly mean and standard deviation step count were calculated using excel for each participant returning their diary. Weekly PA was calculated owing to the variability within the Parkinson's community, and reflecting the multiple variables such as weather, work, and family responsibilities which may have influenced analysis of daily step count. Missing data was recorded, as well as the number of days where nothing was recorded due to ill health.

Step two: descriptive statistics. Simple descriptive analysis was undertaken to provide the researcher with a visual representation of the data. For ordinal and nominal data types, pie charts and bar charts were used, with histograms and box plots used for interval and ratio data or where data was not normally distributed. The Shapiro-Wilks test was used to establish whether data from each secondary measure was normally distributed or not. This test was selected, as it is deemed most appropriate method for small sample sizes (<50 samples) as recruited within this study (Mazhindu and Scott 2014). Where data was found to be normally distributed, the mean value, standard deviation were reported. Where data was not normally distributed, the median value and interquartile range were calculated.

Step three: determining effect sizes. As a feasibility study with a small sample size (n=15 per study arm), a-priori, Effects Sizes (SES) were selected over traditional test statistics. Effect sizes fall under the descriptive statistics umbrella, which aim to illustrate the magnitude or strength of a quantitative finding (Cohen 2013). Much debate exists in the literature between ES and traditional statistical significance testing. Adopting a pragmatic approach, ES were selected for use within this study. The calculation of ES are not dependent upon a large sample, and are advocated as the statistical approach of choice when analysing multiple measures, making it a valid approach within this study. As a feasibility study with a small sample size, conducting significance testing raises potential for increased risk of type II error leading to false negative results to be drawn. Moreover, the reporting of p-values is limited, as they serve only to identify if an effect or difference exists, but do not allow inferences to be drawn on the size of the effect. Finally, ES were selected as they can be used to determine the sample size for potential future pilot RCT's (Lakens 2013) aligning with a key aim of this research study.

Several approaches exist to calculate Effect Sizes (ES), ranging from standardised mean difference (SMD) to correlation co-efficients (Lakens 2013). SMD is most frequently applied within pre and post-test study designs (Lankens 2013). At a basic level SMD is calculated by subtracting the mean of one group from another and dividing the result by the standardised deviation of the population from which the groups were sampled. (Caldwell and Vigotsky 2020) propose two separate approaches to calculating SMD: the magnitude-based SMD and the signal-to-noise SMD. The former is biased towards demonstrating the magnitude of an effect, whereas the latter is closely associated to the probability that a randomly selected individual experiences a positive or negative effect (Caldwell and Vigotsky, 2020). The magnitude based SMD approach was selected for use in this study. Several different approaches to calculating ES exists with Cohens *d* and Pearsons *r* being the most frequently used (Caldwell and Vigotsky, 2020). Cohens *d* was selected as it is designed for comparing means between two groups which aligns with the aims of this study. In contrast Persons r was not selected as it measures the linear relationship between two variables. ES were calculated for each secondary measure, and for each group allowing comparisons to be drawn on whether difference existed within groups (i.e., PDConnect and usual care and between groups.

Step four: subgroup analysis. Aligning with the aims of this study, ES calculations were also conducted to gain preliminary data on the potential effect of PDConnect. To determine if both groups (PDConnect and Usual Care) experienced similar treatment effects or whether differences existed between the groups.

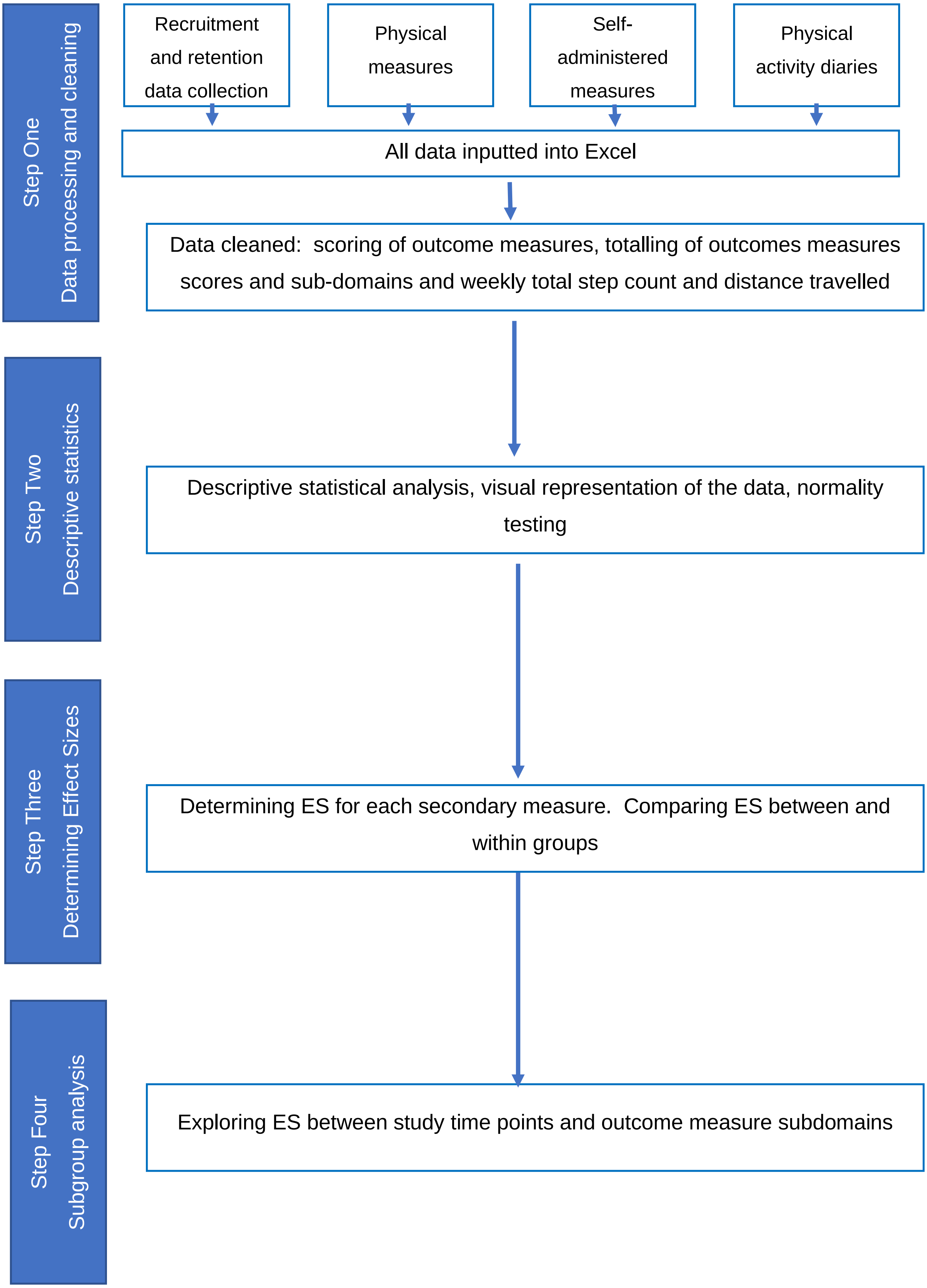


Figure 4.12 Summary to data processing and analysis

4.16.3 Qualitative data analysis

Qualitative data was collected via semi-structured interviews conducted with participants, and staff on completion of the study. The qualitative data was intelligently transcribed by the researcher. Examples of transcribed script are provided in Appendix 32. Participants were provided with opportunity to review their transcript for accuracy prior to analysis and add further comments if required. Interview transcripts were analysed following Ritchie and Lewis' (2003) Framework Analysis Approach. Framework analysis is commonly used within Health-related research (Gale et al. 2013), and is ideally suited to exploring participants' perceptions, experiences, and values, aligning with the objectives of this research. The framework approach was selected as it offers a systematic approach to organise and categorise qualitative data to highlight themes and meaning from within the data (Spencer et al. 2014). Framework analysis is a pragmatic approach, which sits comfortably with the underpinning philosophical stance of this research study (Lockwood, Munn and Porritt 2015), whereby the researcher is interested in exploring the meaning from within the data. Framework analysis was also selected as it is a flexible approach allowing a-priori issues and emerging data themes to guide the development of the analytic framework. This aligns with the study aims, whereby the researcher had pre-defined areas that required exploration for example perceptions of the intervention, but also wished to remain open to discovering the unexpected. Other qualitative approaches that place emphasis on language and how this is conveyed (i.e., Constructivist approaches), or the frequency of themes (content analysis) were discounted, as these do not align with the objectives of this research.

Central to framework analysis is the step-by-step approach to develop a matrix, which provides a structure for researchers to systematically conduct their analysis (Spencer et al. 2014). Although coding is common during data familiarisation, Goldsmith (2021) stated that in some organised data sets, coding is not always required to develop an initial framework. Due to the nature of the study and the purpose of the interviews, the interview addressed key components of the study, therefore an abridged version of Framework analysis was conducted in this study as illustrated in Figure 4.13. The researcher maintained a fieldwork journal throughout the study including data analysis, allowing the documentation of impressions, ideas, and early interpretations of the data. An inductive approach to thematic analysis was adopted, allowing participants views and opinions to dictate the emergence of themes, allowing the researcher to develop a framework based upon these findings. The researcher made notes on their thoughts and understanding of meanings as they went through the transcripts line by line.

Figure 4.13 Framework analysis process adopted within the PDConnect Study

Qualitative data was analysed using Microsoft Excel. Development of an initial framework was discussed with the researcher and a member of the research team. Grouping of themes and categories were conducted by the researcher (JJ) in discussion with the principal supervisor (KC). Following an inductive approach, this initial framework was applied to a small number of transcripts, and further discussions were had on the nature, scope of the themes and categories. The sharing of initial framework matrices, themes and categories were then shared, discussed, and amended with other members of the research team, prior to the frameworks being applied to all transcripts. Microsoft Excel was used to store, and organise the data, enhancing accessibility for the analysis process. Examples of early matrices and field notes are provided in Appendix 33.

Excel was used generate a matrix, and the data was ‘charted’ into the matrix. Data from each category from each transcript were charted, including the use, or tagging of illustrative quotations. The framework matrices and arising themes were then shared and discussed with members of the research team.

As with quantitative data analysis, rigour is equally important within qualitative research. Guba (1981) devised a criterion to enhance trustworthiness of qualitative research like the conventional criteria of reliability, and validity. With this criteria Guba and Lincoln (1981) propose that qualitative research should demonstrate credibility, transferability, dependability, and confirmability. Drawing parallels with convention positivism paradigms Guba and Lincoln propose that credibility aligns with interval validity, transferability with external validity, dependability with reliability and confirmability aligning with objectivity. Tobin and Begley (2004) state that credibility is the alignment of respondent views with those of the researchers views of them. Transferability is associated with providing as much context or “thick descriptions” so that future researchers can make independent assessment of the transferability of the findings (Guba and Lincoln 1989). Dependability and confirmability are mutually exclusive. Dependability is associated with researchers providing clear and logical documentation of their thought and decision-making during analysis. Confirmability is related to the extent to which the researchers’ interpretations and findings have arisen from the original data (Tobin and Begley, 2004). Guba and Lincoln (1989) argue that confirmability is a culmination of established credibility, transferability, and dependability. Table 4.18 details the processes used in this study to ensure a trustworthiness approach was applied to qualitative data analysis.

Table 4.18 Study processes to ensure trustworthiness of qualitative data analysis

Trustworthiness criteria	**Study processes**
Credibility	**Prolonged engagement:** Researcher undertaking the qualitative analysis has over 10 years' experience of working with PLwP. **Persistent observation:** All transcripts were viewed several times to allow immersion within the content **Member checking: T**ranscribed interviews transcripts shared with participants for accuracy
Transferability	Provision of detail of sample characteristics
Dependency and confirmability	**Maintenance of a reflective journal-** theoretical, reflective thoughts, field notes **Organised data storage** **Maintain audit trial** of key decisions, themes, categories Use of framework matrices

4.17 PROGRESSION CRITERIA

Central to feasibility studies is to inform progression to a definitive trial. The CONSORT extension for feasibility and pilot studies (Eldridge et al. 2016) advocates that "Decision processes needed to be embedded into study design which include progression criteria to decide whether to proceed, proceed with amendments or not to proceed". Following the CONSORT extension for feasibility and pilot studies (Eldridge et al. 2016) pre-specified criteria were developed a-priori to assess whether or how to proceed to a definitive future RCT. The traffic light progression criteria system (green (go), amber (amend) and red (stop) proposed by Avery et al. (2017) was adopted. Progression criteria focused upon participant recruitment, protocol adherence, and outcome data, and are detailed in table 4.19.

Table 4.19 Progression Criteria applied within the PDConnect Study

Criteria	Red	Amber	Green
Recruitment rate	Less than 50% of total sample recruited in 6 months (n=<15)	Between 50% and <100% of total recruitment in 6 months (n =15- <30)	100% of total sample (n=30) recruited in 6 months
Withdrawal rate from total sample (n=30)	More than 25% withdraw (n=8)	15 – 25% (n=5-8) withdraw	Less than 15% (n=5) withdraw
Intervention fidelity: 1:1 Physiotherapy (n=6) Group based classes (n=12)	Less than 50% of the 1:1 Physiotherapy delivered as planned Less than 50%(n=6) of group-based class delivered as planned	Between 50-85% of the 1:1 Physiotherapy delivered as planned Between 50-85% group-based class delivered as planned	85-100% of the 1:1 Physiotherapy delivered as planned 85-100% group-based class delivered as planned
PDConnect attendance rate 1:1 Physiotherapy, n= 6 sessions Group based class, n=12 sessions	Attends less than 50% (n≤3) of Physiotherapy sessions Attends less than 50% (n=6) of group sessions	Attends 50-83% (n=3-4) of Physiotherapy sessions Attends 50-75% (n= 4-8 of group sessions	Attends >83-100% (n≥5) of all Physiotherapy sessions Attends 75-100% (n≥9) of group sessions
Return of outcome measures at 6, 18 and 30 weeks	Less than 60% of outcome measures returned at each phase	60-80% return of outcomes measures at each phase	80-100% of outcome measures returned at each phase

4.18 ETHICAL CONSIDERATIONS

Owing to COVID-19 imposed restrictions, consent was taken and recorded using Microsoft Teams by the researcher. The taking of consent was audio-visually recorded for each participant and saved within the site file on the university secure server. Participants were made aware of their right to withdraw at any time, with no impact upon current or future NHS care. Any participants choosing to withdraw, were referred onto further services should this be required, aligning with current practice, and invited to attend a telephone or Microsoft Teams based video call to explore reasons for withdrawal with the researcher. Participants were made aware that participation in the study did not negate referral to ancillary services such as occupational therapy, should an identified need arise.

All data collected as part of this study was stored in accordance with professional regulations (Chartered Society of Physiotherapy, 2013), and aligned with General Data Protection Regulation Act requirements (UK Government, 2018), and in accordance with RGU policies and procedures relating to the collection, storage, and retention of research data (RGU Research Data Management Policy, 2021). Information was stored on a password protected university server to protect confidentiality and was available only to the research team. Paper-based data was stored in a locked metal filing cabinet in the secure research office within the School of Health Sciences. Audio data collected on Microsoft Teams was deleted once transcripts were reviewed by participants. To protect anonymity and maintain confidentiality, each participant was allocated a unique identifier, so that data stored could not be linked back to the individual. A researcher independent to the study maintained the file which contained a list of participant names and their unique identifier, which was stored separate to all other study documentation.

With the growing body of evidence supporting the value of PA, the use of no intervention as a control group was rejected. Those randomised to usual care received what is currently offered as standard practice in NHS Grampian (personal communication), therefore were not perceived to be disadvantaged by participating in this study. All staff participating in the study had relevant Protection of Vulnerable Groups (PVG) checks and health and safety training in place prior to the commencement of the study to ensure participate safety. In addition, several health and safety features were included within the research protocol to protect participant safety.

Beauchamp and Childress (1983) argue that beneficence is a key ethical principle which needs to be considered at all stages of the research process. Bates (2004, 343) defined beneficence as “the quality of doing good”. Table 4.20 details the steps taken within this research to reduce potential for maleficence and to ensure that regardless of randomisation, each participant received a high standard of care.

Table 4.20 Mechanisms adopted to promote beneficence

Research process	**Beneficence considerations**
Study design	Involvement of the Parkinson's community and exercise professionals to inform intervention design Consultation with stakeholders, NHS, RGU:Sport
Recruitment	Use of Parkinson's specialist consultants within recruitment to ensure participants were eligible to participate safely within the study Exercise screening undertaken prior to including within the study to ensure safety when exercising Opportunity to ask the researcher questions prior to consenting to participate
Intervention delivery	All participants were provided with a study manual, to ensure all were informed about intervention delivery All resources were reviewed by members of the Parkinson's community to ensure user-friendliness. Physiotherapy staff were all highly specialised (B6) or above All fitness instructors had a minimum of level 3 REPs equivalent training Intervention was delivered in participants own home to reduce any anxieties associated with transport and access. Risk assessment of the home environment was conducted prior to commencing online engagement All participants were required to sign a participation statement Carers/family members were invited to participate in group-based exercise if they wished Smart Phone were provided for the duration of the study if required
Data collection and analysis	All data was anonymised to protect the identity of participants Participants were given opportunity to reflect and or amend their comments made within semi-structured interviews PLwP on the study steering group committee were involved in qualitative data interpretation
Dissemination	Study finding will be shared at local Parkinson's UK branch meeting, and national service user events, and in the Parkinson's UK lay research journal Participants were kept up to date regarding the study every 3 months as recommended by the NIHR research participation standards. Lay reports will be submitted to CSO and Parkinson's UK

4.19 MONITORING

Retention and adherence rates were monitored throughout this study. With PA participation there is a potential falls risk. All participants were asked to record any falls within their activity diary and contact the researcher directly to report any falls. A priori, more than five participants reporting a fall during the intervention would trigger referral to the Study Research Steering Group. The steering group consisted of the research team, two academics independent to the study and two PLwP. Meetings were held annually, or more frequently as required, with minimum quoracy set at 67 % (two thirds) of appointed members. The study was monitored by all members of the project management group, who also oversaw the conduct of the trial. Virtual steering group committee meetings were held annually, where the researcher updated the committee on study progress, discuss issues which have arisen, seek consensus on addressing issues and to share and discuss study findings.

4.20 CHAPTER SUMMARY

This chapter has considered discussed the pragmatist underpinning of this research, and has expressed the researchers ontological, epistemological, and axiological stance. The researcher has adopted a pragmatic approach recognising that the values of both quantitative and qualitative approaches, by adopting a mixed method approach. The adoption of a fixed convergent parallel design (Creswell and Plano Clark 2011) has permitted the collection of objective data combined with an exploration of the perceptions of those involved within the research.

This chapter has justified the methodological approaches taken, and the methods adopted to address the aims of this thesis. This chapter has also explored how the data collected during the study was analysed and managed. The next chapter will provide the results of this analysis.

CHAPTER FIVE – RESULTS

5.1 CHAPTER OVERVIEW

This section will report the study findings aligning with the study aims and the CONSORT extension for feasibility studies (Eldridge et al. 2016a). The primary outcomes were to assess the feasibility, acceptability, and fidelity of the PDConnect intervention. Table 5.1 summarises the primary outcomes and findings of this study. Sections 5.2-5.4 will report the feasibility, acceptability, and fidelity results. Section 5.5 will report the secondary outcomes.

Table 5.1 Summary of the primary feasibility, acceptability, and fidelity outcomes

	Primary outcome	Finding
Feasibility	Recruit target sample n=30	Achieved, n=31
	Time to recruit to target	12 weeks, mean weekly recruitment rate: 2.6 (SD ± 2.1)
	Time taken to conduct participant recruitment procedures	Participant screening: mean 16 minutes (SD ± 5.21mins) IT induction: mean 24 minutes (SD ± 6.16mins)
	Recruit 4 physiotherapists and 2 fitness instructors	10 weeks Mean time to complete self-directed training: 6 hours
	≥ 75% of participants retained at follow-up at 30 weeks	n=23, 74% participant retention rate
	Withdrawal rates, and rationale	n=8 (26%) withdrew n=2 (%) technology issues n=6 (%) health reason, not related to Parkinson’s
	Participant attendance to ≥75% of PDConnect intervention	100% attendance at 1:1 Physiotherapy 83% attendance to group-based exercise All participants received monthly telephone/video calls
	≥ 75% completion of outcomes	n=31 (100%) of researcher-conducted measures completed. n=1 non responder at week 18, 100% at all other time points
	Activity diary return rate	n=25 (84%) of completed diaries returned
	Time taken to complete outcomes	57 minutes (SD ± 1.5mins) to complete self-administered measures 24 minutes (SD±3.8mins) to conduct researcher-based measures
	Frequency of adverse events	None

Table 5.1 Summary of the primary feasibility, acceptability, and fidelity outcomes (continued)

	Primary outcome	Finding
Acceptability	Satisfaction with PDConnect among participants	1:1 Physiotherapy: n=12 (100%) scored 8 and above on VAS satisfaction scale Group-based exercise component: n=11 (91.7%) scored 8 and above on VAS satisfaction scale n=8 (66.7%) found Microsoft Teams easy to use 100% scored knowledge, communication and approachability of Physiotherapist 8 or above 100% scored knowledge, communication and approachability of Fitness instructor 7 or above n=9 (75%) found the participant manual helpful or very helpful 100% recommended programme to others with Parkinson's
	Experience of PDConnect staff and participants	All staff and participants (n=12) perceived involvement in the PDConnect intervention was positive. n=9 (91.7%) agreed or strongly agreed that participation has increased their PA confidence n=10 (83.3%) agreed or strongly agreed that participation has increased their knowledge and understanding of Parkinson's
Fidelity	Adhere to ≥75% of the PDConnect intended content.	89% of 1:1 Physiotherapy session delivered as planned. 88% of group-based exercise sessions delivered as planned

5.2 FEASIBILITY RESULTS

5.2.1 Participant recruitment

This study aimed to recruit 30 PLwP from the Grampian region of Northeast Scotland. Recruitment to target took 12 weeks (1st December 2020 to 22nd February 2021), with 41 participants contacting the researcher expressing interest in participation, and 31 PLwP entering the study. Most participants (n=19, 46.3%) were made aware of the study through their Parkinson's consultant, with the remaining via the Parkinson's community (29.3%, n=12) or the Parkinson's UK Take Part Hub (24.4% n=10). Two people contacted the researcher in November prior to commencing recruitment following press releases in relation to the fellowship that funded this research. These individuals received a holding email, pending confirmation of ethical approval to commence recruitment. As shown in Figure 5.1 the largest proportion of potential participants contacting the researcher occurred in January 2021, coinciding with the promotion of the study via the Take Part hub.

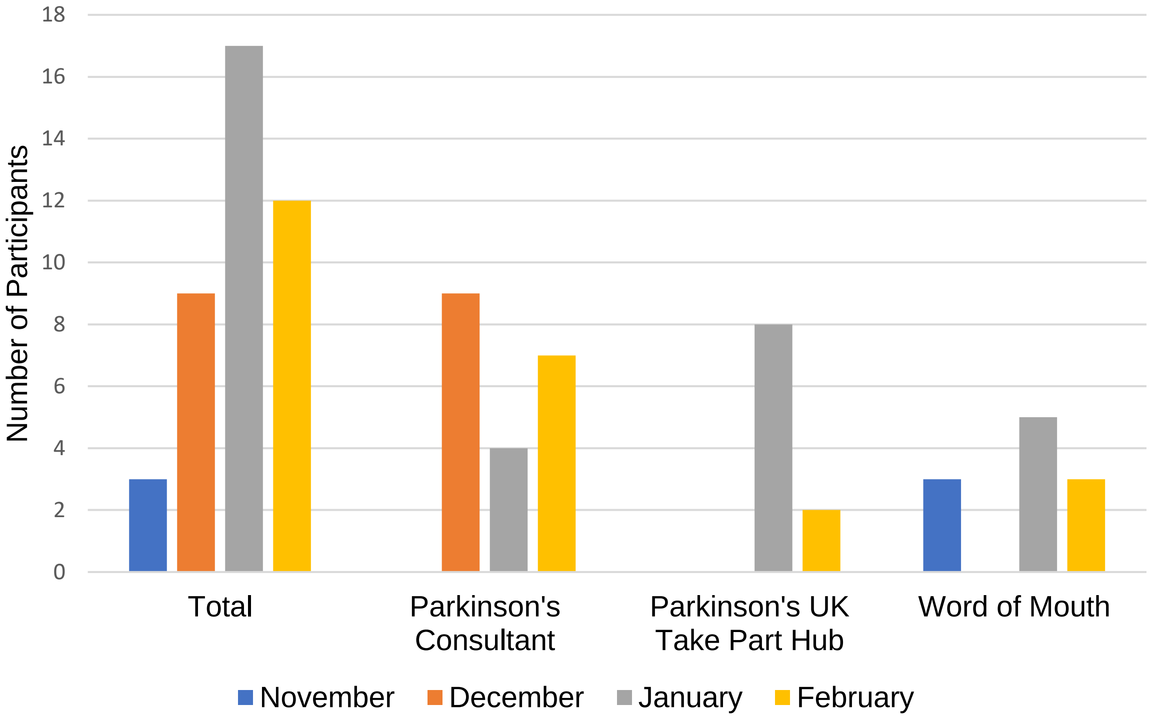


Figure 5.1 Recruitment rate per month for each mode of recruitment

Of the 41 PLwP who contacted the researcher, three were declined, as they contacted the researcher after the target sample was achieved, and one was excluded prior to screening, as their Parkinson's medication regime was unstable, resulting in unpredictable on-off periods. This individual was subsequently referred to the Parkinson's specialist nurse for review and appropriate management. Thirty-seven people were therefore screened by the researcher to confirm diagnosis, and to ensure safety to participate in online exercise. Of these 37, five did not meet the study eligibility criteria (Parkinson's of vascular origin n=2, unconfirmed Parkinson's diagnosis n=2, subacute cardiovascular symptoms n=1) and were excluded from the study. A further person was excluded from screening as they did not wish to commit to a 30-week study for personal and social reasons.

Thirty-one participants met the eligibility criteria, provided informed consent, and were randomised to receive PDConnect (n=16) or usual care (n=15). Participant demographics are provided in table 5.2. The mean age of the sample was 66.4 years old, and 58% were male. There was no statistically significant difference in age between the two groups (p=0.560). Table 5.2 illustrates a varied sample aged between 54 and 82, with time since diagnosis between 6 months and 10 years. Based on the Hoehn and Yahr score, the sample had mild to moderate Parkinson's, with broadly similar UPDRS scores between groups. Using the PASE, the usual care group were less active and reported a lower QoL, however these differences were not statistically significant compared with the PDConnect group (p=0.206, and p=0.372, respectively). At baseline, 94% of participants were taking Levo-dopa as a monotherapy, or in combination with MAO-B Inhibitors (Monoamine-oxidase-B inhibitor) or dopamine agonists. Two participants in the PDConnect group did not take any Parkinson's medication at baseline.

Table 5.2 Participant demographic and clinical characteristics at baseline

Characteristic	**Total sample**	**PDConnect (n=16)**	**Usual Care (n=15)**
Age (Mean and SD)	66.4 years ± 8.1	68.3 ± 8.3	64.6 ±7.6
Sex	13 females (42%) 18 males (58%)	6 females (37%) 10 males (63%)	7 females (47%) 8 males (53%)
Time since diagnosis (Mean ±SD)	4.8 years ± 2.6	4.5 years ± 2.3	5.2 years ± 2.9
Hoehn and Yahr Score (Mode,range)	2.5, range 1-3	2.5, range 1-3	2.5, range 1-3
UPDRS (total) (Mean ± SD)	73.37 (16.14)	72 00 (13.98)	75.00 (18.53)
UPDRS Part III (Mean ± SD)	31.24 (8.82)	32.00 (8.87)	30.43 (9.00)
PDQ-39, (Median, (IQR)	9.64 (5.99-13.28)	8.72 (4.85-13.79)	10.42 (5.99-13.28)
PASE (Mean ±SD)	139.57 ±81.86	157.16 ±80.60	120.84 ±81.67

Abbreviations: SD: standard deviation, IQR: interquartile range, UPDRS: Unified Parkinson's Disease Rating Scale, PDQ39: Parkinson's disease Questionnaire 39, PASE; Physical Activity Scale for the Elderly.

5.2.2 Staff recruitment

Only two Physiotherapists from NHS Grampian contacted the researcher expressing an interest in being involved in delivering the study intervention. Both Physiotherapists subsequently chose not to be involved due to the clinical climate imposed by COVID-19 at that time (January 2021). The recruitment period coincided with NHS system pressures with many

Physiotherapists being redeployed to other services including immunisation programmes. Recruitment was widened to include private Physiotherapists, and those on the NHS Grampian Physiotherapy Bank. Four Physiotherapists meeting the inclusion criteria were identified; two willing to commit to the study, and two to serve as alternates should the first two become unwell or require leave during the study. Table 5.3 details the demographics of the staff involved in the study.

Recruitment of fitness instructors was initiated through RGU:Sport as per the protocol. Due to COVID-19 enforced staff reallocation, RGU employed fitness instructors were not available. Working with RGU:Sport Head of Sport, a freelance fitness instructor known to RGU:Sport was identified. This fitness instructor delivered all group-based exercise sessions, and self-management follow up calls. No withdrawal of staff occurred, and there was no requirement to use alternates during the study.

Table 5.3 PDConnect staff demographics

Staff	**Time qualified**	**Professional experience**	**Responsibility**
Physiotherapist 1	3 years	Musculoskeletal outpatients, elderly assessment, neurorehabilitation, and community care.	Delivered 1:1 physiotherapy to usual care group
Physiotherapist 2	19 years	Neurorehabilitation, outpatients, and community care	Delivered 1:1 Physiotherapy to PDConnect Group
Physiotherapist 3	10 years	Stroke, mental health, community-based rehabilitation, and musculoskeletal services.	Alternate Physiotherapist for usual care group
Physiotherapist 4	24 years	Community care, elderly rehabilitation, and neurology.	Stand in Physiotherapist for PDConnect group
Fitness Instructor	7 years	Personal training, cardiac rehabilitation, musculoskeletal rehabilitation, athletic training, Pilates, yoga, and coaching	Fitness instructor for PDConnect group

5.2.3 Time taken to complete recruitment procedures

As part of this feasibility study, the time taken to complete the following recruitment tasks was recorded:

- Participant telephone screening.
- Participant Microsoft Teams induction and Mi band set up.
- Time taken for staff to complete the training.

5.2.3.1 Participant telephone screening

Telephone screening was conducted by the researcher with the aim of confirming eligibility and ensuring safety to exercise, using a standardised form (Appendix 6). Thirty-minute appointments per participant were allocated to complete the telephone screening. On average, telephone screening appointments took 16 minutes (SD±5.21 minutes). Longer appointments were required for those with more complex presentations and co-existing health conditions.

5.2.3.2 Participant Microsoft Teams induction and Mi band set up

All participants were sent via post a Microsoft Teams and Mi band guide (Appendix 9). The guide provided information on how to use Microsoft Teams and provided a step-by-step guide to set up the Mi band. Provision of the guide was followed up with a Teams video-conference call by the researcher, who provided an induction into the use of Teams and the Mi band, and briefed participants on the next steps within the study. Due to social distancing regulations in February 2021, face-to-face inductions were not possible. Seven (23%) participants required a brief induction (< 15 minutes) as they were already familiar with Teams. Of the remaining participants (n=24, 77%), the average call time was 24 minutes. Five participants required longer calls lasting between 33 and 39 minutes. Two were unfamiliar with how to operate their camera, so extra time was required to adjust settings to address this. One participant had a new device; therefore, assistance was required with setting the laptop up, prior to conducting the induction. A further two participants required assistance with the Mi band and synchronisation with their iPad. All participants were offered a follow-up appointment to promote confidence in using Teams in preparation for starting the study. Only three participants took up this offer, and in each case these calls took less than ten minutes.

5.2.3.3 Time taken for staff to complete the training

Staff training consisted of a self-directed training manual and online tutorial delivered on Microsoft Teams. Due to co-existing work commitments the tutorial element was delivered as two afternoon sessions (1-4 pm). Staff completed the directed training within 4 weeks, with staff reporting that the independent study took no more than 6 hours, with all training conducted within 12 hours. Semi-structured interviews with staff were used to explore perceptions of the training and are reported in section 5.3.

5.2.4 Participant retention

Thirty-one participants entered and 23 completed the study; therefore, the overall retention rate was 74%. Four participants withdrew from each arm of the study, with 50% of withdrawals occurring in the last month of the study. The CONSORT flowchart (Figure 5.2) provides an overview of participant recruitment, enrolment, and retention during the study. Two participants (one from each arm) withdrew due to technological difficulties associated with the intervention. Of these two, one participant from the control group withdrew almost immediately. This participant missed their first appointment, forgot to start wearing their Mi band in week one, and subsequently withdrew, having never attended an appointment. The other participant withdrew 14-weeks into the intervention due to difficulties connecting their camera. Support was provided remotely by the Fitness Instructor and the research team to ameliorate the issue. Due to social distancing restrictions associated with the COVID-19 pandemic addressing IT issues face-to-face was not possible. The remaining six withdrawals were due to health grounds not associated with Parkinson’s, including cardiovascular issues (n=2), COVID-19 (n=1), anaemia (n=1), low back pain (n=1), and an ankle fracture (n=1). Four of six participants who withdrew did so in the last month of the study. Of those who withdrew, 63% were male (n=5), and the mean age was 67.12 years (SD ±7.98)

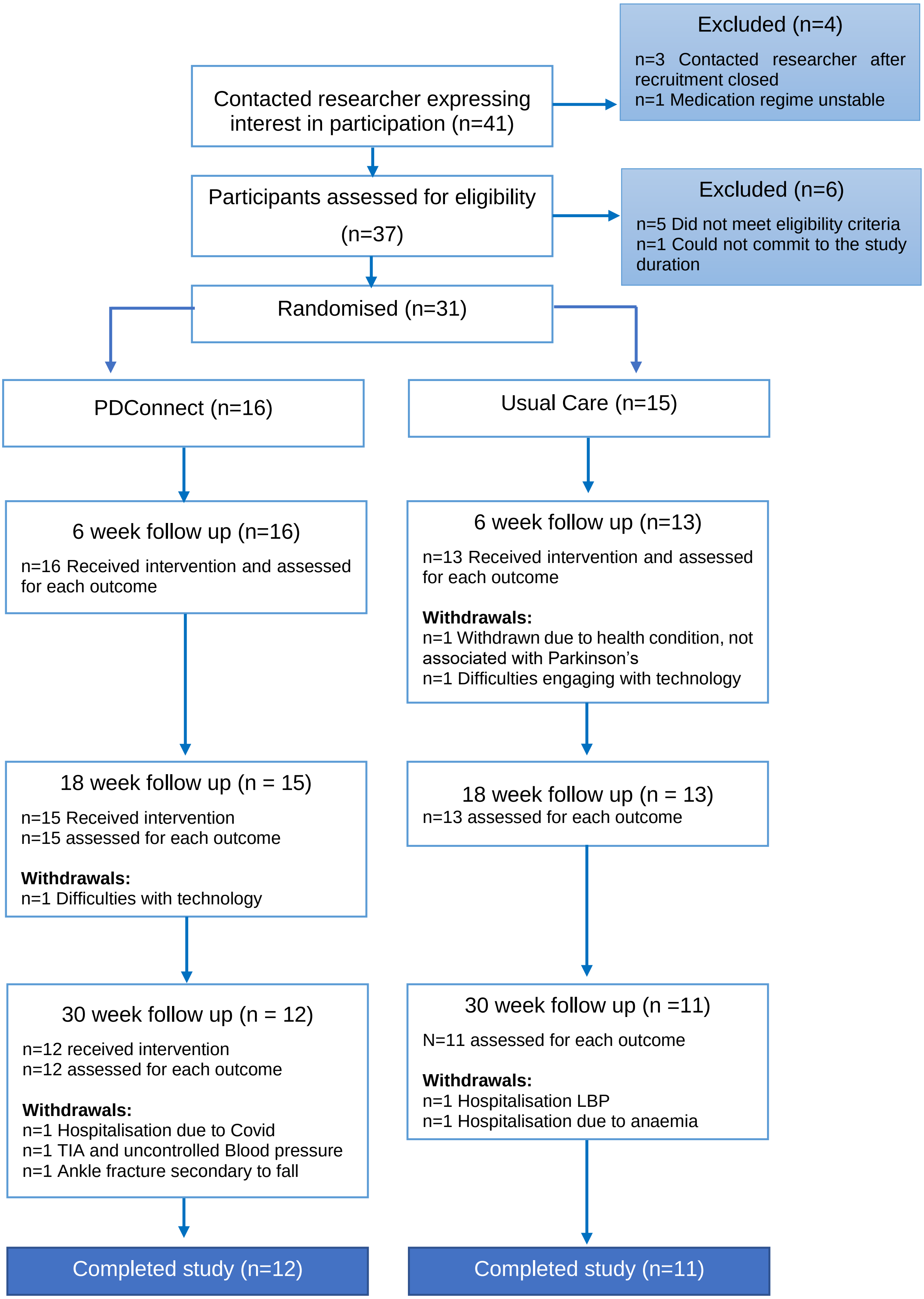


Figure 5.2 CONSORT Flowchart illustrating participant retention and withdrawals.

5.2.5 Attendance

Intervention attendance in the control and intervention groups was collected. Data was also collected on the completion rates of outcome measurements and activity diaries. The time taken to complete the outcome measurements was also recorded. These aspects are discussed below.

5.2.5.1 Intervention attendance

All attendance progression criteria (table 4.18) for each component of PDConnect were surpassed. Attendance at 1:1 Physiotherapy for both the usual care and intervention groups was 100%, excluding participants who withdrew. The group-based exercise attendance rate was 84%, with participants attending on average 10 out of 12 group-based sessions. All participants received their monthly telephone or video-conference calls as planned. Eighteen sessions were missed. Sixty-four per cent of absences were due holidays, with a further eight sessions missed due to hospital appointments or health reasons. Two absences were unexplained.

5.2.5.2 Outcome measurement completion rates

Outcome measures were completed at baseline, and at six, 18 and 30 weeks, and included measures conducted by the researcher via Microsoft Teams, and self-administered measures completed by participants. At each time point, there was a 100% completion rate for measures conducted by the researcher. A small number (n=5) required reminder emails at each time point to complete the self-administered measures. The response rate for the self-completion measures was 100% at baseline, 6 and 30 weeks, with one participant from the PDConnect group not submitting at week 18, despite receiving two reminders. Nine of the 31 participants (29%) opted to complete the measures in paper format rather than online. Those selecting online completion were younger (mean age 65, SD±7.56) compared with those selecting paper format (mean age 71, SD±8.03).

Participants were asked to record their daily step count within an activity diary. A total of 26 (84%) diaries were returned, which included five participants who had withdrawn from the study. Participants who were withdrawn submitted their activity diaries completed up until the point of withdrawal and consented for their data to be analysed. Five participants did not return their completed diaries; this included three participants who had withdrawn from the study, and two participants who completed the study but did not respond. Of those who completed the 30-week intervention (n=23), 21 returned the activity diary (91%).

5.2.5.3 Time taken to complete outcome measures.

The time taken to complete the study measures was recorded at each timepoint (baseline, 6, 18, and 30 weeks). Overall, the mean time for the researcher to complete measures was 23.66 minutes (SD±3.80). The time taken by the researcher to complete measures declined over the four time points as illustrated in table 5.4.

Table 5.4 Time taken to complete researcher conducted measures during study

	Baseline	6 weeks	18 weeks	30 weeks
No. participants	31	29	27	23
Time in minutes (Mean ±SD)	29.26 ± 5.45	22.34 ± 4.38	22.30 ± 4.67	20.74 ± 3.37

All participants received the same self-administered measures at baseline, 6, and 18 weeks. At week 30, in addition to the measures recorded at prior time points, PDConnect participants received questions to explore intervention satisfaction. Overall, the mean time to complete the self-administered measures was 57 minutes. Comparison between groups at each timepoint is illustrated in Figure 5.3. Comparing groups, the mean time for the usual care group was 56.04 minutes (SD±1.88), and 55.70 minutes (SD±4.46) for the intervention group.

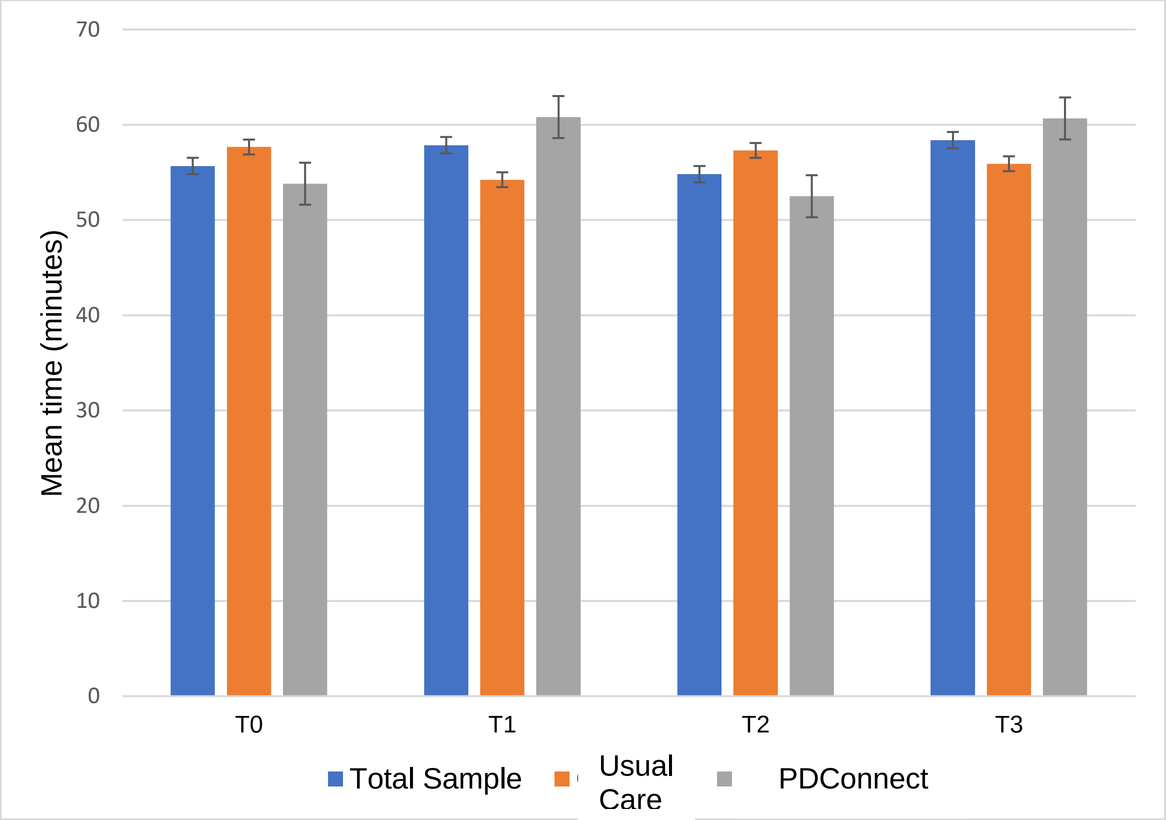


Figure 5.3 Comparison of the mean time to complete self-administered outcomes

Considering the sample as whole, the minimum amount of time to complete the measures was 10 minutes and the maximum was 150 minutes. Perceptions of the outcome measures were explored within the intervention group using semi-structured interviews at the end of the study. Participants reported that completing the measures was a lengthy and repetitive process. Measures were not perceived as burdensome however, with participants acknowledging that completing measures was an integral component of research. The flexibility to start and stop completing the measures was valued, as well as the choice of completing the measures online, or in paper format.

> "*No, no problem at all. It was not a burden. It was good that you could go and start it and then switch it off and then go back to it, so you know, so that was good*." (PDConnect participant (PDC) ID 1)

> "*No, it was part of what we signed up to, so I didn't mind doing it, I didn't have a problem doing it. So, no I did not think it was burdensome*." (PDC ID78)

5.2.6 Adverse events

No adverse events occurred during the delivery of PDConnect or usual care. However, 11 falls were reported during the study period, eight of which were reported by the usual care group. These 11 falls did not occur when receiving the intervention or during participation in prescribed home exercise programmes. Half of the falls reported by the usual care group occurred between 18 and 30 weeks, during which time they were receiving no intervention. No falls were reported between 18 and 30 weeks within the PDConnect group. Two of the falls required hospitalisation. One participant fell during week seven, was kept overnight for observation, and was subsequently discharged. This participant was reviewed by their Parkinson’s specialist nurse and prescribed additional Parkinson’s medication and continued to participate in the study. This participant was subsequently withdrawn at week 25 due to uncontrolled high blood pressure and a suspected TIA. One participant tripped over garden furniture and was admitted to hospital with a tri-malleolar fracture and was withdrawn 18 weeks into the study.

5.2.7 Feasibility summary

The findings presented above demonstrate that participant recruitment and intervention delivery of PDConnect was feasible. As highlighted in table 5.5 all progression criteria except for participant retention, met the a priori progression criteria for a future trial. Participant retention fell just 1% below the 75% progression criterion. Eight participants withdrew during the intervention, two within the first two weeks, one having never attended any appointments. Completion and return of outcome measures and activity diaries were high achieving the progression criteria suggesting high levels of feasibility. Intervention attendance was high and there were no adverse events during intervention delivery. Therefore, PDConnect appears to be a feasible intervention that can be evaluated, and a future large scale effectiveness study should be designed based on these findings.

Table 5.5 Summary of feasibility finding in relation to progression criteria

Criteria	Finding
Recruitment rate	n=31 recruited in 12 weeks
Withdrawal rate from total sample (n=30)	n=8, 26%
Intervention fidelity: 1:1 Physiotherapy (n=6) Group based classes (n=12)	89% of 1:1 Physiotherapy delivered as planned 88% of group-based exercise sessions delivered as planned
PDConnect attendance rate 1:1 Physiotherapy, n= 6 sessions Group based class, n=12 sessions	100% attendance at 1:1 Physiotherapy 83% attendance at group-based exercise sessions All participants received monthly telephone/video calls
Return of outcome measures at 6, 18 and 30 weeks	100% of research conducted measures completed n=1 non responder at week 18, 100% at all other data collection points for self-administered measure returns

5.3 ACCEPTABILITY FINDINGS

Acceptability was explored using quantitative and qualitive measures, the results of which are presented here. Quantitative and qualitative findings are combined and reported in this section. The section will start by considering the views of staff delivering PDConnect prior to exploring participants' experiences of, and satisfaction with, PDConnect.

5.3.1 Acceptability: Staff perceptions

Two Physiotherapists and one Fitness Instructor took part in semi-structured interviews. Staff demographics are provided in table 5.3. The interviews with the PDConnect Physiotherapist and Fitness Instructor lasted 47.36 and 72 minutes respectively. The longer duration with the fitness instructor reflects their role in delivering both the group-based exercise and self-management component (1:1 monthly calls). The interview with the usual care Physiotherapist lasted 15.23 minutes. Adopting framework analysis, dimensions were identified, which were then grouped by similarity of meaning into categories which contributed to the identification of two themes:

- Processes and resources involved in intervention delivery;
- Perceptions of delivering the interventions.

5.3.1.2 Processes and resources involved in the delivery of the intervention.

Within the processes and resource's theme, two subthemes were identified; online delivery and perceptions of study specific resources as illustrated in Figure 5.4. The experience of online delivery was common to all staff regardless of which arm they delivered, whereas perceptions of study-specific resources (e.g., participant manual) only involved those who delivered PDConnect.

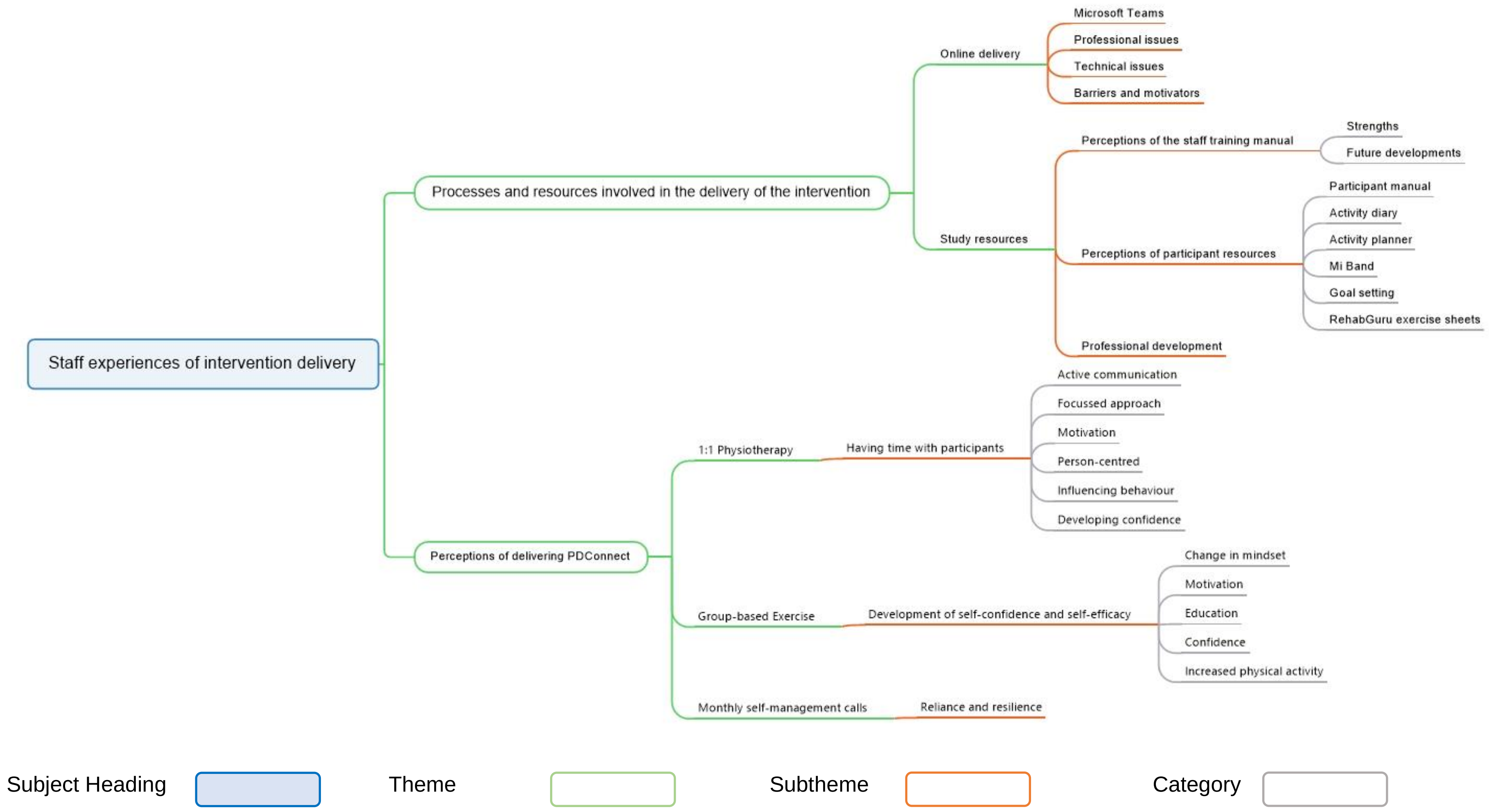


Figure 5.4 **Summary of the qualitative analysis from staff interviews**

5.3.1.2a Online Delivery

Within the subtheme of online delivery, four categories were identified: Microsoft Teams, professional issues, technical issues and barriers and motivators to online delivery.

Microsoft Teams

All staff reported benefits and challenges of using Microsoft Teams. Staff reported that the video conferencing facility of Microsoft Teams was comparable to other platforms such as Zoom:

> *“No major issues that I can remember. Nothing specific to Microsoft Teams that would not also be a problem with other platforms.”* (Staff 001, Usual Care Physiotherapist)

However, staff reported some challenges at the beginning of the study. Challenges included participants ability to access study documents which had been uploaded to Microsoft Teams channels which caused stress and anxiety for some participants:

> “*Once we got it all up and running, it was nice and simple, but it was just those early days and I think there was issues with them being able to access folders and electronic copies.*” (Staff 002, PDConnect Physiotherapist).

The PDConnect Physiotherapist reported that diversity existed in IT skills and the use of Microsoft Teams. Some participants had prior Teams experience, whereas for others, prior IT experience was restricted to email use:

> *“We were asking them to click on a link in an email and for some that is their capacity that they could work at. We could orientate people to Teams a little bit, but you're always going to get such a different level of IT literacy*.” (Staff 002, PDConnect Physiotherapist).

Despite a Microsoft Teams induction and mock appointments being provided by the researcher, staff reported that it took participants time to become familiar and confident using Teams: However, the challenges of using Teams were not perceived by staff to be unique to PLwP:

> *“The biggest issues was with the kind of logistics around Wi-Fi connection, and you know kind of getting signed into Teams and these sorts of things. So, there was a few participants that the first appointment was very much trying to get them set up and my*

> *understanding was that that this was all done before but there was continual issues with that at the first appointment."* (Staff 001, Usual Care Physiotherapist)

> *"You know and once we got over the teething problems….about Microsoft Teams it was not an issue getting people on….But once we kind of got going you know it all worked really well and we set up appointment times and we would just linked in and it all works well."* (Staff 002, PDConnect Physiotherapist)

> *"It worked very well and I didn't have any significant challenges compared to other members of the public that was I working with online at the time."* (Staff 001, Usual Care Physiotherapist).

Microsoft Teams presented different challenges for the Fitness Instructor who delivered the group-based exercise component of PDConnect, as they had multiple participants (n=8) on-screen at each session. The Fitness Instructor reported that the size of the participant images were small, which made viewing and provision of feedback more challenging:

> *"…In a group setting online and seeing small pictures of people on a screen, it was very difficult for me to ascertain whether or not they were doing the exercises correctly."* (Staff 003, Fitness instructor).

Group classes were recorded and shared with participants so they could watch again. During the class the Fitness Instructor would "pin themselves" so that they occupied the main screen, to optimise visualisation of the exercises and ease communication. However, both the Fitness Instructor and participants reported that the pinned function did not carry over into the recording, which reduced the value of the recording when replayed.

> *"….well she was recording it and trying to send us out the recording, so that if anybody missed the session they could do it afterwards or if you got energy, they had to do it twice a week. But it failed in the sense that you she would have everybody up on the screen and focus on herself, highlighting herself, and so you only saw her doing it. But when the recording came out, it had everybody on it, and it doesn't highlight her anymore."* (PDC ID 71)

Professional issues associated with online delivery

The findings illustrated that online delivery resulted in some professional challenges for staff.

Staff reported that aligning the camera to adequately assess participants' movements required patience and effective communication to enable participants to angle their device accordingly.

> *"There was certainly the issues...trying to be able to see something, and moving cameras or getting somebody down on the floor and still seeing them on camera….So I would just sort of you know, just take my time and sometimes I couldn't always see things perfectly. But if it was good enough for what I needed for them that was fine…I tried not to have everything absolutely perfect because, it could make them quite frustrated."* (Staff 002, PDConnect Physiotherapist)

Identification of issues and provision of feedback was perceived to take longer online compared with face-to-face, due to the limited view of a participant:

> *"If I was in the clinic, I would have been able to put my hands on and worked that out really quickly. It probably took us a couple of sessions because I was doing it from observation and trying to instruct but we still worked it out."* (Staff 002, PDConnect Physiotherapist)

> "*You can just see head and shoulders and you might not know their hand was tremoring, that would maybe be something that you would not pick up on, as you wouldn't be able to see it online.*" (Staff 001, Usual care Physiotherapist)

Provision of individual feedback was more challenging for the Fitness Instructor, who had eight participants on a screen at a time. Online delivery required greater reliance on, and adaptation of communication. The Fitness Instructor found that differences in participants' exercise experience, ability and confidence were professionally challenging. The Fitness Instructor reported that the variation in exercise experience resulted in some participants needing more support to ensure correct technique, and/or to select the level appropriate to their ability, which was challenging to manage in the online environment.

> *"What was difficult to start with, a lot of them had never been to a group class before and this was the first time* ***and*** *it was online. I mean bless them. I just wanted to like virtually pick them out of the screen. Some of them didn't know how to squat….From a tutor point of view, the screen was really small and so if I stopped moving, they stopped… I think online really works well because they're in the comfort of their own home…. but the negative is that you can't physically go no or let me tweak your position a little bit, you know?"* (Staff 003, Fitness instructor).

Different perceptions existed between the two Physiotherapists and the Fitness Instructor. Both Physiotherapists reported that online delivery did not negatively impact on their ability to engage with participants. However, the Fitness Instructor reported that it took longer to get to know and develop rapport. Future initial face-to-face sessions or meeting participants on a 1:1 basis prior to the group-based component was proposed by participants to promote rapport building:

> *"I didn't have an issue with online delivery, and you just got to know everyone really well. I feel like I need to meet them all now as you spend so much of your life with them. And then you haven't even met them."* (Staff 002, PDConnect Physiotherapist)

> *"I mean teaching is very hands on, you know, especially within a group that haven't really exercised before in the main and so that was difficult from my point of view…So for the first few weeks, they had to learn me, of course, and so for the first few weeks as well, I had to learn them, very quickly, and they had to learn me and I had to modify a few things. So, you know, speaking slower. And make sure that I just took my time. You know demo'ing and letting everybody get into position, but that was OK once I once we sort of sussed it all out, that went fine.*" (Staff 003, Fitness Instructor)

Technical issues associated with online delivery

Staff found it challenging to support individual issues due to COVID-19 restrictions, the range of devices and operating systems used by participants, as well as the range in IT literacy. Technical issues were, however, isolated to a few individuals, which were addressed within the first two weeks by staff, and a research assistant independent to the study. These technical issues highlight the need for IT support early in intervention delivery, and the potential value of face-to-face induction to ensure confidence in using Teams.

Staff reported issues with Wi-Fi connectivity, which occurred periodically during the study, requiring participants to log out and back in. Staff articulated that Wi-Fi connectivity had potential to cause participant frustration:

> "*There was some kind of ongoing connection issues, like sometimes Wi-Fi would drop out but not anything that we weren't able to remedy. You know sometimes you gave them a quick phone call and manage to get them back online. So, there was always work arounds*." *(*Staff 001, Usual Care Physiotherapist*)*

Barriers and motivators to online delivery

All staff reported that conducting a comprehensive assessment of movement dysfunction was compromised due to screen size, lighting, camera angle, and the inability to adopt a hands-on approach. However, according to the Physiotherapist this promoted a more focused approach to their questioning and improved active listening skills. Physiotherapists also reported that the enforced reliance on observation due to online delivery resulted in them developing a greater appreciation of the amount of guidance participants required to effectively engage with their HEP:

> *"I think that's probably where I learned the most actually, because physio is very hands on, particularly neuro rehab and I couldn't put my hands on anyone and it was very peculiar….it actually taught me to be better at being hands off… because basically for six weeks I just spoke to people and I didn't treat them…so it helped me to kind of stay really focused on what we're trying to achieve within a session."* *(Staff 002, PDConnect Physiotherapist)*

The online environment was reported by staff to offer flexibility, and opportunity to do real-time, real-life rehabilitation undertaken in the participant's home, using equipment that they had to hand, which was perceived as a significant advantage over clinic-based exercise prescription:

> *"Online was brilliant and allowed a lot of flexibility in what we were doing. So, we were able to move around the house. You know, there was even one patient who had had issues with a specific chair -getting in and out of that, so we so we could take the laptop over and have a look at that."* (Staff 001, Usual Care Physiotherapist)

Staff reported many positives associated with online delivery, including participant comfort of being able to exercise within their own home and reduced potential for stigma and embarrassment. They also felt that online participation reduced anxiety at a time when concerns surrounding COVID-19 were high and provided opportunity for exercise when many other exercise opportunities had ceased. Pragmatically, staff acknowledged that online provision of exercise promoted equity of access. With most participants living rurally with populations less than 10,000, and more than 10 miles away from an urban area, staff reported that many participants would not have the capacity or means to attend weekly 1:1 or group-based exercise:

> *"Some of them don't have the ability to drive anymore, they were living on their own or their wives have got issues now and they can't drive them. So, I think online really*

> *works well because they're in the comfort of their own home.”* (Staff 003, Fitness Instructor)

> *“I think they felt safe because of COVID, that there was a lot of people doing a lot to protect themselves and there was one couple desperately wanted to see their grandchild….and the last thing they wanted to do was to catch COVID because as soon as restrictions were lifted, they wanted to go. And so, this [PDConnect] meant that they could be part of it, but not put themselves at risk. So, it really serves a purpose.”* (Staff 002, PDConnect Physiotherapist)

While online was perceived to be flexible and convenient, the capacity to develop a support or social network was perceived as limited. Ice breakers, time for discussion and informal chat were made available, however, staff reported that it was hard to facilitate or optimise social engagement online.

> *“You know it's always lovely to meet people face to face. You know that it would have just been amazing if we'd managed to do that, but we did the best we could due to the restrictions…I think what would have come out of face to face would have been more of the community feel. Because it would have been easier to have banter and would have been easier to say, you know, have these little chats and you know, I go here to so and so… we should meet…. it would become a bit of easier.”* (Staff 003, Fitness Instructor)

Considering future delivery of PDConnect, all staff perceived that a hybrid approach to PA delivery combining face-to-face and online delivery would be beneficial for participants and staff, acknowledging the advantages of both approaches.

> *“I love face-to-face….but I loved that people got to be in the study that wouldn't have been able to get specialist treatments. And so, I'm very happy for hybrid to be part of it. It would be lovely to get people in initially to see them and to not have to spend a couple of weeks working out what's happening where and to kind of be able to assess them.”* (Staff 002, PDConnect Physiotherapist)

5.3.1.2b Study resources

Within the subtheme of study resources, two categories were identified: perceptions of the staff training manual and perceptions of participant resources. Staff provided feedback on the staff manual, providing future recommendations. Staff also provided feedback on the participant resources including: the participant manual, activity diary, activity planner, the activity tracker, goal setting and the home exercise sheets. The findings of these categories are reported below:

Perceptions of the staff training manual

No training was provided to the Physiotherapist who delivered the usual care arm, but they were provided with information to effectively deliver the usual care arm.

> *"I went in feeling prepared, and I knew what it was that I needed to do... I had all the relevant information that I needed for the participants."* (Staff 001, Usual care Physiotherapist)

PDConnect staff (Physiotherapist and Fitness Instructor) received training prior to delivery of the PDConnect intervention. PDConnect staff reported that the training manual provided a comprehensive guide, covering a wide range of topics pertinent to the study:

> *"The training manual is far as I was concerned was very concise. It had a really good flow too. It's lots of information and from my point of view for me coming in as a sort of fitness strength and conditioning person, it gave me a really good insight into Parkinson's as an illness, and the limitations and abilities that I should be looking to expect."* (Staff 003, Fitness Instructor)

The PDConnect Physiotherapist reported that the training consolidated existing knowledge and broadened understanding of areas such as medication and current evidence supporting PA prescription. The Physiotherapist reported that she took one evening to work through the manual. Whereas the Fitness Instructor chose to read the manual several times and used it as a reference guide during intervention delivery.

> *"…To go through the manual, yeah, I think one evening. I just sat and went through it…. I'm a neuro specialist physio, so for me it was a lot of what I knew,..but there was certainly elements of it which it increased my knowledge base and there was like subtle areas so something with Parkinson's medications. I certainly learned a lot during this study, but it's sort of added to my specialist knowledge already because I comprehensively worked with the group every day for six weeks."* (Staff 002, PDConnect Physiotherapist)

> *“Lots of great information. I read it several times. So probably three or four [hours] to be honest and I used it if I was, you know, questioning something. I would go back and reflect on it and because it's the sort of thing that you're never going to retain all the information in one reading. So, I did spend a lot of time and I used it as my sort of reference guide. There was a lot of suitable links in there as well and that you could tap into….so yes, I think that was very thorough.”* (Staff 003, Fitness instructor)

Staff perceived that the training prepared them to deliver the intervention. Strategies to optimise exercise engagement among those with cognitive issues, face to face practical training and certification of training were highlighted as areas for future enhancement:

> “*I think one of the areas where it [the manual] didn’t really cover and that only came out quite later on after you started getting to know the individuals on the trial a little bit better was looking at sort of the cognitive ability to remember movement*.” (Staff 003, Fitness Instructor)

> *“…it would be nice to have received like some type of CPD certificate from a personal point of view, and you know, because I do feel empowered and knowledgeable now to degree with Parkinson's and I'd really like to then be able to use that.”* (Staff 003, Fitness Instructor)

PDConnect staff reported that the session plans were useful providing a framework to ensure the intervention was being delivered as planned, while allowing sufficient autonomy in decision making.

> *“Yeah, I found the session plans really helpful…because I wanted to know what the expectations were of what would be delivered. And as therapists, we can do our individual things, particularly one-on-one with the patient. So, for me, it helped me to think, OK, the study would like it to be at this point at this stage. So, they kind of gave me enough freedom to be individual with the patients but gave me guidance of what we hoped to be adding in each week and what to do.”* (Staff 002, PDConnect Physiotherapist)

Staff perceptions of PDConnect participants resources

Staff had views on the participant resources, which included the participant manual, activity planner, activity diary, activity tracker, goal setting, and the home exercise library.

Staff perceptions of the PDConnect participant manual:

PDConnect staff thought that the manual was comprehensive and covered the information in sufficient detail and in a manner that was accessible. However, it was perceived as lengthy with the potential to be overwhelming for some participants.

> "*It is long, but it was really comprehensive…. because you want to give all the information, but I think it's overwhelming and I think people engaged with it differently, because when I would ask them about it, they'd be like, Oh yeah. And you could tell that they hadn't always read it, you know. Well, maybe they had and they just hadn't retained it." (*Staff 002, PDConnect Physiotherapist*)*

However, staff recognised the need for individual choice with some participants valuing detail, and others not. Setting participants sections that could be reviewed during a 1:1 session, thereby making the manual more interactive, was proposed for future delivery to improve engagement and contextualisation of the material.

> *"It's really hard because some people, they devour such a resource and other people, it's overwhelming.*" (Staff 002, PDConnect Physiotherapist)

> *"I didn't feel there was anything missing, certainly not. Not the that I noticed. Maybe just how patients could consume it, you know. Normally we give such little information. So, it was a wonderful resource. But perhaps how we could get them to interact with it on different levels and maybe how we could incorporate more in what I was doing. So maybe we could make it more interactive." (*Staff 002 PDConnect Physiotherapist*).*

Staff were unsure of the impact the manual had on participants' understanding as staff reported that many participants were very well informed about Parkinson's from the outset. Consequently, the Fitness Instructor felt that the sections on exercise prescription and the benefits of exercise were more beneficial than the pathophysiology.

> *"I think that's really hard because the study people were motivated to come into it anyway and they were a really dynamic bunch. It's sort of self-selecting, you know if you're accepting of your diagnosis and you're going to participate in a study in Parkinson's, you probably are quite well versed in the condition. So, I feel like a lot of people were very knowledgeable to begin with but certainly there were some questions from some patients who were clearly interacting with the resource and going back to it." (*Staff 002, PDConnect Physiotherapist*)*

> "*So, I think that it [the manual] definitely educated them on the benefit and the why. And you know shifted their mindset from… and this isn't verbatim, but one of the gentlemen said, you know, at the start of this trial I just wanted to get to the end and now I see that this is how I need to be*." (Staff 003, Fitness Instructor)

However, the Fitness Instructor reported that the manual was empowering, enabling participants to see the purpose of the exercises they were undertaking.

> *"What was really great from a manual point of view, is that it taught the clients a lot about their condition. I empowered them through the information, and that was so important because they were not just a patient, they were somebody that is taking charge of what was happening to them and you know they then said, now, I understand why I'm doing it."* (Staff 003, Fitness Instructor)

Both staff made recommendations for future iterations of the participant manual. The fitness instructor recommended the use of more lay language:

> *"You know, there's terminology that if you don't know it, you don't know it. And you know, you don't know what anterior and posterior means, then you know that's front and back. So is it speaking in relevant tongue."* (Staff 003, Fitness Instructor*)*

The Physiotherapist suggested changing the format of the training manual, signposting participants to essential and further reading, so the document appears less overwhelming, yet information is still there for those who appreciate detail:

> "*It's always a challenge what you do. Do you give lots? Would you give little? And you're going to get such a varied group of patients with Parkinson's that some will want it all. I mean, I don't know what we do with the students is we give core information. There're additional resources. I mean, I don't know."* (Staff 002, PDConnect Physiotherapist)

Staff perceptions of the activity tracker

Staff reported that a few participants had trouble synchronising the tracker with their devices (i.e., Smartphones or tablets). Issues with synchronisation caused frustration, and/or anxiety as participants were conscious that they were part of a research study, and they wanted to ensure they submitted complete and reliable data. However, these frustrations were not unanimously reported. Frustration also lay with discrepancies in step count when compared with other devices such as Fitbits, Garmin, or Apple watches; this was also reported by participants. Under-reporting of step count was perceived by staff as demotivating for participants.

> *"…some of them had their own Fitbits and Apple watches anyway, so they wore two, and so they could see the discrepancy. There was levels of frustration, you know. 'Well, I've actually gone out and walked five kilometres today and it's not registered there". So anxiety and it was like… you know, because it's like that's the proof that I've done it, and I have done it'…and you could feel that level…. you know when it could be quite a frustration."* (Staff 003, Fitness Instructor)

Staff perceptions of the activity diary

Daily step count and daily activity was recorded in the diary. The activity planner was used to plan weekly PA. The physiotherapist reported that some participants were unclear of the difference between the activity planner and the activity diary initially. Following clarification, the physiotherapist reported that the diary was a useful behavioural change tool, as it promoted participants to reflect on the prior week's activities. The diary also prompted conversations about strategies to address inactivity, or to promote increased PA in subsequent weeks.

> *"People got confused, so some people were filling in the planner, but then mixing it a little bit with their activity and the actual activity that they've done."* (Staff 002, PDConnect Physiotherapist*)*

> *"looking back at the actual activity diary to see what they did, or maybe had done the day before that maybe wiped them out, so it was quite helpful for those who really engaged with it to be able to then talk about pacing and energy conservation and changing the activities." (*Staff 002, PDConnect Physiotherapist*)*

Reviewing activity diaries was more challenging within the group component, with some participants requiring more support than others. Future development of PDConnect needs to further consider how tailoring of support can be optimised within the group component.

> *"With the activity diaries, every week you didn't have same contact and opportunity to have the same contact with all the individuals. And what happened was that there were say a group, maybe two or three that were needing a little bit more attention.*" (Staff 003, Fitness Instructor)

Staff perceptions of the activity planner

The Physiotherapist perceived that the value of the activity planner was limited to the early stages of the intervention, as once participants established a routine they kept to the same routine each week, therefore its value and engagement lessened over time.

> "*I would say the planner kind of faded off with a lot of the patients when they were kind of good at keeping a routine."* (Staff 002, PDConnect Physiotherapist)

In the summer months, PA routines were commonly dictated by the weather, with many people opting for outdoor activities when the weather allowed. The Physiotherapist reported that the planner was a useful behaviour change tool to promote motivation and participant accountability for their own PA. Combined use of the planner and diary focussed conversations about planned and actual activity providing the basis to discuss strategies, for example, energy conservation, pacing, and range of PA undertaken within a week.

> *"The activity planner was really good….I tried to make it part of our sessions to promote accountability….There was quite a bit of talking with patients, kind of like behavioural motivational planning with them, about you know what could you do? When could you do it? And the really good thing about the planner was having morning, afternoon and evening sections, it really got us talking about different sections of the day and getting them to reflect back and think, actually I didn't manage that there because I was fatigued. And then maybe looking back at the actual activity recordings to see what did.*" (Staff 002, PDConnect Physiotherapist)

Staff perceptions of goal setting

Both staff valued the use of goals, particularly to motivate and focus participant engagement. Staff reported that they tended to keep goals small and functional. Incremental progression was adopted as larger goals were perceived to be potentially demotivating, due to the time taken for participants to achieve them. Ensuring that goals were progressive to maintain motivation, while acknowledging that Parkinson's is a progressive condition was noted as a challenge.

> "*We set certainly set goals and I kept it within my notes……we looked at achieving it and then progressing the goals and how we change that. Sometimes it was quite small because they felt like it was…it took a lot to get to that level, and they didn't want to always be chasing the next level. And I think for some people with a progressive disorder, it isn't always about improvements because you know change will come, more*

> *relapses may come… I guess something maybe I didn't do so much of which maybe I should have, but not always looking for improvement which we want, but talking about strategies. But if there's a relapse or a bad day and incorporating that because the reality, is they happen and if we set it up for just, improvement, improvement, it makes them feel like they've failed."* (Staff 002, PDConnect Physiotherapist)

Staff perceptions of the home exercise library

Both staff perceived that the exercise library was a useful and easy to use tool, with a wide range of exercises available to meet participants' needs. Exercise videos and pictures provided clarity, and the option of creating bespoke exercise was also positively received:

> *"I quite liked RehabGURU actually. I haven't used it before, but I've used exercise software before and I really liked that you could load up your own pictures. I never can find the exact exercise that I want. I liked, in comparison to Physio-tools, which is the main commercial one that we use in Physio and that it had some more dynamic exercise-based exercises because with Parkinson's you really want to work on large movements and rotation."* (Staff 002, PDConnect Physiotherapist)

5.3.1.3 Staff perceptions of intervention delivery

The Physiotherapist delivering usual care found it a positive experience and felt that the participants benefited from the intervention.

> *"I did have a very positive experience and I hope that the participants did as well. You know, there's a number of them that really came on well with their exercises and their function and I felt like I was able to do a fairly good job".* (Staff 001, Usual care Physiotherapist)

5.3.1.3a PDConnect Physiotherapist's perceptions of delivery of 1:1 physiotherapy component

PDConnect participants received one hour of 1:1 physiotherapy each week for six weeks. The Physiotherapist perceived that the sessions were of sufficient duration to meet individual participant needs:

> *"Certainly early on an hour was really needed…..But then as we moved through the program 45 minutes or 30 to 45 minutes could have been enough. But what I tried to do, which was part of the programme, was that we actually did the intervention together, so having that amount of time meant that we could catch up, we could review things, we could add in exercise, and review the HEP, and have a rehab session. And so, the*

> *60 minutes, if we're wanting to make sure the intervention happens, I feel it is needed.” (*Staff 002, PDConnect Physiotherapist*)*

Having time with participants was identified as a subtheme, with six associated categories which included: active communication, focussed approach, influencing behaviour, person centredness, motivation, and developing confidence. Illustrative quotes are provided in table 5.6. Illustrative quotes highlight that the Physiotherapist reported that they valued the time to communicate with participants, which facilitated a more focussed approach. The Physiotherapist also reflected that the online delivery altered the therapist/patient dynamic prompting a partnership approach. The frequency of appointments promoted continuity which the Physiotherapist felt enhanced their ability to shape understanding, and behaviour.

The physiotherapist reported that transitioning from 1:1 to the group-based exercise was a source of anxiety for some participants, due to anticipation of change, and concerns about fitting in within a group, and highlighted this as an area for future development:

> *“Just on reflection, I think they really some of them were, were apprehensive about going to the group. They like the one on one. They wanted to kind of keep with that, not because it was particularly me but because it was that one on one and it was, you know, a group environment is always a little bit intimidating and I think they were worried sometimes about how they would fit into it. So maybe we could have looked at assimilating that all a bit better.”* (Staff 002, PDConnect Physiotherapist)

Table 5.6 Illustrative quotes generated in relation to 1:1 Physiotherapy component

Category	Illustrative quotes from the Physiotherapist (Staff 002)
Active communication	*"Yeah, I think that's probably where I learned the most actually, because physio is very hands on. .It actually taught me to be better at being hands off…. because basically for six weeks I just spoke to people and I didn't treat them"*
Focussed approach	*"I think sometimes when you're with someone in the room and you're treating, you go down little rabbit holes. And so, it helped me to kind of stay really focused on what we're trying to achieve within a session"*
Person centred	*"Motivating them to be able to overcome some of those barriers because we were talking, as opposed to when we have a face-to-face sessions, we sort of say they come into our environment and we say OK we're going to do this now and then we say at home you got to do this, whereas it made me much more focused on what happens in their setting"*
Motivation	*"Because it [goal setting and activity planning] was part of the program, it meant that they were being reviewed and it certainly took time to talk through everything and check where they're at and how they found the week and then come up with strategies if there were difficulties or what could they try differently so that behaviour motivational side of it was really relevant"*
Influencing behaviour	*"I had a patient who had, you know had done a great job, but was only walking and I was like we need to get you kind of running….but he was just saying that I don't think that's what I can do now….but by the end of it he was doing running bursts on the beach near where he lived and he was doing high intensity training and had an intensity app on his phone that we loaded up that worked over digital and he would do timed mountain climbers and then move on to the next thing"*
Developing confidence	*"I think there was one of the things about us being able to talk was we could talk through some of their kind of apprehension or barriers to being able to do certain activities. And I think that really helped me to push some of the patients to do more".*

5.3.1.3.b Fitness instructor perceptions of delivery of the group-based exercise component

Challenges associated with transitioning from Physiotherapy to group-based exercise were reported by the Fitness Instructor. The Instructor voiced that their experience would have been enhanced had they met the participants prior to commencing the group, highlighting a potential area for development:

> *"I would have liked to have met them beforehand. I would have liked to have had a bit of discussion about their fears, their apprehensions about the group, is there anything that they would like me to take into consideration before we start. Or is there anything I can do to help put them at ease."* (Staff 002, Fitness Instructor)

Development of exercise self-confidence and self-efficacy were also identified as a subtheme.

> *"I think they felt inspired and motivated"* (Staff 002, Fitness Instructor).

Identified categories included challenging assumptions, changes in mindset, motivation, education, confidence, and increased PA. Table 5.7 provides illustrative quotes from the Fitness Instructor. The Fitness Instructor reported that participation in the group exercise component challenged participants at a physical, emotional, and behavioural level, and provided people with confidence and support to challenge themselves in relation to their PA.

Table 5.7 Perceptions of delivery of the group-based component of PDConnect

Categories	Illustrative quotes from the Fitness Instructor (Staff 003)
Change in mindset	*“Parkinson's had really made them…they didn't know what they could or couldn't or, shouldn't do. It's like they were diagnosed, and some were just left until their annual check-ups and in between times they were just left. So, then they were scared to do anything because they didn't want to make Parkinson worse. So, then they become quite depressed by it. There was one gentleman who said, I need you to speak to you every week, because when I leave you, I feel so much better. And that is just because I have such a positive outlook”*
Motivation	*“One gentleman who seemed really anxious about pushing himself up to the 60-75%mHR, didn’t like the out of breath, he really surprised me, because he signed up to this program where they did HiiT, spin and weights and I was like yeah [thumbs up]. He'd gone from, you know, I'm feeling out of breath now, I'm going to stop, to going I love it.”*
Education	*“So, I think that we definitely educated them on the benefit and the why… One of the gentleman said, you know, at the start of this trial I just wanted to get to the end and now I see that this is how I need to be”*
Confidence	*“From what I could see, it gave them more confidence to move. It showed them that they could re-teach their bodies to move in a way that they thought they had forgotten, or weren’t it able to move. And I think the other thing is that it highlighted to them perhaps that if something is sore and stiff, it's not always just down to Parkinson's”.*

5.3.1.3.c Fitness instructor perceptions of delivery of the self-management component of PDConnect

The Fitness Instructor was asked their views of the monthly telephone calls aimed at reviewing participants’ PA. She reported that many had reduced their PA levels between finishing the intervention and the first telephone call. The fitness instructor suggested that the absence of scheduled weekly group sessions resulted in a decline in PA.

> “*So the first one I was like, right? Let's see how they get on. They hadn't really done much. At that point, you know they needed a schedule. Yeah, and so I said, would you like me to help you write down a calendar, like get this on the calendar and set out what you're doing on a daily basis and get you into the movement.*” (Staff 003, Fitness Instructor)

At subsequent check-ins, the Fitness Instructor indicated that PA had started to improve. The Fitness Instructor proposed that the group-based exercise component could be longer to better support independence with PA, yet acknowledged that longer duration could also promote reliance on the class, and suggested a graded decline of the group-based component may be preferable:

> *"After I had spoken with them, the next two follow up ones were a lot more positive. But I just wondered if by the end of the 12 weeks, they were just getting into it. I saw a huge improvement in what I saw, in confidence, and ability and it would have been nice to have continued that. It was really hard to drop them, to say, that is me now finished. As a population they become quite reliant. So, a longer period, yes but I don't really know how…. they would have to break from it [exercise class] at some point, but I wondered if even titrating them off the exercise class from once a week to once every fortnight. So, titrated, going down rather than just stop."* (Staff 003, Fitness Instructor)

5.3.2 Participants' satisfaction and perceptions of the PDConnect Intervention

Intervention satisfaction was explored quantitatively and qualitatively. The quantitative results will be reported first, followed by the qualitative findings. Twelve PDConnect participants completed the satisfaction survey (Appendix 29) and 14 participants took part in a semi-structured interview. Therefore, all participants who completed the PDConnect intervention returned a satisfaction survey, and most of those who were randomised to PDConnect took part in an interview. Two participants were not interviewed, one withdrew at week 18 due to technology issues and the other was withdrawn on health grounds and were unwell at the time of the interviews.

The survey (Appendix 29) was divided into sections including intervention delivery, staffing, intervention resources and perceived impact.

Intervention delivery

All participants (n=12) reported that they would recommend PDConnect to other PLwP. Using a 11-point VAS, with zero being not at all, and 10 very, all participants rated their satisfaction with the Physiotherapy component eight and above, with 75% indicating ten on the VAS. Using the same scale, 11 participants rated their satisfaction with the group-based exercise component eight and above, with seven participants (58.3%) rating it as ten. One individual scored it as a six.

When asked about the duration of the PDConnect intervention, all participants reported that the duration of the whole PDConnect intervention was “just right”. However as shown in table 5.8, seven participants (58.3%) felt that the Physiotherapy component was too short, and five (41.7%) participants felt that the self-management component was too long.

Table 5.8 Participant views on duration of the PDConnect intervention

	Just right	Too short	Too long
Duration of whole PDConnect intervention	n=12 (100%)	n=0	n=0
Duration of 1:1 Physiotherapy	n=5 (41.7%)	n=7 (58.3%)	n=0
Duration of Group-based exercise	n=7 (58.3%)	n=4 (33.3%)	n=1 (8.3%)
Duration of self-management component	n=7 (58.3%)	n=0	n=5 (41.7%)

When asked if any changes should be made to individual components of PDConnect, as shown in table 5.9, three participants (25%) indicated that changes should be made to the group and self-management components. Open text responses suggested a preference for longer group-based exercise and shorter self-management phase, and tapered progression into the self-management phase.

Table 5.9 Participants responses on changes to the PDConnect intervention.

	Yes	No	Unsure
1:1 Physiotherapy	n=2 (16.7%)	n=9 (75%)	n=1 (8.3%)
Group-based exercise	n=3 (25%)	n=8 (66.7%)	n=1 (8.3%)
Self-management component	n=3 (25%)	n=7 (58.3%)	n=2 (16.7%)

Eight participants (66.7%) reported that Microsoft Teams was easy to use and that they experienced no problems using Teams. A third (n=4, 33.3%) did have problems, four open text comments indicated that one participant found the set-up instructions confusing, one felt that Zoom was easier, Wi-Fi connectivity was cited by another, and one requested personal IT support. Participants were asked to state their preferred mode of delivery of PDConnect if they were to participate in the future. Figure 5.5 illustrates that face-to-face or a combination of face-to-face and online were the most preferred option, with exclusive online delivery being the least preferred option.

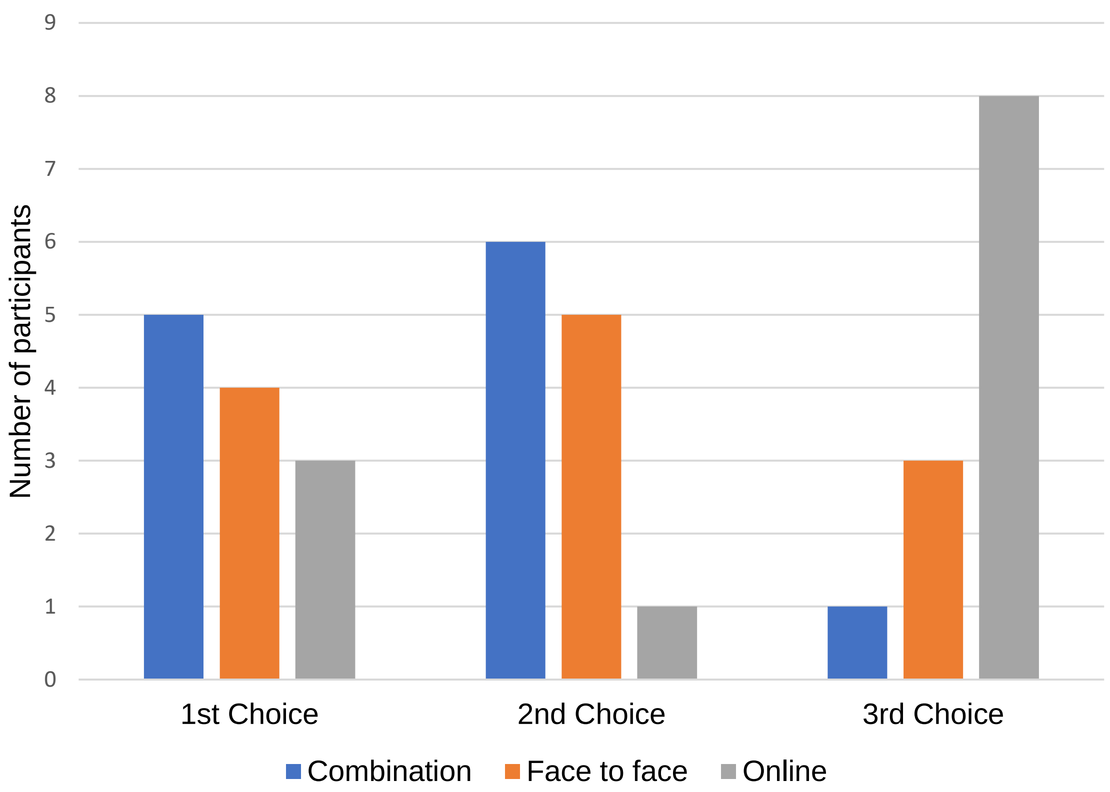


Figure 5.5 Participants preferred mode of delivery of PDConnect.

Staffing

Participants were highly satisfied with staff delivering PDConnect. An 11-point VAS was used to explore participant perceptions of PDConnect staff. With zero being not at all, and 10 being very, ten participants (83.3%) rated the Physiotherapist as very knowledgeable, approachable, and easy to communicate with. One participant rated ease of communication with the Physiotherapist as eight, all other scores were nine or above. Similarly, 11 participants (91.7%) rated the Fitness Instructor nine or above on the VAS scale for ease of communication and approachability. The Instructor's knowledge of Parkinson's was slightly lower, with eight participants (66.7%) rating them as very knowledgeable (i.e., 10), with all participants rating it seven or above.

Intervention resources

The survey explored satisfaction with the intervention resources including the participant manual, the activity tracker, and the home exercise sheets.

Participant manual

Nine participants (75%) reported that the PDConnect manual was helpful or very helpful. One participant was unsure and two (16.7%) reported that it was unhelpful. As shown in Figure

5.6, the manual sections covering the benefits of exercise, getting started with exercise and the activity diary were reported as helpful or very helpful by all participants. Fewer participants (n=6, 50%) valued information on exercise policies and frameworks and five participants (41.7%) were unsure of the value of information on local exercise opportunities. All other sections of the manual were reported as helpful or very helpful by 90% of participants. Ten participants (83.3%) reported that they did not think anything else needed to be added to the manual. Two participants (16.7%) suggested additions could be made. Free text comments indicated that further information on stretching and how Parkinson's can impact on exercise routines were suggested.

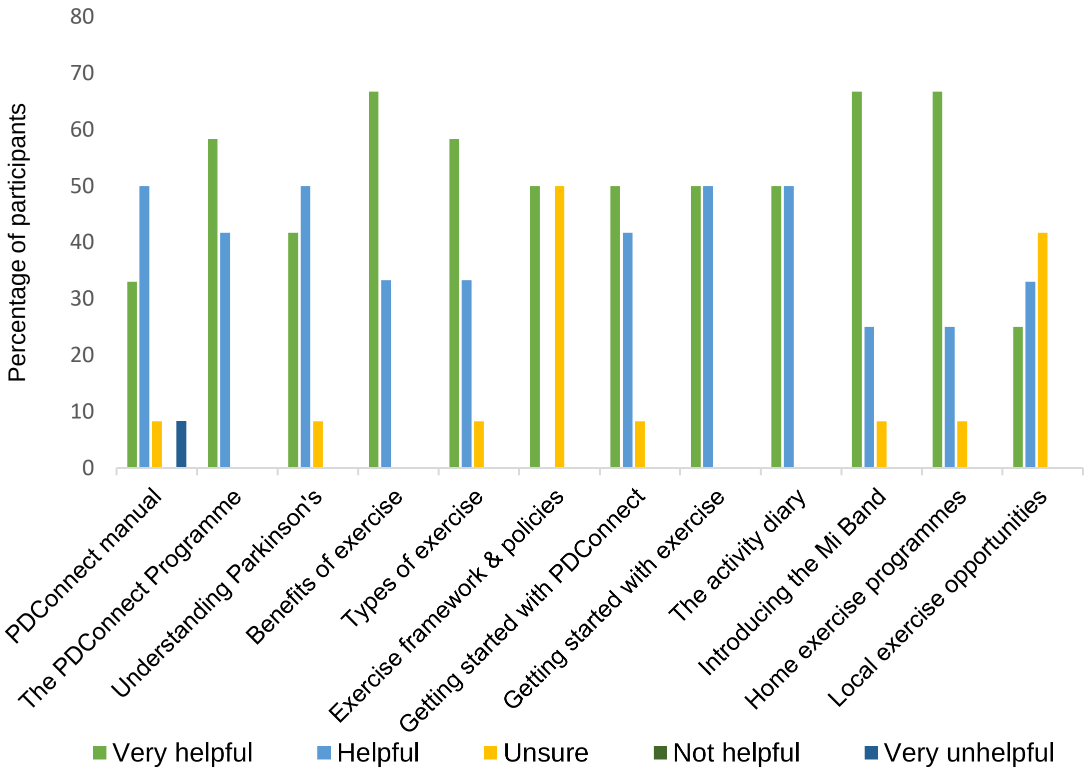


Figure 5.6 Participant's perceptions of the PDConnect manual

Activity tracker

Eleven participants (91.7%) strongly agreed or agreed that the activity tracker guide was easy to follow, with one person being unsure. Nine participants (75%) did not find setting up the tracker complicated, however one participant did and two were unsure (16.7%). Ten participants (83.3%) reported that the tracker was comfortable to wear. Two participants (16.7%) found it difficult to take off and put on the tracker, with the same number being unsure. However, eight participants (66.7%) reported no issues. Ten participants (83.3%) found synchronising the tracker straightforward. Eight participants (66.6%) found it easy to read their daily step count on the tracker. However, a third of participants were unsure or disagreed that they could easily read their step count, suggesting that an alternative device may need to be considered within future studies. Nine participants agreed or strongly agreed that they were confident using the tracker, with one participant being unsure, one disagreeing and one strongly disagreeing.

Variation existed in views of the accuracy of the activity tracker. As shown in Figure 5.7, four participants (33.3%) agreed or strongly agreed that the accuracy of the activity tracker was inconsistent, however the same proportion did not or were unsure. Despite a third perceiving the tracker was inaccurate, the majority reported it motivated them to be active. Using an 11-point VAS score with zero being not motivational and ten being very motivational, nine participants (75%) rated the tracker eight or above. The remaining three participants scored it six, four and three. Ten participants (83.3%) reported that the tracker helped them achieve their PA goals, with two participants being unsure.

Overall satisfaction with the tracker was variable. Using an 11-point VAS, with zero being not satisfied, and 10 being extremely satisfied, nine participants (75%) rated their satisfaction seven and above. However, the remining three people scored it as five, three and two. Of the nine free text comments two related to small font size, five to inaccuracy and two related to comfort.

Home exercise sheets

All participants agreed or strongly agreed that the exercise sheets were easy to follow, making it clear how to perform the exercise at home (58.3% strongly agreed).

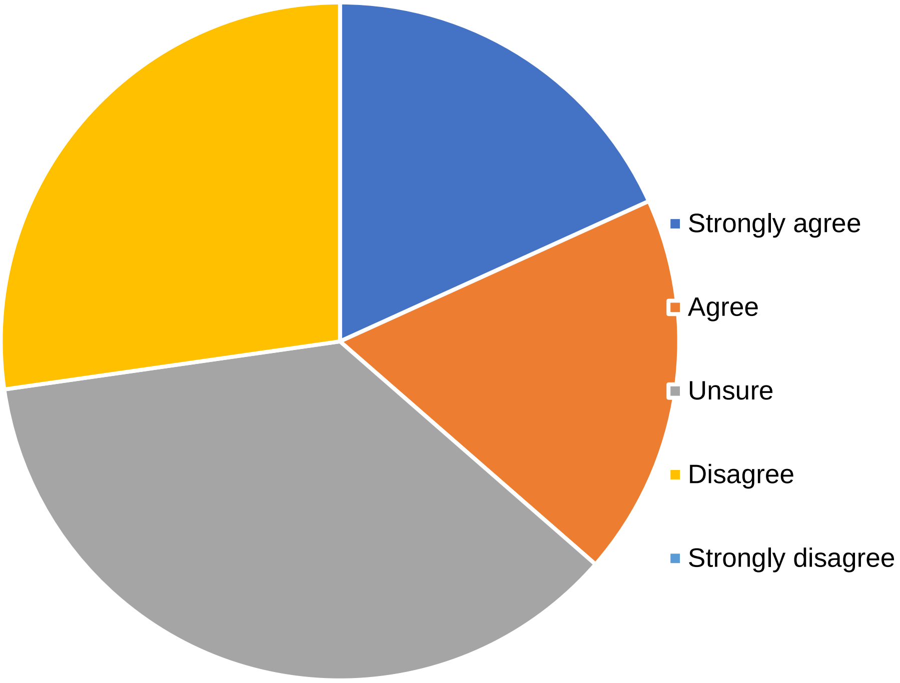


Figure 5.7 Participant views on the accuracy of the activity tracker.

Perceived impact of the intervention

Survey data summarised in table 5.10 indicates that participants perceived that PDConnect improved their exercise confidence and helped them understand the benefit of exercises for their Parkinson's. Similarly, most participants agreed or strongly agreed that participation had improved their understanding of Parkinson's and provided them with strategies to stay active. Most participants (n=9, 75%), felt that goals set during PDConnect motivated them to be active, however, 25% were unsure or disagreed. Overall, participants reported that PDConnect had positively impacted on their Parkinson's, with all participants scoring seven or above on an 11-point VAS where zero indicated no impact, and 10 indicated very much, with seven participants (58.4%) reporting nine or above. All participants reported feeling more motivated to be active because of participating in PDConnect, and nine participants (75%) felt more able to manage their own PA.

Table 5.10 Participant reported impact of participation in PDConnect.

	Strongly agree	Agree	Unsure	Disagree	Strongly disagree
Participation in PDConnect has developed my confidence to participate in exercise	n=8 (66.7%)	n=3 (25%)	n=1 (8.3%)	n=0	n=0
Participation in PDConnect help me see why particular exercises would benefit my Parkinson's	n=8 (66.7%)	n=4 (33.3%)	n=0	n=0	n=0
Participation in PDConnect has improved my knowledge and understanding of Parkinson's	n=3 (25%)	n=7 (58.3%)	n=2 (16.7%)	n=0	n=0
The goals set during PDConnect have kept me motivated	n=4 (33.3%)	n=5 (41.7%)	n=2 (16.7%)	n=1 (8.3%)	n=0
Participation in PDConnect has provide me with strategies to stay active	n=7 (58.3%)	n=4 (33.3%)	n=1 (8.3%)	n=0	n=0

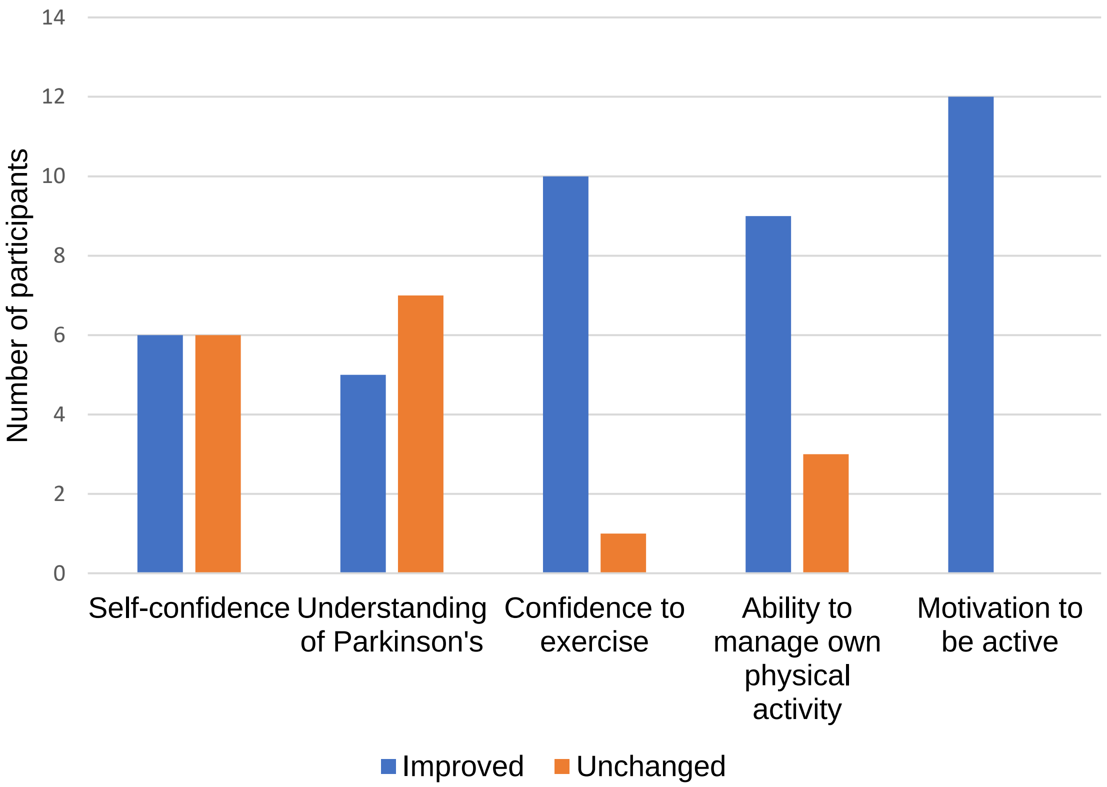


Figure 5.8 Behavioural Impact of participation in PDConnect

As illustrated in Figure 5.9, physical benefits were widely perceived by participants who participated in PDConnect, with over 50% of participants reporting improvement in all physical variables. More than ten participants (83.3%) reported improvements in flexibility, PA participation and fitness levels. No physical variables were reported as worse. However, as shown in Figure 5.10, impact on NMS was less positive. Fatigue and QoL worsened in one participant over the course of the study. Six participants (50%) reported an improvement in fatigue levels, with only two participants (16.7%) reporting improved pain and three (25%) reporting improved quality of sleep.

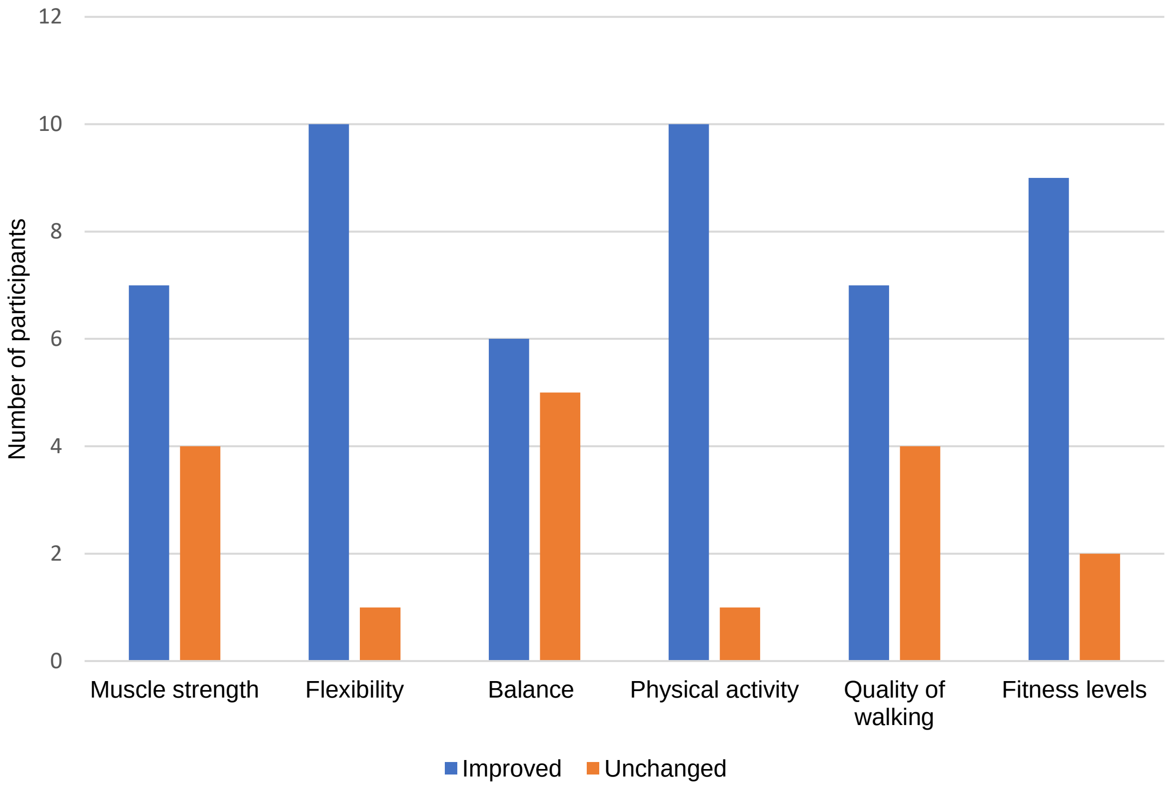


Figure 5.9 Perceived physical impact of participation in PDConnect

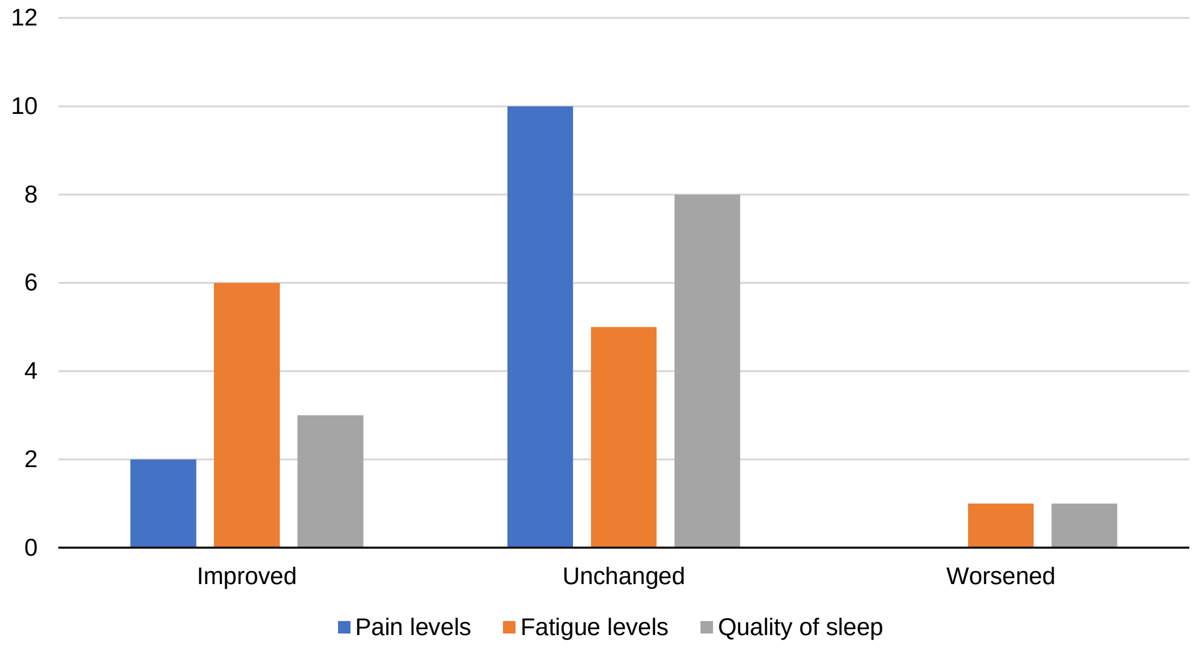


Figure 5.10 Perceived impact of participation in PDConnect on non-motor symptoms

5.3.3 Participants perceptions and experience of PDConnect

The mean duration of the interviews was 37.5 minutes (range 23-52 minutes). Framework analysis resulted in three key themes and seven subthemes being identified as displayed in Figure 5.11. Themes included experience of the research process, intervention delivery, and perceptions of participating in the PDConnect Intervention. The following sub-sections will discuss the qualitative findings using the identified themes as a framework.

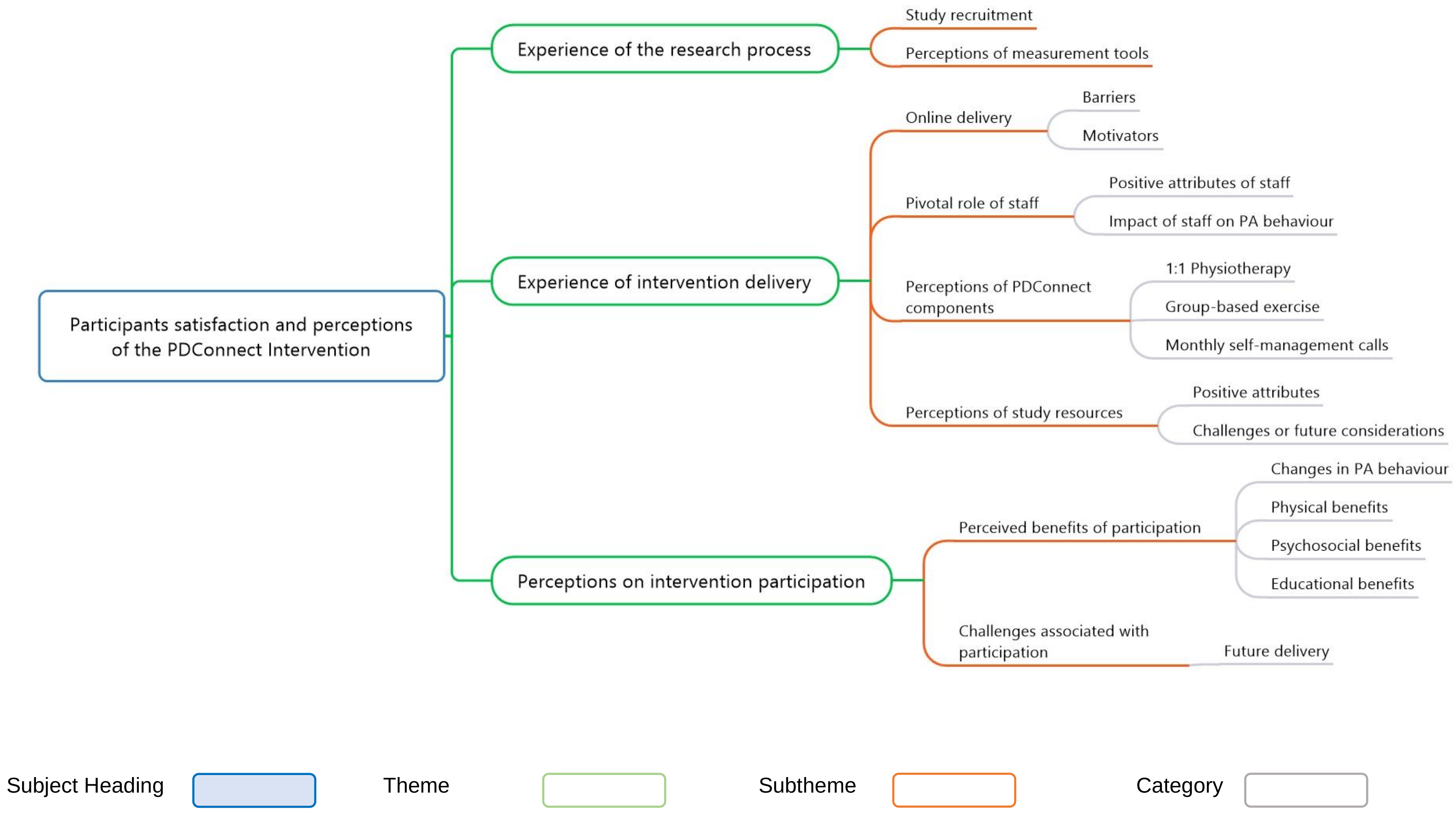


Figure 5.11 Themes, subthemes and categories identified from participant interviews

5.3.3.1 Theme One: Experience of the research process.

Within this theme, two subthemes were identified: the recruitment processes and the perceptions of measurement tools. Key components of the recruitment processes included information received to inform participation, and perceptions of the randomisation process. Participants did not feel that changes to the PIS were required. Participant information sheets were deemed acceptable, and provided adequate information to inform whether to participate or not:

> "*It [participant information sheet] explained what was involved in taking part and what it was all about. Which was enough information, yeah."* (PDC ID 1).

Participants accepted that randomisation was part of the research process. Participants reported that randomisation to usual care or PDConnect did not influence participation. No participants indicated that they would have withdrawn had they been randomised to the usual care group. Indeed, participants expressed a sense of obligation or loyalty once signed up, and a perception that all participation would lead to benefit for the wider Parkinson community.

> *"From knowing a little bit about how research studies work, I thought it was a really important part of it and I could completely understand why it [randomisation] had been done. So yeah, so I was really pleased that it was being done like that. I mean, I was absolutely delighted that I was randomised to the bit that I got. But yes, absolutely, having committed to participate, I would have gone with whichever one I had been chosen for.*" (PDC ID 52).

Two categories were identified from within the subtheme of perceptions of measurement tools: i) perceptions of the measurement tools used; ii) participants' views of which measurements were important to them. Participants reported that completing the measures was a lengthy and repetitive process. While lengthy, it was not perceived as burdensome, with participants acknowledging that completing measures was an integral component of research. Measurement did not have to be completed all at one time, which was valued by participants.

> "*No, no problem at all. It was not a burden. It was good that you could go and start it [complete measures] and then switch it off and then go back to it, so you know, that was good.*" (PDC ID 1)

> "*No, it was part of what we signed up to, so I didn't mind doing it, I didn't have a problem doing it. So, no I did not think it was burdensome*." (PDC ID78)

Completing the measures did result in unintended consequences. Completion of the measures highlighted for one participant and their spouse the potential impact of living with Parkinson's in the future, which was emotionally challenging:

> *"To be honest, I think sometimes it was quite hard to be face-to-face with where you might be going….to be reminded. You know, even when you were ticking something and saying this isn't an issue, there's a good chance it will be, so I think it wasn't something we looked forward to because we like to be living in the now and being very positive… it was hard to sometimes look at it and say, well, we are now scoring zero. But look goodness, look how many stages there are yet to come. That wasn't, something we enjoyed, was it?"* (Wife of PDC ID30)

Well-being, QoL and PA were reported by participants as important to measure in a future study. Self-confidence, anxiety and fatigue, and loneliness were also cited by some participants where these issues were specific to them:

> "*I think the important things are quality of life and well-being*." (PDC ID91)

> "*Probably the physical activity, for me…Quality of life, and improvement in my physical fitness and ability*." (PDC ID78).

5.3.3.2 Theme Two Experience of PDConnect Intervention delivery

Within the intervention delivery theme, the online exercise experience, pivotal role of staff, and study resources were identified as subthemes.

The online exercise experience.

Prior to commencing the study, two participants had prior experience of using Microsoft Teams, with four participants being familiar with Zoom. The remaining six participants had no experience of online videoconferencing. Only one participant had prior experience of exercising online. Issues such as angling the device were reported as challenging by participants, especially when doing floor-based exercises or when participants presented with specific problems, requiring additional assistance from family members:

> *"I didn't really enjoy the lying down ones, but that was purely because it was online and it was difficult to do the exercise, plus keep an eye on the screen."* (PDC ID 52)

> *"The physiotherapy was very good, but the fact that was online made it quite difficult…My husband would need to take the iPad you know and move it around so she [physio] could see."* (PDC ID 49)

Participants also recognised the challenges of online delivery for the staff:

> "*I could see how hard she [physiotherapist] was having to work just to do things like get a full body view of me and things like that, but I don't really feel like I lost out on awful lot because of that."* (PDC ID 52).

> "*Because it was online I thought from her point of view [the fitness instructor], it was difficult for her to monitor everybody."* (PDC ID 52).

Variable internet connectivity was also reported as a challenge associated with online delivery:

> "*all the participants had slightly different internet connection experiences, so it didn't make for an easy discussion in the group.*" (PDC ID91)

> "*the only time I've had a problem is when my Internet goes* down." (PDC ID59)

> *"it all seemed to work quite smoothly. I suppose actually, when we're doing the group stuff there is always delays or interruptions with other people that didn't have connections, connections froze and stuff like that. But it's not really a major thing." (*PDC *ID81)*

The online environment was not widely perceived as conducive to social interaction, and consequently a longer intervention was suggested to accommodate time to develop rapport and for groups to gel.

> *"Communication with peers- I think that yes, it is trickier, when you are all together you are like pals and have a wee conversation about anything almost, but it is more stilted over Teams, but needs must at the time." (*PDC *ID 78)*

> *"I think it's just because we were all coming in at it from a distance point of view and had you met face-to-face, then natural relationships would just have occurred if you know what I mean." (*PDC *ID91)*

> "*The reason I think it [1:1 Physiotherapy] should have been longer is because the first couple weeks I lacked the confidence to deal with Teams one-to-one with someone. So, it took a couple of weeks to get settled in and establish. So, if it had been a little bit longer, you might get more from it." (*PDC ID 1).

Participants reported that Zoom was easier to use, with some participants expressing a preference for Zoom over Teams:

> "*Yeah, it [Microsoft Teams] was a bit difficult, but I mean it works. Just, you know, compared to something like Zoom, it is not as good."* (PDC ID71).

On the other hand, participants conveyed that online exercise was convenient and reduced barriers associated with PA. The reduced need for travel, especially for those living rurally, was seen as a distinct advantages of online delivery by participants:

> *"I actually thought when it all ended up going online, I was really worried about how it would work but for me personally, but it was absolutely superb*." (PDC ID52)

> "*Superb…because you basically just got up and put your jogging bra on and your sweatpants and you're good to go."* (PDC ID91)

> "*So, transport would have been a serious issue for me and I wouldn't be able to do it, so I wouldn't have been a participant in this project if it had not been online*." (PDC ID80)

For those with bradyphrenia, online reduced potential embarrassment and allowed family members to attend which supported participation:

> "*I think the advantage of it being on Teams was that for him and with his processing, was that he had me there and that would have been more embarrassing, and I think he might not have gone, if it had not been on Teams*." (Wife of PDC ID30)

Recognition of the potential barriers and motivators associated with the use of Teams was evident with most participants reporting a preference for a hybrid approach to future delivery.

> "*Probably a combination of face to face and online. I think there are merits in both and there's advantages to both."* (PDC ID51)

> "*Future – I think a bit of both [online and face-to-face] would probably most beneficial…But I think it would be really beneficial maybe at the start, at the beginning to meet as a group together and then do the online stuff. But then meet at the end again, and you know, have a face-to-face at the start and at the end*." (PDC ID58)

The pivotal role of staff

Participants reported that staff were pivotal to their experience of PDConnect. Key illustrative quotes are provided in table 5.11. Staff delivering PDConnect were regarded as motivational, caring, knowledgeable, and professional, which positively influenced PA behaviour. Participants valued the personalisation of care delivered by the Physiotherapist, and the ability of the Fitness Instructor to accommodate a diverse group online. The pragmatic problem-solving approach adopted by the Physiotherapist during the six consecutive 1:1 appointments promoted continuity and adherence with PA, and inspired participants to increase their activity levels. The Fitness Instructor was regarded as supportive and enthusiastic, creating a fun and enjoyable exercise environment, despite the challenges of delivering group-based exercise online to a group with diverse capabilities. The supplementary videos and individual emails were appreciated by participants allowing personalisation of PA. Some participants did not gel as well with the fitness instructor, however these individuals also reported that group exercise was not something that they enjoyed, which may explain this variation.

Table 5.11 Illustrative quotes depicting participants perceptions of staff

PDConnect Physiotherapist	PDConnect Fitness Instructor
I thought her [physiotherapist] delivery and her help was excellent and I much appreciated it and I learned from it." (PDC ID99) “*she tailored the exercises to my abilities, couldn’t be better in relation to my needs… she took it on board what I said, and she focused on what was needed and met my requirements, the fitness instructor was much the same*” (PDC ID1) "*they were incredible and inspirational…the physiotherapist was so lovely, when I achieved my 10 sit ups, she was as excited as I was, she was just lovely… They were both warm and they were both welcoming and knowledgeable and I felt very comfortable with both them*" (PDC ID78) "*I thought she was quite excellent. It was very helpful and very constructive. Being one-to-one was real help, and no, I thought she was quite excellent communication, approachability and knowledge: I think all of those elements she was spot on, I think she was really good. I thought she was personable, felt confident in her and that she was really good*" (PDC ID96)	"*The fitness Instructor was equally as positive in a slightly different way and was all about what you can achieve, not what you can't do…. I thought the fitness instructor had a great personality and was very motivational and also she was quite good at encouraging you to go that little bit further. You know if you could jump, instead of stepping then jump... I really loved doing the high intensity classes at the gym and then I felt I couldn't do them after I got diagnosed and the fitness instructor made me realise that I probably could do them*" (PDC ID91) "*I felt like she had knowledge far, far beyond what even I expected, for a fitness person, I never expected them to be clued up in Parkinson's, but I guess she must've done some preparation…the fitness instructor is remarkable, I mean she's had so much patience, so much enthusiasm, so much encouragement, all from a screen where she's like getting no feedback from us because we're all on mute. I am just in total oar that she was able to do that to be honest*” (ID81) "*The fitness instructor was always smiling and you know nothing was too much bother you know….I think for somebody to be motivational to a group of 8 strangers on a dodgy platform like this Teams meeting stuff, you know, I take my hat off to her and it was very good…* (PDC ID58).

Although participants reported that both staff personalised their programmes, one participant reported that exercising online with others who experienced greater physical challenges caused some discomfort:

> "*I felt slightly self-conscious in a way that… I could see others on the screen who weren't, you know, as fit me, or who were older or more advanced in Parkinson's and it's slightly bothered me bouncing around and jumping about. Feeling that they were perhaps struggling a bit*." (PDC ID52)

Many of the participants voiced sadness when the intervention stopped, with many reporting they would have happily continued with intervention indefinitely, however impracticality of that was also recognised:

> *"I loved it. I was so sad when it finished, I nearly cried."* (PDC ID78)

> "*Well, I think one of the interesting things was when the exercise class came to an end but we're all asking the fitness instructor, could you please keep going? We would be quite happily pay for it, so I think you can take quite a lot from those responses."* (PDC ID91)

> "*Well, yes, of course I would have been very happy to continue with it forever on that one-to-one basis, but that is obviously impractical.*" (PDC ID96)

> "*I mean how do you know how much is enough? I mean you could do that for the rest of your life, and that would be fine, but well, you got to be reasonable about these things."* (PDC ID81).

Participants reported that the weekly sessions helped maintain motivation:

> "*Because we had six consecutive weeks, we're able to try something and then see how that went. It's great and she [Physiotherapist] sent information clear information that you printed off. Didn't you? And every morning for the whole program, really, you did the Physiotherapists programme 5 times the week, it was a positive thing, wasn't it? And we were glad to be involved in it."* (PDC ID 30 and wife)

In relation to intervention delivery, participants voiced that the number of Physiotherapy and group-based sessions should be increased within future iterations of PDConnect. Increased number of sessions were proposed due to increased time required to develop relationships when online, with others simply enjoying the discipline of a weekly planned session:

> "*I think it could have been tailored slightly differently so that….I don't know if it could be any longer, so it's 12 weeks and that seemed to be the right length. But it took a couple weeks for people to gel in as a group. And there could have been a bit more work focused on that. I think sometimes it was difficult for everyone to join in… It's like being the first day at school, getting to know your friends and knowing who to work out. I think there could be a bit more working towards th*at." (PDC ID1)

> *"I mean, it could have went on longer, I think it could have went longer and because it was a very very beneficial*!" (PDC ID71)

> *"I found I was quite disappointed when the sessions had finished. I have found that I my commitment isn't strong and having set meetings would have actually strengthened that, because she constantly reminded me to do some something*." (PDC ID 80)

However, while weekly classes were valued, participants also voiced a need to be personally accountable for their behaviour and acknowledged that there was a potential to become dependent on a weekly intervention.

> *"Well, I liked it because it kind of gave a routine to get up...that was good. The only thing is, I think you could become dependent on it."* (PDC ID91)

Perceptions of the components of PDConnect

1:1 Physiotherapy

The aim of the physiotherapy component was to develop PA self-efficacy and to prepare participants to be comfortable and confident with PA on an individual level prior to moving into the group-based component. When asked whether this aim was achieved, all participants reported that this aim was fulfilled:

> *"I think it improved my confidence and my understanding, yeah, I think it did."* (PDC ID1)

> *"I thought she [Physiotherapist] was quite excellent. It was very helpful and very constructive. was impressed by the whole thing*." (PDC ID 96)

Participants reported that the one-to-one and weekly nature of the Physiotherapy was crucial to the success of this component:

> "*I think it was positive because it was a weekly meeting and that was the motivation… the motivation to keep doing it was the fact that the Physiotherapist was going to be there every week. The first six weeks were very positive, so at the end of that six weeks, I probably felt better than I had done for a wee whi*le." (PDC ID51)

> *"I think it was fact that it was a one-to-one. The Physiotherapist was observing...the Physiotherapist was able to do that on a one-to-one basis, and her comments were personalised to what she was seeing in front of so. I think it helped a lot."* (PDC ID80)

However, further Physiotherapy sessions were raised within the interviews:

> "*I would like more than this six, but the session time was fine, it would have been nice to have maybe 12 sessions*." (PDC ID59)

Group-based exercise component

Participants reported that a greater number of sessions was required to accommodate development of group rapport:

> *"Just that finished too soon for me. More of all sessions, but that is just greed on my part…..I would have benefited from more of the interactive exercise class with the fitness instructor, more often, not just once a week, twice a week. The length of them was fine, well timed."* (PDC ID78)

Qualitative findings highlighted that group-based exercise may not suit everyone. Some participants reported that they relished the group environment, while others reported a preference for 1:1:

> *"it wasn't for me as beneficial as the individual sessions….Partly because by nature of being a group is not going to be as individualized, obviously."* (PDC ID51)

> "*I'm probably happier in a group thing. It just seems more natural to me. I think there's definitely benefits in learning from each other. I thought the Fitness Instructor was hugely effective. I thought she was Supergirl....I mean, I can't fault what she did, and you know it just help solidify whole thing for me*." (PDC ID99)

Participants who were unfamiliar with group-based exercise reported issues with some of the language used:

> *"Initially we struggled with that [group-based exercise]. Nothing against the Fitness Instructor at all, she offered a very strong programme….I think at the end of the first one or two weeks it felt this this isn't working in the same way that Physiotherapy the program worked. You know he had not done a community group exercise before...there was a lot of language and processing is slow anyway...he [husband] was getting stressed before it started. I know there are some people who are real exercise people and who were getting you know personal trainers and things and knew the language but core or you know do the bridge, it was just too much processing, wasn't it?* (Wife of PDC ID30)

The group-based component consisted of 60 minutes of exercise and 30 minutes discussion facilitated by the fitness instructor. There were contradictory views on the effectiveness of the discussions. Participants reported that developing discussion was challenging which some participants attributed to the online environment:

> "*I think some of the educational stuff, people seemed reluctant to open up, and actually give their opinions, so whether this was beneficial for everyone or not I don't know*." (PDC ID52)

> "*I think there was potential there, but I think it's just because we were all coming in at it from a distance point of view and had you met face to face, their natural relationships would just have occurred, if you know what I mean.*" (PDC ID59)

Self-management Component:

Participants reported that more frequent calls would have been desirable, to maintain motivational levels.

> *"You know, it would have been helpful to see to or hear from her more often." (PDC* ID59)

> "*it was very interesting because with the full intervention... you knew that Thursday morning 10:00 o'clock, you were there. Without that it was a case of Oh well, maybe do it Wednesday. Oh no, I have to go somewhere on Wednesday, no worries I will do it on Thursday and then I found it slipping all the time. I just missed the discipline of*

> *knowing at 11:00 o'clock or whatever time on Thursday, get the get the tablet setup.*" (PDC ID58)

While more sessions may have been preferable, participants reported that the “check-ins” maintained motivation, and promoted PA.

> "*Yes, you know, it was suddenly I've got the Fitness Instructor on the phone this week, right come on, let's do some exercise*." (PDC ID 58)

> "*Yeah, I was quite happy with that [monthly check-ins], it was good motivation for me to do exercise. I did my exercises routinely every day, first thing in the morning. Uh, and it was really good, because I suppose I'm happier doing stuff by myself than I am with other people. Because that's the person I am. It's good. It's nice talking to the fitness instructor, she's incredibly supportive.*" (PDC ID81)

Illustrative quotes provided in table 5.12 highlight that overall satisfaction with the PDConnect intervention was high.

Table 5.12 Participants perceptions of PDConnect

ID	Illustrative quotes
PDC 99	"*I'm fitter and probably more committed rather than less committed to staying fit and exercising*."
PDC 01	"*I thought was a worthwhile exercise. I've got a lot from it”*
PDC 52	*“So what it did for me was it taught me to perhaps pace myself better and be more consistent. I mean thoroughly enjoyed it. I thoroughly enjoyed. The very personalized aspect of it, I think for anybody with Parkinson’s that makes a huge difference because it is so unpredictable*."
PDC 91	*“I think the PDConnect programme came in at the stage where I was really quite scared of what the future might hold. So, it gave me level of positivity, so you know the only limitation is me”.*
PDC 81	"*I think it was a necessary Intervention and real benefit to me and to be frank, I miss it now*."
PDC 49	*“It has given me much more confidence."*

Perceptions of study resources

A range of resources was used in the study, some of which were designed specifically for the intervention (participant manual, activity diary, activity planner, goal setting sheets), with others commercially available products for example the Mi band and REHABGuru exercise library.

Participant Manual

Qualitative analysis highlighted mixed views in relation to the participant manual. For some it consolidated existing knowledge and reinforced the value of PA, and for others it focussed the need to be more active:

> "*it was tremendous, I think the researcher should publish it because it brought together in one place all the bits of information you need. Whereas quite often you're looking here and looking there on the Internet for all the little bits. So, it brought together everything in one place, and it was very good and easily explained as well. I like detail and I enjoyed the length of it, but I think it might have been too much for some people*." (PDC ID52)

> "*I think some sections were particularly helpful when it came to having detailed information about proof that exercise can have beneficial effects on Parkinson's symptoms. So, where that information was available or referred to it was actually reinforcing a positive attitude towards exercise. So, it's useful in that regard*" (PDC ID80)

> "*Oh that [the manual] impressed me very much, because I knew I was doing quite well. But when I read the manual, it meant I wasn't doing as well as I thought, I had to double up what I was thinking was good, and that was a bit of a surprise." "I thought I was doing OK, but after reading the manual I felt I wasn't doing quite enough so I worked on that*" (PDC ID59)

> "*it really increased my understanding of exercise. In fact, I don't think I appreciated it until I saw all that information, it's not just lip service it is actually important to do that [exercise] more so than anything else*" (PDC ID91)

However, many participants perceived that the study manual was too lengthy.

> "*I would say definitely overwhelming in amount, but I can scan things, you know, I didn't read every word, but I looked at what seemed relevant to me…. you know, I used as a reference manual rather than rather than reading every page*" (PDC ID99)

Among well-informed participants, pathology-based information was perceived as unnecessary, whereas for others it brought all information together in one document. There was also a sense that while participants accepted their diagnosis, some participants did not wish to be reminded of it. Conversely, some appreciated the level of detail, suggesting that personal preference, or time since diagnosis may influence perceptions:

> Did the manual Influence your understanding of PD*: "I don't think so. I don't think it did for me because I've done a lot of research myself. That said had I received that when it was newly diagnosed- absolutely."* (PDC ID91)

> *"I think going into the causes of Parkinson's and the other some other bits and pieces that I just found a wee bit tough reading it if you like…those of us with Parkinson's are aware of what it is and what causes it and really, I think the Parkinson's study was just a way of me controlling it in some way, and you know, trying to get better so that's what I found, very comprehensive, but maybe a wee bit too much I thought.*" (PDC ID58)

Participants used the manual in different ways: some skimmed the content using it as a reference guide, while others engaged with all content and explored the additional information resources such as the podcasts and videos. Some participants preferred to be self-directed, whereas others expressed a preference to be guided through it. Aligning with staff views, participants suggested that sections of the manual should be released incrementally to support depth of learning:

> *"There's quite a lot to take in at the start, so I realised when I flicked through again later that I although I'd been through it, stuff hadn't really sunk in the first time around. I think because there was such a large quantity there. In smaller lumps would be easier to digest, I suppose. I think it would sink in better if it was drip fed, but it's not really a criticism, you know, I was pretty impressed by what was in that manual."* (PDC ID81)

Activity Tracker (Mi band)

Like the participant manual, mixed views were expressed in relation to the activity tracker. The participants reported that the tracker was simple and easy to use. The ability to self-monitor PA was perceived as a powerful behaviour change tool. Wearing of the tracker was associated with increased PA and a valued goal setting tool:

> “*It was easy to put on. It was easy to use, easy to read, easy to get their data off." (*PDC ID30)
>
> "*I think it served its purpose which was to make me commit to keeping a record and doing something, I thought it was a tool for commitment*." (PDC ID 80)
>
> "*I mean it was perfect. I thought it was a great motivational thing. You could set alarms on it so to remind you to get off your backside, so it was good."* (PDC ID58)
>
> "*Yes, I thought it was good, I still wear it to this day…. I use it more for steps than anything. And if I don't do enough steps and I'll go and do some".* (PDC ID1)

Challenges with the tracker were also identified by participants. The tracker was perceived as inaccurate, particularly during tasks such as golf where upper limbs were fixed, or during activities such as cycling. Under-reporting of steps was commonly reported as some participants wore other activity trackers such as FitBit or Apple concurrently with the tracker. The under-reporting of steps was perceived as demotivating, with participants feeling “cheated” when their activity was either not recorded or inaccurately recorded:

> "*Initially I thought it was a fantastic little thing and until I realised that it was totally under counting my number of steps, I mean sometimes by two or three-fold and again and I actually went on to my treadmill to test it with my Apple Watch and my tracker on the same arm and counting. And it was hugely undercounting.*" (PDC ID 52)
>
> "*One of the things is, I use an exercise bike and it [Mi band] did not count my steps, and I felt cheated."* (PDC ID 49)
>
> "*you pushed it [the buggy] all the way around Queens Park and up and down hills. And then we got back to base and the whole time he had his hands on the buggy. It didn't record…. So there were lots of times when he thought that's not fair, whereas the iPhone thing was recording more steps than the Mi band*.” (PDC ID30)

Qualitative interviews also highlighted that the font on the watch face was commonly perceived as too small, and one participant articulated that the strap was problematic:

> *“I think it was difficult and in fact without my specs I couldn't have seen it*." (PDC ID 80)

> "*I think the strap is the problem and I have had it dropped off my wrist a few times and so I think there's something needing attention there about this strap*." (PDC ID99)

The activity diary

Qualitative data indicated that participants valued the activity diary as a motivational tool, allowing participants to reflect on prior days or weeks activity, and alter their behaviour accordingly:

> *"I mean because it was just you know if you walked 6 miles one day and then 6 miles another day or exercising you could refer back to it and you can say well, last week I've done all that. But this week that's all I have done, so you can up the game a wee bit."* (PDC ID 58)

> *"Yeah, I thought it was a good discipline. It made me much more aware of when I waste time and don't do three blocks a week of 8000 steps in or whatever…. I definitely found that I…without that, I sort of fall out the way of it, so it was definitely good the diary and the recording every day."* (PDC ID99)

> "*Yes, I did keep those [complete diary] and they acted as a prompt. I mean, inevitably I found that my activity levels peaked and troughed to some extent, and if I had a week where I had low step counts or low activity, I feel guilty that I cheated myself…. No, I haven't done enough. So, it was motivating too."* (PDC ID80)

The diary also prompted internal competition, encouraging people to increase their step count, week on week, and raised awareness of activity habits. Some participants found completing the diary burdensome, while others found it a useful prompt to modify activity, if they had had a quiet week, but also a useful tool to look back at and reflect on progress made to date:

> *"There was a lot admin and I mean the filling in of sheets every week."* (PDC ID71)

> *"That [activity diary] helped me. Absolutely, so I must be competitive because I like SMART targets. I like to say right I did I 100 this week and I will do 150 next week or whatever, you know."* (PDC ID 49)

Preferences for an online or paper version of a future activity diary were mixed. Paper was perceived as quicker, whereas online was perceived as preferable among those with micro-graphia:

> *"I preferred the paper version…...because I'm not that technically minded."* (PDC ID 49)

> *"Possibly online, because I was conscious at my handwriting is pretty poor." (PDC* ID 81)

> *"Personally, I preferred the paper version. Yeah, I think it just made it quicker and then you don't have to sit down with the laptop or whatever."* (PDC ID51)

Activity planner

Participants indicated that the activity planner was most useful in the early stages of the study, aligning with the staff views previously reported (section 5.3). With establishment of PA, participants reported that the planners became less useful as they tended to follow the same plan each week:

> *"Then I just found myself that it was repeating. You know, once I get into routine, I thought right Monday was a walk, Tuesday was exercise plus a bit of a walk. Wednesday was golf plus, and exercise, Thursday was a walk plus the online class, Friday, you know, and when it was just a routine and I thought, well it's not changing and so I didn't record on the planner."* (PDC ID58)

Participants who continued to work found the planner less useful as they had restricted time to be active. Others found the discipline of completing the planner valuable, but many found that PA was dictated by factors such as the weather, with many choosing to be outdoors if the weather allowed, and therefore setting a planner in advance was potentially restrictive or impractical, reducing its value:

> *"I tried valiantly to use the planner and I can see the benefit of it, but because of my lifestyle because I'm kind of retired and I tend to prefer doing exercise outside, so I'm influenced by things like is it raining….I would plan it every week, but it went to pot because I would say sun shining and what's the forecast for tomorrow? So, I'll just do that today and I'll do that tomorrow. So eventually I completely gave up.*" (PDC ID52)

> *"The planner, I started to use it but then I didn't use it so much as I tended to grab my exercise depending on the weather, if it was a nice day I would go out for a nice long*

walk, if it was horrible, I would use the treadmill or do more online classes something like that." (PDC ID78)

Goal Setting

As part of PDConnect, staff were instructed to personalise goals to individual need. Goals provided motivation to be active. The value of goal setting was enhanced when staff revisited goals within a session, without staff follow-up, goal setting was perceived as less effective.

> "*The goal setting was good at the beginning and because it concentrated on things like being more consistent.*" (PDC ID52)

> *"I think certainly setting goals monthly was good. It was great when the physiotherapist was doing it because she was actually checking them regularly to see whether you've done it or not and encouraging you to do it and tweaking your goals to stretch you that wee bit further." (PDC* ID71)

> "*Once physiotherapy came to an end nobody was looking at the goals. You were filling it in for your own benefit, but that was the end of it and therefore it lost its potency, I would say."* (PDC ID71)

However, the value of goals was not universally supported, especially among those who were already active, suggesting a personalised approach to goal setting may be indicated.

> "*Yes, it worked for me, it does not work for everyone, but it did work for me."* (PDC ID78)

> *"I kind of felt I didn't need goals, but my goal was to be part of the program. I wasn't really worried about setting myself individual goals and I found that a bit of a struggle.... Very many are just like, well, I'm just going to run 10K in less than an hour or something like that."* (PDC ID81)

This study also highlighted the complexity of goal setting in long-term conditions such as Parkinson's, with one participant reporting the potential demotivating effects of progressive goal setting:

> *"the thing that I found was it slightly demotivating for me because I had a couple of spells where, because of illness.... I felt slightly under pressure because I wasn't achieving the goals and it was, I suppose, a pressure I didn't need that point."* (PDC ID52)

REHABbGuru exercise library

REHABGuru was valued by participants. Participants reported that the exercise videos allowed them to modify their technique, and served as a valued reference guide during study and with many continuing to use them when the study finished:

> “*Yes, I thought it was an excellent resource. Yeah, I was quite intrigued that we could see the video and I thought they were a great aid. In fact, it was good to have them. You know you could actually watch the video and see how people move their body. And you know I went back to it."* (PDC ID 90)

> "*I did refer to them just to make sure I was doing them correctly and I've actually kept them all because they're handy to reference back to."* (PDC ID 52)

> *"Well, I am still using them, and I was looking these last week….I liked them. I found them easy to follow. Its lovely to just have them there. I set them up on my iPad and then just go through my exercise routine with them on there."* (PDC ID78)

> *"I thought that's very good. I particularly liked the app, the functionality that you know, there was an app on your phone so you could go and do some exercises and you could flick through it and Yeah, see how the exercise is supposed to be done or remind you of the sequence or whatever….Easy to follow."* (PDC ID81)

> *"I don't know how you could make it clearer really. I still use them and will continue to use them."* (PDCID49)

Very few negative comments arose in relation to REHABGuru. However, among participants who had a strong PA history they were perceived as less valuable:

> *"I've been doing exercises all my life. I've been into exercise all my life so I don't really need teaching how to do...so I didn't feel there was a need, but they might have been helpful to other people, I don't know."* (PDC ID59)

5.3.2.3: Theme 3 Perceptions of intervention participation

The final theme identified from the participant interviews centred upon their perceptions of participating in the PDConnect intervention. Within this theme, two subthemes were identified: perceived benefits of participation and perceived challenges.

Perceived benefits of participation in PDConnect

Within this subtheme of perceived benefits of participation, four categories were identified:

- Changes in PA behaviour
- Physical benefits
- Psychosocial benefits
- Educational benefits

Changes in PA behaviour

Qualitative findings indicated that participation in PDConnect positively influenced PA behaviour. Illustrative quotes from the interviews provided in table 5.13, highlight that participants reported that PDConnect has shaped the type of PA participants undertake. In addition, participation has also shaped how and when they are active, as well an enhanced their confidence.

Perceived physical benefits of participating in PDConnect

Participants reported that PDConnect promoted the establishment and/or consolidation of a commitment to exercise. Illustrative quotes in table 5.13 demonstrate that participants perceived PA was beneficial. Motivational staff encouraged participants to challenge themselves and to continue with PA out with the class, which some reported led to them to recommence activities they had stopped during Covid or when diagnosed with Parkinson's.

Table 5.13 Perceived benefits of physical activity and changes in activity behaviour

	Illustrative quotes
Changes in physical activity behaviour	“it was absolutely key to me to change my lifestyle at that time. It *actually inspired me to look further for more exercise opportunities. It inspired me to get out and do some Nordic walking and you know inspired me to do other things."* (PDC ID78) "*It has given me much more confidence*."(PDC ID52) *"I think it's been a very positive impact in me. I think it came at the right time from me. I was diagnosed completely out of the blue unexpectedly with Parkinson's. So, I think the PDConnect programme came at the stage where I was really quite scared of what the future might hold. So, it gave me level of positivity, so you know the only limitation is me. I'm just really pleased, privileged that was able to take part…... Because honestly, I mean I've only spoken to a couple other ladies, and we are all really taking something very positive from the experience. So, I think that's fantastic…I'm not going to let it [Parkinson's] stop me and I think part of this program has helped with this thinking”.* (PDC ID91) *“Although I have exercised in the past, it has not always been consistent, now my exercise plan is more regular with daily walks embedded 10,000 steps and I now have golden calf muscles”* (PDC ID49)

Table 5.13 Perceived benefits of physical activity and changes in activity behaviour (continued)

	Illustrative quotes
Physical benefits of participation in PDConnect	*"It gave me a regime to try and stick to because over the period of time it showed me the benefits of it. I just think it was really good fun. It was a very interesting to do… enlightening. I feel very lucky that I've had the privilege to take part in this because it's shown me that you know, with a bit of discipline and bit of exercise. Parkinson's yes it's a pain in the backside, but it's not going to ruin me." (PDC ID71)* *"I'm fitter and probably more committed rather than less committed to staying fit and exercising."* (PDC ID99) "*I think it was a necessary Intervention and real benefit to me and to be frank, I miss it now*." (PDC ID51) *"Well, I do still continue to do some of the exercises. I think altogether, it has been a good help. And it has undoubtably kept me loosened up as the Parkinson's progresses". (PDC ID96)* *"It really spurred you on doing it because you saw huge benefit from doing these things because suddenly getting his jackets on and turning in bed and even going for walks and getting over styles just got easier".* (Wife of PDC ID91)

Psychosocial benefits of participating in PDConnect:

Illustrative interview quotes provided in table 5.14 demonstrate that participation was perceived as a positive experience, with the 1:1 component promoting confidence and the group component being perceived as fun and enjoyable. The intervention provided a safe environment to openly discuss Parkinson's, allowing shared learning and understanding between participants which offered reassurance and comfort. Support from staff and other participants was welcomed, although the latter was limited by the online environment which was not perceived as conducive to social interaction:

When the study ended, many people expressed a sadness and disappointment, with many participants articulating that they would have been happy to continue with PDConnect long term.

> *"I could have happily carried on with it for a very long time."* (PDC ID96)

Educational benefits of participating in PDConnect

Evidence of learning was also identified within the qualitative findings as highlighted in table 5.14. Participants reported that they gained better understanding of what the types of exercise as well as structuring their PA. Participants reported that the opportunity provided by the intervention to talk things through aided depth of understanding of PA as it applied to them.

Table 5.14 Psychosocial and educational benefits reported by participants

	Illustrative quotes
Psychosocial benefits of participating in PDConnect	*"It was a positive thing, wasn't it? And we were glad to be involved in it" (Wife of PDC ID30)* *"I have made friends through this…. but I think more of us would have been friends if we had met each other" (PDC ID78)* *"I would say it's been a very positive experience. I'm very happy to have been part of it." (PDC ID81)* *"I saw people who had never met before, and although I could only see a group, a wee bit of the group at time and I could see people that had more severe Parkinson's than me. And you know, they were really going for it, and I enjoyed it." (PDC ID58)* *"it was nice to hear the other participants, maybe saying something you think… Oh that's how I'm feeling. So, the discussion became quite good." (PDC ID49)* *"For me personally, I live in the country in a big house on my own, with a little dog and it was nice to know that there was somebody out there who cared. I felt it really did me a lot of good to know that you know. I could always contact them or be in touch with them if I had any problems." (PDC ID59)* *"Not really, but we didn't get to socialize with most of the others in the group, it just wasn't possible. But the three women, we are meeting now for coffee once a month".* (PDC ID 49)

Table 5.14 Participants perceived psychosocial and educational benefits of participation (continued)

	Illustrative quotes
Educational benefits of participating in PDConnect	"*The one thing that I learnt primarily was the benefit of stretching exercises. I really never understood that before, and she gave me a lot of stretching exercises which I still do.... you know, for five minutes every morning, really, because it does help. Yeah, I had never understood that before, that was one of the turning points"* (PDC ID 71) *"It brought some awareness too because I was quite active, but how important it was to kind of maintain that level of activity and also push myself from time to time. What really opened my eyes, wasn't just the physiotherapy but some of the balance type exercise*" (PDC ID91) "*I think chance to talk through things...like I never really understood my core. You know, I go to aerobics, and they say strengthen your core. But the chance to sort of actually clarify that...you know, I hadn't understood that as well as I do now, that's due to the Physiotherapists help.... Yeah, just understanding better what I should be trying to do*". (PDC ID99)

Challenges associated with participation:

When asked about future changes to PDConnect, few suggestions were made other than those previously mentioned in relation to greater number of sessions, further IT support and changes to some of the study resources. There was a strong desire by participants that the intervention would continue in the future, and they reported missing the weekly contact with the people they had met during the study.

> *"I mean there's nothing there I could even remotely complain about."* (ID59)

> *"I'm hoping there's going to be more [sessions]."* (ID49)

> *"But it needs to carry on…you know, it needs to be at least once a week for the foreseeable future kind of thing, rather than for 18 weeks and then stop, you know."* (ID71)

> *"I really enjoyed it.... I missed the fact that there's… because every week we were doing something all through the summer, you know, I overlook the Bay and I you know, I would turn my tablet around and show them the bay and we would have a chat about the weather.*" (ID58).

5.3.4 Summary of acceptability findings

Quantitative and qualitative findings indicate that overall, the PDConnect intervention was perceived as acceptable by participants and staff. The recruitment processes, intervention resources and the delivery of PDConnect were all perceived as acceptable. Participants did not suggest changes to the recruitment processes or procedures. Barriers and motivators were highlighted with the use of Microsoft Teams. Participants appreciated the convenience of online delivery, with many acknowledging that they would not have been able to attend if it had been delivered face-to-face. Internet connectivity and some initial teething issues with Microsoft Teams were initially highlighted as key challenges. A third of participants experienced problems, with participants indicating that 1:1 personal IT support would be valued. In addition, the online environment was not perceived as effective for promoting social connection between participants. Both participants and staff reported challenges with adjusting devices to optimise viewing, however, the advantages in relation to convenience were frequently cited. Recognising the benefits and challenges associated with online delivery, both staff and participants indicated preference for hybrid delivery in the future.

Participants perceived that the study resources were acceptable, however changes were suggested to the participant manual in relation to volume and delivery in order to allow tailoring of information. The activity tracker was perceived as a powerful motivation tool, with 75% being satisfied with the device. However, over a third considered it to be inconsistently accurate, and difficult to read, suggesting some amendments may be required. The activity diary was also perceived as a valuable motivational tool, allowing people to reflect on prior PA, and influence subsequent PA behaviour. Staff played a pivotal role in the success of PDConnect, with their knowledge, motivation, and ability to personalise intervention delivery which was valued by participants.

Participants perceived that PDConnect achieved its aim of supporting improved knowledge and understanding of the benefits of exercise and promoted changes in PA behaviour Participants reported that participation led to perceived improvement in strength, flexibility, physical fitness, balance, quality of walking and exercise confidence. However, impact of NMS, specifically fatigue, pain and sleep were in the main unchanged.

Self-reported improvement in knowledge and understanding of PA, and strategies to remain active were reported by all participants as well as reporting feeling more motivated to be active following participation in PDConnect.

Overall PDConnect was perceived as a positive experience by participants and staff. Together with the feasibility findings reported above suggest some minor amendments are required to the intervention resources such as the participant manual and activity tracking device, and further consideration is required to support use of Microsoft Teams and the development of social connection during an online intervention. The findings would suggest that a future trial of PDConnect is warranted to explore the effectiveness on PA behaviour among PLwP.

5.4 INTERVENTION FIDELITY

The Physiotherapy and group-based exercise components were assessed for fidelity. Using a standardised template, intervention components were marked as completed, not completed, attempted or not applicable. Fidelity scores were calculated for each session as the percentage of completed components from the total number of components.

5.4.1 PDConnect 1:1 Physiotherapy Fidelity assessment

On average 89% of components were delivered as intended (range 75% to 96%), surpassing 85% progression criteria outlined in section 4.17. The most common elements omitted were exercise intensity and duration. In eight of the nine sessions viewed, participants were not encouraged to exercise between RPE 10 and 13, and in only three sessions did participants engage in 35 minutes or more of exercise. The mean time spent exercising within the nine sessions was 29 minutes (range 20-38 minutes). In cases where exercise duration was lower, this was commonly dictated by participant preference as many had already completed their HEP prior to having physiotherapy that day, or where time was required to address a problem which had arisen in the prior week.

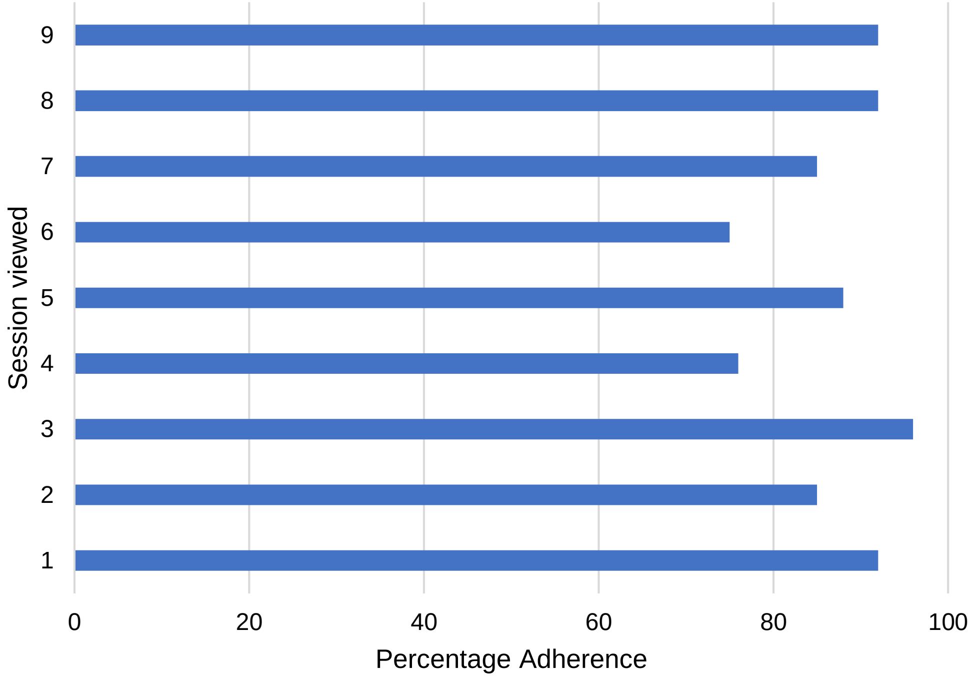


Figure 5.13 Percentage of 1:1 Physiotherapy session delivered as per protocol.

Behaviour change techniques (BCTs) were integrated throughout the PDConnect intervention with the aim of shaping and supporting PA behaviour. BCTs were selected from the BCT taxonomy described by Michie et al. (2011), as discussed in section 4.4.14. Figure 5.14 illustrates the application of BCTs categories in the nine physiotherapy sessions which were randomly selected for fidelity assessment. The BCT categories of regulation (11.0) which includes pharmacological support and reducing negative emotion were not used in any session. Natural consequences, antecedents, and identity (BCTs 5.0, 12.0, and 13.0) were the least frequently used categories. Goal planning, feedback and monitoring and comparison of behaviour (BCTs 1.0, 2.0, 6.0) were the most frequently used.

The mean number of individual BCT's used within a session was 15.4 (range 9-20), with goals and planning, feedback and monitoring, and comparison of behaviour delivered in all sessions (BCT's 1.0, 2.0 and 6.0). The frequency of BCT's use is illustrated in table 5.15.

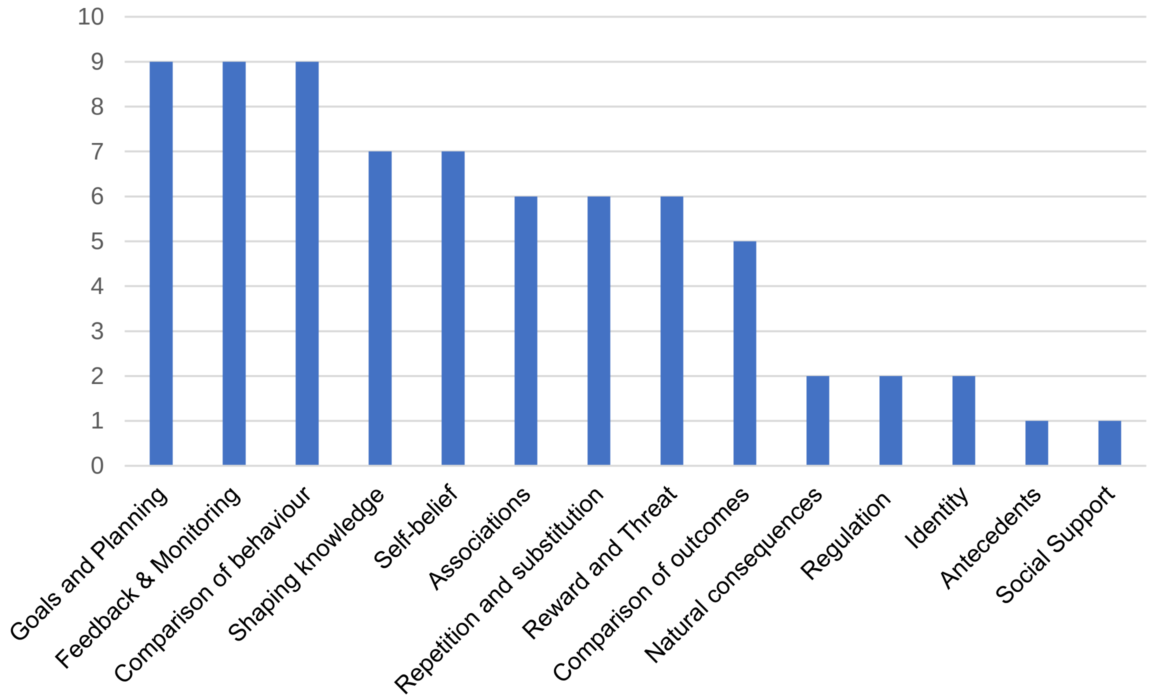


Figure 5.14 The frequency of use of BCTs within the physiotherapy component of PDConnect

Table 5.15 Application of BCT's delivered in 1:1 Physiotherapy sessions

BCT taxonomy		Participant ID Number								
No.	Descriptor	78	30	30	49	51	58	71	80	99
1.1	Goal setting (Behaviour)	✓	✓	✓	✓	✓	✓	✓	✓	✓
1.2	Problem solving	✓	✓	✓	✓		✓		✓	✓
1.3	Goal setting (Outcome)	✓	✓	✓	✓	✓	✓	✓	✓	✓
1.4	Action planning	✓	✓		✓		✓		✓	✓
1.5	Review behavioural goal(s)		✓	✓	✓		✓	✓	✓	
1.7	Review outcome goal		✓	✓		✓				
2.1	Monitoring of behaviour					✓		✓		
2.2	Feedback on behaviour	✓	✓	✓	✓		✓	✓	✓	✓
2.3	Self-monitoring of behaviour	✓	✓		✓		✓	✓	✓	✓
2.4	Self-monitoring of outcome(s)	✓	✓	✓	✓		✓	✓	✓	✓
2.5	Monitoring of outcomes without feedback			✓			✓			
2.7	Feedback on behaviour			✓						
3.2	Social support (practical)						✓			
4.1	Instruction on how to perform the behaviour	✓	✓	✓	✓		✓	✓	✓	
4.2	Information about antecedents						✓			
5.1	Information about health consequences	✓	✓		✓				✓	
6.1	Demonstration of the behaviour	✓	✓	✓	✓		✓	✓	✓	✓
6.2	Social comparisons		✓			✓	✓			✓

Table 5.15 Application of BCT’s delivered in 1:1 Physiotherapy sessions (continued)

	BCT taxonomy	Participant ID Number								
No.	Descriptor	78	30	30	49	51	58	71	80	99
7.1	Prompts/cues	✓			✓	✓	✓	✓	✓	
8.1	Behavioural practice/rehearsal	✓		✓	✓					✓
8.2	Behavioural substitution				✓		✓			
8.3	Habit formation	✓	✓		✓				✓	
8.7	Graded tasks						✓		✓	
9.1	Credible source			✓						
9.2	Pros and Cons	✓		✓	✓		✓		✓	
10.4	Social reward	✓		✓	✓	✓	✓		✓	
10.9	Self-reward			✓					✓	
12.1	Restructuring social environment									✓
13.2	Framing/reframing	✓				✓		✓		
13.4	Valued self-identity							✓		
15.1	Verbal persuasion about capability	✓						✓		
15.2	Mental rehearsal of successful performance						✓			
15.3	Focus on past success	✓		✓	✓	✓		✓	✓	
15.4	Self-talk							✓		

5.4.2 Group-based Intervention fidelity

On average 88% of components were delivered. The components which were commonly omitted from the group-based component included:

- advising on delayed onset of muscle soreness,
- reminding participants to complete their activity diary
- encouraging exercise at RPE 13-15
- advising on local community-based exercise opportunities
- checking that participants had read the study manual

The mean duration of exercise sessions was 63 minutes (range 58-66 minutes). Warm up and cool down typically took between 8-10 minutes. For each exercise the fitness instructor demonstrated a range of levels of complexity, allowing personalisation of approach depending on ability.

Fewer BCTs were used within the group-based sessions. The BCTs used within the eight sessions assessed for fidelity are summarised in table 5.16. The mean number of BCTs used within a session was 16, (range 13-19). Monitoring, feedback, and self-monitoring of behaviour 2.1, 2.2, 2.3), self-monitoring of outcome (2.4), demonstration of the behaviour (6.1), prompts and cues (7.1) and behavioural practice (8.1) were the most frequently used BCTs. The following BCTs were not used: feedback on outcome behaviour (2.7), social comparisons (6.2), behavioural substitution (8.2), graded tasks (8.7), restructuring social environment (12.2), framing/reframing (13.2), valued self-identity (13.4) and self-talk (15.4).

Table 5.16 The frequency of BCT's delvered within the group-based sessions

	BCT taxonomy	**Group exercise session date**							
No.	Descriptor	3rd June	7th June	17th June	14th June	10th June	28th June	1st July	5th July
1.1	Goal setting (Behaviour)				✓	✓			✓
1.2	Problem solving	✓	✓	✓	✓	✓	✓		✓
1.3	Goal setting (Outcome)				✓	✓			
1.4	Action planning	✓			✓	✓	✓		✓
1.5	Review behavioural goal(s)				✓	✓			✓
1.7	Review outcome goal				✓	✓			
2.1	Monitoring of behaviour	✓	✓	✓	✓	✓	✓	✓	✓
2.2	Feedback on behaviour	✓	✓	✓	✓	✓	✓	✓	✓
2.3	Self-monitoring of behaviour	✓	✓	✓	✓	✓	✓	✓	✓
2.4	Self-monitoring of outcome(s)	✓	✓	✓	✓	✓	✓	✓	✓
2.5	Monitoring of outcomes without feedback						✓		
2.7	Feedback on outcome of behaviour								
3.2	Social support (practical)						✓	✓	✓
4.1	Instruction on how to perform the behaviour	✓	✓	✓	✓	✓	✓	✓	✓
4.2	Information about antecedents						✓		
5.1	Information about health consequences							✓	✓
6.1	Demonstration of the behaviour	✓	✓	✓	✓	✓	✓	✓	✓
6.2	Social comparisons								

Table 5.16 The frequency of BCT’s delvered within the group-based sessions (continued)

	BCT taxonomy	Group exercise session date							
7.1	Prompts/cues	✓	✓	✓	✓	✓	✓	✓	✓
8.1	Behavioural practice/rehearsal	✓	✓	✓	✓	✓	✓	✓	✓
8.2	Behavioural substitution								
8.3	Habit formation	✓	✓		✓				✓
8.7	Graded tasks								
9.1	Credible source	✓	✓	✓	✓				
9.2	Pros and Cons	✓		✓	✓		✓		✓
10.4	Social reward	✓				✓	✓	✓	✓
10.9	Self-reward		✓	✓	✓	✓	✓	✓	✓
12.1	Restructuring social environment								
13.2	Framing/reframing								
13.4	Valued self-identity								
15.1	Verbal persuasion about capability	✓	✓					✓	
15.2	Mental rehearsal of successful performance								
15.3	Focus on past success	✓	✓	✓	✓	✓	✓	✓	✓
15.4	Self-talk								

5.4.3 Fidelity summary

Fidelity assessment findings were good with 88-89% of the planned PDConnect Intervention components being delivered by staff. Within the Physiotherapy sessions the mean time spent on PA was one minute under the 30 minutes recommended, whereas within the group sessions, typically the exercise was three minutes longer in duration. In both components RPE was an element that was omitted. In the Physiotherapy sessions, effort levels were rarely referred to, whereas within the group sessions working a higher effort was repeatedly mentioned, however the term RPE was rarely used. A range of BCTs were employed throughout PDConnect with a greater number of BCTs used in the physiotherapy compared to the group-based component.

5.5 SECONDARY OUTCOME MEASURES

The following section presents the findings for the secondary outcome measures. Secondary outcomes were measured at baseline, at six, 18 and 30 weeks and were collected to provide some preliminary data on outcomes such as PA, motor and non-motor symptoms, depression and anxiety, fatigue, function, self-efficacy, and QoL. Collection of secondary measures allowed the calculation of effect sizes to inform sample size calculation for a future effectiveness study. A suite of outcome measures were employed in order to inform selection of the most appropriate measures for use in a future effectiveness study.

Measures selected included those which measured: i) PA levels ii) Parkinson’s symptoms, and iii) those which assess the impact of living with Parkinson's. This section will present the descriptive analysis in relation to these three categories. In addition, effect sizes were calculated using Cohen’s *d* (Cohen, 2013) for each secondary measure to explore the difference at each timepoint between the groups. Effects sizes were categorised as small (*d* = 0.2), medium (*d* = 0.5) or large (*d* = 0.8) (Cohen, 2013). Point estimates (*d*) for each measure are provided, however it is recognised that the groups were small, and therefore all effect sizes will lack precision. Effect sizes have been provided to illustrate trends between groups at each time point.

5.5.1 Physical activity measures

Physical activity was measured using the activity tracker and the use of two self-reported PA measures (PASE and PASiPD, Washburn et al. 1993 and 2002 respectively). Exercise self-efficacy was measured using the Exercise Self-Efficacy Scale (Resnick and Jenkins, 2000) and balance was measured using the Activities-specific Balance Confidence Scale (Haung and Wang, 2009). PDConnect participants also recorded daily physical activities in a diary.

5.5.1.1 Step count

Daily step count was recorded using the activity tracker and documented within the PA diary. Table 5.17 illustrates the mean step count at set time periods during the study. At baseline, the usual care group had a higher mean weekly step count compared to the PDConnect group. However, this was not statistically significant (p=0.175). In both groups, step count improved at each time point, however, the usual care group had a larger mean change from baseline to the end of the study (1,117 steps) compared with the PDConnect group (536 steps).

Table 5.17 Comparison of mean step count at study data collection points

	Week 1 Mean (SD) Step count	**Week 2-6** Mean (SD) Step count	**Week 7-18** Mean (SD) Step count	**Week 19-30** Mean (SD) Step count
Usual Care	7236 (3864)	7978 (3789)	7975 (3963)	8353 (4756)
PDConnect	5956 (2698)	6718 (2754)	6489 (2889)	6492 (3253)

5.5.1.2 Physical activity diaries

PDConnect participants were asked to keep a diary of the PA they undertook. Participants engaged in a wide variety of PA as illustrated in Figure 5.15. Walking was the most frequently self-reported PA, followed by HEP, and gardening. Those clustered into ‘other’ included tennis, running, paddleboarding, fishing, cycling, Zumba, swimming, dance, Nordic walking, Pilates, and hiking.

Over the duration of the study, the mean number of walks per week was 4.29 (SD±0.63). Seven of the 14 participants returning the activity diaries reported no walking in one or more weeks. Some participants provided reasons for not recording walking, for example being unwell. Others reported they had been doing gardening; therefore, although they had been active, they had not been for a walk.

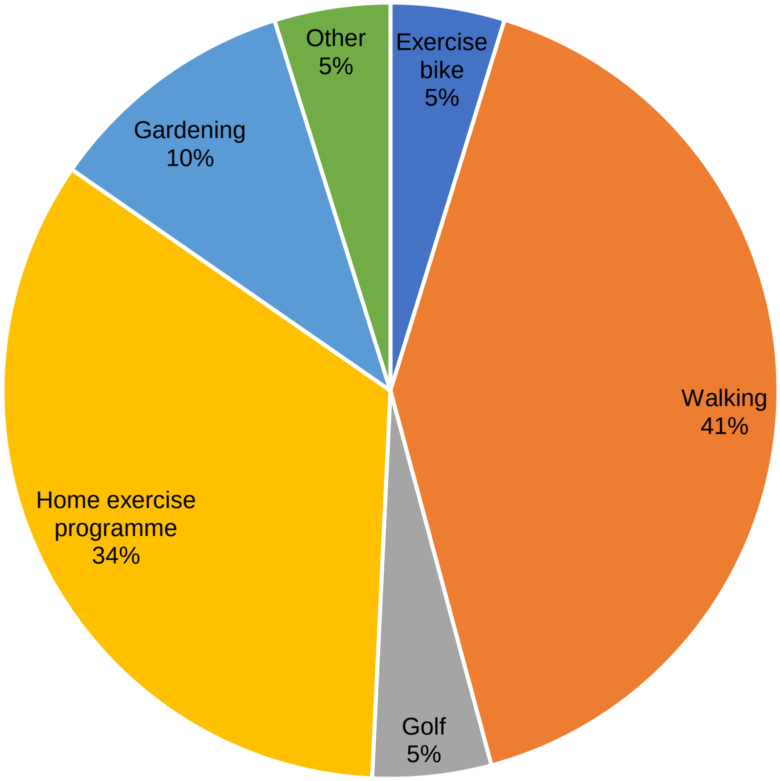


Figure 5.15 Physical activity types undertaken by PDConnect participants.

Over the course of the 30-week study the mean number of self-reported PA sessions was 7.9 (SD±1.2) per week. The mean number of PA sessions rose at the beginning of the study and declined as the study progressed, as shown in Figure 5.16. During the delivery of 1:1 Physiotherapy, the mean number of weekly PA sessions was 9.48, which declined to 7.72 during the group component and dropped again to 7.29 during the self-management phase which are illustrated on Figure 5.16 as dashed lines. The lowest mean number of sessions per week was six recorded in week 24, whereas the highest was 11 in week 3.

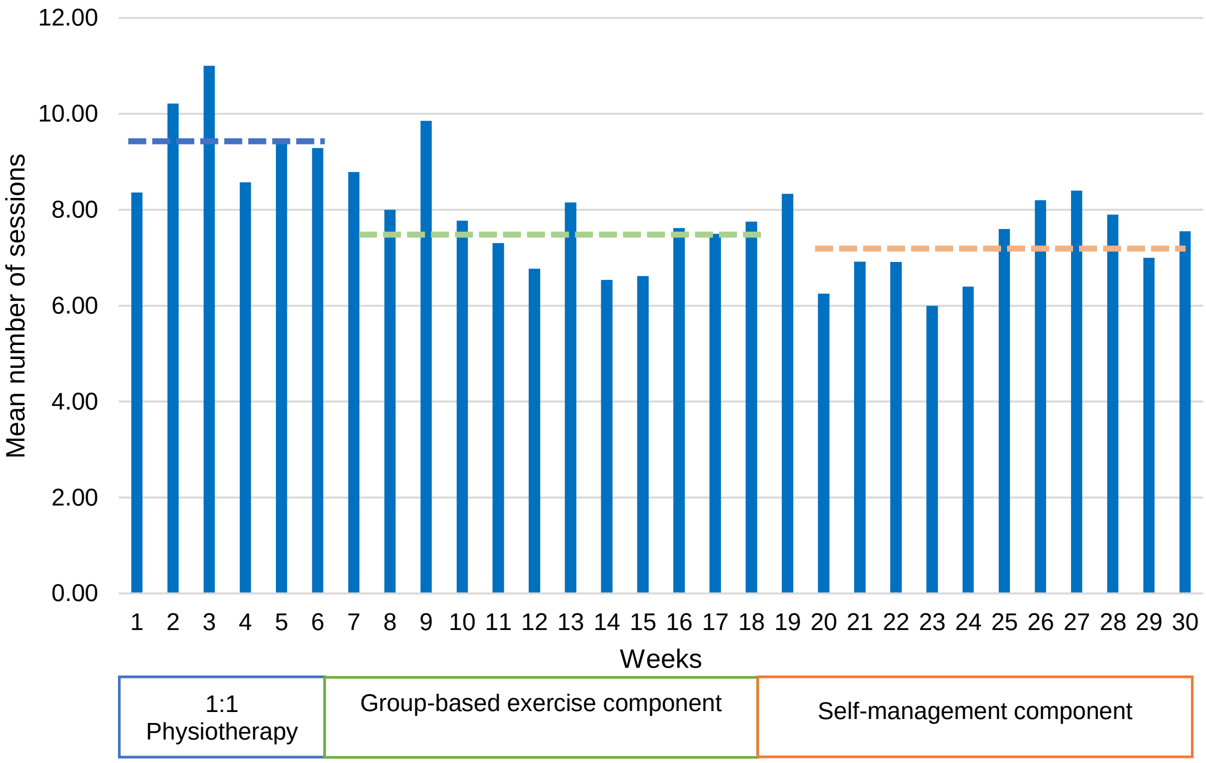


Figure 5.16 Mean number of weekly physical activity sessions undertaken by PDConnect participants.

5.5 5.3 Self-reported physical activity, exercise self-efficacy and balance measures.

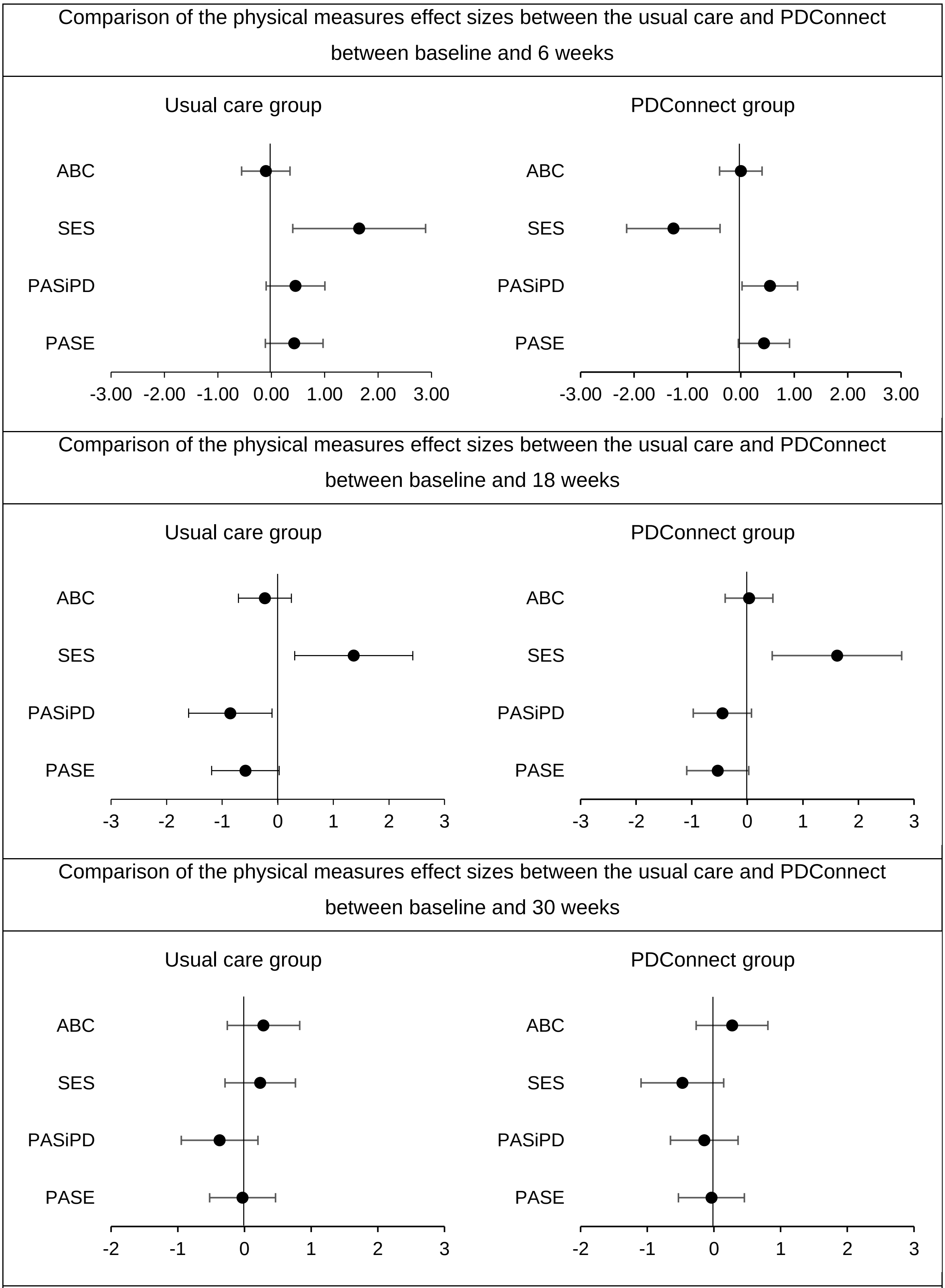
Table 5.18 provides descriptive statistics for the PASE, PASiPD, SES and ABC at each data collection point, and effect sizes (ES) are illustrated in Figure 5.17.

Table 5.18 Descriptive analysis of the Physical activity measures

	Baseline		6 Weeks		18 Weeks		30 weeks	
Measure	PDConnect	Usual Care	PDConnect	Usual Care	PDConnect	Usual Care	PDConnect	Usual Care
PASE Mean (SD)	157.16 (80.60)	120.84 (81.67)	203.40 (97.69)	185.70 (137.65)	179.62 (43.28)	136.80 (80.06)	172.74 (43.28)	147.96 (55.25)
PASPiD Mean (SD)	13.95 (9.12)	10.05 (5.46)	21.74 (12.78)	17.51 (11.24)	15.17 (10.04)	15.77 (12.15)	13.71 (5.61)	12.00 (10.40)
SES Mean (SD)	56.48 (13.01)	56.00 (18.14)	28.87 (19.00)	28.15 (19.53)	61.21 (18.06)	62.15 (22.23)	52.4 (18.96)	64.91 (23.57)
ABC scale Mean (SD)	82.8% (20.6)	84.6% (15.9)	82.7% (17.9)	83.9% (19.4)	81.6% (14.5)	83.5% (16.3)	87.0% (14.5)	85.5% (16.8)

Abbreviations: PASE: Physical activity scale for the elderly, PASPiD: Physical activity scale for people with disability, SES: Self-efficacy for exercise scale, ABC Activities-Specific Balance Confidence

🟧 Indicates above normal value for that measure



Comparison of the physical measures effect sizes between the usual care and PDConnect between baseline and 6 weeks

Usual care group

PDConnect group

Comparison of the physical measures effect sizes between the usual care and PDConnect between baseline and 18 weeks

Usual care group

PDConnect group

Comparison of the physical measures effect sizes between the usual care and PDConnect between baseline and 30 weeks

Usual care group

PDConnect group

Abbreviations: ABC: Activities-specific Balance Confidence Scale, SES: Self-efficacy exercise scale, PASE: Physical activity scale for the elderly, PASiPD: Physical activity scale for individuals with disability.

Figure 5.17 Physical Outcomes Effect sizes by group and timepoint

Physical Activity Scale for the Elderly Scale (PASE)

The PASE scores are based on reported frequency, duration, and intensity of activity over the previous week, with higher scores indicating higher PA levels. The normal values for the PASE for those under age 70 is 142.9 ±98.5 (Washburn et al. 1999). As shown in table 5.17, baseline PA levels in the usual care group were below normal values, whereas the PDConnect aligned with normal values. PDConnect participants were more active at baseline and continued to be more active at all other time points as shown in table 5.18, and their PA level at week 30 remined higher compared to baseline.

PDConnect PASE scores improved between baseline and six weeks, the mean difference (MD) was 46.24, with a small ES (*d*= 0.43, 95% CI -0.05 to 0.90). The mean difference in PASE scores between baseline and 30 weeks was 15.58, but no effect was shown (*d*=-0.03, 95% CI: -0.53 to 0.45). In the usual care group, a similar trend arose, with PA levels increasing between baseline and six weeks with a small ES (MD: 64.86, *d*= 0.43, 95% CI: -1.11 to 0.97). As the 95% CI passes through zero, this would suggest a lack of precision within the data. As with the PDConnect group, PASE scores PA declined between six and 18 weeks in the usual care group. However, between baseline and 30 weeks, PASE scores improved: mean difference: 27.12, however as shown in Figure 5.17 no effect was reported (*d*=-0.02, 95% CI 0.52 to 0.46).

Physical Activity Scale for Individuals with Physical Disability (PASiPD)

The PASiPD is a modified version of the PASE developed for people with physical disabilities. Normal values for the PASiPD for those over the age of 51 is 16.5 (SD±13.4, Washburn et al. 2002). As shown in table 5.18, the mean PASiPD scores were below normal values at all time points except for week six in both groups. A similar trend was reported in the PASiPD as with the PASE. Figure 5.17 shows that both groups demonstrated improvement in PASiPD scores between baseline and 6 weeks with small and medium effect sizes (PDConnect MD: 7.79, *d*=0.54, 95% CI: 0.02 to 2.06, Usual care MD: 7.54, *d*=0.45, 95% CI -0.10 to 1.00). Although a small ES in the usual care group was highlighted, the 95% CI crossed zero, suggesting a lack of precision in this finding. As shown in table 5.18, PA levels declined in both groups between six and 18 weeks but remained higher than baseline levels. At the 30-week time point the PASiPD score had returned to baseline in the PDConnect group, whereas the usual care group the PASiPD scores had also declined but remined higher than baseline. Between baseline and 30 weeks, the mean difference in PASiPD indicated a decline in PA in both groups, with a small effect (PDConnect: MD: -0.24, d= -0.14, 95% CI: -0.65 to 0.36, Usual Care: MD: 1.95 d=-0.37, 95% CI -0.94 to 0.20).

Exercise for Self-efficacy Scale (SES)

This self-report scale asks participants to rate self-efficacy on a 0-10 scale, with 0 being not confident and 10 being very confident. No normal values are available for this measure. As shown in table 5.18 self-efficacy was broadly similar at baseline between groups, however variation existed in self-efficacy as evidenced by the large standard deviations. The mean difference in SES in PDConnect group between baseline and six weeks indicated a decline in self-efficacy, and this effect was shown to be large (PDConnect MD: -27.61, *d*= 1.26, 95% CI -2.14 to 0.39). Between baseline and 18 weeks, the change in mean differences indicated an improvement in exercise self-efficacy with a large effect (MD: 4.73, *d*=1.6, 95% CI: 0.44 to 2.77). However, this improvement was not maintained at 30 weeks. Overall, between baseline and week 30, self-efficacy declined with small effect size (MD: -4.08, d=0.47, 95% CI -1.09 to 0.62), however the broad confidence interval would suggest a lack of precision with this finding.

In contrast, the mean difference in SES between baseline and six weeks suggested improved exercise self-efficacy, with a large effect in the usual care group (MD: 27.85, d=1.65, 95% CI 0.40 to 2.89). Self-efficacy continued to rise at subsequent time points for the usual care group. The mean difference in SES improved between baseline and 30 weeks in the usual care group, with a small effect (MD: 8.91, d=0.23, 95% CI: -0.29 to 0.76).

Activities-specific Balance Confidence Scale (ABC Scale)

The ABC scale is a self-report balance confidence measure. Each item is rated 0-100%, with the 100% indicating complete confidence and 0% as no confidence. The ABC scores in both groups were above 80% at each time point. Eighty percent or over is indicative of highly functioning, physically active adults (Meyer et al.1998). The minimally clinically important difference (MCID) for this measure is 11.2% (Dal Bello-Haas et al. 2011).

As shown in table 5.18 the mean balance confidence levels remained broadly constant, with both groups demonstrating an improvement during the 30 weeks, although improvements did not surpass the MCID which may reflect the high level of balance measures at baseline. Changes in mean difference in balance confidence between baseline and 30 weeks indicated improvement within a small effect in both groups (PDConnect group: MD: 4.2, d=0.27, 955 CI: -0.26 to 0.8, Usual care group: MD: 0.9, d=0.28, 95% CI -2.5 to 0.82), although as the CI passes through zero, these findings lack precision.

5.5.2 Parkinson's Symptoms Measures

The Unified Parkinson's Disease Rating Scale (UPDRS)

This scale consists of four subsections: non-motor and motor aspects of living with Parkinsons, motor examination and motor complications. Questions within each subscale are scored between zero (no problems) to four (severe problems), therefore a lower score is indicative of lower disability. The UPDRS scores at each time point for both groups are provided in table 5.19, and Figure 5.18 illustrates the effect sizes at each data collection point.

UPDRS I Non-motor aspects of Daily living

The UPDRS I combines researcher and self-report aspects, exploring the impact of NMS. As illustrated in table 5.19, the UPDRS I were similar in both groups at baseline and at six weeks, however in both groups the standard deviations were wide suggesting heterogeneity in relation to NMS. Changes in the UPDRS I between baseline and 18 weeks did not surpass the MCID of 2.64 points as detailed by Horvarth et al. (2017). However as shown in Figure 5.18 changes in mean differences between baseline and six weeks suggested in improvements in UPDRS I with a small effect in both groups (PDConnect: MD: -1.38, *d*= 0.34, 95% CI -0.11 to 0.79, Usual Care: MD: 1.16, *d*=0.2, -0.27 to 0.67), however in both groups the confidence interval crosses zero suggesting a lack of precision.

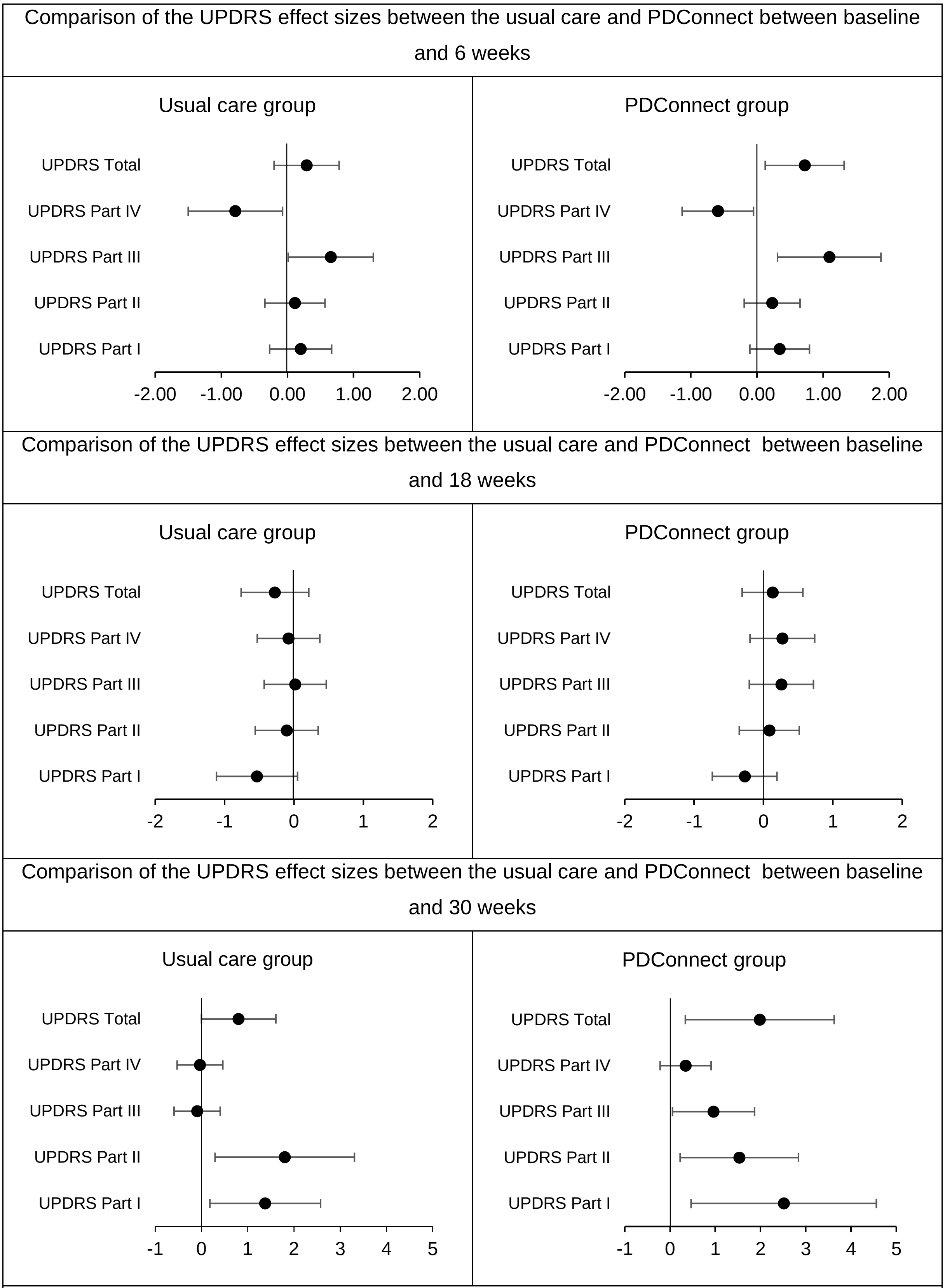
As shown in table 5.19, both groups demonstrated a large change in mean in UPDRS I score surpassing the MCID between week 18 and week 30 indicating less severe impact of NMS, however in both groups the standard deviation was broad. Figure 5.18 illustrates that the change in mean differences in UPDRS baseline and 30 weeks indicate improvement with a large effect (PDConnect group: MD: 8.9, d=2.51, 95% CI: 0.46 to 4.55, Usual care: MD: 7.76, d=1.37, 95% CI: 0.18 to 2.57)

Table 5.19 Descriptive analysis of the UPDRS by group and timepoint

	UPDRS I (mean (SD)		UPDRS II (mean (SD)		UPDRS III (mean (SD)		UPDRS IV (mean (SD)		UPDRS Total (mean (SD)	
	PDConnect	Usual Care	PDConnect	Usual Care	PDConnect	Usual Care	PDConnect	Usual Care	PDConnect	Usual Care
Baseline	16.56 (5.53)	17.66 (3.97)	22.75 (7.25)	25.80 (7.25)	32.00 (8.87)	30.43 (9.00)	0.50 (0.52)	1.13 (2.23)	71.81 (13.98)	75.03 (18.53)
6 weeks	15.18 (3.83)	16.50 (4.88)	21.56 (4.95)	24.30 (7.07)	22.65 (8.15)	24.11 (7.68)	2.16 (2.12)	2.61 (2.39)	61.15 (12.35)	67.34 (16.87)
18 weeks	16.33 (3.73)	18.23 (5.54)	21.28 (4.61)	15.00 (7.67)	20.86 (6.96)	25.15 (12.56)	1.72 (1.73)	3.00 (2.08)	59.66 (12.35)	79.84 (36.46)
30 weeks	7.66 (3.14)	9.90 (7.42)	8.41 (5.05)	11.18 (6.43)	15.70 (4.16)	23.90 (12.62)	1.25 (1.35)	3.27 (2.57)	33.95 (11.20)	48.27 (25.56)

UPDRS I: Non-motor aspects of Daily living, UPDRS II: Motor aspects of living with Parkinson's, UPDRS III: Motor Examination, UPDRS IV: Motor Complications

🟧 Indicates change surpasses MCID



Comparison of the UPDRS effect sizes between the usual care and PDConnect between baseline and 6 weeks

Usual care group

PDConnect group

Comparison of the UPDRS effect sizes between the usual care and PDConnect between baseline and 18 weeks

Usual care group

PDConnect group

Comparison of the UPDRS effect sizes between the usual care and PDConnect between baseline and 30 weeks

Usual care group

PDConnect group

UPDRS: Unified Parkinson's Disease Rating Scale, Part I: Mentation, Behaviour, and Mood, Part II: Activities of daily living, Part III: Motor section, Part IV: therapy complications.

Figure 5.18 Between group comparison of the UPDRS effect sizes

UPDRS II Motor aspects of living with Parkinson's.

The UPDRS II was section completed by participants. A change of 2.64-points is regarded as a MCID (Horvath et al. 2017). The UPDRS II scores remained constant within the PDConnect group between baseline, six and 18 weeks, with small improvements but these did not surpass the MCID. In contrast, between baseline and 18, and baseline to 30 weeks, the Usual Care group demonstrated improvements which surpassed the MCID for this UPDRS subsection.

Between 18 and 30 weeks as shown in table 5.19 the mean UPDRS II dropped by 12.87 in the PDConnect group surpassing the MCID. The usual care group also improved, with a 2.92 change in UPDRS II points just surpassing the MCID. Figure 5.18 illustrates the changes effect sizes for the UPDRS II. Small effects sizes in UPDRS II are illustrated between baseline and 6 weeks, however the confidence intervals are broad (MD: 1.19, *d*=0.23, 95% CI: -0.19 to 0.42), suggesting no effect for the PDConnect group. As with UPDRS I, Figure 5.18 illustrates an improvement in the UPDRS II between baseline and 30 weeks with a large effect for both groups (PDConnect MD: 14.34, *d*=1.53, 95% CI: 0.22 to 2.83, Usual Care: MD: 14.62, *d*=1.80, 95% CI 0.29 to 3.30).

UPDRS III Motor Examination (mUPDRS)

The UPDRS III was completed by the researcher at each time point. Shulman et al. (2010) stated that minimal clinical important differences were between 2.3 and 2.7, moderate between 4.5 and 6.7, and large above 10.7. As shown in table 5.19, baseline UPDRS III scores were broadly similar, with the PDConnect group having lower scores suggesting less motor dysfunction. Moderate MCIDs were reported for both groups between baseline, and the 6-week timepoint (Usual care mean change 6.32 points, PDConnect 9.35). No MCID’s were noted between the 6 and 18-week timepoints. Between 18 and 30 weeks both groups improved, however no MCID was demonstrated in the usual care group, however a change of 5.15 points in the PDConnect group representing a moderate MCID.

As illustrated in Figure 5.18, small to large effects sizes were demonstrated within the PDConnect group. Between baseline and 30 weeks, mean changes in UPDRS III indicate improved motor symptoms with a large effect (MD: 16.30, d=0.96, 95% CI 0.05 to 1.86). In contrast, no effect was reported in the usual care group (MD: 6.5, d=-0.09, 95% CI, -0.59 to 0.40)

UPDRS IV Motor Complications

The low scores in both groups indicate that fewer participants reported motor complications related to medications. No MCID’s were achieved by either group at any timepoint.

As shown in table 5.19 between baseline and 6 weeks the mean UPDRS IV scores in each group increased suggesting worsening motor complications, although the standard deviation were broad suggesting variation in reporting, however medium effect sizes were observed as illustrated in Figure 5.18. Effect sizes illustrated in Figure 5.18 would suggest a trend to improving UPDRS IV over the course of the intervention but the large confidence intervals crossing zero would indicate that these are not practically significant.

Total UPDRS Score

Low total scores were evident at week 30 in both groups suggesting low disease severity, although this could also reflect the omitted assessment of rigidity and balance which could not be conducted online for safety reasons. Minimal clinically important differences for the total UPDRS have been reported as minimal: 4.1-4.5, moderate 8.5-10.3, and 16.4 to 18.7 points (Shulman et al. 2010).

As shown in table 5.19 the total UPDRS scores improved at each time point in the PDConnect group. Large MCID's were noted between baseline and six weeks and between 18 and 30 weeks, with medium to large effect sizes also reported in these time frames (baseline to 6 weeks: MD: 10.66, d=0.72, 95% CI 0.12 to 1.32, baseline to 30 weeks :37.86, d=1.93, 95% CI: 0.33 to 3.62). A small MCID was evident in the usual care group between baseline and six weeks with a change of 7.96 points in the usual care group, however the effect size was small and the large confidence interval passing through zero, suggests no effect (d=02.9, 95% CI -0.20 to 0.7.8). The mean total UPDRS score increased by 12.5 points between 6 and 18 weeks in the usual care group suggesting increased Parkinson's severity, however the standard deviation was large (36.46), suggesting marked heterogeneity with the sample. Mean difference in the total UPDRS score between baseline and 30 weeks improved by 22.27 points in the usual care group suggesting improvement in Parkinson symptoms, and a large effect size was also observed (d= 0.80, 95% CI -0.00 to 1.60).

5.5.3 Parkinson's non-motor symptom measures

Non-motor symptoms are prevalence in Parkinson's, of which depression, apathy, anxiety, and fatigue are frequently reported (Rodriguez-Blazquez et al. 2021). The Parkinson's Fatigue Scale (Brown et al. 2005), Parkinson's Anxiety Scale (Leentjens et al. 2014), the Lille Apathy scale (Sockeel et al. 2006), and the Geriatric depression scale (Yesavage et al. 1983) were used at each data collection timepoint.

Apathy

The Lille Apathy Scale is based on participants' experiences over the last 4 weeks. The scale ranges from-36 to +36, with a higher score associated with greater apathy. Apathy was not reported in either group at any time point with the highest score reported being -26. Reports of apathy remained broadly constant over the 30-week study with neither group demonstrating a change of greater than 2 points in either direction (table 5.20). No MCIDs are available for this measure.

Fatigue

The Parkinson's Fatigue Scale (PFS) encompasses 16 self-completion questions which explore the presence and impact of fatigue. Scores range from 16 to 80 with higher scores indicative of increased fatigue. No MCID for the PFS exists (Friedmann et al. 2010) to guide whether these changes in fatigue should be interpreted as clinically meaningful. Table 5.20 highlights that PDConnect group had higher levels of fatigue at all time points compared to the usual care group. As illustrated in figure 5.19, in both groups, mean fatigue levels improved between baseline and 6 weeks, with a small effect in the usual care group and a large effect in the PDConnect group (Usual care: MD: 6, d=0.25, 95% CI -0.23 to 7.3, PDConnect: MD: 14.5, d=1.01, 95% CI 0.27 to 1.75).

As shown in table 5.20 fatigue scores continued to improve between week 6 and 18 in the PDConnect group, but this improvement was not maintained with median values suggesting an increase in fatigue levels between week 18 and 30 in the PDConnect. As illustrated in Figure 5.19, between baseline and 30 weeks, fatigue levels worsening in the PDConnect group with a small effect (PDConnect group: MD: -1.5, d= -0.4 3, 95% CI: -1.03 to 0.16) while no effect was shown in the usual care group in the same period.

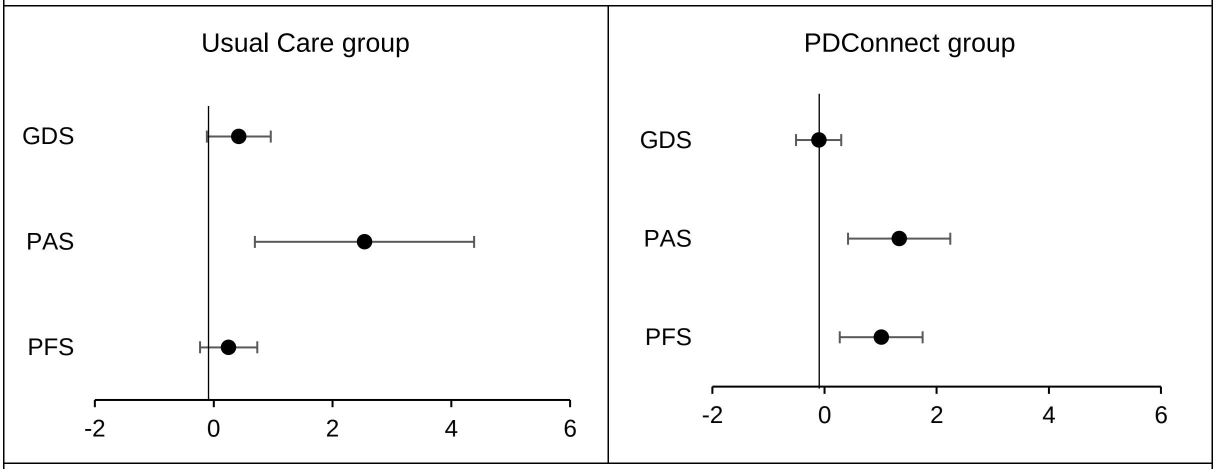
Parkinson's Anxiety Scale

This self-report scale has a maximum score of 48, where higher scores are associated with greater anxiety. Both groups had low levels at anxiety at baseline, however large inter-quartile ranges in both groups at each point suggest a large data spread and variability in anxiety. The usual care group reported higher anxiety at baseline compared to the PDConnect group. As shown in Table 5.20 and Figure 5.19 anxiety levels declined in both groups between baseline and six weeks, and the effect sizes were shown to be large in both groups (PDConnect: MD: 15, d= 1.33, 95% CI: 0.42 to 2.24, Usual Care: MD: 16, d= 2.54, 95% CI 0.69 to 4.38). Fatigue remained low at the remining timepoints.

Table 5.20 Descriptive analysis non-motor measures by group and timepoint

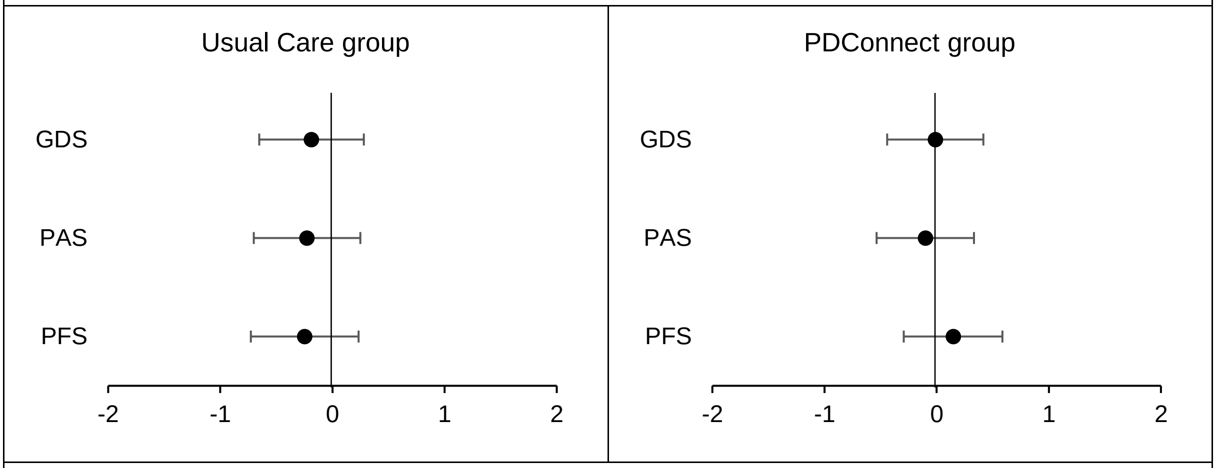
	Baseline		6 Weeks		18 Weeks		30 weeks	
Measure	PDConnect	Usual Care	PDConnect	Usual Care	PDConnect	Usual Care	PDConnect	Usual Care
LAS Mean (SD)	-26.81 (6.46)	-28.14 (4.41)	-28.68 (2.72)	- 26.46 (5.41)	- 29.46 (5.15)	-28.84 (3.18)	-30.91 (2.23)	-28.36 (5.50)
PFS Median (IQR)	47.5 (33.7-57.5)	38.0 (27.0-54.0)	3.0 (29.0-48.0)	32.0 (20.0-52.0)	38.5 (32.7-47.5)	36.0 (24.5-54.5)	49.0 (32.0-57.5)	3200 (20.0-57.0)
PAS Median (IQR)	17.0 (14.0-25.5)	21.0 (18.0-26.0)	2.0 (1.3-8.7)	5.0 (2.5-9.5)	3.5 (1.0-6.5)	5.0 (4.0-12.0)	5.5 (2.0-7.7)	5.0 (0.0-13.0)
GDS Mean (SD)	7.5 (3.8) n=9 (56%) No depression n=7 (44%) Mild depression	7.4 (5.3) n=9 (60%) No depression n=5 (33%) Mild depression	8.1 (4.7) n=10 (63%) No depression n=6 (37%) Mild depression	5.2 (3.8) n=10, (77%) No depression n=3, (27%) Mild depression	8.3 (5.0) n=9 (75%) No depression n=3, (25%) Mild depression	6.2 (4.9) n=10, (77%) No depression n=3, (27%) Mild depression	6.6 (5.2) n=9 (75%) No depression n=3, (25%) Mild depression	1.1 (1.2) n=11 (100%) No depression
Abbreviations: LAS: Lille Apathy scale, PFS: Parkinson's Fatigue Scale, PAS: Parkinsons Anxiety Scale, GDS: Geriatric Depression scale								

Comparison of the PAS, PFS and GDS effect sizes between the usual care and PDConnect between baseline and 6 weeks


Usual Care group

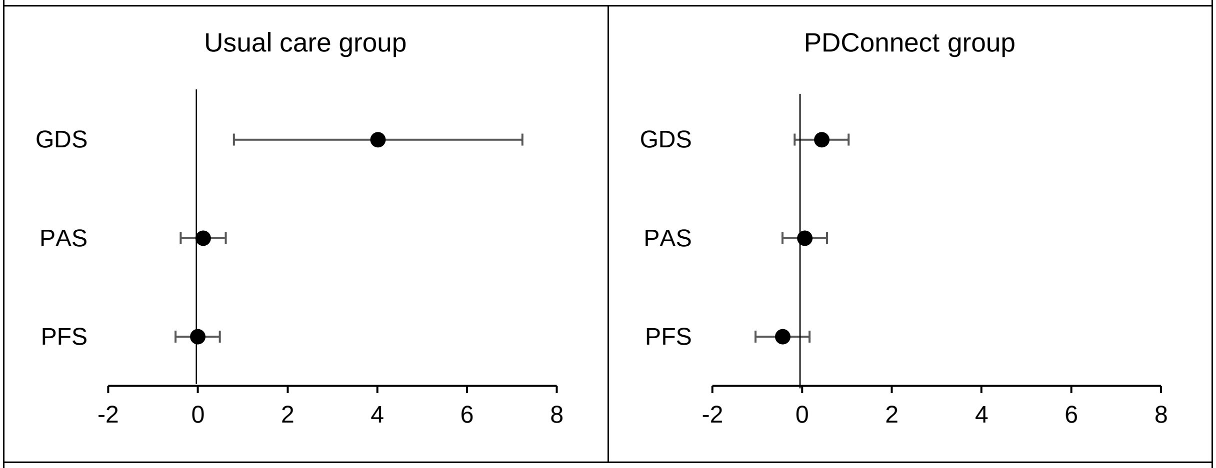
PDConnect group

Comparison of the PAS, PFS and GDS effect sizes between the usual care and PDConnect between baseline and 18 weeks


Usual Care group

PDConnect group

Comparison of the PAS, PFS and GDS effect sizes between the usual care and PDConnect between baseline and 30weeks


Usual care group

PDConnect group

Abbreviations: GDS: Geriatric Depression Scale, PAS: Parkinson's Apthy Scale, PFS: parkinsons Fatigue Scale

Figure 5.19 Comparison of the PAS, PFS and GDS effect sizes

Depression

The GDS is a 30-question self-report measure used to identify depression among elderly people. A score of 0-9 indicates no depression, between 10-19 indicates mild depression, with scores of above 20 associated with severe depression (Yesavage et al. 1983). Prior studies have reported mean GDS scores of 9.7 for PLwP (Mondolo et al. 2006). The mean GDS scores suggest that none of the participants had severe depression, however as shown in table 5.20, nearly a third of participants had mild depression at each timepoint except for the usual care group at week 30.

In the PDConnect group, depression declined between baseline and week 6, and week 18 and then improved at week 30. Mean differences in depression between baseline and 30 weeks indicate a positive trend with a small effect size (MD: 0.9, d=0.43, 95% CI -0.16 to 1.03) as illustrated in Figure 5.19. In the usual care group, depression declined between baseline and 6 weeks, and increased marginally (from 5.2-6.2), before improving again at week 30. Comparing baseline to 30 weeks, depression improved substantially from 7.4 to 1.1 with a very large effect size (MD: 6.3: d=4.0, 95% CI 0.80 to 7.23)

5.5.4 Impact of the intervention on living with Parkinson's

A suite of measures were used to explore the impact of the intervention of living with Parkinson's. These included the Schwab and England Activities of daily living scale (Schwab, and England 1969), the Warwick Edinburgh Mental Health, and Well-being Scale (WEMWBS, Tennant et al. 2007), Parkinson’s Disease Questionnaire-39 (Jenkinson et al. 1997), and the Nottingham Health Profile (Hunt et al. 1985*)*. Table 5.21 provides the descriptive analysis of these measures for both groups at each timepoint. In addition, table 5.22 and 5.23 summaries specific domains of the PDQ-39 and Nottingham health profile respectively.

Table 5.21 Descriptive analysis of daily living measures

	Baseline		6 Weeks		18 Weeks		30 weeks	
Measure	PDConnect	Usual Care	PDConnect	Usual Care	PDConnect	Usual Care	PDConnect	Usual Care
Schwab Mean (SD)	85.6 (8.9)	84.0 (11.8)	87.5 (5.7)	86.1 (12.6)	86.4 (17.8)	84.6 (13.9)	88.3 (9.3)	87.2 (6.4)
WEMWBS Mean (SD)	47.18 (17.79) n=2 participants scoring ≤ 40	53.00 (8.64) n=1 participant scoring ≤ 40	53.25 (9.61) n=2 participants scoring ≤ 40	56.07 (6.93) n=1 participant scoring ≤ 40	51.14 (8.28) n=1 participant scoring ≤ 40	53.15 (8.22) n=1 participant scoring ≤ 40	50.00 (8.73) n=2 participants scoring ≤ 40	52.81 (10.11) n=1 participant scoring ≤ 40
PDQ-39 SI Mean (SD)	9.82 (5.60)	12.24 (7.89)	9.58 (6.04)	12.32 (11.67)	10.32 (6.64)	12.10 (8.92)	10.01 (10.11)	13.92 (7.15)

Abbreviations: Schwab: Schwab and England activities of daily living scale, WEMWBS: Warwick Edinburgh Mental Health and Well-being Scale: PDQ-39 SI: Parkinson's disease 39 Questionnaire summary index

Schwab and England Activities of Daily Living Scale

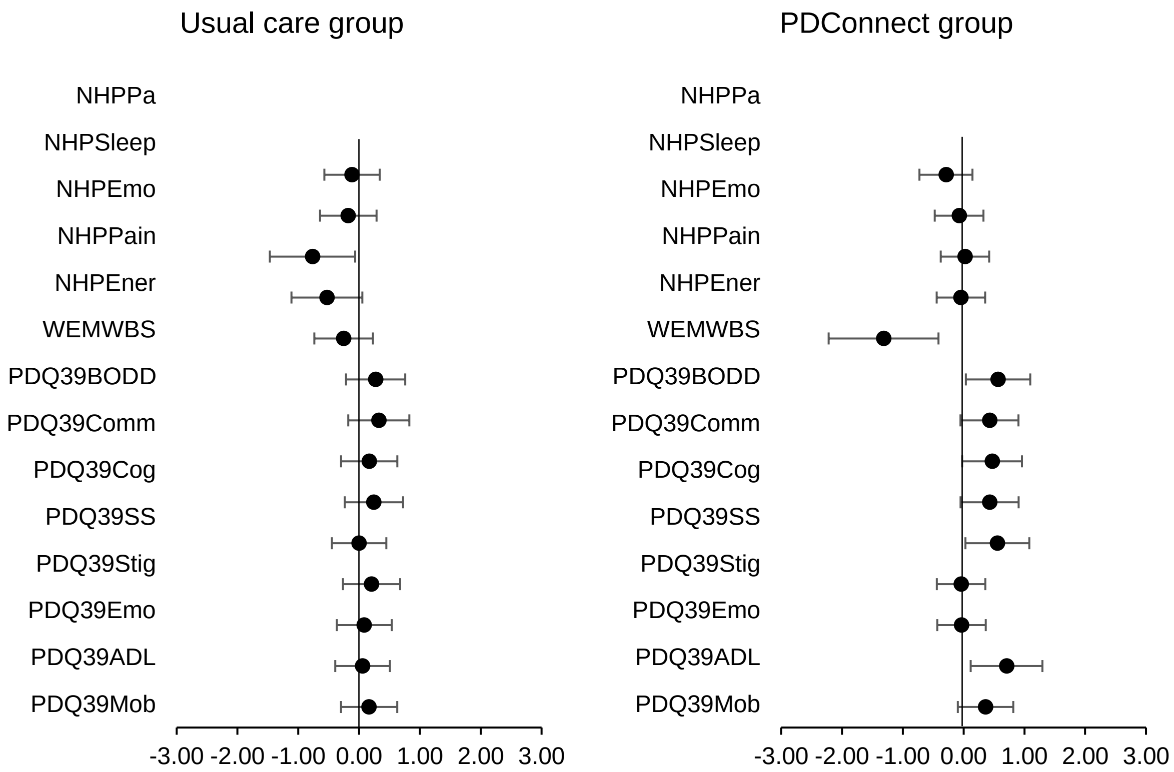
The Schwab and England is a self-report measure which assesses functional ability. People are asked to rate themselves on a scale of 0-100% with 0% representing complete dependence and 100% being completely independent. A 10% change in scores is regarded as clinically meaningful (Shullman et al. 2010). No clinically meaningful changes were reported in either group at any time point. This may reflect the high level of function at baseline within both groups, as 65% of participants were classified as independent (i.e., scores ≥90%) using this measure. As shown in Figure 5.20 small mean differences (<3%) were noted suggesting improvement in level of independence with ADL in both groups. However, the standard deviations were wide suggesting variation within groups.

Warwick Edinburgh Mental Health and Well-being Scale (WEMWBS)

The WEMWBS is a 14-item scale which assesses well-being in the general population. Scores range from a minimum of 14 to a maximum of 70, with higher scores associated with higher mental well-being, and lower scores (<40) associated with depression (Tennant et al. 2007). The mean WEMWBS score for the general adult population studies is 50.7 (Tennant et al. 2007). The results presented in Table 5.21, indicate that the participants in this study align with the general adult population. As can be seen from Table 5.21, mental well-being fluctuated during the intervention, with both groups having small mean changes between each timepoint.

In the PDConnect group mental well-being improved between baseline and six week with a medium effect (MD: 6.07, d=0.57, 95% CI: 0.04 to 1.10), as illustrated in Figure 5.20. However, this improving trend was not maintained, with mean WEMWBS dropping at each subsequent time point, although it remined above baseline at week 30. Between baseline and 30 weeks, there was a declining trend in mental well-being for the PDConnect group, but not effect was shown as illustrated in Figure 5.20 (MD: 2.82, d =-0.17, 95% CI -0.68- to 0.34). A similar pattern emerged for the usual care group, with improved mental wellbeing between baseline and 6 weeks, although with small effect (MD: 3.07, d=0.27, 95% CI -0.22 to 0.76) prior to gradually declining over the remining timepoints. Mean changes between baseline and 30 weeks indicated a decline in mental well-being with a small effect (MD: -0.19, d= -0.30 95% CI: -0.80 to 0.18).

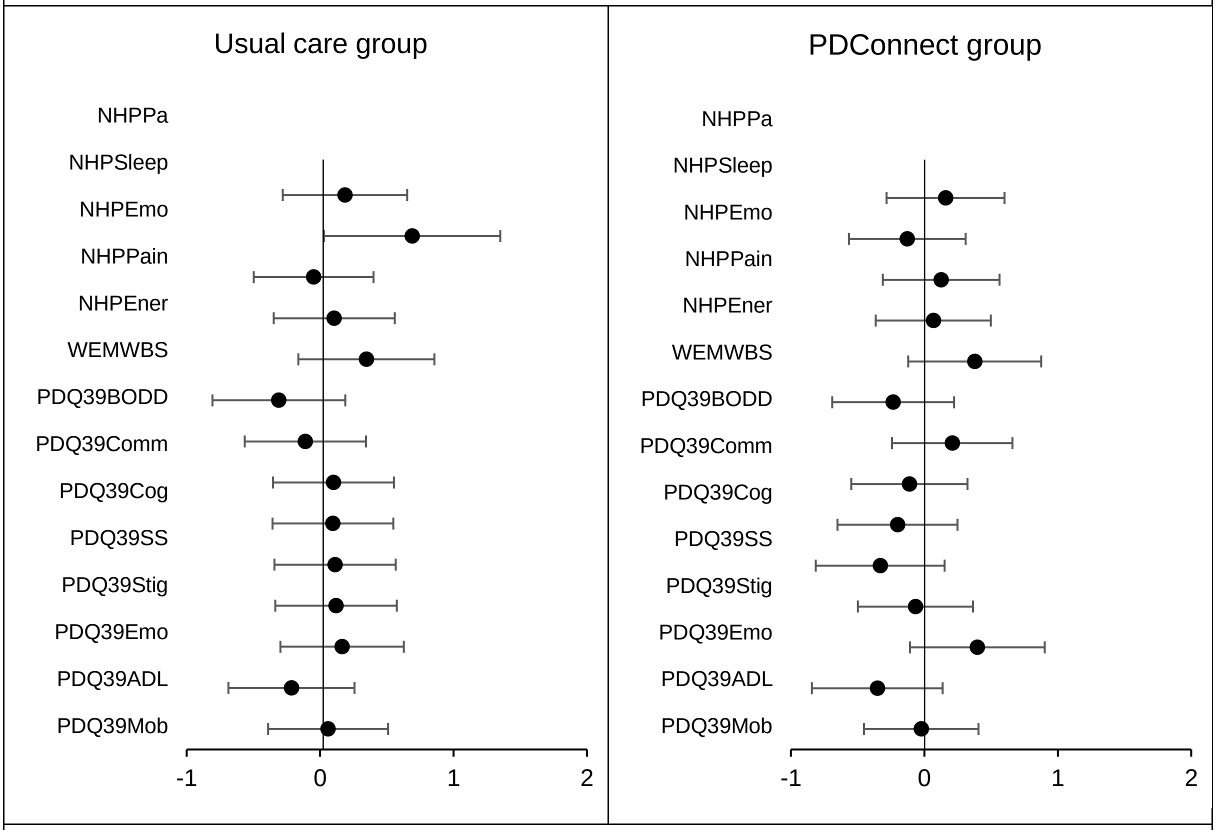
Comparison of the NHP, WEMWBS and PDQ39 effect sizes between the usual care and PDConnect between baseline and 6 weeks



Abbreviations: *NHP: Nottingham Health Profile, NHPPa: Physical activity domain of NHP, NHPSleep: Sleep domain of NHP, NHPEmo: Emotional Reaction domain of NHP, NHPpain: Pain domain of NHP, NHPEner: energy domain of NHP, WEMWBS: Warwick Edinburgh Mental Well-being Scale, PDQ-39BODD: PDQ-39 bodily discomfort domain, PDQ-30Comm: PDQ39 communication domain, PDQ39Cog: Cognition domain, PDQ39SS: Social support domain, PDW39Stig: Stigma domain, PDQ39Emo: Emotional well-being domain, PDQ39ADL: Activities of daily living domain, PDQ39Mob: mobility domain.*

Figure 5.20 Quality of life and well-being effect sizes by group and timepoint

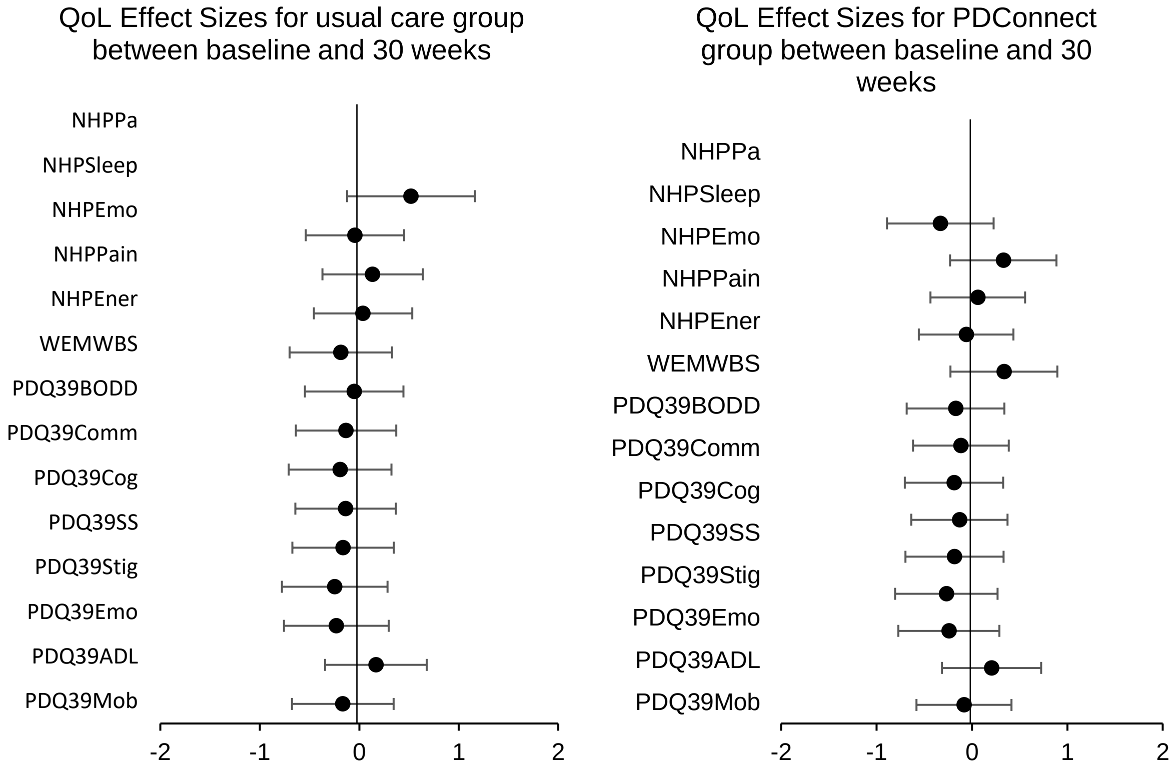
Comparison of the NHP, WEMWBS and PDQ39 effect sizes between the usual care and PDConnect between baseline and 18 weeks



Abbreviations: *NHP: Nottingham Health Profile, NHPPa: Physical activity domain of NHP, NHPSleep: Sleep domain of NHP, NHPEmo: Emotional Reaction domain of NHP, NHPpain: Pain domain of NHP, NHPEner: energy domain of NHP, WEMWBS: Warwick Edinburgh Mental Well-being Scale, PDQ-39BODD: PDQ-39 bodily discomfort domain, PDQ-30Comm: PDQ39 communication domain, PDQ39Cog: Cognition domain, PDQ39SS: Social support domain, PDW39Stig: Stigma domain, PDQ39Emo: Emotional well-being domain, PDQ39ADL: Activities of daily living domain, PDQ39Mob: mobility domain.*

Figure 5.20 Quality of life and well-being effect sizes by group and timepoint (continued)

Comparison of the NHP, WEMWBS and PDQ39 effect sizes between the usual care and PDConnect between baseline and 30 weeks



QoL Effect Sizes for usual care group between baseline and 30 weeks

QoL Effect Sizes for PDConnect group between baseline and 30 weeks

Abbreviations: *NHP: Nottingham Health Profile, NHPPa: Physical activity domain of NHP, NHPSleep: Sleep domain of NHP, NHPEmo: Emotional Reaction domain of NHP, NHPpain: Pain domain of NHP, NHPEner: energy domain of NHP, WEMWBS: Warwick Edinburgh Mental Well-being Scale, PDQ-39BODD: PDQ-39 bodily discomfort domain, PDQ-30Comm: PDQ39 communication domain, PDQ39Cog: Cognition domain, PDQ39SS: Social support domain, PDW39Stig: Stigma domain, PDQ39Emo: Emotional well-being domain, PDQ39ADL: Activities of daily living domain, PDQ39Mob: mobility domain.*

Figure 5.20 Quality of life and well-being effect sizes by group and timepoint (continued)

Parkinson’s Disease Questionnaire-39 (PDQ-39)

The PDQ-19 is a 39 item self-report health-related QoL measure specifically for PLwP. The 39 questions cover 8 dimensions including: mobility, ADL, emotional well-being, stigma, social support, well-being, cognition, communication, and bodily discomfort. Overall score (PDQ-39 SI) are provided in table 5.21, and dimension scores are provided in Table 5.22. No MCID’s exist for the PDQ-39 SI, however higher scores are associated with poorer QoL. PDConnect participants had a higher QoL at all time points compared to the usual care group. PDQ-39 SI which provide a global impact of Parkinson on health status, remained relatively unchanged with small mean differences in both groups at each timepoint.

The means and standard deviations for the PDQ-39 domains are provided in Table 5.22: Within the PDConnect group, small mean changes occurred between baseline and 6 and 18 weeks in the mobility domain suggesting improvement, although as shown in Figure 5.20, a small effect was reported only between baseline and 6 week (MD: 3.13, d=0.36, 95% CI: -0.09 to 0.82) but no effect was reported between baseline and 18 week or 30 weeks. In the usual care group, no effect was reported at any time point as shown in Figure 5.20.

In the ADL domain mean differences fluctuated over the course of the intervention, suggesting some improvements and declines. Mean differences in the ADL score between baseline and week 30 would suggest improvement, this effect was small in the PDConnect group (MD: 5.9, d=0.20, 95% CI -0.31 to 0.72) but no effect was reported in the usual care group.

The cognition, bodily discomfort and communication domains also fluctuated over the duration of the study; large standard deviations exist within that domain suggesting heterogeneity within this domain.

Table 5.21 Summary of PDQ-39 dimension for each group at all timepoints

Dimension	**Baseline Mean (SD)**		**6 Weeks Mean (SD)**		**18 Weeks Mean (SD)**		**30 Weeks Mean (SD)**	
	Usual care	PDConnect	Usual care	PDConnect	Usual care	PDConnect	Usual care	PDConnect
Mobility	20.33 (18.72)	12.03 (15.12)	14.42 (17.59)	8.91 (8.06)	13.84 (12.73)	8.93 (13.47)	12.05 (11.45)	12.21 (21.81)
ADL	18.23 (18.72)	15.62 (14.87)	14.10 (16.36)	8.59 (10.48)	16.98 (13.23)	11.01 (11.16)	14.58 (12.92)	9.72 (9.78)
Emotion	14.72 (13.99)	9.63 (10.94)	10.90 (17.64)	10.15 (14.11)	9.29 (9.02)	7.74 (7.10)	12.50 (12.22)	10.42 (11.31)
Stigma	8.75 (13.32)	5.86 (9.54)	5.29 (6.68)	6.25 (9.41)	4.33 (8.22)	6.70 (12.61)	5.68 (8.59)	3.90 (7.65)
Social Support	4.45 (6.73)	3.65 (7.43)	2.56 (5.25)	1.04 (4.17)	1.92 (4.99)	4.17 (8.49)	3.79 (8.63)	3.64 (7.44)
Cognition	20.00 (16.74)	20.22 (16.18)	13.46 (14.84)	16.41 (12.88)	12.02 (13.61)	19.64 (16.78)	14.77 (15.38)	12.38 (15.86)
Communication	14.44 (15.89)	12.50 (17.48)	10.90 (14.59)	7.29 (10.33)	9.61 (12.19)	8.93 (10.06)	10.78 (8.17)	4.58 (8.16)
Bodily discomfort	35.55 (20.77)	24.48 (21.40)	26.92 (26.17)	17.18 (15.36)	28.77 (26.72)	15.47 (10.77)	28.03 (21.82)	24.72 (24.56)

Nottingham Health Profile (NPH)

The NHP is a self-report 38 item questionnaire that assesses physical mobility, pain, sleep, social isolation, emotional reactions, and energy levels (Hunt et al. 1980). Scores range from 0 indicating no distress to 100 indicating severe distress. No normative data is available for PLwP. Summary scores are provided in Table 5.23. At baseline the PDConnect group, had lower energy levels (36.30 compared with 18.21 in usual care group), whereas pain levels at baseline were higher among the usual care group compared to the PDConnect group (22.71 and 8.43 respectively). All other domains were broadly similar.

Energy levels in both groups improved between baseline and the 6-week time point (Usual care by 7.2 points and by 25 points in PDConnect) however, in both groups scores gradually worsening at all subsequent timepoints returning to levels broadly similar to baseline by week 30. Pain, emotional reaction, sleep, and physical abilities demonstrated some improvement from baseline and remined constant at all other time points, however in these domains scores at baseline were low, indicating potential flooring effect. However as with all previous measures, standard deviations were broad suggesting heterogeneity within the sample. As illustrated in Figure 5.20, the variation in the data for the Nottingham Health Profile is also evident in the ES which showed an overall trend to decline but the confidence interval were broad highlighting the heterogeneity within the sample.

Table 5.23 Comparison of NHP domains between groups

Domain	Baseline Mean (SD)		6 weeks Mean (SD)		18 weeks Mean (SD)		30 weeks Mean (SD)	
	Usual care	PDConnect	Usual care	PDConnect	Usual care	PDConnect	Usual care	PDConnect
Energy level	18.1 (27.07)	36.30 (34.39)	10.90 (26.43)	11.61 (17.25)	23.58 (38.78)	27.84 (34.75)	20.66 (34.56)	35.73 (40.67)
Pain	22.71 (27.49)	8.43 (20.64)	10.61 (16.73)	7.55 (18.29)	12.85 (20.51)	10.71 (26.36)	11.11 (21.17)	11.09 (22.85)
Emotional reaction	12.95 (13.30)	4.54 (5.77)	4.02 (8.03)	4.96 (7.33)	3.51 (9.30)	5.42 (8.52)	5.80 (14.56)	6.44 (10.14)
Sleep	21.38 (25.18)	21.11 (30.34)	22.00 (25.11)	19.61 (26.79)	21.56 (24.47)	9.68 (19.15)	20.28 (22.82)	25.29 (30.14)
Social isolation	5.6 (12.40)	6.82 (12.98)	1.73 (22.53)	12.93 (23.68)	0.00 (0.00)	8.76 (15.77)	0.00 (0.00)	8.90 (16.81)
Physical abilities	13.90 (15.79)	11.16 (15.81)	8.90 (14.22)	7.58 (11.19)	10.81 (12.23)	11.89 (21.72)	75.68 (14.84)	10.08 (14.44)

5.5.5 Global impression of change score

All participants were asked to complete a global impression of change score at week 30. As shown in Figure 5.21, six participants (50%) of those receiving PDConnect reported feeling much improved with a further two participants (17%) reporting a minimal improvement. Conversely, only one participant (10%) reported feeling much improved in the usual care group. More people receiving usual care reported being minimally or much worse by the end of the study compared with those in PDConnect (6 versus 2 participants).

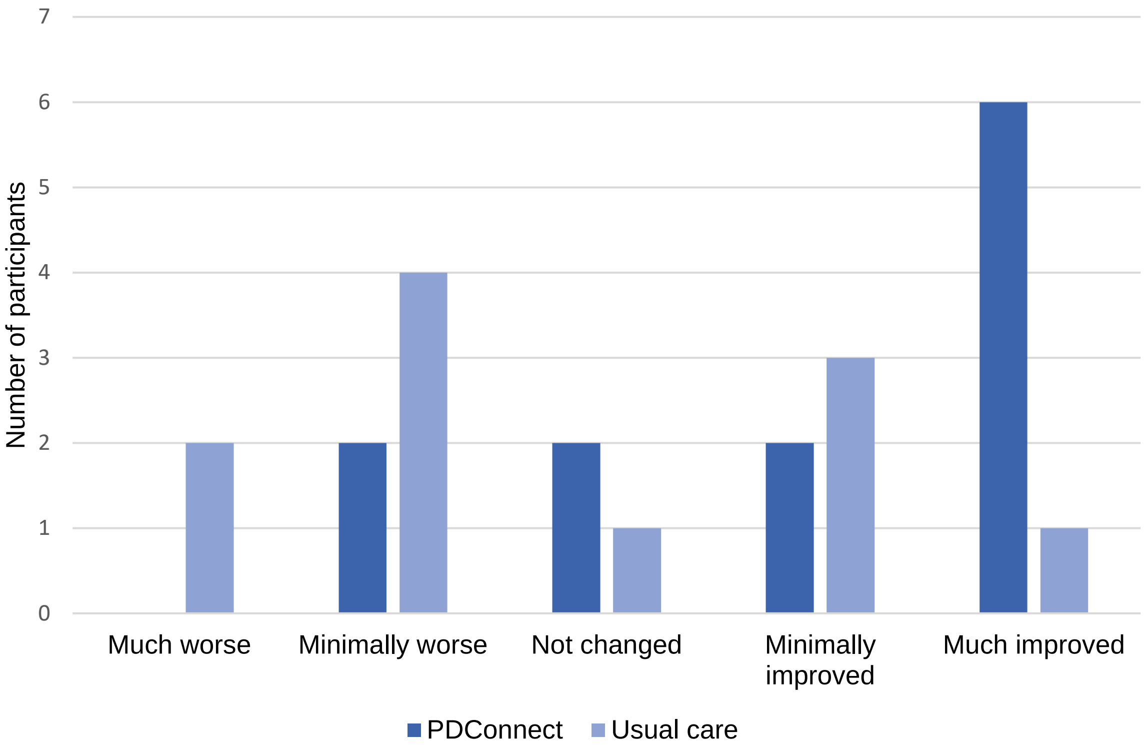


Figure 5.21 Between group comparison of Global Impression of Change scores

5.5.6 Summary of secondary outcomes

This study employed a wide range of outcome measures, which were repeated at four timepoints during the study. Due to the small sample, large variations were seen within both groups with all outcome's measures, indicating lack of uniformity in response for either group. Analysis of secondary outcomes highlighted some trends which are worthy of further exploration in a future study. Trends from descriptive and effect size findings emerging from this study suggest that PASE scores improved over time in the PDConnect group, as well as improvements in motor and total UPDRS scores. Suggesting that these measures hold most promise for consideration within the future trial of PDConnect.

The effect sizes within the PASE were small, whereas small medium and large effect sizes of the UPDRS were reported. This would suggest that the UPDRS would be preferable to use as a primary outcome measure in a future study. However, the UPDRS is widely criticised for being symptom focussed, and with less emphasis placed on the impact on everyday life (Hendrick and Khasawnen 2021). Qualitative interviews conducted in this study explored participants views of what measures were important to them. Physical activity was the most frequently reported, as well as QoL and well-being. As the focus of the PDConnect intervention is to support PLwP to increase PA, using the PASE as a primary measure would seem a pragmatic choice.

5.5.7 Power calculation

Power analysis is a requirement within research to determine the smallest sample size that allows researchers to detect a specified effect of a given test (for example the PASE) at the desired level of statistical significance and power. While large samples increase the precision of estimates and increase statistical power to conduct hypothesis tests, large trials are costly. Power analysis allows researchers to make statistically informed judgements to determine the minimum sample size required.

Power calculations are essential to determine how many people are needed within a study to avoid type II errors and can be performed to enable reliable inferences to be drawn which can be generalised to a population. Type II errors occurs when researchers fail to reject the null hypothesis when they are false (Bowling, 2014). Therefore, power calculations are designed to reject the null hypothesis when it is incorrect.

Based on the quantitative findings of the current feasibility study, the PASE or the UPDRS were considered as primary measures for a future study. As the focus of the PDConnect intervention is to promote increased PA, and support PA self-management, the PASE was selected as the primary measure within a future study. Qualitative findings in the current study highlighted that measures of PA were important to PLwP, which adds further support for adopting the PASE as a primary outcome measure in a future study. It is proposed therefore that the UPDRS, QoL and well-being measures should be used as secondary measures.

Prior to conducting the power calculations several factors need to be considered, including the type of statistical test to base calculations on and the magnitude of the effect to test for. To test whether the PDConnect interventions would create improvements beyond a control, a factorial ANOVA analysis was selected. A factorial ANOVA was selected as multiple factors need to be considered within the analysis for example: time, and group number, therefore a one-way ANOVA would not be appropriate.

Few studies have used the PASE as a primary outcome measure within Parkinson's or within neurology. Prior studies have shown that the PASE has a small response to change ES (d=0.23) with cancer patients (Granger et al. 2015). Based on the data from the current study, the effect sizes difference between the usual care and the intervention groups were small (d=0.003). Therefore an effect size of 0.05 was selected, assuming that a small effect size will be demonstrated within a future trial. A power level of 0.80 was selected, therefore on at least 80% of occasions the null hypothesis would be rejected. The level of significance or α level was set at 0.05, which will allow for a less than 5% chance of rejecting the null hypothesis when in fact it is true (Type 1 error). An r value of 0.5 was selected, reflecting the lower ES reporting in the current study due to the small sample size involved. Based on these variables the sample size calculation using G*Power statistical software estimated that 274 participants per group would be sufficient for 80% power (α = 0.05). However, owing to the PASE estimates being routinely low, and based a small heterogeneity sample samples of between 548 and 1000 maybe required.

Given the participant retention rate demonstrated in the current study, an additional 20% is recommended to accommodate this loss. Therefore, to ensure that a future trial of PDConnect is adequately powered to detect a change in the primary outcome (PASE) a total sample of 658 would be required.

5.6 RESULTS CHAPTER SUMMARY

This study has demonstrated that recruitment and delivery of PDConnect is feasible. This study satisfied all progression criteria except for participant recruitment which fell 1% below the progression criteria. The delivery and experience of participating in PDConnect was shown to be acceptable and satisfactory for participants and staff.

Participants reported that involvement in PDConnect lead to improvements in muscle strength, flexibility, balance, and physical fitness. Participation was also reported to improve PA levels, confidence to be active and provided participants with strategies to maintain PA levels. Participants also reported an improved understanding of the benefits of PA for their Parkinson's. Participant global impression of change scales demonstrated that a larger proportion of PDConnect participants felt much improved at the end of the study compared to those in the usual care group.

Three key themes were identified from the participant qualitative interviews. These themes surrounded participants experience of the research process, experience of the intervention delivery and perceptions of impact of participation in PDConnect. Participants found the research process acceptable and understood the need for research processes such as randomisation. Experience of intervention participation was positive. Online delivery of PA was regarded as acceptable, reducing the barriers typically associated with PA, such as transportation. Participants provided recommendations of how the online experience could be enhanced within a future trial to optimise engagement and develop social connection. Staff were perceived to play a pivotal role in intervention delivery. In particular the provision of a personalised approach and the staffs motivation and support with intervention delivery was highly valued by participants. Study specific resources were perceived as acceptable. Modifications were recommended in relation to the future delivery of the PDConnect manual, and the use of the activity tracker.

Analysis of the secondary measures highlighted some promising trends which warrant further exploration is an appropriately powered study. Due to the small sample size, large variation existed within the data, however based on the findings of this study, it is proposed that the PASE measure be used as a primary measures within a future trial, with the UPDRS, health and well-being and QoL as secondary measures. Using the PASE as a primary measure, it estimated that 274 participants per group would be sufficient for 80% power ($\alpha = 0.05$). In recognition of the retension rate demonstrated in the current study, an additional 20% is recommended to accommodate this loss. Therefore, to ensure that a future trial of PDConnect is adequately powered to detect a change in the primary outcome (PASE) a total sample of 658 would be required.

CHAPTER SIX – DISCUSSION

The aim of this study was to determine the feasibility and acceptability of a multi-component intervention (PDConnect) aimed at promoting PA and self-management among PLwP. This study demonstrated that PDConnect is feasible and acceptable, satisfying all progression criteria, except for participant retention, which was within 1% of meeting this criterion. This chapter highlights the key findings from the study and discusses them in the context of existing literature. It then considers the strengths and limitations of this study and makes recommendations for future research.

6.1 REVIEW OF KEY RESULTS

The feasibility outcomes of this study and progression criteria included participant recruitment, participant retention, intervention attendance, outcome measure response rate, safety, and intervention fidelity. Except for participant retention, all progression criteria were met. Participant recruitment was completed within twelve weeks, participants attended 100% of all physiotherapy sessions, and 83% of group-based exercise sessions, and attended all self-management sessions. Outcome measurement response rate was 99%, and 84% of activity diaries were completed and returned. No adverse events were reported during intervention delivery or participation in HEP. Intervention fidelity was high with 88% compliance with session plans. Participant retention rate was 74%, one percent below the a priori progression criteria.

Acceptability outcomes included perceptions, experiences, and satisfaction with the delivery of, and participation in PDConnect. PDConnect was perceived as highly acceptable, and participants and staff reported high levels of satisfaction. Intervention content, support materials and mode of delivery were acceptable and appropriate for participants and staff. Future modifications to the participant manual, the IT induction and the activity tracker were suggested by participants and staff. Perceived improvement in PA levels, PA confidence, motor symptoms, physical parameters such as muscle strength and the ability to self-manage PA were reported by participants. Staff played a pivotal role in motivating and supporting participants to be active, and the online environment was perceived to reduce PA barriers but was limited in the promotion of social interaction.

Secondary measures including PA, motor and NMS, QoL, and health and well-being measures were nested in this feasibility study to identify which measure(s) may be appropriate for use within a future trial, and to inform sample size calculation. When asked what measures were important to measure in a future trial, measures of PA, well-being, and QoL were most valued by participants. Step count improved in both groups, as did the PASE scores, although standard deviations were large indicating a lack of uniformity of response. Preliminary descriptive analyses indicated an improvement in both groups in relation to the UPDRS. Small to large ES indicated improvement across a range of outcomes, although confidence intervals were large indicating low precision. Large ES for improved Parkinson's symptoms using the UPDRS were reported in favour of PDConnect between baseline and 30 weeks.

6.2 DISCUSSION OF RESULTS IN CONTEXT OF CURRENT RESEARCH

This section discusses the results in relation to prior research and explores how the results from this study contribute to the PA evidence base for PLwP. Section 6.3 will discuss the feasibility objectives in relation to the PDConnect study prior to discussing acceptability of the intervention in section 6.4.

6.3 FEASIBILITY OF DELIVERING PDCONNECT.

6.3.1 Objectives 1 and 2: Feasibility of participant recruitment processes

The recruitment rate in this study was 2.6 participants per week, with the target population achieved within 12 weeks. The recruitment rate in this study exceeds the median recruitment time of 0.2 participants per month reported in a review of RCT's funded by the United Kingdom Health Technology Assessment Programme (Walters et al. 2017). The current study finding also contrasts with findings from Parkinson's UK which highlighted that many trials struggled to recruit to target between 2020-21 (Personal communication). Recruitment to Parkinson's trials is acknowledged as challenging due to the age of the Parkinson's community, potential for cognitive impairment and co-existing morbidities (Picillo et al. 2015). It is estimated that over 85% of Parkinson's trials are delayed due to recruitment, and 30% are discontinued due to failure to recruit (Dobkin et al. 2020).

Several factors individually and collectively may explain the high recruitment rate in the current study. Firstly, combining consultant recruitment with a national approach using the Parkinson's UK Take Part Hub may have increased awareness of the project at a time when NHS appointments were significantly restricted due to COVID-19. Secondly, engagement in PA has been widely promoted by Parkinson's UK, resulting in an increased awareness of the value of PA which may have positively influenced recruitment. The recruitment rate may also reflect the demand for PA by PLwP. The 2017 Parkinson's UK audit identified that less than half of PLwP are referred to Physiotherapy to receive guidance on PA (Parkinson's UK, 2017), with the majority of people only receiving guidance when gait and balance dysfunction impact on functional capacity. Equally, prior systematic reviews highlight a supply and demand issue, with lack of access to PA cited as a barrier to involvement (Allen et al. 2012; Hunter et al. 2019).

The researcher is also well-known within the Parkinson's community, which may have further influenced participant recruitment. Thirdly, no restriction was placed on age within the inclusion criteria which is a commonly cited barrier to research recruitment in Parkinson’s (Vaswani, Tropea and Dahodwala 2020), with those who are older commonly excluded due to safety considerations. Finally, recruitment coincided with COVID-19, therefore the appetite for interventions supporting PA participation was potentially greater as access to PA was significantly reduced (Simpson et al. 2022). Future trial recruitment may take longer due to the legacy of COVID-19 which has resulted in longer Consultant waiting times. This may negatively impact consultant-based referrals. In addition, local community PA opportunities are now widely available which were not at the time of recruitment, therefore appetite to participate in a PA research study may be less attractive. However, the absence of COVID-19 opens potential to consider other recruitment pathways such as Physiotherapists and third sector organisations which were not possible at the time of this study, therefore may mitigate the impact of Consultant waiting times.

The aforementioned factors may have positively influenced the recruitment rate reported in this study. However, these factors may also have resulted in the recruitment of a select sample who were more motivated and well-informed than the typical Parkinson’s population. The mean age of participants in the current study was 66.4 years, therefore may not be typical of the wider Parkinson's population. A recent systematic review highlighted that the mean age of PLwP participating in research was 60, yet the typical age of onset of Parkinson's is 69.6 years (MacLeod et al. 2018) suggesting that typically research participants are generally unrepresentative of the population age distribution of Parkinson’s. In addition to age, PA studies involving PLwP have been criticised for recruiting only those in the early stages (Hoehn and Yahr stages 1-1.5) of Parkinson’s (Ellis and Rochester 2018). In the current study, 57% of participants were classified in the mid-stages of Parkinson's (Hoehn and Yahr stage 2.5-3), despite the mean age of the sample being younger than the typical Parkinson’s population.

Suggesting that this study has demonstrated that it is feasible to recruit and safely deliver online PA to those in the early to mid-stages of Parkinson's.

Due to convenience sampling, a quarter of participants heard about the study through the Parkinson's UK Research Support Network, therefore are potentially drawn from a research informed population, which may not be representative of the wider Parkinson's community. A survey conducted by the Michael J. Fox foundation highlighted that although 80% of PLwP indicated they would consider participating in a trial, fewer than 10% participate (Vaswani, Tropea and Dahodwala 2020). Recruitment of a small proportion of the Parkinson's community limits generalisability and understanding of impact of interventions (Vaswani, Tropea and Dahodwala 2020).

The sample in the current study was also small, with limited cultural diversity. Arguably the sample demographics was not culturally diverse it reflected the majority culture in the Northeast of Scotland, however this does not reflect the picture nationally. As a small feasibility study, this study did not aim to recruit a representative sample, however future research needs to consider a more culturally diverse population. A cross sectional study involving Asian, Black, and White PLwP, demonstrated that the Black and Ethnic Minority (BME) communities present with a different Parkinson's phenotype with a greater motor and NMS burden, shorter disease duration, and higher rate of cardiovascular co-morbidities (Sauerbier et al. 2021). The BME Parkinson's community therefore are potentially at greater risk of deconditioning, and a higher rate of cardiovascular pathology emphasising the need for individual tailoring of PA prescription. In addition, it is widely accepted that the barriers and motivators towards PA differ among under-served communities (Koshoedo et al. 2015; Ige-Elegbede et al. 2019). A meta-ethnographic synthesis exploring the barriers to PA among BME groups without Parkinson's, demonstrated that PA is commonly perceived as a Western concept, resulting in lower PA engagement within these communities (Koshoedo et al. 2015). The perception that PA requires special clothing, and attending a gym, were highlighted as key barriers to maintaining cultural norms and therefore PA involvement (Koshoedo et al. 2015). Similarly, a qualitative systematic review highlighted that within certain cultures there was an expectation that women should stay at home, thereby limiting PA involvement (Ige-Elegbede et al. 2019). In contrast, for men PA was not deemed necessary due to the physicality of their work (Ige-Elegbede et al. 2019). Neither of these two reviews involved PLwP; however, they highlight a range of different factors which need to be considered to support PA engagement in underserved populations.

Future inclusion of a culturally diverse sample including under-served groups of PLwP is paramount to ensure the findings of a future PDConnect trial will translate into real-world application. Vaswani, Tropea and Dahodwala (2020) made several recommendations to promote the recruitment of a diverse sample, many of which were adopted within the current study, for example: collaborative recruitment strategies and involving PLwP in the development of participant facing documentation. Recommendations from a recent rapid review on research inclusion included developing cultural competency of the research team, and the inclusion of a diverse advisory panel to support inclusion within the research process (Bodicoat et al. 2021). These recommendations need to be considered within a future trial of PDConnect. Recruitment in the current study was conducted in the Northeast of Scotland due to proximity to the researcher. A further recommendation for a future trial of PDConnect would be to conduct a multicentre trial, including parts of the UK where population diversity is greater. A multi-centre study could also address other under-served communities such as those living remotely and rurally, and thus reduce health inequalities within these communities by providing access to a specialist service currently not available to them. However, a future study would also need to make sure adequate provisions are in place for example, providing Wi-Fi enabled devices, to avoid digital exclusion among those living remote and rurally.

6.3.2 Objective 3: Feasibility of staff recruitment processes

COVID-19 had a negative impact on recruitment of staff. The recruitment period (November 2020-February 2021) coincided with NHS staff redeployment to support the national immunisation programme. World Physiotherapy estimate that 90% of Physiotherapy services in Europe were disrupted because of COVID-19, with only essential services being staffed at that time (World Physiotherapy 2022). Due to the impact of COVID-19 on the work environment, staff were less willing to take on new roles, despite backfill and funding being available. Widening of recruitment to include private and bank Physiotherapists was necessary to achieve the staff required to deliver this study. As the legacy of COVID-19 continues to negatively impact service provision, the ability to recruit staff remains a threat to research practice nationally. A future trial may therefore need to plan for a longer recruitment period to ensure successful staff recruitment, or alternatively, directly employ staff to deliver the intervention.

6.3.3 Objectives 4 and 5: Participant retention and reasons for withdrawal

In the current study participant retention fell one percent below the threshold (75%) for progression to a full trial. Limited literature exists on retention rates in PA studies, particularly for online PA interventions due to the infancy of this mode of delivery (Quinn et al. 2020). Landers and Ellis (2020) reported a retention rate of 87% following a Parkinson's telehealth-based intervention. However, this study was a walking programme supported by telehealth, therefore what was required of participants as well as the intervention dose differed from the PDConnect intervention. A systematic review including 26 studies on the effectiveness of PA interventions for sedentary older people, reported that the attrition rate was 28% (Howlett et al. 2019) which is comparable to the current study. A systematic review exploring recruitment and adherence rates in face-to-face Parkinson's PA trials reported that 69% of the 90 studies retained at least 85% of participants (Allen et al. 2012). However, 70% of the PA interventions included in the Allen review were of short duration, lasting ten weeks or less (mean 8.3 weeks), which may explain the higher retention rates compared with the current study which lasted 30 weeks. Longer duration studies such as the ‘ParkInShape’ study, which compared high intensity aerobic cycling with a stretching programme, had an attrition rate of 19% (van der Kolk et al. 2019). Both groups exercised three times a week for six months, 22% of the aerobic group and 17% of the stretching group withdrew from the study, which again is broadly similar to retention rates reported in the current study. In the current study, two participants withdrew within the first two weeks having never commenced the intervention, with the remaining six withdrawals occurring after 12 weeks. Withdrawal of six participants was attributed to health conditions not associated with Parkinson's. A future trial of PDConnect therefore needs to recruit a large sample to ensure that it is adequately powered, and also needs to consider over-recruiting participants, to acknowledge the impact of intervention duration, and the prevalence of co-morbidities. In the current study, six participants were withdrawn on health grounds, therefore an additional 20% of participants may be required above that indicated from sample size calculations, to allow for inevitable attrition.

Inclusion of progression criteria is a requirement of the CONSORT extension for pilot and feasibility studies (Eldridge et al. 2016a), however limited guidance exists to facilitate interpretation of progression criteria (Mellor et al. 2021). Avery et al. (2017) recommends that data relating to progression criteria should not be considered in isolation. Rather, additional data should be used to support decision making about whether a study should proceed to a full trial or not (Avery et al. 2017). Similarly, a methodological review on the characteristics of progression criteria involving 160 studies indicated that progression criteria were often considered in parallel with other factors integral to trial success, such as intervention acceptability (Mellor et al. 2021). As all other progression criteria were met in the current study, and high satisfaction and acceptability were reported by participants and staff, would indicate support to progress PDConnect to a future trial.

6.3.4 Objective 6: Intervention attendance

Intervention attendance in the current study was 100% in both groups for the Physiotherapy component and 83% for the group-based component. Attendance in the current study was comparable to an Australian study where telehealth participants attended 84% of the sessions (Flynn et al. 2021). Limited research exists to guide what constitutes high, medium, or low attendance, owing to a variety of definitions and measures being used between studies (Hawley-Hague et al. 2016). A study exploring a combined educational and PA intervention for low back pain (LBP) categorised high attendance as above 69%, and medium above 38% (Ris et al. 2021). However, a systematic review on adherence to therapeutic exercise for LBP, categorised high between 80 and 99%, and low between 0-79% (Nicolson et al. 2017). Applying either of these criteria to the current study would suggest attendance was high. In contrast, a 12-month study exploring the feasibility of the Monash Health and Fitness programme for PLwP which was delivered face-to-face, reported that PLwP attended 30% of the sessions (Danoudis and Iansek 2022). While online delivery of PA remains in its infancy, the online medium may serve to mitigate many of the barriers associated with PA, which may explain the higher attendance reported in online studies compared to the Monash Study. Due to the design of the current study, the impact of online delivery on attendance cannot be ascertained. However, participants reported that online delivery removed PA barriers, particularly transportation, with many stating that had PDConnect not been online they would have been unable to attend. What remains unknown is whether online delivery promotes enhanced attendance compared to face-to-face delivery, or whether individual components within an intervention are pivotal in influencing attendance. Future research comparing matched interventions delivered online and face-to-face is required to explore this further.

A recent qualitative study explored the factors which promoted long-term PA attendance. Cleary, Rossi and States (2020) identified that a varied and challenging workout delivered by staff who were knowledgeable about Parkinson’s provided motivation to regularly attend a PA intervention. In addition, the belief that PA was beneficial for the Parkinson’s community was an influential factor by prior research (Cleary, Rossi and States 2020). Similar findings were reported in the current study: participants reported that staff played a pivotal role in motivating and challenging them in relation to their PA. Participants felt they had to match the effort put in by the staff. Participants in the current study reported that the motivation provided by staff challenged their perceptions about what was possible, which promoted attendance as they felt inspired. Staff knowledge of Parkinson's was also identified in the current study as a factor which motivated participants, providing reassurance among participants that they were doing the right type of PA for their Parkinson’s.

Gaining strength and inspiration from being active with others was another theme identified by Cleary, Rossi and States (2020). A similar theme was not identified within the current study, which could be attributed to the online delivery compared to face-to-face delivery in the study conducted by Cleary, Rossi and States (2020). In the current study, participants perceived that online delivery offered limited capacity for social connection. Strength and inspiration to attend was drawn only from the staff delivering the intervention rather than from peers. The importance of social cohesion, highlighted by Cleary, Rossi and States (2020) is consistent with the conclusions of a qualitative systematic review conducted by Hunter et al. (2019), highlighting the importance of social connection to support long-term PA participation for PLwP. The impact of PDConnect on long-term PA was beyond the scope of this study; however, current evidence would indicate that social connection is integral in supporting PA, therefore modifications may be required to facilitate social connection prior to conducting a future trial. The perceived limitations associated with online delivery and future recommendations are discussed in more detail in section 6.7.

The high attendance reported in the current study could be attributed to COVID-19. Limited supervised PA opportunities were available at the time of the study, with closure of leisure facilities, community PA classes, and access to Physiotherapy due to COVID-19. Therefore, the lack of alternatives could have promoted attendance. However, participation was unanimously reported as a positive experience, with many reporting sadness when it stopped. Several participants reported willingness to personally fund the Fitness Instructor to continue to deliver the classes, suggesting that adherence was not solely attributed to COVID-19. Participants willingness to fund further sessions while positive, also raises the need to consider the sustainability of PA long-term. At the time of the study, opportunity to signpost participants to local PA was limited due to COVID-19. It would be recommended within a future trial, that supporting transition post-intervention, to local opportunities would be required.

Qualitative findings indicated that continuity offered by the weekly supervised sessions, and the motivation provided by staff were key motivational factors promoting attendance. These findings are in keeping with prior studies, which have demonstrated that supervised PA positively influences attendance as well as PA behaviour. Lai et al. (2020) compared self-regulated exercise (SRE) with supervised exercise delivered via a tele coach. The SRE group demonstrated 35.9% lower attendance, spent 48% less total time exercising, and 74.5% less time exercising at moderate intensity compared to the tele-coach assisted exercise. Similarly, the PDSafe study - an exercise intervention aimed at reducing falls in Parkinson's-highlighted that supervision was associated with greater effort and commitment to participating in PA

(Rowsell et al. 2022). Supervised PA has been shown to be more effective than unsupervised PA in other long-term conditions such as arthritis, intermittent claudication, and cardiovascular disease (Fokkenrood et al. 2013; Vemulapalli et al. 2015; Chaudhry et al. 2022). The dependency on supervision may be greater among PLwP due to the low motivation caused by dopamine dysregulation combined with the high prevalence of apathy and fatigue (den Brok et al. 2015). Establishing whether participants in the current study were dependent on supervision was out of the scope of the current study; however, PA levels (step count and PASE scores) remained relatively unchanged between weekly and monthly supervised components of PDConnect, suggesting that PA did not decline when supervision levels were reduced. Yet, many reported that they missed the weekly sessions, suggesting that the value of supervision is not restricted to promoting PA.

In the current study, participants reported that weekly supervised sessions provided continuity, with participants valuing feedback on their performance, and opportunity to problem-solve PA barriers which facilitated the development of exercise confidence. This finding is in keeping with systematic reviews which found that interventions including feedback on performance, and self-monitoring, positively influenced self-efficacy among healthy older adults (Ashford, Edmunds and French 2010; French et al. 2014). Development of self-efficacy has been identified as a key determinant of PA in PLwP. A cross-sectional study involving 164 participants demonstrated that PLwP who report high self-efficacy were twice as likely to engage in regular PA than those with low self-efficacy (OR: 2.34, 95% CI: 1.30–4.23). More recently, Stevens, Stanton and Rebar (2020) suggested that self-efficacy and PA are self-perpetuating, with improved self-efficacy serving as a catalyst for maintaining motivation to be active as well as increasing PA levels. This perpetuating cycle was seen in the current study with self-reported confidence and PA engagement being reported by participants.

Staff were perceived as pivotal in the current study. The motivational nature of staff, their ability to personalise intervention delivery, and make the sessions enjoyable were key factors promoting attendance. These findings are consistent with prior qualitative systematic review findings (Hunter et al. 2019), and more recent mixed-methods and quantitative studies summarised in table 2.2. The impact of staff training or the use of motivational coaching within the delivery of PDConnect cannot be determined from this study; however, the current study adds to current evidence base demonstrating that the key attributes of staff delivering PA for PLwP include: motivational, knowledgeable, caring, and an ability to make sessions fun and enjoyable.

6.3.4.1 Reasons for non-attendance

Holidays accounted for 63% of absences, with a further 13% attributed to medical appointments. The group component was delivered between mid-April and July 2021, which coincided with the summer holiday period and the relaxing of the year-long COVID-19 travel restrictions, which may explain the high proportion of absence for holidays. Several participants had become grandparents during the study and/or had children living abroad, therefore the motivation to visit family after a year of restricted travel was high. Some participants continued to participate even though they were on holiday, but for others, due to their holiday destination, this was not possible. The potential to participate in supervised online PA, even when on holiday further highlights the flexibility online delivery offers over more traditional modes, which may appeal to a variety of ages and in addition support the long-term delivery of PA.

6.3.5 Objectives 7 and 8: Outcome measurement and activity diary return rate

6.3.5.1 Outcome measure response rate

Following the CONSORT extension for pilot and feasibility studies the current study used several outcome measures to inform which measures would be most appropriate for use in a future trial (Eldridge et al. 2016a). Completion of measures conducted by the researcher was 100%. The response rate of self-administered measures was 99%. The positive response rate may reflect that participants were cognisant that their involvement in this study may potentially benefit the wider Parkinson’s community, and the role of the research in shaping future service provision. Altruism is frequently cited in the research as a factor which motivates people including those with Parkinson's to participate in research (Valadas et al. 2011; Olsen, DePalma and Evans 2020). Interview data indicated that participants felt a sense of loyalty to the study once they had consented to participate and a sense of giving back was widely reported, which may also explain the high response rate. As mentioned previously, the high response rate may be indicative of a highly motivated, research- informed sample.

6.3.5.2 Activity diaries return rate.

The return rate of activity diaries was also high (n=22, 92%), and is broadly comparable to larger RCT’s such as PDSafe, where diary completion was between 85 and 89% (Chivers Seymour et al. 2019). Interview data highlighted that divided views existed in relation to preference for paper or online activity diaries. Interview data highlighted that environmental sustainability, and micrographia were key motivators for an online format. Conversely, ease of looking back at the prior week’s activities, and no requirement to log on to a device to access the diary were reported as motivational factors for paper-based diaries. The relationship between age and IT confidence was not explored; however, interviews suggested that micrographia, prior IT experience, and the type of device used were influential factors for online preference, rather than age. Preference for online was also demonstrated with 70% of participants in the current study opting to complete the self-administered measures online rather than on paper. Using online means to collect data is associated with improved accuracy, and lower costs (Vaswani, Tropea and Dahodwala 2020). Online data collection may also assist with streamlining of participants data collection reducing participant burden and aiding participation retention.

The potential for inaccuracy and unreliability when using diaries with PLwP has been highlighted previously (Papapetropoulos 2012). The Movement Disorders Task Force convened a panel of experts to identify a set of evidenced-based characteristics for an e-diary. While some of the criteria developed specifically target motor fluctuations, the recommendations highlight the value of data visualisation, clinometric properties, and technology-based outcome measures which could be applicable to an e-PA diary (Vizcarra et al. 2019). These recommendations advocate that e-diaries should include visual representation of patient activity, percentage completed, and progress reports. In addition, active data collection including questions, tasks, visual analogue scales, combined with passive data collection such as wearable activity trackers, which can be completed anytime regardless of time or place (Vizcarra et al. 2019). The development of an e-diary requires further consultation with the Parkinson's community prior to conducting a future trial of PDConnect. Recognising the variation in preference, and digital literacy, further co-production work involving PLwP is recommended prior to a future trial to ensure resource accessibility and to minimise digital exclusion (Ellis and Earhart 2021).

6.3.5.3 Time taken to complete outcome measures

Feasibility outcomes also included the time taken to complete measurements to guide scalability and practicality of a future trial. The mean time to complete researcher-administered measures was 24 minutes, and 57 minutes for participants to complete the self-administered measures. Completion of measures and time commitment for research have been highlighted as barriers to research participation among PLwP (Vaswani, Tropea and Dahodwala 2020). In the current study the completion of measures was not perceived as burdensome, but the measures themselves were widely reported as repetitive. Overlap existed between questionnaires, which was unavoidable, and was understood by participants to be a necessary part of the research to establish which measures should be included within a future trial. Some participants found specific measures irrelevant, for example Parkinson's Fatigue scale (PFS), as they were unaffected by this symptom. A similar trend emerged with other NMS measures suggesting that the impact and/or distribution of NMS varied between participants. A cross sectional study involving 402 PLwP reported that the mean number of NMS reported by PLwP was 16, with over half of the participants reporting that their NMS fluctuated with time (Rodriguez-Blazquez et al. 2021). Variation in reporting of NMS may also reflect the broad inclusion criteria adopted in the current study. Over half of the sample were categorised as Hoehn Yahr stage 2.5-3.0, and prevalence of NMS has been reported to increase with Parkinson's severity (Chaudhuri 2006). Prior to conducting a future trial of PDConnect, careful consideration is required in relation to selecting NMS measures. A recent systematic review highlighted that NMS were improved with PA, providing justification for including NMS measures in a future trial. Due to the fluctuating nature of NMS and variation in presentation between participants, adopting a patient global impression of change scale (PGIC) specifically in relation to NMS maybe preferable. PGCI's have been used in Parkinson's research and have been shown to correlate with UPDRS change scores to a stronger degree than clinical impression of change scores (Dashtipour 2015). PGIC's offer many advantages. PGCI's are easy to use as participants are asked to rate the difference between their current and previous NMS on a Likert scale. More importantly, they allow participants to select a construct for example, fatigue or apathy which they judge to be important to their health, ensuring the relevance of the data collected to that individual.

When planning the development of a future trial, scalability and participant burden needs to be considered. Over the course of the study, the mean time spent by participants completing self-administered measures was 228 minutes and 96 minutes per participant to complete the researcher-based measures. In addition to self-administered measures, participants were asked to document step count, attend the intervention, and participate in HEP's. Collectively this has the potential to be burdensome which may negatively impact completion rates, and/or intervention adherence, as well as pose financial implications for future trial delivery. An objective of the current study was to identify which measures should be included within a future trial. Health and well-being, QoL and PA were highlighted by participants as preferable, therefore future participant and staff burden would be anticipated to be smaller following streamlining of measures. Participant burden is widely recognised as a concept but is poorly defined and quantified (Lingler et al. 2014). Based on work within Alzheimer's, Lingler et al. (2014) highlighted that measurement frequency carried greater burden compared with assessment length. Lingler et al. (2014) made several recommendations to offset participant burden, some of which were included within the current study such as patient reported outcomes, and options in relation to completion. However, the use of technology was also advocated, which could be explored further within a future trial of PDConnect.

Completion of the UPDRS is recognised as time consuming (Jha et al. 2020). A proof-of-concept study (Kassavetis et al. 2016), and cross validation study (Jha et al. 2020) highlighted the potential of smartphone technology to reliably assess the motor subsection (UPDRS III) negating the need for researcher involvement. Smartphone technology provides a flexible, low-cost objective approach to repeated monitoring of motor symptoms, facilitating scalability and improved quality of data collection. Large research consortiums such as Mobilise-D are developing validated digital mobility outcomes with the aim of informing personalised care and improving healthcare delivery that can be reliably used within clinical trials (Mobilised-D, 2022). Use of technology to support outcome measurement was not considered in the current study. Recognising the growing body of research highlighting the merits of using smartphone technology, the use of digital solutions to enable objective assessment requires further consideration for application within any future trial.

6.3.6 Objective 9 Adverse events

No adverse events were reported during the delivery of the intervention, or when participating in HEP's. Eleven falls were reported during the study, but these were not attributed to the intervention (Usual care n=8, PDConnect n=3). The falls rate in the current study (35%) was lower than shown in prospective Parkinson's study which reported falls rates between 45 and 68% (Paul et al. 2014). In the main, falls were minor slips and trips, however two falls required hospitalisation, one requiring an overnight stay, the other required orthopaedic surgery for a tri-malleolar fracture. The lower rate could be indicative of the younger age of the sample and/or the lower disease severity indicating less balance dysfunction.

Fewer falls could also be attributed to the environmental risk assessments conducted prior to commencing the study, and the inclusion of health and safety checks within weekly staff session plans. Equally, dependency on retrospective recall of falls may have resulted in an underestimation, a factor reported previously among PLwP (Hunter et al. 2018). Participants were asked to record and report any falls immediately, as this has been shown to improve recall accuracy (Allen, Schwarzel and Canning 2013). However, falls tended to be reported at the assessment points, highlighting potential for recall bias, which may explain the lower falls rate reported.

Unsupervised home-based PA interventions are becoming more common, therefore the ability to capture accurate and more importantly timely data on falls to inform current and future rehabilitation is essential. Use of smartphone technology may allow more accurate data collection in relation to time, location, and severity of falls, reducing dependency on recall. The inclusion of apps such as the iFall which has been co-produced with PLwP (Morris et al. 2022), and is currently undergoing feasibility assessment could be considered within a future trial involving PDConnect, to improve the accuracy of reporting and reduce research and participant reporting burden.

6.4 ACCEPTABILITY OF PDCONNECT

PDConnect was regarded as acceptable, and satisfaction was high among participants. Participation in PDConnect was regarded as a positive experience, with all participants stating that they would recommend PDConnect to other PLwP. Participants reported that PDConnect achieved its aim of increasing levels of PA and supporting PA self-management. As a multi-component complex intervention, it is unlikely that any single aspect, or component of PDConnect can directly explain the satisfaction, and acceptability reported by participants. Rather, acceptability and satisfaction are likely to be attributed to several co-existing and co-dependent factors. This section will begin with discussing the acceptability of the PDConnect intervention. In particular, the online delivery of PDConnect, the experience of individual components of PDConnect, the study resources and the perceived benefits of PDConnect will be explored. Finally, acceptability of the factors associated with the study design and methodology will be discussed. The key findings will be explored, and discussed in the context of existing research, and will highlight issues for consideration for future trial delivery.

6.4.1 Acceptability of online delivery of PDConnect

Historically, research has focussed on PA interventions undertaken within clinical or community settings (Colón-Semenza et al. 2018). Online delivery of healthcare including PA is becoming more prevalent. However, research on online delivery of PA within Parkinson's is limited (Quinn et al. 2020). The current study demonstrated that online delivery of PDConnect was acceptable to those delivering and receiving PDConnect. However, refinements were also identified which warrant further exploration prior to undertaking a definitive trial.

Overall, participants found the delivery of PDConnect using Microsoft Teams acceptable, adding to the growing body of evidence supporting the use of online delivery in the management of PLwP including PA (Dorsey et al. 2016; Lai et al. 2020; Shah et al. 2020; Larson, Schneider and Simuni 2021). The Scottish government predicts greater future use of telehealth (Scottish Government, 2021); therefore, the findings of this study are timely, demonstrating the feasibility and acceptability of online delivery of PA for PLwP.

Undoubtably, the acceptability of online delivery via Teams may be reflective of the absence of face-to-face PA options at the time of the study, which may have biased responses as discussed previously. However, participation in PA online was perceived as convenient, reducing barriers associated with transport, costs, and stigma, which is congruent with a prior systematic review (Hunter et al. 2019), and more recent mixed methods studies (Lai et al. 2020; Shah et al. 2020; Bennett et al. 2022), suggesting that COVID-19 was not the sole factor influencing acceptability.

The benefits of online delivery reported in the current study are similar to those reported by Bennett et al. (2022) who explored the experiences and perceptions of PLwP who participated in the PDEX programme which incorporated the Parkinson's Wellness Recovery approach to PA. Participants in the PDEX study received face-to-face delivery prior to transitioning to online delivery. Bennett et al. (2022) reported that PLwP's preference was for online delivery, due to the convenience this offered. Similarly, participants who took part in a feasibility study of the Engage-PD intervention, a PA coaching programme delivered online, reported that over half of the sample would not have chosen to participate had it not been delivered online (Shih et al. 2022). In the current study, participants reported that the convenience offered by online delivery mitigated issues with transport infrastructure, rurality, distance, and dependency on others, which all promoted attendance. A large proportion of participants lived more than 15 miles away from Aberdeen city. Public transport can be infrequent, requiring multiple changes, which was a perceived barrier for attending face-to-face sessions. Some participants lived 80 miles away from Aberdeen, making attending a face-to-face session in Aberdeen impractical and not sustainable. The convenience of online delivery was also recognised by staff in the current study, as PDConnect provided opportunity for participants to access a specialist service which would otherwise not have been available to them. The Kings Fund reported that the lack of access to services, particularly for those with long-term conditions, was a key factor influencing health inequalities (Kings Fund, 2013). Therefore, in Scotland where health inequalities are well-documented (The Health Foundation, 2023), an online approach may help to address the divide in access to health care. Recent population statistics indicate that nearly a third of Scotland's population live in accessible small towns, remote small towns, and remote rural areas, accounting for over 1.5 million of the total population (Scottish Government, 2021). Those living in these areas have a higher median age than those living in urban areas (Scottish Government, 2021). Therefore, provision of online PA may offer a pragmatic solution to offering access to specialist services while also addressing current health inequalities.

Online delivery of PA was shown to be acceptable in the current study, and as highlighted may hold potential in addressing health inequalities in Scotland. However, the delivery of healthcare online has been criticised for accentuating health inequalities due to digital exclusion (Seifert 2020). Digital exclusion is defined as the gap between people with and without access to digital technologies and is recognised among the older population and those with disabilities as a barrier to online engagement (Office for National Statistics, 2021). In the current study, additional funds were provided by Parkinson's UK, so that Wi-Fi enabled devices could be provided to minimise digital exclusion, however these funds were not required. Lack of requirement to supply devices could be attributed to convenience sampling, reflecting the socio-economic status and/or age of the current sample, who were younger than the typical Parkinson's population (MacLeod et al. 2018). However, it may reflect increased internet accessibility nationally. The Office for National Statistics (2021) reported that in 2020, 85% of UK adults aged between 66 and 74 used the internet, suggesting that digital exclusion may have lessened following COVID-19. While current data would suggest greater internet access among older adults, the current sample was small, and therefore may not be reflective of the larger Parkinson’s community. Recognising that 15% of older adults do not access the internet, it would be recommended that future research involving online delivery of PA should seek additional funding to provide participants with devices to avoid digital exclusion, and to minimise the potential for sample bias. Furthermore, to optimise online engagement and reduce anxiety associated with being online support to develop digital literacy is also required.

6.4.1.2 Challenges associated with delivery of PA Online

Current research indicates that online usage has grown exponentially during COVID-19 (Feeney et al. 2021), however, digital literacy remains low (Lai et al. 2020) , and is a commonly cited barrier to use (Nimmons et al. 2022). The Scottish Government (2023) define digital literacy within the national Digital Framework as the “skills to use technology to engage in learning through managing information, communicating and collaborating, problem-solving and being creative, and the appropriate and responsible use of technology.”

In the current study, the level of digital literacy varied from those who were highly competent, to those whose experience was limited to sending emails. For some participants, this was their first experience of video conferencing. The variation in digital literacy among PLwP has been reported in prior studies. In a mixed methods study comparing self-regulated versus tele-coached PA delivered via an app, Lai et al (2020) reported that some PLwP required greater time to get confident using the technology. Similarly, Bennet et al (2022) explored PLwP’s preferences of the PDEX programme. Twenty-five per cent of the sample reported challenges engaging with the technology when the programme transitioned from in-person to online delivery via Zoom. This would suggest that regardless of the platform used, for example Microsoft Teams, Zoom or an app, PLwP need additional time to develop digital literacy and confidence in using technology. In addition to becoming familiar with the platform, participants in the current study reported that operational issues such as setting up their device and optimising the camera position were challenging initially. Operational challenges were also reported by Lai et al. (2020) and Bennett et al. (2022) which like the current study were restricted to the initial stages on the intervention. These IT operational challenges are not restricted to delivery of PA. An opinion piece on the use of telehealth within neurology services also reported challenges associated with IT capabilities, connection issues and camera positioning (van den Bergh et al. 2021).

Internet connectivity was problematic due to the local internet infrastructure for those living rurally, which was intensified during adverse weather. The 2017 Public Health Digital Health strategy produced by the UK Government reported that over half of Scottish households have superfast broadband, but this drops to a third in rural areas (UK Government, 2017). Several prior studies have reported issues with connectivity when delivering PA online (Lai et al. 2020; Bennet et al. 2022; Shih et al. 2022) or healthcare in general (van den Bergh et al. 2021). In the current study Microsoft Teams was perceived by participants as more temperamental, and less user-friendly compared to other platforms such as Zoom, although views were mixed, with some reporting no issues as at all. Online delivery of the Engage-PD intervention reported that 15% of participants experienced problems with Zoom that took more than 15 minutes to address (Shih et al. 2022). This would suggest that technical issues may exist regardless of the platform used. Zoom was not considered for use in this study, as it was not regarded as GDPR compliant at the time of the study, and its use was not supported by NHS Scotland (Personal communication). Therefore, had NHS Physiotherapists been recruited to deliver the intervention, they would have been unable to deliver the intervention on Zoom. Teams was also selected as it allowed the sharing and storing of documents. Accessing documents within Teams at the beginning of the study was challenging for some, which may also have added to the perception that Zoom is more user-friendly. Research to date has focussed on perceptions of online delivery of healthcare (Powell et al. 2017) or made comparisons between video versus phone consultations (Gonzalez et al. 2022). However, no studies were located which directly compared two differing platforms, which may reflect the relative infancy of online delivery of healthcare (Quinn et al. 2020)

An IT induction and mock appointments were provided in the current study. Despite these inductions, a minority of participants reported IT issues in the initial stages of the study. Staff involved in the delivery of the current study reported that challenges experienced by participants were not unique to PLwP, but reflected the challenges reported by many older adults using technology at the time of the study. Based on the findings of the current study, it is recommended that an IT familiarisation period should be built into future intervention delivery for those who require it, to address differences in digital literacy. Similar recommendations were highlighted in the feasibility and pilot studies conducted Lai et al (2020), and Bennett et al (2022). A familiarisation period would also serve to mitigate any operational issues, such as setting up the device and optimising camera position which were also highlighted by participants as issues in the current study. A period of familiarisation facilitated by staff would improve initial engagement with Teams, ensuring confidence, and minimising anxieties associated with getting online.

6.4.1.3 Practical limitations of online delivery of physical activity

Focus groups with PLwP who received virtual tele-coached PA, reported that the lack of hands-on feedback from the instructor was a limitation (Bennett et al. 2022). Similarly, in the current study, preference for face-to-face sessions was articulated by the few participants who had specific issues such as joint pain. Participants reported that initial face-to-face engagement was perceived as necessary for efficient assessment of needs. Staff delivering PDConnect also perceived that assessment and diagnosis often took longer online compared to in-person assessment. However, staff and participants reported that online did not detract from the quality of care received. Rather, staff reported that online provided greater opportunity for listening to participants, facilitating a partnership approach to delivery which would not have been afforded clinically. In contrast, among UK-based Neurologists, a qualitative study highlighted that many Neurologists reported reduced confidence in clinical decision-making, resulting in additional in-person appointments to verify online assessment findings (Courtney, Blackburn and Reuber 2021). New patients, and those with communication difficulties and/or cognitive impairment were deemed less suitable for online consultation (Courtney, Blackburn and Reuber 2021). The differences between the current study and that reported by Courtney, Blackburn and Reuber 2021 may reflect that those with complex movement dysfunction and cognitive impairment were excluded from the current study. As Parkinson's is a progressive condition, it would be recommended that online healthcare interventions including PA may need to have contingencies in place, so that where appropriate, face-to-face reviews with members of the multidisciplinary team could be offered when circumstances change.

6.4.1.4 Future mode of delivery of PDConnect

When participants were asked to rank their preferences for mode of delivery of future iterations of PDConnect, 42% (n=5) indicated that hybrid delivery was their preferred choice. However, owing to the small sample size, preference for face-to-face was 33% (n=4) and online 25%

(n=3) highlighting the mixed views within the sample. Both staff and participants expressed a preference for hybrid delivery, delivering a ‘best of both worlds’ approach allowing capacity to develop social connection as a group while acknowledging the convenience of online participation. Cleary, Rossi and States (2020) demonstrated the importance of social cohesion for PLwP in a qualitative study exploring perspectives of participation in group-based PA. Group dynamics were shown to promote a positive attitude towards life and enabled shared learning (Cleary, Rossi and States 2020). The group served as the “glue” suggesting that benefits of group-based PA extend beyond the physical benefits. Limited capacity to promote social integration was the most frequently reported reason for supporting hybrid delivery in the current study, with a very small minority reporting hands-on intervention as a motivating factor. These findings are congruent with the Engage-PD study which provided five personal coaching sessions over a three-month period (Shih et al. 2022). Engage-PD was grounded in self-determination theory, and like the current study adopted a motivational coaching approach to delivery. Participants in the current study reported that initiating conversations was more challenging online with a group of people they had never met. A lack of social connection or a desire for hybrid delivery was not reported by Flynn et al. (2021) or Lai et al. (2020) who conducted pilot studies of telehealth-based PA interventions. These contrasting findings could be explained by the fact that both the current and the Engage-PD study were delivered exclusively online, whereas in the studies conducted by Lai et al. (2020) and Flynn et al. (2021) participants attended a face-to-face component prior to receiving PA delivered online. Therefore, social connection with other members of the group may have been established prior to going online, which was then maintained online, whereas in the current study the group was new to everyone from the outset.

In the current study, staff and participants reported that face-to-face introductions, and further incorporation of ice breakers beyond session one, would have encouraged greater group rapport and cohesion. The need for additional sessions may be justified, recognising the communication challenges experienced by PLwP (Miller et al. 2007). Hypophonia, and changes in receptive aspects of understanding and processing, lead to changes in cognitive-language function, all of which are likely to be intensified within the online environment. Online tone of voice, facial expressions, body language and visual cues can be distorted, leading to misinterpretation of communication (Tyson 2014). Communication issues also have the potential to negatively impact on mood and social interaction. Social interaction impairment, anxiety, and mood disturbance are commonly reported in Parkinson's in parallel with communication issues (Yu and Wu 2013; Broen et al. 2016), further supporting the notion that a future trial of PDConnect needs to consider adding additional sessions to optimally support social connection.

In the current study, opportunity for developing social connections was perceived as limited, however, qualitative findings highlighted when participants transitioned to the self-management component they missed catching up with peers, and sharing the “week’s news”, suggesting some social connection occurred. Arguably, the perceived lack of potential for social networking may also reflect that the intervention was delivered during COVID-19, therefore capacity to meet out with sessions was very limited, which may have influenced participants’ perceptions. On completion of the study, four participants met up, and continue to do so, and a further two remain in contact online due to where they live, accounting for half of the PDConnect sample, suggesting some social connection did occur as a result of participation.

Due to the infancy of online delivery of healthcare, few studies have explored the impact of online delivery on social interaction, or the long-term impact of telehealth-based PA interventions (McFarland, Coufopolous and Lycett 2021). The current study has demonstrated that online delivery of PA using Microsoft Teams was regarded as acceptable. However, it has also highlighted that prior to a future PDConnect trial, consideration needs to be given to including a familiarisation period to ensure all participants are comfortable with the technology required to participate and additional time built into the intervention to support the development of social connection online.

6.4.2 Acceptability of the individual components of PDConnect

The introduction to this thesis highlighted that PA is beneficial for PLwP, yet limited research has explored the optimum means of delivery. The literature review highlighted some key Parkinson's specific multicomponent interventions such as ParkFit, Engage-PD, Exceed-PD, and ParkSafe which incorporate PA with the aim of increasing PA levels, supporting changes in PA behaviour, and improving function and reducing falls. Table 6.1 summarises the key components and resources embedded within PDConnect and compares these with other multicomponent interventions for PLwP which have been discussed with this thesis. While overlaps exists between these interventions, PDConnect is novel in that it combines both one-to-one and group-based PA, potentially offering a more scalable approach to supporting PA engagement in the long-term.

All components of PDConnect were perceived as acceptable, with all participants stating they would recommend PDConnect to others. It was widely perceived that PDConnect met the aims of supporting increased PA and ability to self-manage PA. Most participants reported that their PA had increased, which is supported by improved PASE scores. Eleven (92%) participants expressed increased awareness of strategies to support long-term PA, with all participants undertaking a mean of eight PA sessions per week. These findings are based on a small number of participants; however, they highlight a positive trend which warrants further exploration in an appropriately powered study.

The benefits of PA are widely established; what remains unknown is the optimum means of delivery. Crucially, what needs to be determined is which components of an intervention are the “active ingredients” which elicit change in relation to PA. Identifying the active components of an intervention is essential for implementing, replicating, and synthesizing successful approaches (Michie et al. 2013). As a complex multi-component intervention, several factors were identified which influenced participant acceptability. These factors included: personalisation of intervention delivery, Parkinson’s specialist staff, motivational coaching, and development of self-efficacy.

6.4.2.1 Personalisation of intervention delivery

Due to the heterogeneity of Parkinson's, a personalised approach is widely advocated (Titova and Chaudhuri 2017; Ryden and Lewis 2019). Current evidence-based clinical guidelines advocate a personalised approach to PA prescription (Radder et al. 2020; Osborne et al. 2022), and the synthesised findings of a qualitative review reported that personalised care including PA is valued by PLwP (Hunter et al. 2019). Although personalisation of care is frequently cited as essential, it is a frequently missing part of Parkinson’s care (Tenison et al. 2020). Despite personalisation of care being widely advocated within health policy, comparatively little guidance is available to support application, which may explain inconsistent application within practice. Personalisation of intervention delivery was frequently reported by participants as a key factor in relation to acceptability of PDConnect. Within the current study several factors may have contributed to this sense of personalisation including staff understanding of Parkinson’s, motivational coaching, use of BCTs, and the weekly delivery of the intervention, which individually and collectively may have positively impacted participants’ self-efficacy. The current study was not designed to explore the correlation between cause and effect; however, the current study highlights some positive trends which require further examination in an appropriately powered study.

Table 6.1 Comparisons of multicomponent Parkinson's physical activity interventions

	ParkFit (van Nimwegen et al 2011)	**ParkSafe** (Chivers Seymour et al 2019)	**Engage-PD** (Shih et al, 2022)	**Exceed PD** (Sajatovic et al. 2017**)**	**PDConnect**
Parkinson's trained staff	✓	✓	✓		✓
Motivational coaching	✓		✓		✓
1:1 Physiotherapy	✓	✓	✓		✓
Group based PA				✓	✓
Self-management skills	✓			✓	✓
Goal setting	✓		✓	✓	✓
Health contract	✓				✓
Education provision	✓	✓		✓	✓
Delivering of HEP	✓	✓	✓	✓	✓
Self-monitoring of PA	✓		✓		✓
Activity planning					✓
Activity diaries	✓	✓	✓		✓
Duration	Year 1: 19 Physio sessions, and 16 coaching sessions. Year 2: 23 Physio sessions and 12 coaching sessions	12 sessions lasting 1-1.5 hours over 6 months	5 sessions over 3 months, combining exercise and motivational coaching	12 weekly sessions, 1-hour self-management, and 40 minutes exercise	30 weeks: 18 weekly sessions, monthly calls for 3 months

6.4.2.2 Parkinson’s specialist Staff

Participants reported that the staff understanding of Parkinson's instilled a sense of confidence, as they felt that their wider health issues had been considered in relation to PA prescription. Participants reported that the ability of staff to contextualise education enabled them to understand the relevance of activities, in relation to individual needs which was especially valued by participants. Preference to attend PA programmes delivered by Physiotherapists (OR 1.51, 95% CI: 1.08-2.11, p=0.02) or Fitness Instructors (OR 1.91, 95% CI: 1.18-3.09, p=0.009) with Parkinson's experience has been highlighted previously in a discrete choice experiment involving 540 PLwP (Paul et al. 2021). The importance of Parkinson's informed staff, and personalised care has also been highlighted in a qualitative review and a Voice of the Customer study among PLwP. (Hunter et al 2019, Vlaanderen et al. 2019). Although the impact of staff training was not directly explored in this study, the positive findings are supportive of prior research, which suggests that Parkinson's specialist staff optimise care delivery (Ypinga et al. 2018).

The Parkinson's NICE Guidelines (2017) advocate that PLwP should be seen by a Parkinson’s Specialist. A retrospective analysis of health insurance claims in the Netherlands demonstrated that seeing a Parkinson's specialist Physiotherapist was associated with enhanced health outcomes and improved cost effectiveness (Ypinga et al. 2018). Competencies for HCP’s working with progressive neurological conditions were published in 2019 (AHP Competencies for Progressive Neurological conditions Framework 2019), however, no formal training exists to support achieving these competencies, and a lack of clarity exists to inform what constitutes a “specialist”. This would suggest that while the NICE advocates PLwP should be seen by a Parkinson’s specialist, few exist.

A survey conducted by Nijkrake et al. (2009), asked HCPs to rate their Parkinson's expertise between zero representing insufficient and four representing very good. Of the 198 HCPs in the study, 75% self-reported that they lacked sufficient Parkinson's expertise. Between self-reported experts and non-experts, no difference was found in the number of years worked, or the setting where they worked. Self-reported experts saw more PLwP than non-experts, however this was less than ten PLwP per year. This Dutch study may not be representative of Parkinson's expertise in the UK but would suggest that expertise is typically gained through experience rather than formal training. The 2019, the Parkinson’s UK audit highlighted a knowledge and skills gap in the current workforce (Parkinson’s UK, 2019), with many HCP’s reliant on their undergraduate training which typically encompasses four to six hours of Parkinson's training (personal communication). Staff delivering PDConnect reported that the training was acceptable and provided them with the necessary knowledge and skills to deliver the intervention, which was reiterated by participants. This would suggest the 12 hours of self-directed learning and practical based teaching was sufficient to provide the necessary expertise. When considering scalability of PDConnect and a future trial, staff highlighted preference for face-to-face delivery of practical based training, which needs consideration when seeking future funding.

6.4.2.3 Motivational Staff

PDConnect staff were perceived as motivational, which participants reported inspired them to challenge themselves and re-establish PA that had been discontinued following diagnosis. All participants reported feeling more motivated and confident to engage in PA. These findings, while based on a small sample, are positive, as a meta-analysis conducted by den Brok et al. (2015) demonstrated that 40% of PLwP had apathy and over half of PLwP with apathy had concomitant depression. Motivational coaching was integral to staff training, and intervention delivery, which may have contributed to the positive impact on motivation and exercise confidence reported by participants in this study. Survey data highlighted that Engage-PD participants perceived that the motivational coaching received via Zoom positively influenced their PA behaviour (Shih et al. 2022). Although, the Engage-PD was a single cohort study involving no control group, the findings of the current and the Engage-PD study add to a growing body of evidence advocating motivational coaching.

Motivational coaching is regarded as an effective means to support behaviour change (Howlett et al. 2019). An Australian cross-sectional survey identified that Physiotherapists perceived themselves as knowledgeable about psychosocial approaches including motivational coaching. However, only 25% of the 251 Physiotherapists surveyed used motivational coaching in practice, and over 80% identified the need for further training (Driver, Lovell and Oprescu 2021). This would suggest that motivational coaching needs to be a consistent element in undergraduate education and/or staff development post qualification.

The motivational delivery by staff could simply reflect their individual affect. Both the Physiotherapist and Fitness Instructor were both experienced in their field; therefore, experience could have been a contributory factor. Fidelity assessment identified consistent use of open-ended questions, affirmation, reflective listening, summarising, conveying empathy, and promoting problem solving, suggesting consistent application of motivational coaching approaches. Whether the application of motivational coaching was influenced by the training provided, or simply reflective of prior experience cannot be determined. An Australian study involving Physiotherapy and Occupational Therapy students highlighted that teaching motivational coaching skills to students was challenging (Norris et al. 2019). With a growing body of evidence advocating motivational coaching (Fortune et al. 2019), would suggest that motivational coaching should remain an integral part of future staff training.

6.4.2.4 Development of Self-efficacy

The literature review highlighted that self-efficacy is a key determinant of PA. A large survey involving over 2000 PLwP, demonstrated a statistically significant improvement ($p<0.01$) in self-efficacy in those who attended Rock Steady boxing™ compared to those who did not (Larson et al. 2022). Similarly, the Engage-PD study demonstrated improvement in exercise self-efficacy between pre and post intervention with a large effect size (Shih et al. 2022). In contrast, in the current study self-efficacy declined between baseline and week 30. This contrasting finding could be attributed to several factors. The Engage-PD study was shorter in duration (12 weeks) and self-efficacy was measured only once using a different measure limiting ability to draw comparisons between the studies. Using the same measure of exercise self-efficacy as in the current study. The differences in self-efficacy outcome between the Larson study and the current study could be explained by the timing of assessment. In the Larson study self-efficacy was measured once, whereas in the current study self-efficacy was measured at multiple points (baseline, 6, 18 and 30 weeks). A meta-analysis of studies exploring PA self-efficacy in the general population demonstrated that self-efficacy is most enhanced within short duration interventions between two and eight weeks (Ashford, Edmunds and French 2010), which may also explain the fluctuation in self-efficacy reported in the current study. As shown in table 5.19, self-efficacy changed with time. Lower self-efficacy coincided with transitions between PDConnect components and when the intervention ceased but was higher during periods which offered continuity. Therefore, the decline in self-efficacy could be attributed to the length of the intervention, and influenced as self-efficacy was recorded at the end of the intervention which may have negatively influenced the findings. Bandura (2004) stated that self-efficacy is influenced by multiple factors including experience and emotions in adults. A literature review conducted by Edwards and Sackett (2016) highlighted gender differences in self-efficacy in the general population, with females reporting lower self-efficacy. Within Parkinson's, a study using multivariate analysis study examined the factors which influence PA among 285 PLwP. Regression analysis highlighted that self-efficacy was the primary determinant of PA among males whereas for females the key determinant was enjoyment (Urell et al. 2021). Highlighting the complexity and multiple factors which may have influenced self-efficacy in the current study.

The continuity offered by weekly delivery of PDConnect may have contributed to improved perceived self-efficacy in the current study. Prior low-dose PA interventions have not demonstrated clinically meaningful differences for PLwP (Clarke et al. 2016). In contrast, in the current study 91% of participants reported increased activity levels. In the current study, weekly sessions provided opportunity to ask questions and discuss challenges which had arisen in the previous week. Time to discuss future needs was ranked number three in a top ten of unmet needs reported by PLwP (Vlaanderen et al. 2019), highlighting the importance to those living with Parkinson's. Participants in the current study reported that they valued regular opportunity to receive feedback, shape knowledge, monitor activity levels, and develop and refine skills, all of which are BCTs known to positively influence PA (Howlett et al. 2019). While limited research has explored the use of BCTs within Parkinsons, a systematic review exploring PA intervention for people following Stroke, identified that goal setting, problem solving, activity planning and feedback on behaviour, and credible source were promising BCT's associated with influencing PA behaviour within the Stroke community (Moore et al. 2018). The relationship between self-efficacy, use of BCTs and intervention continuity is beyond the scope of this study. Little is known about self-efficacy in Parkinson's (Ellis et al. 2011), however, this study would suggest that PDConnect had a positive impact on perceived PA behaviour, activity levels, and exercise confidence; however, improvement in self-reported exercise self-efficacy measured by Self-Efficacy for Exercise Scale was not reported. Further research is required to explore whether this contrasting finding is due to the psychometric properties of the Self-Efficacy for Exercise Scale or whether it is reflective of the multiple variables which impact upon participant reporting. Understanding these relationships is integral to designing effective interventions to target PA participation among PLwP.

6.4.2.5 Future recommendations in relation to PDConnect components

Although only 25% of participants (n=3) felt that changes to the Physiotherapy component were required, these are important to consider. Increasing the number of Physiotherapy sessions was the most frequently reported change required; however, there was also widespread acknowledgement that this was not feasible, nor practical, implying that additional sessions were perceived as desirable, but perhaps not essential. While specialist Physiotherapy is advocated in the Parkinson's NICE guidelines (NICE, 2017), and associated with improved outcome (Ypinga et al. 2018), six sessions were selected as this aligns with current NHS practice (Personal Communication). Additional Physiotherapy sessions would potentially limit the transferability of PDConnect into existing healthcare services. Moreover, the aim of PDConnect was to promote PA self-management, therefore provision of indefinite Physiotherapy would arguably serve only to promote dependency rather than promote independence.

Similar to the Physiotherapy component, 25% of participants articulated that changes were required to the group exercise component. Additional sessions were suggested, with many expressing disappointment when group sessions ended. Additional sessions were perceived as necessary due to the challenges of online delivery and challenges with personalising intervention delivery during the group component. Provision of a one-to-one session with the Fitness Instructor prior to starting the group could be considered. This additional session would allow discussion of individual needs, providing opportunity to develop rapport with the Instructor. This additional session may also reduce anxieties associated with transitioning from Physiotherapy, which may have impacted self-efficacy as reported earlier. Equally, personalisation may have been better facilitated if allocation to the Monday or the Thursday exercise group had been based on ability, rather than participant preference. This could have resulted in greater standardisation of ability within a group and made the task of personalising PA prescription easier for the Fitness Instructor. An international qualitative study exploring perceptions of aquatic therapy for PLwP demonstrated that mixed views existed in relation to grouping people by ability (Carroll et al. 2022). Those in favour perceived this enabled everyone in the group to benefit and avoid challenges with seeing one's future self. In contrast, Carroll et al. (2021) highlighted preference for mixed abilities as people could learn from those who had greater experience of living with Parkinson's. Introducing an additional session and allocating groups based on ability requires further consultation with the Parkinson's community prior to proceeding to a future trial.

Preference for one-to-one or group PA may have influenced findings in the current study. Sajatovic et al. (2017) compared individual versus group delivery of the EXCEED programme which combined exercise with self-management among 30 PLwP who had depression. No difference in depression scores were reported between groups, but group participants reported that they valued the socialisation element. However, other studies have reported preference for individual PA. A discrete choice experiment involving 540 PLwP demonstrated lower preference for group PA (OR 0.72, 95% CI: 0.54-0.96, p=0.03) compared to individual PA (Paul et al. 2021). However, Mantri et al. (2019) who surveyed 75 PLwP, reported that 53.2% preferred exercising with others suggesting equal preference. In their qualitative systematic review Hunter et al. (2019) identified opportunity for social cohesion, and shared experience were key motivators for group PA. Equally, barriers such as potential to see your future self were also reported as a barrier. In the current study the fitness instructor was "pinned" on the screen during delivery of the class, resulting in their image occupying the main screen, which may explain why only one participant reported that they felt self-conscious exercising with others who were less able. Preference for group or individual PA fell out with the scope of this study, however it is recognised that PDConnect may be less preferable for those who do not like exercising with others.

Perceptions of the self-management component were mixed. Satisfaction was lower than that reported for either the Physiotherapy and group exercise components, however only 25% of participants suggested changes should be made to this component. Participants were asked to continue their PA unsupervised during the self-management component, and received a monthly check in-call, which may explain the lower satisfaction reported. An Australian study comparing centre-based and home exercise supported by telehealth for PLwP demonstrated no difference in outcome, but those unsupervised at home reported lower satisfaction and intervention acceptability (Flynn et al. 2021). In the current study lower satisfaction could also be attributed to the transition between the group and self-management components. After attending 18 consecutive weekly supervised sessions of Physiotherapy and group exercise, dropping to a monthly check-in call was perhaps abrupt, and may not have allowed participants time to adjust. Therefore, a stepped-down approach into the self-management component may be preferable for some participants and needs further consideration prior to a future trial.

The current study also highlighted that greater personalisation of the self-management component may be warranted in future iterations of PDConnect. Free text comments from the survey indicated that some participants would have liked a greater number of check-in calls. Qualitative analysis identified that participants with lower levels of motivation expressed greater need for more contact to maintain PA. A literature review by McAuley et al. (2011) proposed that motivated adults report higher self-efficacy and are more physically active. Similarly, Bandura's (2004) Social Cognitive Theory proposes that self-efficacy determines motivation and behaviour in adults, and more recently Ellis et al. (2011) identified that self-efficacy is strongly associated with whether PLwP are active or not. While this study did not explore the relationship between PA self-efficacy and preferred frequency of monthly self-management calls or PA levels, self-efficacy scores ranges were broad within the sample. Variation in self-efficacy scores may explain the divide in opinion in relation to frequency of self-management calls. Alternatively, varied views on the frequency of self-management calls could be explained by dopamine deregulation in Parkinson's which is associated with lower levels of motivation and apathy (Rowe et al. 2008; den Brok et al. 2015). Equally the variation may reflect the small convenience sample recruited in the current study. The number of participants and study design limits capacity to draw conclusions, however, what this study has highlighted is that motivational levels vary among PLwP, and specific tailoring of the self-management component intervention is required to optimally support long-term PA.

In other neurological conditions such as Multiple Sclerosis (MS) web-based platforms have been used to support PA self-management. Busse et al. (2022) demonstrated that an interactive web-based platform combined with web-based or face-to-face coaching via a

Physiotherapist was feasible and acceptable. Like PDConnect, the "LEAPS" intervention incorporated goal planning, education, and self-monitoring, with the aim of promoting self-management. Limited research exists exploring the use of digital technology to support health and wellness self-management in older people (Doyle et al. 2021). However, web-based self-management programmes have been shown to be feasible in other conditions which occur in older age such as cardiovascular disease (Engelen et al. 2020) and Arthritis (Trudeau et al. 2015) suggesting that web-based platforms are feasible among older people. The inclusion of an interactive platform to support self-management used in conjunction with PDConnect may help maintain motivation and therefore promote self-management among PLwP and warrants further consideration prior to further research into PDConnect.

6.4.3 Acceptability of study resources

Resources developed specifically for the PDConnect intervention were perceived as acceptable by participants and staff. In general, qualitative interviews highlighted resources needed to be flexible, enabling participants to pick and choose depending on their perceived need, with resources available in both electronic and paper format depending on individual preference. Modifications to the PDConnect manual and the Mi band were suggested by participants and are therefore discussed here.

6.4.3.1. PDConnect manual

The PDConnect manual was deemed acceptable with 83% of participants rating it as very helpful or helpful. A prior systematic review highlighted that limited evidence existed to guide the content of educational interventions to support PA in Parkinson's (Alushi et al. 2022). Two systematic reviews were unable to confirm the effectiveness of self-management programmes for PLwP due to the heterogeneity in content, dosage, and outcomes used (Tuijit et al. 2020; Alushi et al. 2022). However, these reviews indicated that credible sources of information, and education were associated with effective self-management. The current study indicated that information pertaining to the benefits of PA and types of PA contextualised to their Parkinson's and HEPs were most valued by participants. This finding aligns with systematic review findings which emphasised the need for focussed education on the role of benefits of PA and strategies to support PA habit formation to support PA self-management (Alushi et al. 2022). In the current study, participants reported that increased understanding of why they need to undertake a specific type of PA improved motivation, and adherence. Combined education and exercise programmes such as ParkFit have been shown to positively influence PA behaviour however changes in the primary outcome were not statistically significant (van Nimwegen et al. 2013). In the current study, participants demonstrated improved PASE scores over the intervention, with participants undertaking a mean of eight PA sessions per week, and 92% reporting increased awareness of strategies to support remaining active. Further research is required to explore the impact of PDConnect on PA behaviour and levels among a larger, more representative sample and the impact on PA behaviour long term.

Ninety percent of participants found the information on Parkinson's very helpful or helpful, however qualitative findings highlighted divergent views. Opinions were dependent upon participant level of knowledge of Parkinsons, time since diagnosis, level of acceptance, and personal preference for detail, highlighting modifications are required to the manual to allow tailoring of education to individual need and preference. The use of an app or an interactive web-based platform as used within the LEAPS study may be preferable to use in future iterations of PDConnect which would enable education to be drip-fed, with sections mapped to individual weekly sessions, rather than providing the document in its entirety up front. Signposting within the manual could also be improved, as emphasis was placed on content during development, with less focus on how participants should interact or use the manual. Better signposting would enable the delivery of targeted information with specific skills training within supervised sessions which has been shown to enhance self-management skills (Tuijit et al. 2020). It is recommended therefore that further refinement of the manual is required, involving PLwP from a diverse cultural background to ensure content, accessibility, and transferability to the wider Parkinson’s community. In addition, reflecting the growth and perceived acceptability of technology in healthcare, the development of web-based participant resources co-produced with PLwP should also be considered. An online manual would offer many advantages including: tailoring of education, wider range of learning materials accommodating broader range of learning preferences, easy to update and maintain, and would enable scalability and facilitate implementation of PDConnect.

6.4.3.2 The Mi band activity tracker

Participants found the Mi band acceptable to wear, set up and use, however many participants reported that the Mi band was unreliable. Poor reliability demotivated some participants, as PA was not consistently recorded. Few studies have explored the reliability of commercially available activity trackers in Parkinson's (Lamont et al. 2018; Pradhan and Kelly 2019). In the current study, a third of participants perceived that the Mi band under-estimated their steps, when walking with their arms fixed, or when using an exercise bike, or walking indoors. Prior studies have demonstrated that tracker reliability varies between tasks, with lower reliability associated with discontinuous walking (Wendel et al. 2018). The reliability of wearable technology is dependent on the placement of the device and embedded algorithms. Wrist worn accelerometers such as the Mi band, measure PA by quantifying accelerations of movement (Liu, Wanigatunga and Schrack 2022), whereas activities such a cycling, and gardening can only be accurately captured through devices that measure heart rate and estimated minutes of activity (Pradham and Kelly, 2020). Thigh and waist mounted devices are more reliable than wrist worn devices (Lamont et al. 2018), however, they are less user friendly as a self-monitoring device. A systematic review exploring the validity and reliability of commercially available activity trackers reported that devices underestimated step count particularly at slow walking speed (Evenson, Goto and Furberg 2015). Therefore, the inaccuracy of the Mi band could also be explained by the combined effects of bradykinesia and rigidity, leading to reduced arm swing, walking speed, as well as step and stride length during gait (Morris et al. 1994). Indoor walking, therefore, which is typically slower, and discontinuous could also be frequently inaccurately recorded due to inadequacies of the underlying algorithms.

Commercially available trackers offer a cheaper and more accessible alternatives to research grade devices. Lamont et al. (2018) compared two commercially available trackers with ActivPaL™ (PAL Technologies, LTD) a research-grade accelerometer among PLwP. Both devices demonstrated moderate consistency when compared to the ActivPaL, however reliability was inconsistent at slow walking speeds (intra-class coefficient 0.36), and neither device provided a good indication of activity intensity. More reliable means of assessing PA using research grade devices such as the ActivPaL™, are not without their limitations. Recording capacity is limited to 14 days (Edwardson et al. 2017) and they lack capacity for self-monitoring and real-time feedback which are important components of self-management. More recently, continuous objective measurement (COM) platforms have been developed, such as the wrist worn Parkinson's KinetiGraph®, however the focus of these devices is to capture motor symptom fluctuation rather than PA (Pahwa et al. 2018). While daily step count is a common PA metric it focusses on stepping behaviour. Arguably, in Parkinson's, where gait dysfunction is prevalent, step count may not be the metric of choice to assess PA. Step count is also limited as it provides limited data on gait quality, and no indication of activity intensity. Mobilise-D (http://www.mobilise-d.eu/) is an international clinical research consortium aiming to produce validated and accepted digital mobility outcomes including body worn sensors for long term condition including Parkinsons. Mobilise D aims to develop condition specific algorithm which can be embedded within wearables allowing more accurate assessment of gait within clinical trials. Use of these validated algorithms produced by Mobilise-D embedded within a wrist worn device within a future study should be considered to ensure more reliable means of monitoring step count.

Lamont et al. (2018) explored the accuracy of the Garmin Vivosmart® and the FitBit™ Charge HR™ with the ActivPAL™ among PLwP. Both Garmin® and Fitbit™ were found to be valid measures of step count among PLwP, however they were less accurate with lower cadences. Lamont et al. (2018) concluded that commercial activity trackers could be instrumental in self-management providing real-time feedback, and promote self-monitoring, and goal setting. However, research grade trackers may be preferable if PA data is required to identify changes in functional status to inform treatment modification. In the current study, although participants perceived the Mi band to be unreliable, most participants reported that the Mi band provided motivation to be more active, and aided achievement of activity goals. Similar to the conclusions of Lamont, the participants in the current study regarded the Mi band as effective at shaping and influencing PA behaviour. In addition, participants reported that the use of the Mi band in conjunction with the activity diary, the Mi band promoted self-monitoring of PA, and provided a valued PA prompt.

Patel et al. (2021) conducted a quasi-experimental study exploring PLwP experiences of six different activity trackers including the Mi band. The Mi band was reported as comfortable, easy to put on, but ease of use was poorly scored. The findings of the current study are consistent with Patel et al. (2021). Participants reported that the Mi band was acceptable and overall satisfaction of the Mi band was high, stating the Mi band was comfortable, easy to put on and off and synchronise. However, the font on the display was small, and difficult to read.

Wearing of a tracker long-term was perceived as acceptable, with most participants opting to continue to use the device on completion of the study. In relation to a future trial, this study confirms that long-term use of an activity tracker is acceptable among PLwP and is seen is a powerful tool to shape PA behaviour. Owing to rapidly evolving technological advances, further engagement with the Parkinson community will be required to select a device that balances cost, readability, comfort, and accuracy prior to undertaking a trial of PDConnect.

6.4.3.3 Activity diaries

The activity diary and planners were designed so that participants could plan and record their daily step count and PA. Use of the activity diary in this study was found to be feasible and acceptable. The activity diaries were perceived by staff and participants as motivational, promoting PA, by providing a means to reflect and discuss prior activity, promote goal setting, and formulate action plans for the forthcoming weeks.

Diaries are commonly used to assess motor fluctuations or response to medication in Parkinson's (Papapetropoulos 2012). Although frequently used, the validity of diaries are widely criticised due to potential negative impact of recall bias, social desirability, and stigma, leading to inaccurate data (Papapetropoulous 2012). Limited literature has explored the use of PA diaries with Parkinson’s. Frost et al. (2016) conducted a multiple case study randomised crossover trial involving 33 older people who were enrolled in a walking programme. Participants were asked to document their PA every day for four weeks while concurrently wearing an activity tracker (ActivPAL™). No significant difference was shown between ActivPaL™ data and self-reported PA. The diaries were shown to be acceptable, not burdensome; however, adherence was low with a third of participants not recording their PA daily. In contrast, 84% of diaries were returned in the current study. High adherence could be explained by the dual purpose of the diaries: i) to document activity; ii) a tool to promote discussion, and reflection on the prior week’s activity within supervised sessions. Findings from the case study aspect of the Frost study highlighted three factors that optimise activity completion and adherence, these included: perception that the diary is an important data collection tool (diary salience), ease of recalling the activity (activity salience) and the type and amount of data participants are asked to record (Frost et al. 2016). As mentioned previously, convenience sampling may have resulted in recruitment of a motivated sample, promoting diary salience. Equally, activity diaries were shared with staff to monitor weekly PA, which may have reinforced diary salience. Activity salience may have been facilitated by the ease of retrieving the daily step count from the Mi band. The findings of this study would suggest that the use of activities diaries is feasible and acceptable, but also provides preliminary evidence that the impact of activities diaries is perhaps greater when embedded within intervention delivery, rather than solely used as a means of monitoring.

In the current study, participants were provided with a paper-based activity diary, with access to an electronic version if they wished to complete the diary in this format. A future study of PDConnect should consider the use of a digital diary to document PA. Use of a digital diary would address issues reported by participants in relation to micrographia and environmental sustainability. A digital diary may also serve as a powerful behaviour change tool providing a visual representation of their weekly activity and how this aligns with their weekly activity goals. Synchronisation of the activity tracker with the diary would also serve to reduce participant burden and increase accuracy of reporting. Prior to a future trial, consultation involving the Parkinson's community is warranted to explore views on the use of digital diaries, and perceived barriers and motivators.

6.4.4 Perceived benefits of PDConnect

Participation in PDConnect was regarded as a positive experience, with perceived changes in physical symptoms, and PA levels.

6.4.4.1 Perceived changes in physical symptoms

Many systematic reviews have demonstrated that PA improves strength, balance, flexibility, and aerobic capacity (Yitayeh and Teshome 2016; Aburub et al. 2020; de Oliveira et al. 2021; Flynn et al. 2021; Okada et al. 2021; Gamborg et al. 2022; Gollan et al. 2022). The findings of the current study are congruent with prior research. Using global impression of change scales (GICS) participants reported improved strength, flexibility, physical fitness, and balance. GICS are widely used in health research (Kamper, Maher and Mackay 2009), however, they are equally criticised for the dependency of participant recall. Martínez-Martín et al. (2016), demonstrated moderate level of agreement between patient clinical impression change scores with the Hoehn and Yahr scale and measures of anxiety and depression, suggesting that GICS can be used reliably in practice. In other long-term conditions such as low back pain, pooled findings from a systematic review indicated excellent patient test-retest reliability of GICS (ICC=0.84, 95% CI: 0.65 to 0.94, I^2=85), however validity as a measure of overall change was shown to be questionable (Bobos et al. 2020). Due to study design and exclusive online delivery, objective measures of strength, balance, fitness, and balance were not possible in the current study. A future trial aimed at exploring the effectiveness of PDConnect needs to include objective reliable and valid methods to assess these parameters, however recognising the heterogeneity of Parkinson's, the use of GICS should also be considered as valid approach to measurement.

A future trial of PDConnect needs to carefully consider which objective measures to use. Forty percent of participants reported that balance was unchanged during the study. The lack of change could be attributed to a potential ceiling effect. At baseline ABC scores were 82%, suggesting high level of function, exceeding the normative values (73.6%) for PLwP (Mak, Pang and Mok 2012). A future PDConnect trial may need to consider the use of an objective balance measure such as the MiniBESTest. Godi et al. (2020) reported that the MiniBESTest was sensitive to change among a sample of early to mid-stages of Parkinson's, suggesting this measure may be preferable to use. The MiniBESTest was planned for use in the current study but was omitted due to safety reasons when the study moved to online delivery as a consequence of COVID-19. Equally, the lack of change in balance reported could be attributed to balance being insufficiently challenged during the intervention due to safety considerations associated with online delivery of PA. Clinic-based balance interventions have been shown to be more effective at improving balance in Parkinson's compared with home-based interventions, which the authors attributed to the level of supervision afforded clinically (Shen et al. 2016). The introduction of a 1:1 session with the Fitness Instructor prior to commencing the group component as proposed in the narrative review would allowing staff to effectively review individual ability, tailor PA prescription accordingly which may address these potential issues within a future trial.

Physiotherapy guidelines for PLwP recommend the inclusion of flexibility training (Osborne et al. 2022), however this recommendation was based on one moderate quality study, which focussed on spinal flexibility, but did not address flexibility of the limbs. Osborne et al. (2022) highlighted the need for further research to examine the impact of flexibility training. In the current study 91% of participants reported improvements in flexibility. This improvement could be attributed the intervention dosage, personalised prescription, or the education provided by the manual which was reinforced by staff. All participants reported an improved understanding of the benefits of PA, in particular the benefits of stretching, reiterating the value of combined delivery of education and PA.

The ParkFit multicentre RCT incorporated Physiotherapy, activity coaches, an educational brochure, and activity monitoring, and involved more than 500 PLwP (van Nimwegen et al. 2013). While this study demonstrated no statistically significant improvement in the primary PA outcome, activity diaries used in the ParkFit study demonstrated statistically significant improvements in PA levels, with participants spending an extra 1.5 hours per week more than controls (van Nimwegen et al. 2013). In the current study, participation positively influenced PA, with activity diary data indicating participants engaged in eight or more PA sessions per week. Self-reported PA was not recorded at baseline, therefore directed comparison of pre- and post-intervention cannot be made, however, 83% of participants reported that their PA levels had improved during the study. While positive, these findings are based on self-reported PA. A recent large systematic review compared self-reported versus device measured PA in sedentary adults (Prince et al. 2020). Pooled analysis highlighted that self-report measures underestimated sedentary time by 1.74 hours per day compared to devices. Prince et al. (2020) recommended shorter recall periods should be used to improve accuracy. Promoting shorter recall, adds further support for future use of an app or an online platform, which could generate reminders, allowing same day recording of PA, thus minimising potential risk of recall bias. Equally the use of more reliable activity trackers based on algorithms validated for use with Parkinson's would enable future research to compare actual and self-reported PA.

Evidence-based guidelines advocate that PA programmes for PLwP should incorporate strength, flexibility, balance, aerobic style amplitude with an emphasis on large amplitude and functional movements (Osborne et al. 2022). A recent quantitative study demonstrated that PLwP participated in 24 different types of PA (Song et al. 2022). In addition, among the 263 participants, walking was the most frequently reported form of PA regardless of stage of Parkinson’s. (Song et al. 2022). The findings of the current study are consistent with that of Song et al (2022). Analysis of the activity diaries in the current study revealed 17 different forms of PA reported by participants of which walking, HEP’s and exercise bikes were the most frequent forms of PA. Participation in a broad range of PA may explain the broad benefits associated with strength, balance, flexibility, and fitness reported by participants in the current study. Equally, the broad range of PA could be explained by the improved understanding of the benefits of PA reported by participants. Walking has been reported as one of the most disabling features of Parkinson's (Mirelman et al. 2019). A review indicated that gait impairments arise early in the condition (Mirelman et al. 2019) and are associated with loss of independence (Shulman et al. 2008), and reduced QoL (Perez-Lloret et al. 2014). In a large study involving 628 PLwP, Shulman et al. (2008) highlighted that increased Parkinson’s severity was associated with reduced ADL function. Transitioning from Hoehn and Yahr stage II-III was highlighted as a pivotal point when gait impairment impacted independence levels (Shulman et al. 2008). In the current study, 54% of the sample were categorised as Hoehn and Yahr stage 2.5-3, however walking remained the most frequently reported PA, undertaking a mean of 4.3 walks per week. The impact of PDConnect on walking, and maintenance of independence cannot be determined by this study, however the exploration of the long-term impact of PDConnect on PA would be a recommendation within a future trial.

6.4.4.2 Improved physical activity levels

Prior studies have highlighted that a significant proportion of PLwP are sedentary (Lord et al. 2013; Benka Wallén et al. 2015). As highlighted in the literature review (section 2.3) several barriers exist making getting started and maintaining PA challenging for PLwP. Findings from the current study indicated that 91% of participants reported that their PA level had increased because of participating in PDConnect. Although the findings of the current study cannot be generalised to the wider Parkinson's population, they highlight a positive trend. Increased PA participation has been associated with slower rate of symptom decline in Parkinson’s. A longitudinal study involving 3408 PLwP demonstrated that consistent PA engagement experienced smaller declines in mobility and QoL (Rafferty et al. 2017). A similar study exploring the impact of lifestyle factors including PA on Parkinson's progression and survival reported that PA was associated with slower motor and cognitive decline (Paul et al. 2019). The findings of this study provide preliminary indication that when supported PLwP can be enabled to increase their PA levels. Further research is required to determine the effect of PDConnect on PA levels and long-term PA behaviour.

The current study findings are congruent with the ParkFit and Engage-PD studies which demonstrated improved PA (van Nimewegen et al. 2011; Speelman et al. 2013; Shih et al. 2022). ParkFit was grounded in Social Cognitive Theory, and like the current study incorporated the use of Parkinson's specialist staff, motivational coaching and BCT techniques such as goal setting. Engage-PD was grounded in self-determination theory, and combined PA prescription with motivational coaching, education, and goal setting (Shih et al. 2022). Common to these studies including current study is the combined delivery of PA prescription, education, motivation coaching and the application of BCTs such as goal setting. To date, research has focussed on which form of PA is superior, with less emphasis on how best to deliver PA to support changes in PA behaviour among PLwP. The current study adds to the existing body of literature suggesting that prescription of PA in isolation is insufficient and advocates that PA should be delivered as part of multicomponent intervention which enables PLwP to overcome PA barriers (Keus et al. 2013; Ellis and Rochester, 2018; Osborne et al. 2022). Michie et al. (2011) define behaviour change techniques as the active ingredients within an intervention which influence behaviour change. Qualitative findings from the current study indicated that personalisation of PA prescription, motivational staff, self-monitoring, education, and the continuity offered by PDConnect were key factors influencing PA participation. Future research is therefore required to determine the effectiveness of PDConnect and the impact on PA behaviour.

In addition to participant perceived increases in PA, step count data and the self-reported PASE scores also indicate an improvement in PA from baseline, although these changes were small. Small changes may reflect the high baseline PASE scores (157.16) in the PDConnect group which exceeded normative values for older adults (Washburn et al. 1999). Among a sample of 75 Parkinson’s veterans, PASE scores were reported as 135 (Mantri et al. 2019), although the population was older than in the current study which may explain the lower PASE score.

The small changes in PASE scores in the PDConnect group could be indicative of a ceiling effect. Some evidence exists to support a potential ceiling effect as PASE scores improved over the course of the study in the usual care group, but the PASE scores were lower in this group at all time points compared to the PDConnect group. Effect size data also indicated improvement in PASE in both groups, but the 95% CI were broad indicating a lack of precision. Lack of precision may be a consequence of the broad inclusion criteria adopted in this study. No limit was placed on age, or time since diagnosis. As a result, five participants (16%) were classed as Hoehn and Yahr stage 3 at baseline and 12 (39%) were categorised as stage 2.5. Stages 2.5-3 indicate mild to moderate bilateral Parkinson's with those at stage 3 also having some postural instability whereas the remainder of the sample (n=13) were stages 1-1.5 presenting with unilateral or unilateral plus axial involvement. Combined with a small sample, this variation in Parkinson's profile was a likely contributing factor in the variation of data reported. Research has shown PLwP benefit from PA regardless of when they start (Rafferty et al. 2017), and prior PA studies have been criticised for only recruiting those in the early stages of the condition (Silva et al. 2019). Recognising the benefits of PA for all stages of Parkinson's, it would be recommended that a future trial should recruit a broad sample, however consideration should be given to grouping participants by ability within the group-based component as suggested previously and within data analysis whether the impact of PDConnect differs between the Hoehn and Yahr stages.

Over the course of the study, the mean number of self-reported PA sessions per week was eight, exceeding the current PA guidelines (WHO, 2022). While positive, the small sample size, and the potential for responder and social desirability bias limit potential to draw reliable conclusions (Bowling 2014). Furthermore, the PA session time and PA intensity was not recorded, therefore whether the 150 minutes of moderate to high intensity activity was achieved is unknown. With increasing evidence supporting the benefits of moderate to high intensity PA (Johansson et al. 2020), recording the time and RPE may be advisable in future studies involving PDConnect.

A prior review of PA for PLwP demonstrated the benefits of PA but the review also highlighted that typically once PA interventions cease, adherence declines and the effects on outcomes are diminished (Lauzé, Daneault and Duval 2016). The findings of this review highlight the need for a sustainable means of maintaining PA, beyond the end of normal Physiotherapy care, is required. Other studies have shown in the absence of direct PA supervision, PA adherence declines. A mixed methods pilot study which randomised 20 PLwP to unsupervised home exercise or exercise delivered via tele-coach demonstrated that the unsupervised group, spent 48% less time exercising than the tele-coach group (Lai et al. 2020). In contrast, data from the activity diaries in the current study indicated that the number of PA sessions per week remained constant from week 7-30, including the unsupervised self-management component between week 18 and 30, implying potential maintenance of behaviour change. Gardner (2015) argues that achievement of meaningful outcomes is dependent upon repeat behaviours, therefore behaviour change should be viewed as a long-term process. Gardner (2015) also highlights that newly adopted behaviours are precarious, and without habit formation, motivation wanes, behaviour can revert. This would suggest that interventions need to be long enough to initiate and support behaviour change, but also of sufficient length to support habit formation which is associated with maintenance of behaviour change.

Maintenance of PA behaviour as suggested in the current study could be attributed to the 30-week duration PDConnect, may have been long enough to initiate and maintain PA. Repeated behaviour is pivotal to habit formation (Wood and Rünger 2016), as well as the development of a routine (Gardener, 2015), therefore the weekly delivery of PDConnect may also have supported PA habit formation in the current study. The long-term impact of the PDConnect intervention was out with the scope of this study. A future trial of PDConnect should also consider the impact on PA behaviour beyond the end of the intervention to explore the impact it has on PA habit formation.

6.4.5 Acceptability of research design, and methodology

The processes and resources developed to support recruitment were perceived as acceptable among participants. Participants were accepting of the need, and outcome of randomisation and associated randomisation with good quality research. While randomisation was viewed positively by all participants, due to the study design and methods adopted, these findings may not be representative of PLwP for several reasons. Firstly, due to convenience sampling, a quarter of participants heard about the study through the Parkinson's UK Research Support Network, therefore are potentially drawn from a research informed population, which may not be representative of the wider Parkinson’s community as reported in section 6.3.1. Secondly, randomisation may have been viewed positively, as the control arm also received 1:1 Physiotherapy, so regardless of randomisation, they received an intervention which was otherwise not available at the time due to COVID-19. In the absence of COVID-19, active control groups are associated with enhanced recruitment, with a large proportion of PLwP citing that the prospect of receiving a placebo over active treatment was a reason not to participate in research (Vaswani, Tropea and Dahodwala 2020), highlighting the importance of retaining an active control in a future trial. Finally, only those receiving PDConnect were interviewed following completion of the study, therefore the perceptions of the control arm are unknown. However, no dropouts occurred after randomisation from either group, and the completion of measures at each time point was high within both groups, inferring that randomisation was acceptable among the sample as a whole. A sense of loyalty and commitment once signed up to participate, was strongly voiced within qualitative interviews, with participants keen to get involved in a project which may benefit the wider Parkinsons community.

Completion of measures as reported earlier was not perceived as a physical burden by participants, however in relation to acceptability, one participant reported an emotional burden associated with measurement completion. The negative way many questions were worded, provided unsolicited insight into the type, range, and severity of symptoms individuals may face in the future. Others reported that the measures did not adequately capture the heterogeneity of Parkinson's, its diurnal fluctuation, and how this impacts on everyday function, which is consistent with current research (Pahwa et al. 2020). No consensus exists to guide outcome use within Parkinson’s trials involving Physiotherapy or PA (Keus et al. 2009). The measurements used in this study were selected based upon psychometric properties, capacity to measure common Parkinson's symptoms and use in previous studies. Despite established psychometric properties, these measures are open to criticism. Many offer only a snapshot in time, or are dependent on recall over a week, or longer, and/or on an individual’s state of mind at the time of completion (Pahwa et al. 2020). The impact of an individual’s state of mind was particularly pertinent at the time of this study due to the stress associated with social distancing, and travel restrictions due to COVID-19. The Lancaster report commissioned by Parkinson's UK, highlighted increased levels of anxiety due to COVID-19 which was negatively associated with behaviour, physical and NMS (Simpson et al. 2022). A qualitative study by the same authors suggested that COVID-19 caused a “double whammy” for PLwP, accentuating pre-existing physical and psychological issues and creating new ones (Simpson et al. 2022, p869), which may explain the variation in participant responses with the measures used in this study, both within and between groups.

The lack of sensitive clinical rating tools, that can accurately detect meaningful changes in function is increasingly acknowledged (van der Bergh et al. 2021). This has led to calls for the development of more reliable measures (Evers et al. 2019), and measures that assess whether current health interventions deliver, and measure what matters to PLwP (Coulter 2017). Due to the breadth of Parkinson’s symptoms, there is a growing recognition of the need for person-centred measures based upon their experience of living with the condition (Fix et al. 2018). Participants in the current study indicated that PA, QoL and health and well-being were domains which they valued most. While measures incorporating these domains were used in the current study, future research involving PDConnect may benefit from working more closely with PLwP to ensure what is measured, is important to them.

The current study took steps to include patient reported outcomes measures including the Global Impression of Change Scale, as well as measures of well-being and QoL. QoL which encompasses well-being and satisfaction are more holistic, and avoids focus on individual symptoms, which may be more valid among a heterogeneric condition such as Parkinson's. Debate exists over the merits of generic or condition specific QoL measures. Parkinson's specific QoL measures such as the PDQ-39 capture the impact of motor and NMS, however research has shown that these factors change over time (Politis et al. 2010), making the measures unreliable when used at repeated intervals within a study. Inability to draw comparisons with the general population, or with other patient groups has also been cited as a limitation of condition specific QoL measures such as the PDQ-39 (Schrag, Jahanshahi and Quinn 2000) Despite reports of lower sensitivity (Lorgelly et al. 2017), generic QoL measures that explore the impact on general health may be preferable, while also allowing comparability and consistency across, and between patient groups. The EQ-5D is one of the most frequently used generic measures of QoL (Wisløff et al. 2014), that is advocated by NICE (NICE 2020), and has also been shown to strongly correlate with the PDQ-39 (Schrag, Jahanshahi and Quinn 2000). Following the MRC guidelines for complex conditions, the next step for PDConnect is to assess its effectiveness (Skivington et al. 2020). Therefore, the ability to assess the impact of Parkinson's on QoL in comparison with normal healthy adult populations using the EQ-5D may be valuable within future renditions of PDConnect. In addition to assessing the effectiveness of PDConnect, the EQ-5D could also be used to assess quality-adjusted life years, as part of a cost utility analysis, allowing exploration of the cost-effectiveness of PDConnect. Recognising the value of both generic and condition specific QoL measures, it would be recommended both the EQ-5D and the PDQ-39 should be used in a future trial of PDConnect.

6.5. INTERVENTION FIDELITY

Intervention fidelity was high for both the 1:1 Physiotherapy and group-based exercise component (89, and 88% respectively). High fidelity could be attributed to the detailed session plans provided to staff or the training provided prior to delivery. Staff reported that the session plans provided a framework, allowing capacity to balance professional autonomy, with personalisation of delivery, while meeting the aims and objectives of the intervention. Failure to deliver exercise for 35 minutes and promoting working at RPE level 13-15 during 1:1 Physiotherapy were the most frequently omitted fidelity criteria. The American College of Sports Medicine guidelines (American College of Sports Medicine 2009) advocate that adults should participate in bouts of 30 minutes of exercise. Thirty-five minutes was selected in the current study recognising the additional time needed for PLwP to transition between exercises. When looking at the current study findings holistically, the failure to meet these criteria was not deemed negatively for several reasons. Firstly, participant satisfaction was high – 100% of participants scoring seven or above on an 11-point VAS, and all participants indicated that the Physiotherapy component achieved its aim of supporting development of a PA habit, increasing activity levels, and promoting understanding of the benefits of PA. Secondly, staff reported that shorter exercise duration was commonly dictated by participant preference, with some participants having completed their daily PA prior to their Physiotherapy appointment, therefore participants preferred to use the time to gain feedback on their HEP or discuss issues which had arisen in the prior week. Thirdly, the ability of the Physiotherapist to personalise session delivery was a key theme arising from the qualitative data and was perceived as a valued component of the intervention. Personalisation of care and adoption of a partnership approach involving shared decision have been highlighted as essential component of Parkinson's management (Tennsion, et al. 2020; Vlaanderen et al. 2019). Achieving a balance between intervention fidelity, and providing personalised care is required. The findings of the current study suggests that while the PA element may have been below (mean 29 minutes) the a-priori agreed time, this was not detrimental to participant satisfaction and highlights the need for capacity within an intervention to balance PA participation, personalisation, and participants preference. Arguably, however, feedback on PA technique has been shown as a valuable BCT within other neurological conditions such as Stroke (Moore et al. 2018). In a future trial involving PDConnect, staff session plans could stipulate the need for all PA sessions to include a minimum of 30-minutes of PA which would allow 30 minutes to conduct aspects delivered within the 1:1 Physiotherapy component.

Participant preference during a 1:1 Physiotherapy session may also have influenced the application of RPE. Physical activity prescription during the 1:1 Physiotherapy sessions tended to focus on strength, balance, and flexibility, with many participants choosing to include the aerobic element within their daily walking programme. Emphasis therefore was on movement quality, and technique refinement delivered in combination with education and feedback, therefore RPE was of less relevance. PA prescription during PDConnect was personalised to individual need, therefore while the pre-set exercise times and intensity were not consistently met during Physiotherapy, they were incorporated into the overall delivery. Standardisation of delivery is central to intervention fidelity, and research reporting, but balancing this with the needs of participants is also required, especially within a heterogenic and complex condition such as Parkinsons. The need to balance intervention delivery and personalisation has been clearly demonstrated in the current study. However, with a growing body of evidence highlighting the benefits of moderate-to high intensity and the potential neuroprotective role (Johansson et al. 2022), it is essential that within a future trial of PDConnect, that sessions plan make clear of the need for PLwP to gain experience and insight as to what RPE feels like for them so that they can apply this to participation in their own HEP's to ensure that they optimise their effort levels. Educational research suggests that learning preferences change as adults age. A systematic review demonstrated preference for audio-visual learning resources among older adults (Goodman and Lambert 2023). Alternatively, many PLwP report bradyphrenia, resulting in slower processing speeds, therefore written information may be preferable. To accommodate a broad range of learning preferences and processing capabilities, a combination of approaches is recommended in a future trial of PDConnect. In the current study information on the rate of perceived exertion was provided in the participants manuals; however, this could be augmented with video case studies involving people with Parkinson's which may provide a better insight for future participants to guide the effort they adopt when exercising.

Intervention fidelity was also high (88%) for the delivery of the group-based component of PDConnect. Promoting exercising at RPE 13-15 was also omitted within the group-based component of PDConnect – however the instructor frequently encouraged participants to work at their maximal effort but did not use the term RPE. Providing information on delayed onset of muscle soreness (DOM's) and reminding participants to engage with the PDConnect manual were also frequently omitted. Due to expiry of recorded sessions on Microsoft Teams, fidelity assessment was only conducted on later group-based sessions. Omission of DOM's, and reference to the manual, could reflect that these elements were mentioned in the first six group-based session, and were no longer required in the latter six sessions. Advising participants on local PA opportunities was also frequently omitted, this was most likely explained by the lack of community opportunities available at that time due to the COVID-19 imposed social distancing restrictions. Participants were instead signposted via email to online PA opportunities such as the Parkinson's Excellence Network Exercise Hub You Tube resources as an alternative.

In contrast to 1:1 Physiotherapy, the mean duration of exercise provided during the group-based component was 63 minutes (range 58-66 minutes), exceeding the 60 minutes proposed. Participants did not comment on the brief over run of sessions within the qualitative interviews and high levels of satisfaction were reported with this component (92% reporting 8 or above on a VAS for satisfaction). Fidelity assessment identified that the over-run was attributed to slightly longer transition needed between exercises particularly getting down to the floor as participants needed time to re-position their devices.

6.6 SECONDARY MEASURES

While this study was not powered to detect a difference between groups, effect size calculations were conducted to determine which measures may be either important and/or appropriate to use in a future trial. In addition, effect sizes, were undertaken to signpost which measure should be used within a power calculation to guide appropriate sample sizes in a future trial. While several ES trends were reported indicating improvement, wide confidence intervals also existed in several measures indicating a lack of precision which was attributed to the small and varied sample.

6.6.1 Physical activity measures

Regardless of group allocation, improvements in PA were reported as measured by the PASE between baseline and 6 weeks with a small effect size. However, this pattern did not continue during the study. These findings would suggest that 1:1 Physiotherapy prompted increased PA, which then waned when Physiotherapy was discontinued. It could also be hypothesised that participants may have over-estimated their PA at baseline, which influenced their self-reported scoring at the second timepoint. Overestimation of PA has been frequently cited among the adult population, especially among those who are inactive (van Sluijs, Griffin and van Poppel 2007). As the current study took place during COVID-19, which negatively impacted PA levels, participants may have inadvertently overestimated their PA at baseline. Alternatively, in relation to the PDConnect group, the lack of change seen may reflect a ceiling owing to high baseline PA levels, especially those in the PDConnect group, where baseline PASE scores were above that of normative values of older adults and PLwP. Equally, the small effect sizes related to the PASE could be indicative of the small sample sizes in this study (n=12), broad confidence intervals were noted at all data points suggest a lack of precision in results. The PASiPD is an adapted version of the PASE for those with disabilities. Similar effect size patterns were noted with the PASiPD as were reported in the PASE. However, qualitative data highlighted poor applicability to the current study sample, with questions on yard work, and lawn work which participants found hard to relate to and hence score.

Measures of PA were identified by participants in the current study as a key outcome which should be included within a future study. The PASE has been used in longitudinal studies involving de novo PLwP, and those with established Parkinson's, as part of a larger Parkinson's Progression Markers initiative (PPMI) study, which is an international, multicentre, observational study (Mantri et al. 2018; Amara et al. 2019). Both studies involved over 300 PLwP and demonstrated the ability of the PASE to detect changes in PA over time. The finding of the study add strength to the notion that the small effect sizes reported in the PASE in the current study may be attributed to the small sample used in the current study.

The most recent study published from the PPMI group used multivariate analysis which demonstrated that regular PA as measured by the PASE, resulted in slower deterioration of Parkinson's symptoms, in particular gait, postural instability, and activities of daily living (Tsukita, Sakamaki-Tsukita and Takahashi 2022). The PASE divides PA into leisure, household, and work-related activities in addition to regular PA (Washburn et al, 1993). Information was provided to participants as described by Washburn, however scoring of what constitutes high, medium, or low PA varied between participants, and the potential for overlap between questions on walking and specifically strength training was apparent when cleaning the data prior to analysis. Future use of PASE would benefit from providing additional explanation to guide participant responses to improve accuracy of reporting.

Measurement of PA was the most frequently reported measure that PLwP valued and reported should be included into a future trial. The aim of PDConnect was to support PLwP increase their PA levels and support them to self-manage their PA. Therefore, having PA as a primary outcome in a future study would seem a pragmatic choice. In the absence of verified and validated algorithms which currently can be embedded within wearable technology that accurately capture PA data within Parkinson’s, the use of measures such as the PASE offer an objective means of quantifying PA over time. The PASE offers advantages over other PA questionnaires such as the International Physical Activity Questionnaire as it is validated for use for those aged above 65, which aligns with the largest proportion of PLwP. Therefore, the PASE was selected as the primary outcome measure for a future trial of PDConnect. A power calculation was conducted as detailed in section 5.5.7, which indicated that a minimum total sample of 548 would be sufficient for 80% power ($\alpha = 0.05$). However, owing to the PASE estimates being routinely low, and based a small heterogeneity sample samples of between 548 and 1000 maybe required.

6.6.2 The Unified Parkinson's Disease Rating Scale

Improvements in UPDRS Part I-III and total UPDRS were noted with large effect sizes between baseline and 30 weeks, suggesting a positive impact on ADL, mood, motor symptoms and motor complications in the PDConnect group. In contrast, large ES were only reported for parts I and II of the UPDRS indicating improvement between baseline and 30 weeks, suggesting limited impact on motor symptoms within the usual care group. These findings would suggest a positive intervention effect in the PDConnect group; however, the confidence intervals were broad, suggesting heterogeneity in response. The positive impact of PA on UPDRS reported in the current study is consistent with prior studies. A recent meta-analysis involving 14 PA studies involving 574 PLwP reported that resistance training reduced UPDRS motor subception scores (indicating improvement) compared with controls (Zhou et al. 2022). Similarly, the double-blind ParkInShape study which explored the effects of an aerobic PA intervention compared to a stretching programme undertaken three time a week for six months among PLwP reported a statistically significant change in the motor subception of the UPDRS (van der Kolk et al. 2019). UPDRS improvements reported by van der Kolk study were also clinically relevant as UPDRS was assessed during the off-phase when patients were unmedicated, thereby removing the potential confounding effect of medication.

Although the findings would indicate a positive impact of PDConnect on the UPDRS is consistent with prior research, caution is required with results interpretation. Part I and III of the UPDRS were conducted by the researcher online, therefore the assessment of rigidity and postural instability were omitted. The researcher conducted the UPDRS Part I and III at each timepoint. The researcher has undergone training in the use of the UPDRS and completed the training videos, however training did not encompass reliability testing which may have influenced findings. Some studies have demonstrated high intra and inter tester reliability and test re-test reliability between Neurologists and Parkinson's specialist nurses (Metman et al. 2004; Palmer et al. 2010), whereas others have reported poor correlation between Neurologists, Resident Doctors, and Nurses (Post et al. 2005). No studies have explored the reliability of UPDRS undertaken by Physiotherapists. In addition, the older version of the UPDRS as described by Goetz et al. (2003) was used in the current study rather than the updated 2008 version, due to licence and cost implications. The four subsections remain constant between the two versions, with the newer version placing greater emphasis on impact of symptoms as opposed to prevalence. All measures were taken during the on-phase (i.e., within approximately 30 minutes of taking medication), therefore participants were optimally medicated which as reported earlier may have served as a confounding factor, however many of the questions responses require reflection over the last week, limiting the impact of the potential source of bias.

The UPDRS is widely regarded as the gold standard measure for Parkinson's in both clinical and research practice. In the absence of clinical biomarkers, the UPDRS is often used as a “proxy” (van der Kolk et al. 2019, pp1005), offering a comprehensive tool to assess motor, and non-motor impairments. The UPDRS has been shown to be reliable and valid (Goetz et al. 2008) and survey conducted by the Movement Disorders Society (MDS) highlighted that 87% of the membership use the UPDRS within research and 70% use the UPDRS within clinical practice (Movement Disorders Society Outcome Measure Task Force 2003). Frequent use of the UPDRS with research enables comparisons between studies. Despite widespread use, the UPDRS is open to criticism. As reported by Evers et al. (2019), the UPDRS is limited in that it provides only a snapshot of an individual, capturing only short-term effects, therefore does not provide an accurate impression of Parkinson’s progressions, or the motor and non-motor fluctuations which occur as part of the condition or in response to medication. An analytical analysis of the UPDRS conducted by (Hendricks and Khasawneh 2021) highlighted that the UPDRS does not consider the co-existence of co-morbidities which may serve as a confounder. In addition, bias exist within the measures which focusses on bradykinesia, but places less emphasis on tremor and postural instability (Hendrick and Khasawnen 2021).

Although the UPDRS is subject to criticism, in the absence of other comprehensive measures which include the measurement of motor and NMS and their impact on function, it is recommended that a future trial of PDConnect should include the UPDRS as a secondary outcome. Recognising that over 85% of researchers use the UPDRS within research practice (MDS Outcome measures Task Force, 2003), the use of the UPDRS in a future trial would allow comparisons to be made between studies. In addition, recognising the value of open science research using a frequently used measure allows potential for data sharing across studies to improve statistical power and study impact, and facilitate translation of findings into practice.

The MDS membership survey highlighted that 98% of the membership used the motor section of the UPDRS (sections III), whereas only 60% used the section I (mentation). The UPDRS combines self-administered, and researcher or clinician completed subsections. Each subsection of the UPDRS is calculated separately negating the need to use all sections, as each section has its own established psychometric properties (Goetz et al. 2008). Prior RCTs exploring PA such as the ParkInShape study only used two UPDRS sections - motor and motor complications (UPDRS III and IV, van der Kolk et al. 2019), whereas the ParkFit Study used only the motor section (van Nimewegen et al. 2011, 2013). Preference for using the motor subsection of the UPDRS reflects the impact that PA has on the motor symptoms. A recent systematic review exploring the effect of community PA in Parkinsons, identified 22 studies all which used the motor section of the UPDRS as a primary or secondary outcome (Yang et al. 2022).

It is recommended that within a future trial of PDConnect should include the use of the updated UPDRS recognising its universal use within Parkinsons research as a secondary measure. Equally, recognising the potential for participant burden, use of the UPDRS III motor section is also recommended. It is also recommended that the researcher should participate in reliability training provided by the Movement Disorders society for the updated UPDRS measure.

6.6.3 Measurement of self-efficacy

Effect size patterns varied in relation to SES. Improvements were reported in self-efficacy in the usual care group, between baseline and 18 weeks with a large effect size, suggesting a positive impact of Physiotherapy on self-efficacy, which was maintained for 12 weeks after physiotherapy ceased. The small ES between baseline and 30 weeks, maybe reflective of a waning of effect over time but could also reflect the changes in weather, daylight hours at the time of data collection. Adverse weather is a known PA barrier (Hunter et al. 2019), and the shorter days which are encapsulated in the SES may reflect the changes in SES reported at the final assessment time point.

Effects size patterns varied within PDConnect. Overall, between baseline and 30-weeks self-efficacy declined with a small effect size. Several reasons may explain this decline in self-efficacy. Firstly, Bandura (2004), reported that self-efficacy is influenced by experiences, and emotion in healthy adults, therefore the high prevalence of depression, apathy, and fatigue among PLwP may provide some explanation. Secondly, exercise self-efficacy has been shown to be lower among females (Edwards and Sackett 2016), and therefore the greater proportion of females randomised to the PDConnect group may in part explain the limited impact of the intervention on self-efficacy. Thirdly, the SES asks participants to rate between 1-10 “how confident are you right now that you could exercise three times per week for 20 minutes, for example if you were in pain”. Therefore, the potential for day-to-day variation in response is high. Finally, participation in the 1:1 Physiotherapy may have highlighted discrepancies between perceived abilities at baseline and actual ability leading to over-estimation of self-efficacy between the two time points which may also explain the negative findings.

Improved exercise self-efficacy between baseline and 18 weeks with a large effect size was demonstrated, which coincides with the period of Physiotherapy and group-based exercise, inferring a positive impact of the supervised components of PDConnect, however this was not carried over to the end of the study. Lower exercise self-efficacy at the 30-week point may be reflective of waning self-efficacy during the 12-week unsupervised component of PDConnect and or maybe reflective of the realisation that the intervention was coming to an end, which negatively influenced reporting. Qualitative data supports this notion with many participants reporting sadness when the intervention ceased. Fluctuation in reported self-efficacy is consistent with prior PA studies. McAuley et al. (2003) explored self-efficacy within a group of older adults, also reported declining in self-efficacy at the beginning and end of the study. MacAuley et al. (2003) suggested initial over estimation of self-efficacy maybe a factor, or as suggested in relation to the current study, declining self-efficacy may be indicative the realisation that participants would now need to exercise alone.

The global impression of change scale used in the current study indicated that exercise self-confidence had increased during the study, however this is not reflected in the self-efficacy for exercise scale used in the current study. Little is known about self-efficacy in Parkinson's (Ellis et al. 2011), however, this study would suggest that PDConnect had a positive impact on perceived PA behaviour, activity levels, and exercise confidence however, improved objective exercise self-efficacy was not reported.

Several studies have highlighted the importance of self-efficacy in relation to PA behaviour (Ellis et al. 2011; Ellis and Motl 2013; Hunter et al. 2018). Further research is required to explore whether the findings of the current study are due to the psychometric properties of the SES or whether it is reflective of the multiple variables which impact participant reporting. Understanding these relationships is integral to designing effective interventions to target PA participation among PLwP. Since undertaking this study, a new measure- the PDQ-Exercise have been developed specifically for PLwP, and encompasses exercise self-efficacy (Morley et al. 2021) but published research to date only illustrates outcome measure development (Morley et al. 2021). Therefore, further research is required to determine which measure of self-efficacy is preferable to use as secondary outcome in a future trial of PDConnect.

6.6.4 Measures of quality of life, health and well-being and function

Quality of Life and functional measures showed inconsistent and small effects, with large confidence intervals suggesting a varied effect within and between groups. The small sample and differing NMS profiling between participants and their fluctuating nature may explain the variation seen within analysis. The Schwab and England ADL scale and the Nottingham Health Profile which aim to measure functional mobility, activities of daily living, pain, sleep, and emotional reactions showed no particular trends within the current study. As these domains are also captured in measures such as the UPDRS and QoL measure, it is recommended that these measures should not be included within a future trial of PDConnect. The use of both generic and condition specific QoL measures would be recommended for use within a future trial of PDConnect offering capacity to draw conclusion of the impact of PDConnect on QOL as well as offering potential to undertake cost effectiveness analysis.

6.7 STUDY STRENGTHS AND LIMITATIONS.

6.7.1 Study strengths

To date, research has focussed on PA prescription for PLwP, however the optimal means of delivery to support long-term participation has been largely overlooked. This is study adds to the limited body of research which has explored an intervention which aims to support PLwP to be active. The development of the PDConnect intervention was informed by current evidence, and in collaboration with PLwP and exercise professionals which highlighted the key ingredients to potentially optimise long-term physical activity. Consultation with PLwP was conducted throughout, to ensure suitability and accessibility of all materials as well as to shape the direction of the study. The methods selected were considered and align with current guidelines for researching complex interventions (Skivington et al. 2021). Similarly, the reporting is transparent and aligns with best-practice guidance (Thabane et al. 2016). Response rates to questionnaires was high, as well as intervention adherence. All progression criteria except for participant retention were met. This study demonstrated that PDConnect is feasible to deliver and is highly acceptable among PLwP.

6.7.2 Study Limitations

6.7.2.1 Methodological limitations

This study adopted a pragmatic design exploring the feasibility and acceptability of an intervention; however, it was not without its limitations in relation to research processes and study design. Convenience sampling is prone to sample bias, and as a result may not be representative of the total population. Additionally, convenience sampling from the same geographical area led to limited ethnic and cultural diversity, and a sample that was younger than the mean age of diagnosis reported in incidence studies (Macleod et al. 2018). To maintain participant safety during this online intervention, those with severe balance abnormalities and significant cognitive issues were excluded, therefore only those in Hoehn and Yahr stages I-III were included. The use of convenience sampling may have caused selection bias (Bowling 2014). Baseline PASE for the total sample (139.58, (SD±81.86) was similar to the normative values (144 for males and 112 for females) for people aged between 65 and 69, suggesting that the sample was not recruited from a sedentary population. However, the large standard deviation in the PASE score suggests a wide variation in PA levels within the sample. Similar variation was reported in a retrospective observational study by (Tsukita, Sakamaki-Tsukita and Takahashi 2022) involving 237 people with early Parkinson's (mean age 63), where PASE scores ranged between 110.5 and 250.5. It is also not known whether lower levels activity at baseline reflect normal behaviour or whether it reflects the reduced exercise opportunities available during COVID-19 (Simpson et al. 2022). Convenience sampling may also have resulted in the recruitment of PLwP who were more motivated, which may also limit transferability to the general population. The current study was not powered or designed to detect differences between groups, therefore the findings of the current study are not generalisable. Therefore, future studies need to consider within a larger sample, the effects of PDConnect on PLwP with different PA profiles.

Other forms of bias such as performance bias were minimised as the same exercise professionals delivered all interventions. Researcher bias was also limited by using a researcher independent to the intervention delivery, who conducted and recorded all interviews using Microsoft teams. Transfer bias occurs when there are unequal participant losses between groups (Pannucci and Wilkins 2010). No transfer bias occurred in the current study. However, Bell et al. (2013) argues that equal dropout rates between groups does not guarantee that the results are not biased; rather it is dependent on the dropout mechanism. As six of the withdrawals were caused by a new health condition (e.g., anaemia), which could not have been predicted, there is confidence that no transfer bias occurred.

Participants retention fell 1% below the a priori progression criteria for this study potentially indicating a stop to a future trial of PDConnect. However as discussed in section 6.3.3, retention broadly aligns with other studies which have undertaken PA interventions of greater than 12 weeks. Avery et al. (2017) recommends that data relating to progression criteria should not be considered in isolation. Rather additional data should be used to support decision making about whether a study should proceed to a full trial (Avery et al. 2017).

Therefore, as all other progression criteria were met, and acceptability of study processes, intervention delivery and resources were perceived as acceptable by participants it is recommended that future research is undertaken to explore the effectiveness of PDConnect.

The design of the current study is also subject to limitations. Firstly, the volume of the interventions received by both arms was not equal. The Intervention arm received an additional 12 weeks of group-exercise and monthly phone calls for three months. As the principal aim of this research was to determine the feasibility and acceptability of PDConnect rather than effectiveness, equity in volume was not a consideration for this study design. In the current study usual care reflected the number of Physiotherapy sessions typically provided within the NHS (personal communication). Increasing the intervention dose of the usual care group would not reflect standard practice and would limit ability to determine whether PDConnect is or is not superior to usual care. Therefore, a future study should aim to incorporate whether those in the usual care group needed subsequent follow up to Physiotherapy during the study period.

Secondly, owing to the nature of the intervention, participants could not be blinded, potentially impacting on the reliability of the findings. Knowledge that they were in the intervention group could potentially have positively biased their responses to some of the self-reported measures. Personal bias from the researcher is also a potential source of bias, as they had developed the intervention, and is known within the Parkinson’s community as a strong advocate for PA. This may have inadvertently influenced participants during completion of the measures. Personal bias was controlled by ensuring that the researcher was blind to participant allocation until all quantitative data analysis was complete. All participants were reminded at each measurement point not to disclose their group allocation, and the focus of the measurement points would be measures not to discuss any other issues related to the study nor their Parkinson's. Consequently, no disclosures of allocation were made by participants.

Thirdly, as a feasibility study several measures were used in this study. Selecting measures which were sufficiently sensitive and specific, which could be employed in a heterogeneous population aged between 50 and 85 was challenging. Measures used were recommended by the MDS International task force or had been shown to be reliable and valid among the older adult population. However, the UPDRS for example while regarded as the gold standard measure (Bloem and Stocchi 2015), is also widely criticised (Hendricks and Khasawneh, 2021). As noted earlier, the UPDRS is reported as biased towards bradykinesia and has limited utility in the early stages when motor impairments are subtle (Hendricks and Khasawneh, 2021), which may have affected findings in this study as the sample were young with less severe motor impairments. Further, a ceiling effect was noted in some measures for example the ABC score which may also have negatively impacted on the results. Some measures were redundant for some participants as they did not experience certain symptoms, for example fatigue. Redundancy was particularly evident among measures of NMS. As noted earlier several the self-report measures rely on participant recall which may have introduced bias, as well as the potential of the impact of COVID-19 on mental well-being which may have led to an over or underestimation of responses.

Reliability of the UPDRS was further compromised as it was conducted online. Elements of the UPDRS III (Motor section) were omitted e.g., testing of rigidity. Similarly, measures of dynamic balance such as the MiniBESTest, and the TUAG were also removed due to online delivery of PDConnect, therefore no objective measures of balance were included. Future online interventions such as PDConnect need to ensure that they can include a range of measures which can be conducted safely and effectively.

Many of the measures were self-administered. While this allowed participants to work through the measures at their own rate, self-administration introduces potential for recall bias (Bowling et al, 1994). Many measures required recall over the prior 7 days, raising potential for responses to be over or under-reported. Due to the high prevalence of cognitive dysfunction in Parkinson's (Aarsland et al. 2021), the ability to accurately recall prior experiences maybe questionable. Equally, participants may have been too embarrassed to report some symptoms such as hallucinations, although arguably some may have found it easier to do as part of a survey rather than direct to a researcher. Some of the measures carried an emotional burden, and some participants reported that some questionnaires focussed on symptoms which did not affect them (e.g., Parkinson fatigue scale) highlighting the heterogeneity of the condition. Future work is required to explore what is important to measure involving a larger sample to inform the measures to be used in future PA trials.

Also, all measures captured a snapshot which is unavoidable, however measures therefore fail to capture the extremes of their functional ability. Reporting within measures is also dependent upon PLwP recognising the presence of their symptoms. (Maier and Prigatano 2017) demonstrated that PLwP commonly under report medication wearing off, bradykinesia and dyskinesia, as well as struggle to distinguish between motor symptoms. Underreporting is common due to the insidious decline, resulting in many PLwP perceiving their symptoms as normal, leading to further under-reporting (Stamford, Schmidt and Friedl 2015) or due to cognitive decline leading to difficulties in recall or identification of symptoms (Pahwa et al.

2020). These factors may have affected the reliability of the finding reported in the current study.

All participants completed the same measures at each time point. In addition, those who were randomised to PDConnect also completed an intervention satisfaction questionnaire and a semi structured interview at the end of the study. However, no satisfaction questionnaire was provided to the usual care group. Future evaluation of the PDConnect needs to include satisfaction questionnaires within both groups so that valid and reliable comparisons between groups can be drawn.

6.7.2.2 Impact of COVID-19

Throughout this thesis reference has been made to the impact of COVID-19. Most significantly, COVID-19 necessitated a change to online recruitment, intervention delivery and measurement. Although online delivery of PDConnect has been shown to be feasible and acceptable, the impact of COVID-19 introduces potential for bias. Recruitment and motivation to participate may have been bolstered due to the lack of alternative PA interventions on offer at the time of the study. While lack of access to technology was not shown to be a barrier, digital exclusion is broader, encompassing motivation, perceived worth, skill and education (Watts 2020), which may also have impacted upon the study findings. COVID-19 has also been shown to have significantly impacted PLwP, in relation to physical, emotional health (Simpson et al. 2021), which may have influenced responses and behaviour during the course of the study. Therefore, while this study indicated positive findings, further research is required in relation to the acceptability of online delivery of PA out with COVID-19.

6.8 RECOMMENDATIONS

Future research should aim to control for the limitations of the present study. This study demonstrated in addition to feasibility and acceptability, that PDConnect may be effective for increasing PA and supporting PA self-management in PLwP. Following the MRC guidelines for complex interventions the next stage of feasibility testing is to test whether this intervention works in ideal or actual conditions compared to other practices (Skivington et al. 2021). Therefore, the next stage of testing PDConnect would require a randomised controlled trial designed to evaluate the effects of PDConnect compared to usual care.

The current study demonstrated that it was feasible to deliver PDConnect online. Feedback from participants was mixed in relation to future delivery. Hybrid delivery of PDConnect combines the benefits of face-to-face and online delivery, however, presents operational logistical challenges and potentially limits scalability of PDConnect. Current evidence recommends PA prescription for all stages of the condition from diagnosis. Training a team of staff to deliver PDConnect would allow people to access PDConnect regardless of where they live, with potential to reduce health inequalities as currently few have access to specialist services. Online delivery would also serve to make PDConnect available to underserved communities. Therefore, it is recommended that a multicentre trial which explores the effectiveness of PDConnect online is undertaken.

The current study has highlighted several modifications to the current PDConnect intervention which need to be addressed prior to a future trial to optimise participant experience and delivery, as listed below**:**

Wi-fi-enabled tablets: Future research funding applications should include funds to cover the costs of Wi-Fi enabled tablets which could be provided to participants so to minimise the potential for digital exclusion. It is also recommended that the researcher works with Parkinson's UK and local government agencies, who are currently developing resources to support the development of digital literacy, so to minimise exclusion on this basis.

Participant recruitment: A broader approach to participant recruitment is required to ensure that the future sample includes under-represented groups and has broader cultural and ethnic diversity. Involvement of BME communities within the study steering group is essential, to ensure that recruitment strategies are inclusive of the wider Parkinson's community. Recruitment rates in the current study may have been bolstered due to the lack of PA opportunities available at the time due to COVID-19. A longer duration may be required to recruit a future sample, as community-based PA opportunities have now returned to pre-COVID-19 levels.

Staff recruitment: A larger RCT would necessitate training of several more staff. Staff recruitment was identified as a challenge in the current study because of COVID-19. Challenges within the NHS continue to persist, therefore as with participants, longer recruitment periods, and contingency plans are recommended to enable staff recruitment. Contingencies could include the employment of staff to directly deliver the intervention. Future online delivery of PDConnect would also allow staff to be recruited from anywhere, not limited to a single geographical area as in the current study.

Staff training: The use of a training manual, supported by workshops as undertaken in the current study should be augmented with more detailed discussion of weekly session plans to ensure standardisation of delivery. Further, in the absence of COVID-19, practical workshops could be included to better support PA prescription. This needs to be captured and costed into a future research funding application. With a larger group of staff an online forum created to address any issues which staff may encounter as they are delivering the intervention would also be recommended, to provide guidance from the principal researcher as well as serving as a peer support group for staff delivering the intervention. Pre-and post-training evaluation forms would be used to assess training in future. Formal assessment of staff competency was not assessed in the current study. Recognising that Parkinson's competencies exist for HCPs, an assessment component to the training could be considered which could be accredited by a Higher Education Institution. In the absence of any formal Parkinson's specialist training courses nationwide, the option of accreditation of learning may enhance recruitment of staff, providing a recognition of learning.

If PDConnect were shown to be effective by means of a future definitive trial, staff training could be made more widely available through existing NHS training platforms for example TURAS, or directly through the Parkinson's UK Excellence Network Learning Hub. In addition, if the evidence of need and effectiveness of PDConnect is established, the objective would be to work NHS patterns and key stakeholders to integrate PDConnect into routine care delivery of PLwP.

Microsoft Teams Induction: The current study highlighted that some participants required additional support to engage effectively with Microsoft Teams. It is recommended that the induction materials are reviewed to ensure clarity, in collaboration with PLwP. Consideration is also required on whether induction resources need to be amended for Android or Apple platforms and accommodate differences between tablets and laptops. Development of a "how to get ready for your online appointment guide" would also be recommended to help trouble shoot issues for example adjusting the camera angle which was identified during the study. Future applications for research funding should also include staff costs to support a two-week IT familiarisation period for those who require this to support engagement which could be provided for the first two weeks of the study. An IT familiarisation period would support development of digital literacy, and trouble shoot issues associated with using the technology.

PDConnect Participant manual: Modifications are required to the participant manual, which need to be taken forward when planning a future trial of PDConnect. The development of an online platform is suggested which would facilitate personalisation of education and enable the mapping of educational content to individual sessions promoting consolidation of learning and understanding. Web-based resources have been shown to be acceptable for people with Multiple Sclerosis (Busse et al, 2022) allowing people to select the education relevant to them. Web-based resources would aid scalability of PDConnect, but ensure information remains current, however would infer addition costs to support website design, development, and maintenance. The current study did highlight differing preferences in relation to online or paper-based resources therefore in light of variation in preference more than one approach may need to be offered to optimise engagement and preference in future trial involving PDConnect.

Outcome measurement: Response rate to measurements conducted throughout the current study was high and they were not perceived as burdensome. As a feasibility study a large battery of measures were employed, to inform which measures should be used in a future definitive trial. Combining feedback from participants, and effect size analysis, a power calculation has been conducted using the PASE as a primary measure. It is also recommended that the motor subsection of the UPDRS, EQ-5D, PDQ-39, MiniBESTest, and step count should be included in a future trial as secondary outcomes, allowing inferences to be drawn on the potential impact of PDConnect on motor symptoms QoL, gait and balance. Quality of life was perceived as a valued domain to measure by the participants in the current study. Future use of generic measures such as the EQ-5D as highlighted in the discussion, would allow the assessment of the impact of Parkinson's on QoL in comparison with normal populations, allowing illustration of the impact and effect of PDConnect on PLwP. If PDConnect were to be shown to be effective, implementation within clinical practice would be the next logical step. The additional advantage of using a generic measure such as the EQ-5D would also permit the assessment of quality-adjusted life years, as part of a cost utility analysis, allowing exploration of the cost effectiveness of PDConnect. In addition, more objective means of reporting falls should be included in a future study, consideration needs to be given to use of an app or real time method of recording falls reporting. Further exploration is needed to inform which measure of self-efficacy should be used, pilot work comparing the SES used in the current study compared with the new PDExercise measures should be considered prior to conducting a future trial. Similarly, the use of technology to capture the impact of Parkinson's has evolved rapidly. Recording Parkinson's motor symptoms such as tremor, and consequences of Parkinson’s such as falls, may be more reliably recorded through use of apps while reducing participant burden. Review of the current evidence base in relation to measurement is required prior to consulting with the Parkinson’s community to gauge their views and opinions.

Self-monitoring of physical activity: The use of the Mi band to measure step count and PA requires further consideration prior to conducting a future trial of PDConnect. The lack of reported reliability of the Mi band was perceived as demotivating, as it underestimated actual PA. Conversely others recognised the utilitarian attributes of the Mi band and perceived it as a powerful behaviour change tool, rather than an objective measure of PA. With wearable technology challenges exist in relation to balancing cost and reliability. More recent studies have adopted pragmatic approaches, using mobile phone apps to measure step count (Shootemeijer et al. 2022), whereas more expensive devices such as the Personal KinetiGraph (PKG) watches which are recommended by NICE are also developing capability to measure PA, however the reliability of these devices to measure PA is currently unknown. Findings from the Mobilise-D consortium due later in 2023, aim to produce scientifically verified algorithms specifically for Parkinson's gait which would allow more accurate recording of step count, however the cost implications of licencing these algorithms and embedding them within wearable technology is currently unknown. Further discussion with the Parkinson's community is also required to further understand the roles of activity trackers, to ensure best fit in relation to cost, practicality and shaping behaviour for a future trial and PA.

Development of social connection: The opportunity to develop social connection was perceived as limited in the current study. It is recommended a future trial of PDConnect should include a 1:1 session between the fitness instructor and participants to ensure the group-based component is tailored to individual need. Further inclusion of ice breaker sessions should be built into the session plan to promote social connection. In the current study education content were pre-planned for the first 6 weeks, with the subsequent six guided by participants choice. It is recommended that this is switched in future delivery so that the first six sessions are more informal and promote discussion of topics relevant to getting to know each other prior to sessions which focus on Parkinson's.

Personalisation of self-management component: When seeking funding for a future trial, additional costing needs to be considered so that if required an extra call could be made in the first month of the self-management component to support transition to this phase.

6.9 CONCLUSIONS

The current study adds to the growing evidence that online telehealth interventions can be used to support PLwP to participate in PA. This study has demonstrated that it was feasible to recruit to and deliver a multi-component PA intervention, combining specialist physiotherapy and group-based exercise to support increased PA and PA self-management. Recruitment, adverse events, and outcome measure response rates all satisfied progression criteria. Participants recruitment did not quite meet the progression criterion, however taking a holistic view of all other feasibility and acceptability measures, it is recommended that this study proceeds to a full trial. This study demonstrated that online delivery of PDConnect was feasible and acceptable among PLwP. The current study has also highlighted the potential benefits of a PA intervention for PLwP which incorporates self-management skills, BCTs, motivational coaching and education delivered by specialist Parkinson's staff. Several recommendations have been made to guide future research development. However, in order to establish the optimum means of delivering PA for the wider Parkinson's community further research is needed with a larger, a more diverse sample to explore the efficacy of PDConnect and the sustainability of this model of delivery.

CHAPTER SEVEN – REFERENCES

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CHAPTER EIGHT – APPENDICES

8.1 APPENDIX 1: OVERVIEW OF THE CONTENT OF PARKINSON'S SPECIFIC SELF-MANAGEMENT PROGRAMMES

Self-management Programme	**Programme summary**
EduPark Patient education for persons with PD and their Carers.	European collaboration. Eight, sessions lasting 90 minutes each. Topics include Information, self-monitoring, health empowerment, Stress management, Anxiety and depression, carers challenge, social competency, social support, and summary. Delivered by interactive means, incorporating active discussion, in session tasks, setting of homework, and active discussion based upon homework. Group based intervention.
Living well with Parkinson's	Six 1.5-hour seminars run weekly. Content of the sessions included knowledge about Parkinson's research, medication, physical exercise, nutrition, and the emotional and psychological aspects of living with Parkinson's. Group based intervention
Parkinson's enrichment programme	4 hour per week for 5 weeks. Topics included: education, exercise, recreation, and socialization/support. Delivered by Trainee Social Workers, supported by topic specific experts. Group based intervention
Swedish National Parkinson's School (NPS)	NPS provides PLwP and families with knowledge and tools to enhance ability to live and handle life with Parkinson's. The program is based on cognitive behavioral therapy. Includes 7 topics: introduction, anxiety and depression, enrichment activities, stress, self-monitoring, and my future with Parkinson's. Each lasting 2 hours, involving group discussions
Hertfordshire Neurological Services Self-Management Program	3 modules including: What is self-management, living well and condition specific information. Delivered in a group form by members of the multidisciplinary team. Designed for neurological conditions

Self-management Programme	**Programme summary**
Chronic Disease self-management Programme (CDSMP) Lorig et al (2001)	6 weeks, each session lasting 1.5 to 2 hours, facilitated by 2 certified trainers, one of which has a LTC. Combination of education and support group. Providing information relevant to chronic disease self-management, delivered via interactive sessions on feedback and problem-solving, decision making, resource utilisation, patient provider relationships and encourages the sharing of personal experience and strategies for living – features which may provide its participants with emotional, informational, and belonging support.
Strive to Thrive	Adopted the CDSMP model above but included one other additional session specific for PLwP.
Mindfullness	Mindfulness-based lifestyle program including a two-hour facilitated group session once a week for 6 weeks, with one hour dedicated to exploring and practicing mindfulness and the other hour dedicated to other lifestyle elements in the ESSENCE model (Education, Stress management, spirituality, exercise, and nutrition)

8.2 APPENDIX 2: COMPLETED CONSORT AND TIDIER CHECKLISTS

CONSORT 2010 checklist for reporting a pilot or feasibility trial (Eldridge et al. 2016)

Section/Topic	**Item No**	**Checklist item**	**Reported on page No**
Title and abstract			
	1a	Identification as a pilot or feasibility randomised trial in the title	**1**
	1b	Structured summary of pilot trial design, methods, results, and conclusions (for specific guidance see CONSORT abstract extension for pilot trials)	**14**
Introduction			
Background and objectives	2a	Scientific background and explanation of rationale for future definitive trial, and reasons for randomised pilot trial	**19**
	2b	Specific objectives or research questions for pilot trial	**108**
Methods			
Trial design	3a	Description of pilot trial design (such as parallel, factorial) including allocation ratio	**120**
	3b	Important changes to methods after pilot trial commencement (such as eligibility criteria), with reasons	**129**
Participants	4a	Eligibility criteria for participants	**126**
	4b	Settings and locations where the data were collected	**172**
	4c	How participants were identified and consented	**135**
Interventions	5	The interventions for each group with sufficient details to allow replication, including how and when they were administered	**140**
Outcomes	6a	Completely defined prespecified assessments or measurements to address each pilot trial objective specified in 2b, including how and when they were assessed	**172**

	6b	Any changes to pilot trial assessments or measurements after the pilot trial commenced, with reasons	**NA**
	6c	If applicable, prespecified criteria used to judge whether, or how, to proceed with future definitive trial	**198**
Sample size	7a	Rationale for numbers in the pilot trial	**134**
	7b	When applicable, explanation of any interim analyses and stopping guidelines	**NA**
Randomisation			
Sequence generation	8a	Method used to generate the random allocation sequence	**136**
	8b	Type of randomisation(s); details of any restriction (such as blocking and block size)	**136**
Allocation concealment mechanism	9	Mechanism used to implement the random allocation sequence (such as sequentially numbered containers), describing any steps taken to conceal the sequence until interventions were assigned	**136**
Implementation	10	Who generated the random allocation sequence, who enrolled participants, and who assigned participants to interventions	**136**
Blinding	11a	If done, who was blinded after assignment to interventions (for example, participants, care providers, those assessing outcomes) and how	**173**
	11b	If relevant, description of the similarity of interventions	**NA**
Statistical methods	12	Methods used to address each pilot trial objective whether qualitative or quantitative	**188**
Results			
Participant flow)	13a	For each group, the numbers of participants who were approached and/or assessed for eligibility, randomly assigned, received intended treatment, and were assessed for each objective	**210**
	13b	For each group, losses and exclusions after randomisation, together with reasons	**210**
Recruitment	14a	Dates defining the periods of recruitment and follow-up	**204**

	14b	Why the pilot trial ended or was stopped	**NA**
Baseline data	15	A table showing baseline demographic and clinical characteristics for each group	**206**
Numbers analysed	16	For each objective, number of participants (denominator) included in each analysis.	**204**
Outcomes and estimation	17	For each objective, results including expressions of uncertainty (such as 95% confidence interval) for any estimates.	**NA**
Ancillary analyses	18	Results of any other analyses performed that could be used to inform the future definitive trial	**277**
Harms	19	All-important harms or unintended effects in each group	**277**
	19a	If relevant, other important unintended consequences	**NA**
Discussion			
Limitations	20	Pilot trial limitations, addressing sources of potential bias and remaining uncertainty about feasibility	**356**
Generalisability	21	Generalisability (applicability) of pilot trial methods and findings to future definitive trial and other studies	**361**
Interpretation	22	Interpretation consistent with pilot trial objectives and findings, balancing potential benefits and harms, and considering other relevant evidence	**NA**
	22a	Implications for progression from pilot to future definitive trial, including any proposed amendments	**361**
Other information			
Registration	23	Registration number for pilot trial and name of trial registry	**120**
Protocol	24	Where the pilot trial protocol can be accessed, if available	**120**

Funding	25	Sources of funding and other support (such as supply of drugs), role of funders	**120**
	26	Ethical approval or approval by research review committee, confirmed with reference number	**120**

TIDieR (Template for Intervention Description and Replication) Checklist (Hoffman et al. 2014)

Item		
1	Provide the name or a phrase that describes the intervention	1
2	WHY: Describe any rationale, theory, or goal of the elements essential to the intervention.	146
3	WHAT: Materials: Describe any physical or informational materials used in the intervention, including those provided to participants or used in intervention delivery or in training of intervention providers. Provide information on where the materials can be accessed	146
4	Procedures: Describe each of the procedures, activities, and/or processes used in the intervention, including any enabling or support activities	146
5	WHO PROVIDED: For each category of intervention provider, describe their expertise, background and any specific training given.	136
6	Describe the modes of delivery of the intervention and whether it was provided individually or in a group.	138
7	WHERE: Describe the type(s) of location(s) where the intervention occurred, including any necessary infrastructure or relevant features.	138
8	WHEN AND HOW MUCH: Describe the number of times the intervention was delivered and over what period of time including the number of sessions, their schedule, and their duration, intensity or dose.	146
9	TAILORING: If the intervention was planned to be personalised, titrated or adapted, then describe what, why, when, and how.	146
10	MODIFICATIONS: If the intervention was modified during the study, describe the changes	NA
11	Planned: If intervention adherence or fidelity was assessed, describe how and by whom, and if any strategies were used to maintain or improve fidelity, describe them.	177

12	Actual: If intervention adherence or fidelity was assessed, describe the extent to which the intervention was delivered as planned.	269

8.3 APPENDIX 3: SUMMARY OF IRAS AMENDMENTS REQUIRED DURING THE STUDY

Date	Amendment type	Rationale for amendment	Date granted
16/04/2020	Initial submission	N/A	30/06/2020
1/10/2020	Major amendment	Change to the mode of delivery of the study from face-to-face to solely online delivery for both control and intervention arms. Required changes to all study documentation	11/11/2020
25/11/20	Minor amendment	All study measurements to be completed online. Removal of some measures to ensure participant safety. Changes required to participant information sheets, measurement manuals, and research protocol.	27/11/2020
29/01/21	Minor amendment	Changes to Mi band design since initial user manuals submitted. Therefore, manuals required updating prior to commencement	31/01/21

8.4 APPENDIX 4: CHANGES TO INCLUSION CRITERIA

Changes to study inclusion criteria and outcome measures due to online delivery.

Original Inclusion Criteria	**Adapted Inclusion Criteria**
• Confirmed diagnosis of Parkinson's • Stage I-III Hoehn and Yahr Scale • Mild to severe gait disturbance with a score of ≤2 on the Unified Parkinson's disease Rating Scale (UPDRS) item 29 • Able to walk independently with or without a walking aid further than 100m • Stable medication for more than 3 weeks • Able to speak and understand English without assistance • Have a tablet or laptop, which is compatible with Microsoft Teams, with inbuilt webcam.	• Confirmed diagnosis of Parkinson's • Stage I-III Hoehn and Yahr Scale • Mild to severe gait disturbance with a score of ≤2 on the Unified Parkinson's disease Rating Scale (UPDRS) item 29 • Self-reported ability to walk independently with or without a walking aid further than 100m • Stable medication for more than 3 weeks • Able to speak and understand English without assistance.
Original Outcome measures	**Adapted Outcome measures**
• Unified Parkinson's Disease Rating Scale (UPDRS) • Timed up and Go • MiniiBESTEST • Activities-specific Balance Confidence scale (ABC) • Mi Band • 10m walk test • 6 minute walk test • Physical Activity Scale for the Elderly (PASE). • Physical Activity Scale for individuals with Physical disabilities (PASIPD). • Self-Efficacy for Exercise Scale • Schwab and England Activities of Daily Living Scale • Lille Apathy Scale (LAS) • Parkinson's Fatigue Scale (PFS) • Parkinson's Anxiety Scale (PAS) • Geriatric Depression Scale (GDS) • Parkinson's Disease Questionnaire PDQ-39 • Nottingham Health Profile (NHP)	• Unified Parkinson's Disease Rating Scale (UPDRS) • Activities-specific Balance Confidence scale (ABC) • Mi Band • Physical Activity Scale for the Elderly (PASE). • Physical Activity Scale for individuals with Physical disabilities (PASIPD). • Self-Efficacy for Exercise Scale • Schwab and England Activities of Daily Living Scale • Lille Apathy Scale (LAS) • Parkinson's Fatigue Scale (PFS) • Parkinson's Anxiety Scale (PAS) • Geriatric Depression Scale (GDS) • Parkinson's Disease Questionnaire PDQ-39 • Nottingham Health Profile (NHP) • Patient global impression of change score

8.5 APPENDIX 5: CONSULTANT RECRUITMENT PACK

The consultant information pack consisted for the following items:

Power point slide deck including outline of the study

Confirmation of the study ethical approval (provided in appendix 5)

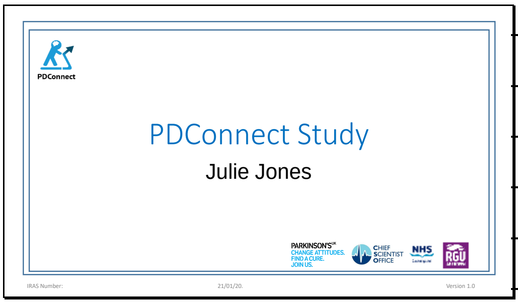
Participant information sheet

Letter of invitation

Researcher’s contact details for participants

Consultant recruitment power point deck

Slide 1



PDConnect Study

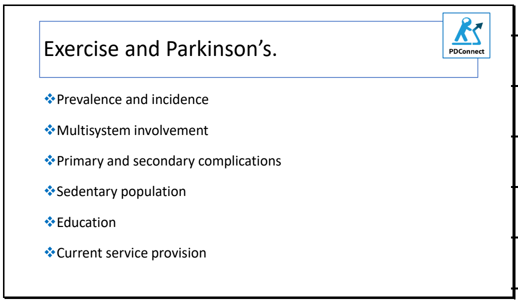
Julie Jones

IRAS Number:

21/01/20.

Version 1.0

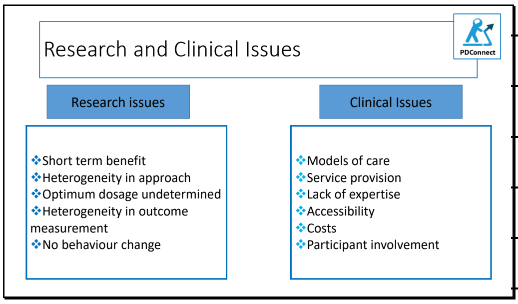
Slide 2



Exercise and Parkinson’s.

- Prevalence and incidence
- Multisystem involvement
- Primary and secondary complications
- Sedentary population
- Education
- Current service provision

Slide 3



Research and Clinical Issues

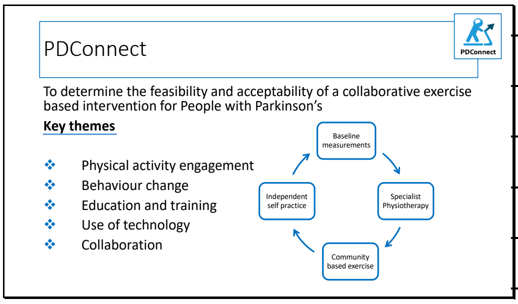
Research issues

- ❖Short term benefit
- ❖Heterogeneity in approach
- ❖Optimum dosage undetermined
- ❖Heterogeneity in outcome measurement
- ❖No behaviour change

Clinical Issues

- ❖Models of care
- ❖Service provision
- ❖Lack of expertise
- ❖Accessibility
- ❖Costs
- ❖Participant involvement

Slide 4



PDConnect

To determine the feasibility and acceptability of a collaborative exercise based intervention for People with Parkinson's

Key themes

- ❖ Physical activity engagement
- ❖ Behaviour change
- ❖ Education and training
- ❖ Use of technology
- ❖ Collaboration

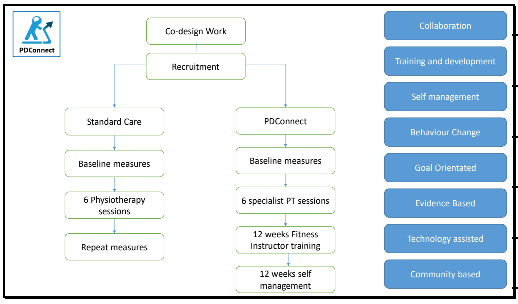
Baseline measurements

Specialist Physiotherapy

Community based exercise

Independent self practice

ide 5

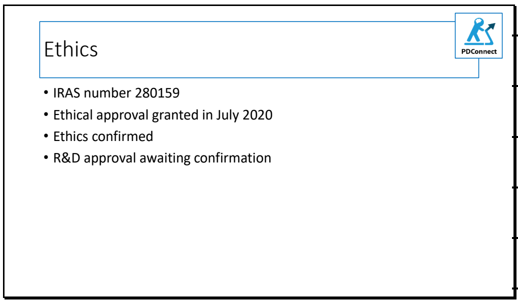


Slide 6

Study Inclusion Criteria

Inclusion Criteria	Exclusion Criteria
Confirmed diagnosis of Parkinson's **Stage I-III Hoehn and Yahr Scale** **Mild to severe gait disturbance with a score of ≤2 on the UPDRS item 29** **Able to walk independently with or without a walking aid greater than 100m** **Stable medication for more than 3 weeks** **Able to speak and understand English without assistance** **Have a tablet/laptop with a webcam, that is Microsoft Teams compatible**	Secondary or atypical Parkinsonism Severe, unpredictable episodes of motor fluctuation Use of medications known to interfere with cognitive function History of neurological diseases other than Parkinson's Any unstable mental or physical condition that prevent consenting and participating in exercise. Unstable or uncontrolled medical conditions

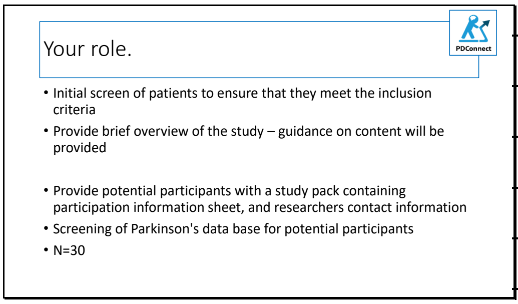
Slide 7



Ethics

- IRAS number 280159
- Ethical approval granted in July 2020
- Ethics confirmed
- R&D approval awaiting confirmation

Slide 8

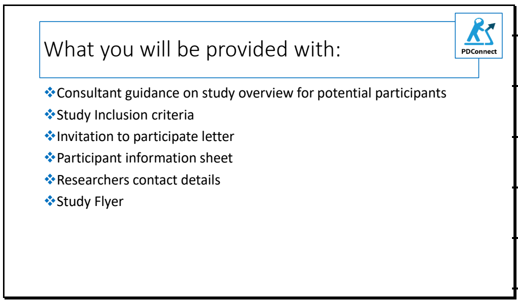


Your role.

- Initial screen of patients to ensure that they meet the inclusion criteria
- Provide brief overview of the study – guidance on content will be provided

- Provide potential participants with a study pack containing participation information sheet, and researchers contact information
- Screening of Parkinson's data base for potential participants
- N=30

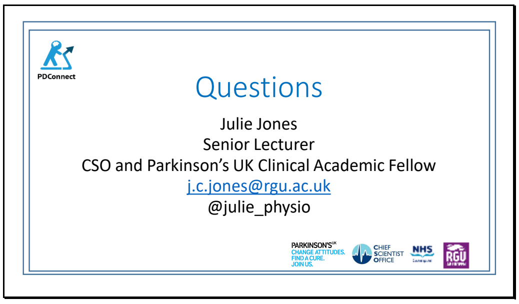
Slide 9



What you will be provided with:

- Consultant guidance on study overview for potential participants
- Study Inclusion criteria
- Invitation to participate letter
- Participant information sheet
- Researchers contact details
- Study Flyer

Slide 10



Questions

Julie Jones
Senior Lecturer
CSO and Parkinson's UK Clinical Academic Fellow
j.c.jones@rgu.ac.uk
@julie_physio

PDConnect

Participant Information Sheet

Study Title: Exercise for people with Parkinson's -the PDConnect study

You are being invited to take part in a research study. Before you decide whether you wish to take part, it is important for you to understand, why the research is being done, and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear, or should you require any further information, please do not hesitate to contact the researcher. The details are available on the last page of this document. Take time to decide whether you wish to take part. Thank you for reading this.

Introduction:

The benefits of exercise for people with Parkinson’s are widely known; however, over 70 per cent of people with Parkinson’s are regarded as sedentary. Therefore, services need to be designed to get people with Parkinson’s being more active and supporting them with long-term engagement in exercise. This study aims to explore the feasibility and acceptability of exercise intervention. It will compare a group receiving exercise with another group receiving exercise combined with guidance and group work.

Why have I been chosen?

You have been chosen because you have Parkinson’s, and this study is looking at exercise provision for people with Parkinson’s. This study will be conducted by Julie Jones from the School of Health Sciences, Robert Gordon University (RGU), two senior physiotherapists employed within NHS Grampian and two fitness instructors employed at RGU:Sport.

Do I have to take part?

No, it is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet and be asked to sign a consent form. You will be given a copy of both forms to keep. If you decide to take part, you are still free to withdraw at any time and without giving a reason.

Taking part in the study.

If you decide to take part, you will receive a screening assessment, which will be conducted by Julie Jones, over the phone. This screening assessment should take no more than 10 minutes. This is to ensure that you meet the study inclusion criteria, and that you have no medical reason that would prevent you from exercising safely. As this study is being delivered exclusively online, to participate in this study you will need access to a tablet or laptop for the duration of the study. In addition, you will require a reliable and stable internet connectivity.

To participate in the study, you will need to be willing to download software called Microsoft Teams to your device.

What is Microsoft Teams?

This study is being delivered entirely online using Microsoft Teams. Therefore, to participate in this study you will need a device such as a laptop, ipad, or other tablet-type device, which the Microsoft Teams app can be down loaded to. Microsoft Teams is free to download and is an online platform which allows audio and video calls and sharing of information. Microsoft Teams is a secure and closed channel, which only the researchers and those participating in the study will have access too. Exercise sessions will be delivered using Microsoft Teams so you will be able to see, hear and speak with the staff in real time, and it also allows you to contact the staff to ask any questions, and we can send you information during the course of the study. Microsoft Teams was selected as this platform is used by the NHS, and is compliant with general data protection regulations (GDPR).

Measuring your activity.

You will be provided with an activity tracker, which looks like a watch (see diagram below).

Mi Band activity tracker

This device will collect data on your daily step count, and the amount of time that you have been active. Julie will set this device up for you, using a username of your choice, and will show you how to synchronise it with a Smart phone to download the data. This information will be provided to you also in written format so you have this as a resource should you need it. If you do not have a Smart Phone, Julie will be able to provide you with one for the duration of the study, so that we can collect data on your daily step count. Physical activity data will be collected by the activity tracker and will then be shared with the researcher each week during the course of the study. Your physical activity data, your username, and age will also be retained on the tracker’s database (Mi band, Huami Information Technology company). Your name and contact information are not required therefore your data will not be identifiable to the commercial company.

After collecting your step count data for a week. Julie will also undertake some baseline assessments, involving some physical test to assess your level of function, as well as provide you with some questionnaires for you to complete which ask your opinion, and views on your activity levels and perceived quality of life. This should take no more than one hour to complete. These measures will be conducted online using Microsoft Teams.

Following completion of these measures, you will be randomly allocated to receive either:

Group A) Physiotherapy: Exercise and Guidance provided by NHS Physiotherapists delivered to you online via Microsoft Teams

Group B) PDConnect: A programme developed for this study which consists of Exercise, guidance and group work provided by NHS Physiotherapists and Fitness Instructors – the PDConnect Programme delivered to you online via Microsoft Teams.

The table below details the commitment required for each of the exercise interventions.

	Usual Care-Exercise and Guidance	**PDConnect- Exercise, guidance and group work**
Attend	Six one-hour sessions of Physiotherapy provided by an NHS Grampian Physiotherapist These sessions will be delivered online, using an online platform called Microsoft Teams.	Six one-hour sessions of Physiotherapy provided by an NHS Grampian Physiotherapists. Physiotherapy sessions will be delivered online, using a platform called Microsoft Teams. 12 weeks of 1.5 hours of group-based exercise delivered online, using a platform called Microsoft Teams. 12 weeks of self-management, where you will follow a home exercise plan independently at home. This will be supported by a monthly telephone call from the fitness instructor to support exercise participation.
Complete	Complete an activity diary Be tested at the beginning of the study, again at 6, 18, and 30 weeks Wear an activity monitor for 30 weeks	Complete an activity diary Be tested at the beginning of the study, again at 6, 18, and 30 weeks. Wear an activity monitor for 30 weeks. Take part in interviews at the end of the study. These will be conducted online, using Microsoft Teams.

What are the possible disadvantages and risks of taking part?

As with any physical activity, there is a small risk of accident/injury. However, regardless of which group you are randomised to, you will see a qualified exercise prescriber, who will provide treatments, which address your individual needs. Through the use of video conferencing, you will have the opportunity to practice all exercises under supervision, as the staff will be able to see you performing the exercises and can stop at any time without giving a reason. To protect your safety while exercising at home, a standardised protocol adopted by Parkinson's UK for safe delivery of exercise at home will be followed.

What are the possible benefits of taking part?

The benefits of taking part regardless of randomisation, all participants will receive physiotherapy tailored to your individual need, and a tracker for use for the duration of the study to monitor physical activity. For those of you randomised to receive PDConnect, you will receive longer-term support with exercise provision, which may have a greater benefit for your Parkinson's.

What happens when the research study stops?

The research study involves multiple data collection points. Once all the sessions have been completed, the principal researcher will analyse the data and write up the study findings for publication within a scientific journal. Each participant will receive a copy of his or her measurement's that were taken over the duration of the study, and there will be opportunity to discuss these with the researcher on completion of the study. All participants should they wish will receive a written lay summary of the study findings and notified of any publications within scientific journals.

All participants will be provided with an activity tracker for the duration of the study (30 weeks). Should participants require to borrow a Smart phone for the duration of the study to allow downloading of physical activity data, phones will be provided by the research team. On completion of the study, all participants will be asked to return the activity tracker, and the Smart Phone. Participants will be provided with a prepaid envelope so that the devices can be returned to the research team through the Royal Mail special delivery service.

Photography and Videoing:

During the course of the study, the research team may wish to take some photographs, which will be used by the research team when compiling reports for publication, or for use within presentations to the Parkinson's community and at professional conferences. If you do not wish your photograph taken, you may still participate in the study, we will ensure that we do not take any photos of you during the course of the study. All photographs will be stored in line with data protection guidelines and will be kept for five years following completion of the study.

A small number of the physiotherapy and group-based exercise sessions will be video recorded, this is so that the researchers can review how the intervention was delivered. This video footage will be used solely for research purposes and will not be shared out with the research team. This video footage will be destroyed when data analysis has been completed.

What if something goes wrong?

In the unlikely event of an accident/injury, appropriate first-aid measures will be applied. In the event that you were to fall at home when conducting your home exercise plan, you should seek immediate medical attention if required. If no medical attention is required, please record within the activity diary that a fall has taken place. All falls, whether requiring medical attention or not, must be reported by phone or email to Julie Jones, who will advise whether you should continue with the study or be withdrawn.

If you have any complaints about the conduct of this study, you should contact The Convenor, School of Health Sciences Research Ethics Committee, Robert Gordon University, 01224 263250 (SREC@rgu.ac.uk), Or Laura Binnie, Head of School of Health Sciences 01224 263251(l.m.binnie@rgu.ac.uk). The convenor of the ethics committee and Head of School have a responsibility to ensure that research is conducted in a lawful and ethical manner.

Will my taking part in the research be kept confidential?

Yes, all the information you share will be kept confidential. All the data we collect from you will be anonymised i.e., your name will not be able to be linked to the measurements or diary entries, as each participant will be allocated a unique identifier at the beginning of the study. In addition, your participation in this study will be confidential and we will not disclose the names of our participants. The researchers and their research supervisor will only see your data.

Any communications between you and the research team sent over Microsoft Teams, for example your home exercise programme, will be sent to a personalised folder which only you and the research team can access.

Findings will be reported for the participants as a group and no individuals will be identified in any reports. All information will be collected and stored within the requirements of General Data Protection Regulation Act (GDPR, 2018) and Data Protection Act (1998), and in accordance with RGU policies and procedures relating to the collection, storage and retention of research data.

What will happen to the results of the research study?

The results will be written up by the researcher and submitted as their doctoral research thesis. The results will be published in appropriate academic journals, and presented at local, and national conferences. All data will be anonymised therefore, you will not be identified in any reports or publications.

Who is organising and funding the research?

Julie Jones, (Principal investigator and doctoral student), is conducting the research under the supervision of Professor Kay Cooper who will also monitor the study's progress. The study is being jointly funded by the Chief Scientist Office and Parkinson's UK.

Who has reviewed the study?

The study has been approved by the School of Health Sciences Research Ethics Committee, RGU (SHS 20/21) research ethics committee (280159) and by NHS Grampian Research & Development.

What do I do now?

If you are interested in taking part or would like to discuss the study further before deciding, please contact Julie Jones, ✉ j.c.jones@rgu.ac.uk or ☎ 01224 263282

Thank you for considering taking part in this research study. Please discuss this information with anyone you wish prior to deciding.

Letter of Invitation

Dear X

RE: Invitation to particicpate in a research study

In Aberdeen City and Shire there is a group of researchers who are exploring exercise for people with Parkinson's. They are looking to recruit people living with Parkinson's in Aberdeen City and Shire, to participate in their study. The researchers who are based at Robert Gordon University have asked NHS Grampian to help identify appropriate people to participate in this study. As you have Parkisnons, you are potentially eligible to participate in this study. I-would like to encourage you to read the attached information and to consider volunteering to take part. The researcher will conduct an additional short telephone screening assessment to check whether there is any reason that you should not take part in the study.

The study is looking at the feasibility and acceptibility of exercise for people with Parkinson's. Should you wish to particpate you will undergo some baseline assessments, and then you will be randomised to receive one of two different approaches to exercise which will both be delivered online via Microsoft Teams. Should you wish to participate, attached is a participant information sheet which provides you with more information about the study, as well as the researcher's contact details, should you wish to get involved.

Kind regards

Consultant Neurologist

Researchers contact details

SRRG Number: SHS20/21 IRAS Number: 280159

Invitation to participate in a research study.

A collaborative approach to exercise provision for people with Parkinson’s – a feasibility study of the PDConnect programme.

You are invited to take part in a research study which will the investigate the feasibility and acceptability of an exercise programme for people with Parkinson's.

We are interested in recruiting people with Parkinson's aged living in Aberdeen City or Shire.

For more information about the study, please contact the principal investigator Julie Jones.

✉ j.c.jones@rgu.ac.uk ☎ 01224 263282

16th April 2020, Version 1.0

8.6 APPENDIX 6: TELEPHONE SCREENING DOCUMENT

Appendix 6 Telephone Screening Document

PDConnect

Telephone Screening Document

The telephone conversation is set here as a guide to ensure a standardised approach to the telephone screening. Please use the boxes below to log the potential participant's responses.

Participant name:__________________________

Researcher: Thank you for getting in contact with me and expressing an interest in participating in the PDConnect study. Before we go any further, do you have any questions that you would like to ask me about the study?

Researcher: Did you understand that you could be randomised to either of the approaches to exercise?

Researcher: Did you have any concerns about participating?

Researcher: Do you have a laptop or a tablet that can be used in the study?

Researcher: Do you have a good and stable internet connectivity?

Health Screening Questions:

Researcher: You consultant has ensured that you meet the inclusion criteria for this study based upon your Parkinson's. But I have a few screening questions that I just wish to ask you to ensure that you are safe to exercise, so if it is ok, I shall just run through these questions with you. These questions are adapted from the Physical Activity Readiness Questionnaire (PAR-Q). If you have any questions or you unsure, please feel free to stop me.

How would you describe your general health and fitness?

Have you ever done any structured exercise? (Please circle)

If yes, what types of exercise did you enjoy?

Medical History:

	YES	**NO**
Have you had a major illness or injury in the last 5 years		
If yes, please could you give me some details		
Are you receiving treatment for any diagnosed medical condition?		
If yes, please could you give me some details		
Are you taking any prescription medication?		
If yes, please could you give me some details		
Do you ever get unusually short of breath with very light exertion?		

Ever have pain, pressure, heaviness, or tightness in the chest area?		
Regularly have unexplained pain in the abdomen, shoulders or arm?		
Ever have severe dizzy spells, or episodes of fainting?		
Regularly get lower leg pain during walking that is relieved by rest?		
Ever experience palpitations, or irregular heartbeats?		
Do you have any aches, pains or problem areas that you think I should know about		
Please indicate any other health problems you suffer from which you have not already mentioned		
Is there anything that you think may limit your ability to participate in exercise?		

Researcher: do you have any further questions you would like to ask me?

Based on the conversation, the researcher will make a decision as to whether the participants can participate. In the event that they cannot, the reason(s) will be discussed with the person, and if required they will be referred to their GP for further investigation /management

<u>If a person is eligible:</u>

Researcher: So following our discussion, I see no issue why you cannot participate in the study. Are you still happy to proceed and participate in the study? Or would you like more time to consider?

Researcher: If you are happy to proceed, the next step is to make an appointment to undertake the baseline assessments. This takes about an hour. When would be suitable for you to do this.

Agreed appointment date and time:___ ________

Agreed actions:

8.7 APPENDIX 7: RESEARCH SUPPORT NETWORK TAKE PART HUB FLIER

Promotion of the PDConnect study via the Research Support Network

We have an opportunity for people with Parkinson's to take part in some research assessing a specifically designed exercise programme.

Exercise for people with Parkinson's - the PDConnect study

Julie Jones, a research physiotherapist at Robert Gordon University, is investigating the most effective way of delivering exercise to people with Parkinson's, to help them adopt a more active lifestyle. The research hopes to see if a remotely delivered programme can promote personalised exercise, physical activity, and self-management.

Who do the researchers need?

30 people diagnosed with Parkinson's who are able to walk 100
metres independently. You must also have access to a laptop or tablet with a webcam, which is compatible with Microsoft Teams.

Julie is looking for people who live in the Grampian region of Northeast Scotland.

What's involved?

Taking part in an organised programme of activities called PDConnect or receiving six one-to-one online physiotherapy sessions over a total of 30 weeks. For more information, please read the information sheet.

Interested in taking part?

Please contact Julie via email j.c.jones@rgu.ac.uk or phone 01224 263282 before 31 March 2021. Email Julie

This opportunity is not managed by Parkinson’s UK.

Maybe this research isn't for you?

We realise that not every piece of research is right for everyone.

To find more opportunities near you, use our postcode searchable Take Part Hub which is regularly updated with new research looking for people like you.

Best Wishes,
Amelia Hursey
Research Participation Lead

8.8 APPENDIX 8: PARTICIPANT CONSENT FORM

PDConnect

CONSENT FORM

SRRG reference number: **SHS/20/21 IRAS No: 280159**

Study title: *A* collaborative approach to exercise provision for people with Parkinson's – a feasibility study of the PDConnect programme

Name of Researchers: Julie Jones (Principal Investigator)

Please initial box

1. I confirm that I have read and understand the information sheet dated 24/11/2020 (Version 1.4) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason ☐

3. I understand that I will be required to download the Microsoft Teams app to my laptop or device to participate in this study. ☐
4. I understand that within Microsoft Teams information relating to my personal involvement will be shared only with the research team. ☐
5. I understand that within Microsoft Teams chat forums my contributions can be viewed by the research team and others participating in the study. ☐
6. I understand that individuals will look at data collected during the study from The Robert Gordon University, where it is relevant to my taking part in this research. I give permission for these individuals to have access to the data ☐

7. I understand that participation involves participation in remote delivery of exercise, and assessment of physical activity and functional ability ☐

and I understand the implications of this, which have been explained to me.

8 I understand that my emergency contact details will be held on a locked channel within Microsoft Teams accessible only by the physiotherapists, fitness instructors, and researchers, for emergency use only during the remote delivery of the study. ☐

9. I understand that participation involves the collection of data about my physical activity, which will be stored by a third party provider (Mi Band: Huami Information Technology Company. ☐

10. I understand that my GP and Consultant will be informed about my involvement in this study. ☐

11. I consent for any pictures to be taken during the study to be shared for promotional purposes and within publications and presentations associated with the study. ☐

If you do not consent to photography, you can still take part in the study and the researcher will ensure that pictures of you are not used for these purposes. ☐

12 I consent for video footage to be taken during the study to be used research purposes only. I understand that this video footage will be destroyed by the research team on completion of the analysis ☐

13 I give permission for the 1-1 interview to be audio-recorded and for anonymised quotes to be used in study reports and conference presentations. ☐

14 I agree to take part in the above study ☐

Date:

Name of participant:

Signature: video recorded as per protocol Date:

Name of person taking consent: Date:

Signature: Date:

Two copies to be retained: one for researcher and one for participant.

8.9 Appendix 9: Microsoft Teams and Mi Band Induction

PDConnect

Microsoft Teams and Mi band User Guide for Participants

This study is funded by:

PARKINSON'S UK
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.

CHIEF
SCIENTIST
OFFICE

Microsoft Teams User Guide

This document has been put together to introduce you to Microsoft teams, why it has been selected for use within this study, and most importantly serve as a guide so that you can use it effectively during the course of this study.

Prior to commencing this study Julie will provide an introduction to the use of Microsoft Teams, and get you set up, so that you are good to go. The next few pages have been put together as a guide which you may wish to browse through in your own time, to clarify your understanding.

What is Microsoft Teams?

Microsoft Teams is an online platform produced by Microsoft, which provides a secure way of communicating with people involved in this study. Microsoft Teams has many functions, allowing audio calls, video calls, and sharing information for example; word documents all in the one area. So think of it an online platform where you can send and receive emails, make phone calls and have meetings with other people who are involved in the study. Microsoft Teams allows you to communicate privately with individuals or for you to communicate to a wider group.

Microsoft Teams is a secure and closed channel, which only the researchers and those participating in the study will have access too. Therefore, instead of us coming to your house to prescribe exercise, Microsoft Teams allows us to see and talk to you remotely. Exercise sessions will be delivered using Microsoft Teams so you will be able to see, hear and speak with the staff in real time. Any information which we need to send to you in relation to the exercise session can be emailed directly to you, and should you have any questions you can use Microsoft Teams to contact us, so you do not have to wait till your next session. We can also book appointments with you using Microsoft Teams and send you reminders, so you will not forget when your appointments are.

PDConnect

Microsoft Teams User Guide

Why has Microsoft Teams been selected for use within this study?

1. Microsoft Teams is General Data Protection Regulation (GDPR) compliant therefore is endorsed by the NHS as a platform that aligns with information governance. This means that information shared this platform is secure.
2. Microsoft Teams allows the collaboration between organisations. As this study spans both academic, health service and community sectors, this seemed ideal.
3. The functionality of the Microsoft Teams Platform allows the sharing of information between colleagues, participants, while also offering a facility for closed groups to allow confidential individual discussions.
4. Microsoft Teams is free to download and use.

Microsoft Teams will be used for the following during the course of this study:

- Delivery of all consultations, and all treatment interventions
- Providing you with any information you need to participate within your prescribed treatment
- Scheduling of your appointments
- A means of communication (audio and visual) between you participants, those delivering the intervention and the research team.

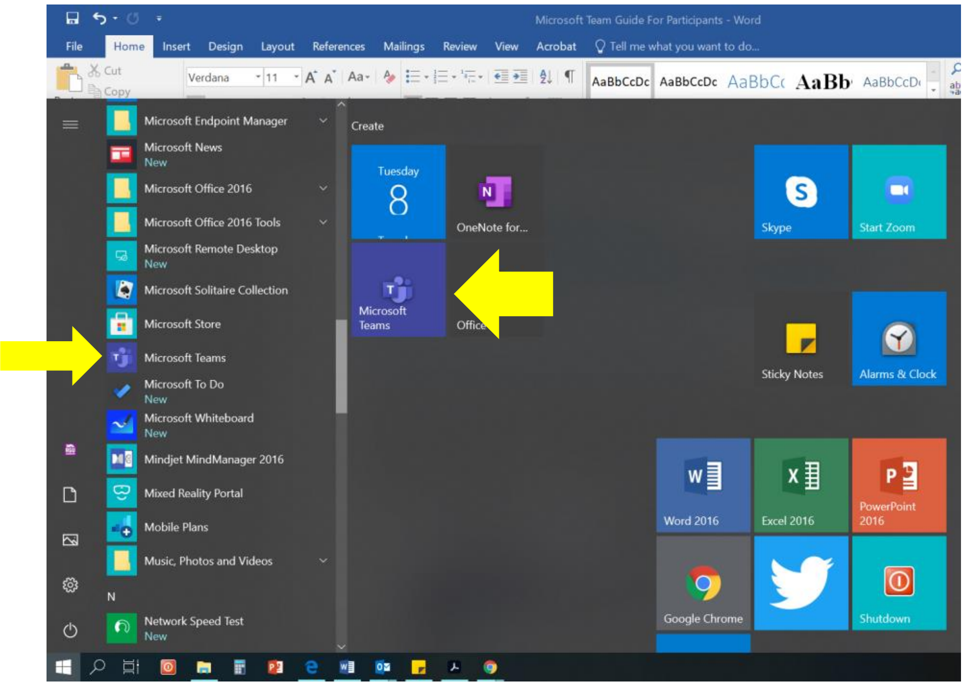
Getting started

If you don't have Teams you can download the Windows desktop app from http://teams.microsoft.com/downloads

MAC Users: You can download the desktop app for Mac here (OS X 10.10+) https://teams.microsoft.com/downloads

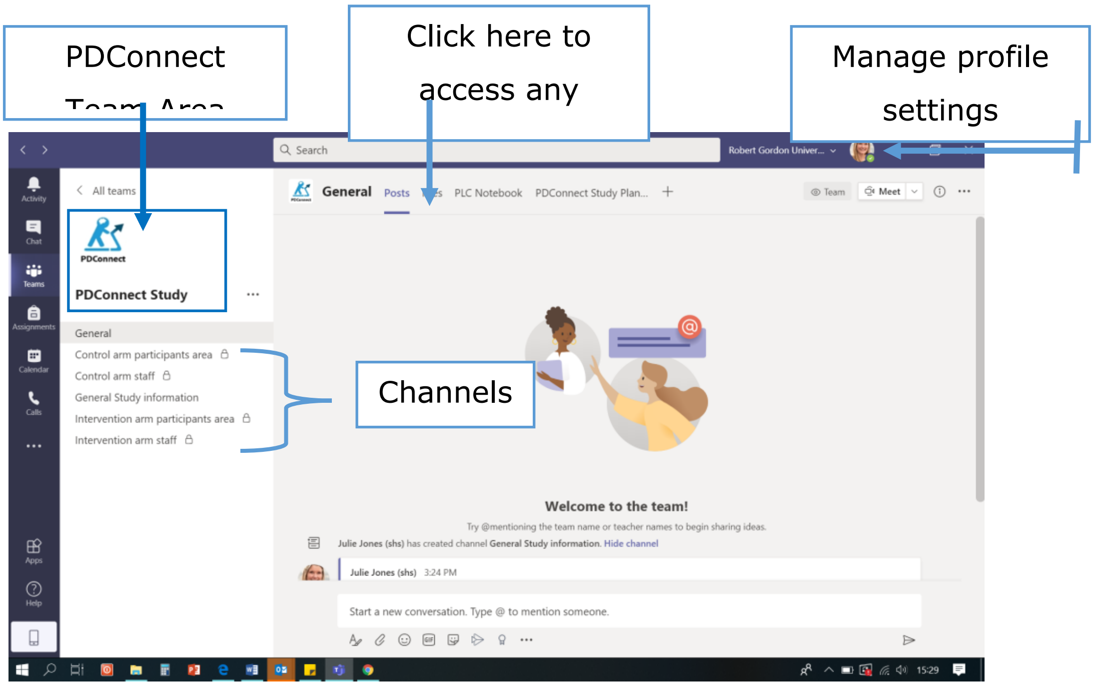
Locating and opening Microsoft Teams

Once you have downloaded Microsoft Teams, it will normally open up every time that you switch on your device. If it does not open up automatically you will find Microsoft Teams on your home screen and shown below by the yellow arrows. Clicking on either of these will open up Microsoft Teams.



Navigating your way around Microsoft Teams:

Once you open up Microsoft Teams you will be see a page like the one below. Within Microsoft Teams, a team is a collection of people, conversations, files, and tools—all in one place. Within a team you will find channels, which are similar to folders. Channels contain specific team information dedicated to a particular aspect of a project, or topic. Selecting a channel will allow you to explore Posts, Files, and other tabs. Have a look at the diagram below and your screen to familiarise yourself with how things are presented within Microsoft Teams.



Welcome to the team!

Try @mentioning the team name or teacher names to begin sharing ideas.

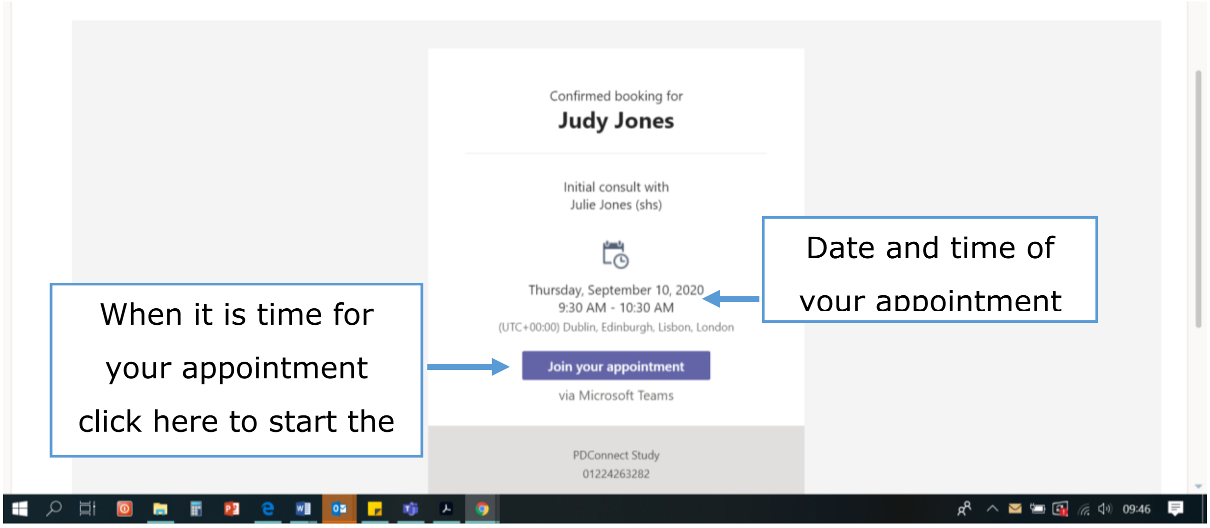
Julie Jones (shs) has created channel General Study information. Hide channel

Julie Jones (shs) 3:24 PM

Start a new conversation. Type @ to mention someone.

Engaging in Online video exercise sessions.

You will receive an email invitation to participate in an exercise session. An example is given below for a mock patient called Judy Jones. Before you Click the link, make sure your camera is switched on, and you are ready to start your appointment.



Confirmed booking for
Judy Jones

Initial consult with
Julie Jones (shs)

Thursday, September 10, 2020
9:30 AM - 10:30 AM
(UTC+00:00) Dublin, Edinburgh, Lisbon, London

Join your appointment
via Microsoft Teams

PDConnect Study
01224263282

When it is time for your appointment click here to start the

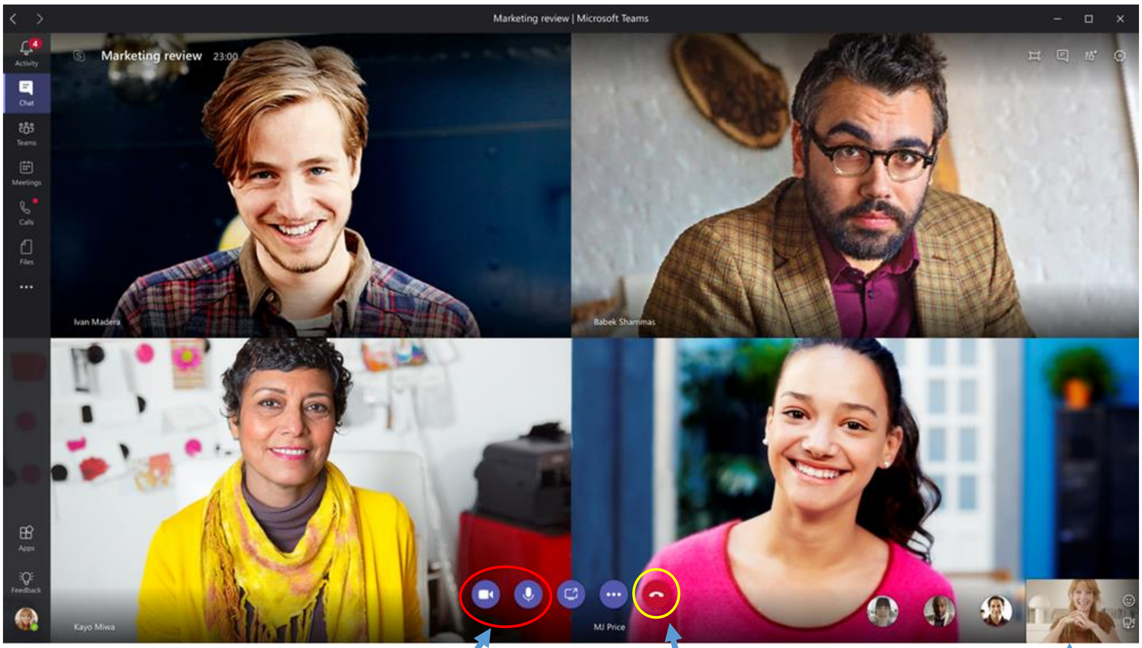
Date and time of your appointment

By clicking the link will take you to the video page where you should see yourself and the person who is delivering the session today.

Using technology for the first time is always a daunting prospect for anyone. But these anxieties are even bigger when you need to use the technology to access an appointment, as none of us like to be late or keep people waiting. Julie will provide you with an induction on how to use Microsoft Teams. In addition, prior to your first appointment Julie will organise a mock appointment which can be used as a dry run, to make you feel more confident using the technology, so it all works smoothly on the day.

Engaging in online video exercise sessions.

Below is an example of what a video call may look like if several people were meeting all together. The image below has been labelled so you can be familiar with what all the icons do and mean.



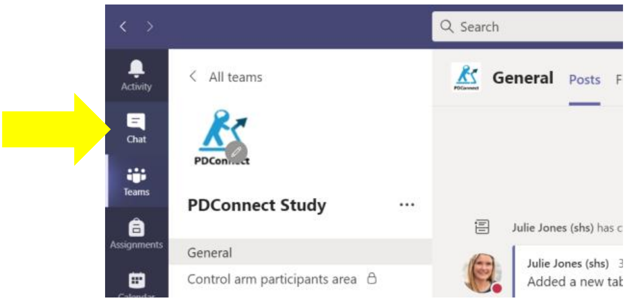
These 2 icons tells you that your camera and your microphone is on. If you wish to switch either of these off you just need to

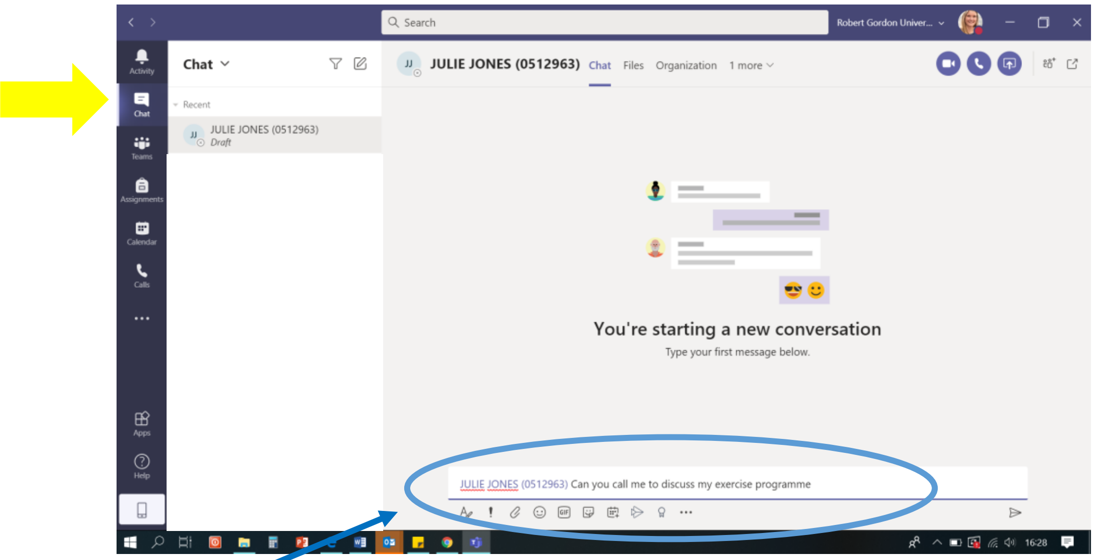
When you wish to leave the call click on this icon

If you were on this call, this small image of person would be an

Contacting staff during the study.

You are welcome to contact the staff at any time during the study. If you wish to communicate with a specific member of staff, and for your communication to remain private between you and that person. Click on Chat as highlighted by the yellow arrow.





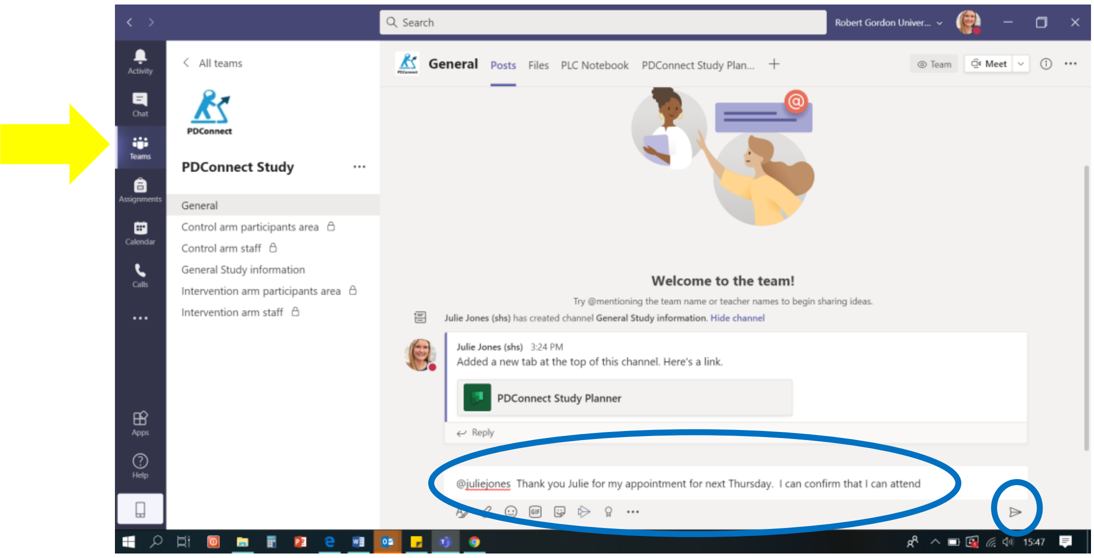
You're starting a new conversation

Type your first message below.

JULIE JONES (0512963) Can you call me to discuss my exercise programme

Put the name of the person you wish to send a message to first, then type your message, and click the arrow to send

If your question is general and you do not mind it being seen by anyone who is part of this study, you can add a message as illustrated below



Welcome to the team!

Try @mentioning the team name or teacher names to begin sharing ideas.

Julie Jones (shs) has created channel General Study information. Hide channel

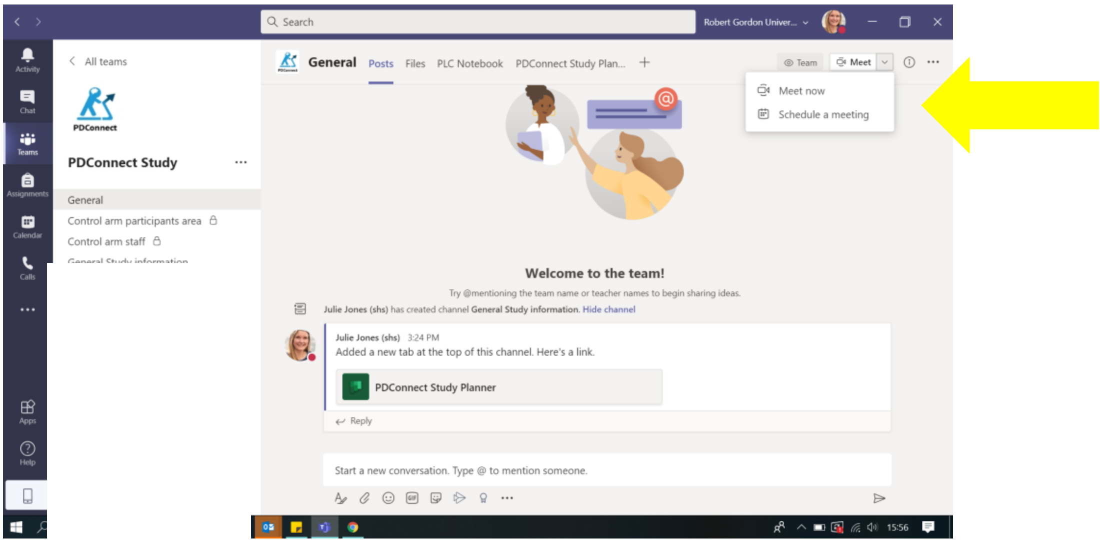
Julie Jones (shs) 3:24 PM
Added a new tab at the top of this channel. Here's a link.

PDConnect Study Planner

@juliejones Thank you Julie for my appointment for next Thursday. I can confirm that I can attend

Starting a meeting:

To schedule a planned or impromptu meeting, click meet in the top Right-hand corner as indicated in the diagram below. By clicking this box, you will be given the option of meeting someone now or schedule a meeting.



Welcome to the team!

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Julie Jones (shs) has created channel General Study information. Hide channel

Julie Jones (shs) 3:24 PM
Added a new tab at the top of this channel. Here's a link.

PDConnect Study Planner

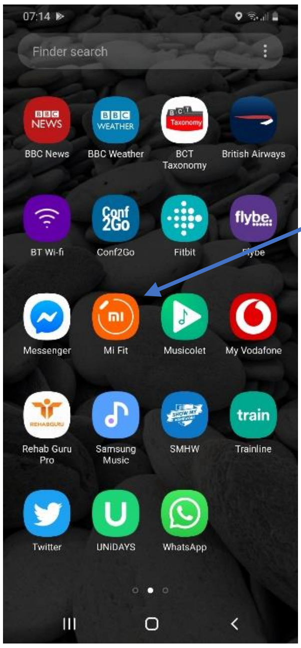
Start a new conversation. Type @ to mention someone.

PDConnect

Mi Band

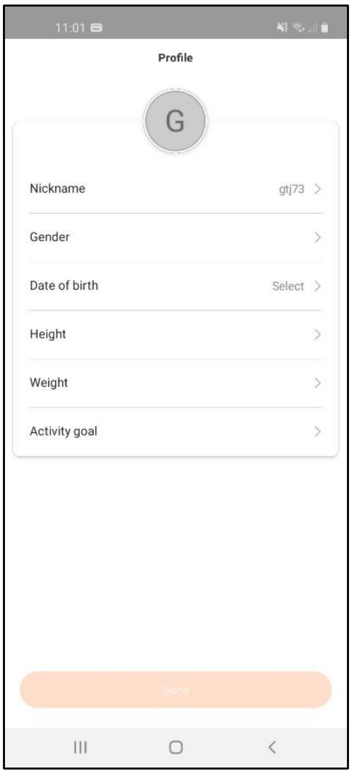
To be able to view your daily step count and look at your weekly step count you will need to download the Mi Fit app to either your Smart Phone or tablet.

To do this go to the App store on an apple device such as an ipad, or to Play store if you have an android device. Type Mi Fit into the search bar. The icon for the Mi Fit band 5 app looks like this:



Install this app to your device following the instructions on screen. Once this has installed you should be able to see this app on your home screen.

1. Click on the Mi Fit app, and it will then as you to log in or creat an account. **Please click create an account**
2. Follow the instructions on screen. You will be asked to select your country/region, and then provide an email address and password. Then enter the verification code provided on screen.
3. Read the software agreement and privacy policy, and if you are happy to agree, click agree, and then click the sign up button



Nickname gtj73

Gender

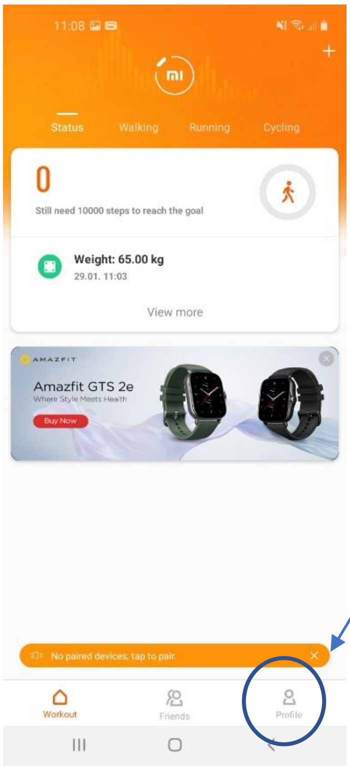
Date of birth Select

Height

Weight

Activity goal

Once you have clicked on sign in, you will be taken to this page. Please complete each of these sections as indicated on the screen and then click done



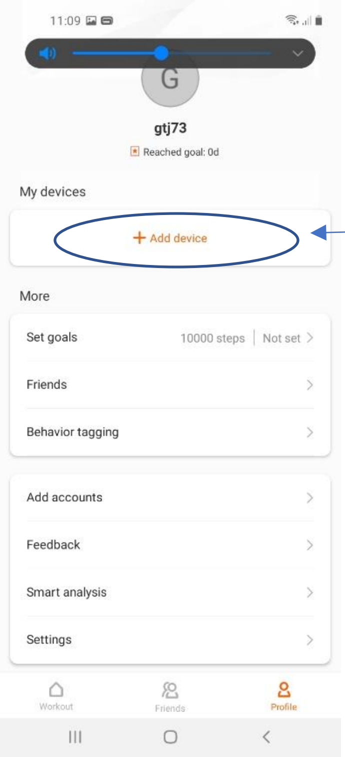
0

Still need 10000 steps to reach the goal

Weight: 65.00 kg
29.01. 11:03

No paired devices, tap to pair.

That should then take you to this page. Then click on profile in the bottom right-hand corner.

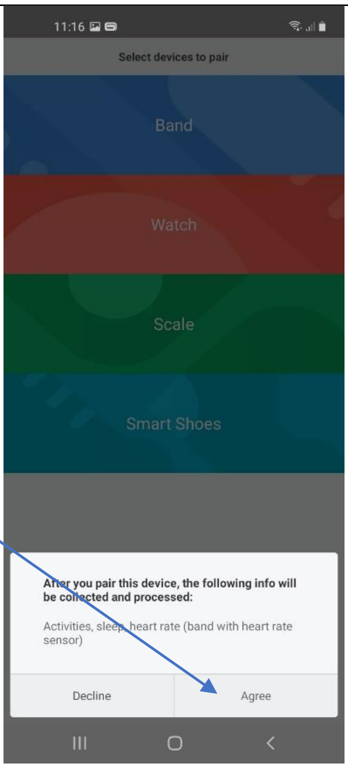


Make sure your Bluetooth setting is switched on your tablet or smart phone.

Click add device

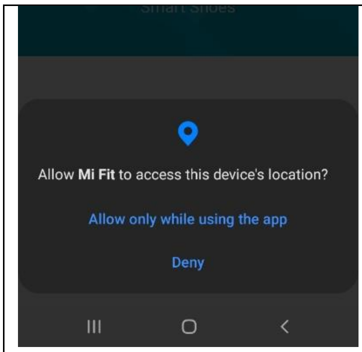
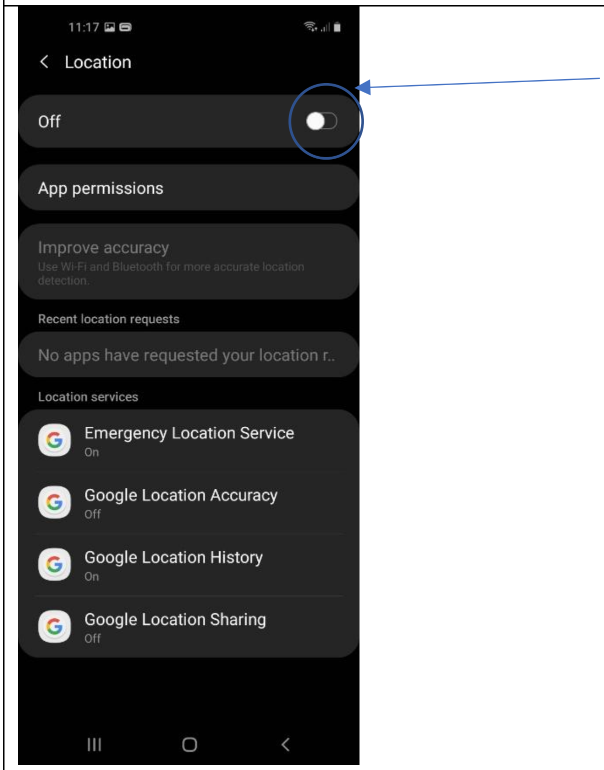
Click on BAND

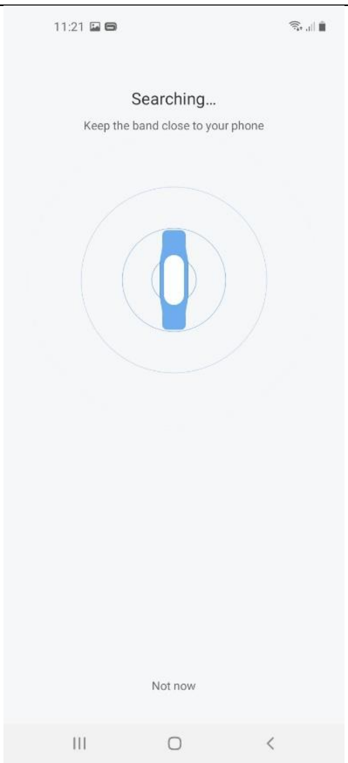
And click agree to the pop-up box at the bottom.



After you pair this device, the following info will be collected and processed:

Activities, sleep, heart rate (band with heart rate sensor)

 Allow **Mi Fit** to access this device's location? Allow only while using the app Deny	This box will then pop up next. Please click allow only when using the device. This may require you to change your settings on your tablet or phone.
 11:17 Location Off App permissions Improve accuracy Use Wi-Fi and Bluetooth for more accurate location detection. Recent location requests No apps have requested your location r.. Location services Emergency Location Service On Google Location Accuracy Off Google Location History On Google Location Sharing Off	Within your settings, location needs to be switched on.

Place your watch near the phone, and you phone will search for the device. Once it has found the Mi band 5, click pair and the watch will then be synchrnised with the app. You are now ready to go.	 Searching… Keep the band close to your phone

PDConnect

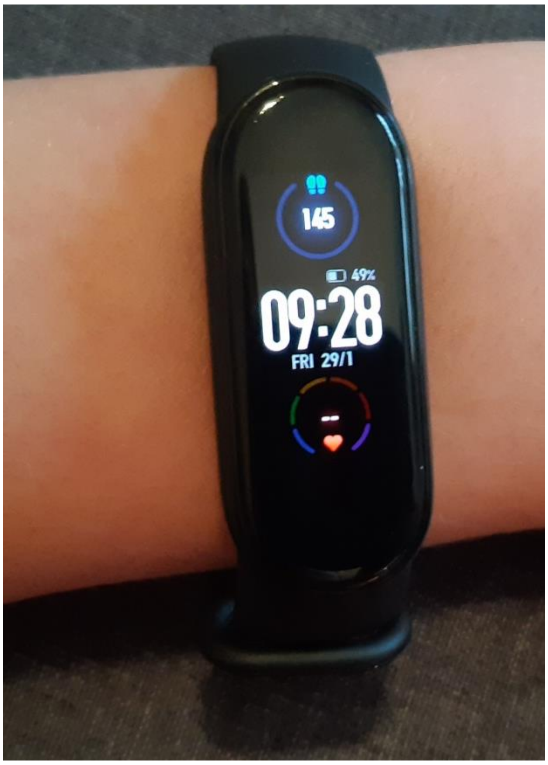
YOUR MI ACTIVITY TRACKER

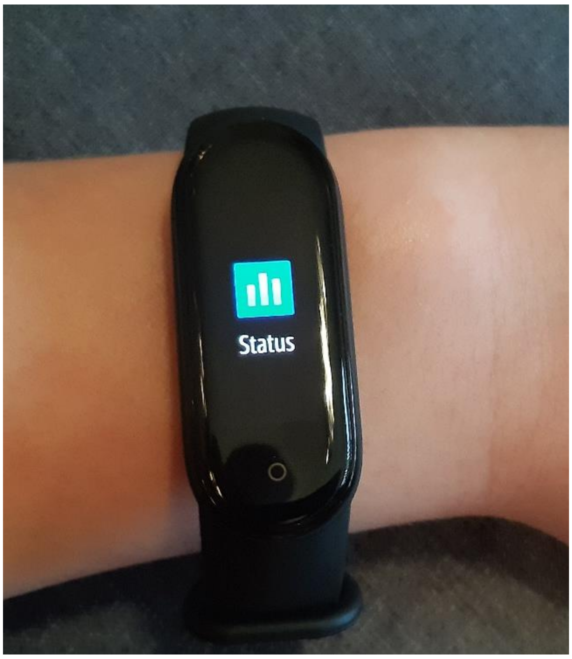
As part of the study, you will receive a Mi band, which is a wrist worn activity tracker. Everyone who is part of this study will receive one for the duration of the study. We would very much like it if you could wear this device every day for the entirety of the study, which is approximately 30 weeks.

PDConnect

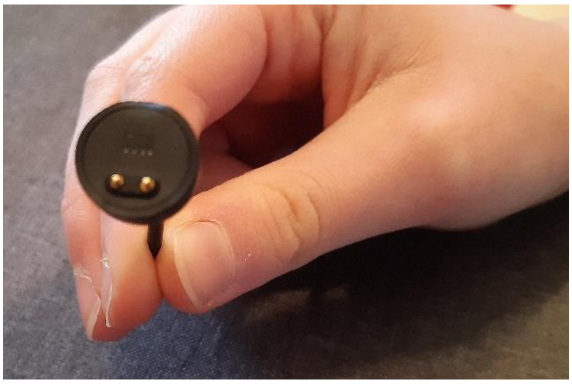
Preparing to use your Mi Band

Getting to know your Mi Band.

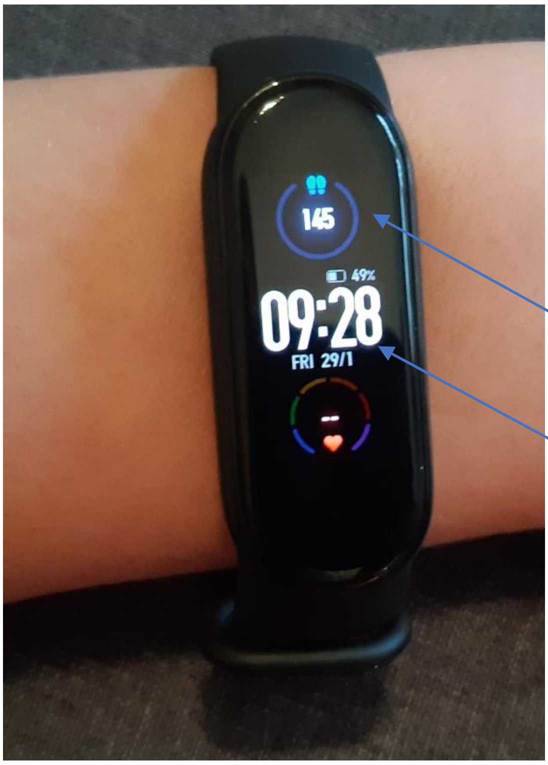




Mi band Charging components



Wearing the Mi Band



When wearing the Mi band, to conserve power the screen will automatically switch off. However, it will still be recording information. To see the time on the watch, tap

Cumulative daily step count

Date, time, battery level

Any activity that you undertake will be counted. At midnight, the device resets itself and it will return to 0. You will be able to view prior days step count through the Mi Fit phone

By touching the bottom of the screen and sliding your finger up the face of the watch, you can see other features on the watch. Tapping the status icon as shown in the picture will tell you your total

Fastening your Mi Band

Charging your Mi Band:

You can check your battery level by touching the bottom of the watch face and the battery life is illustrated on the watch face. When the battery is low, please charge it. The battery normally lasts 5 days without charging.

To charge: Take the watch off. Connect the charger head to the back of the watch, aligning it with the two emtal spots on the back of the watch. It is magnet so it will click on. Then plug the USB post into a plug or charging unit. To check when complete- all bars should be full.

Battery charging points

Attach the charging cable to the back of the watch as shown

Attach the sensor and cable to a USB plug or point and switch on to charge. Disconnect when battery is 100% full.

Showering and bathing:

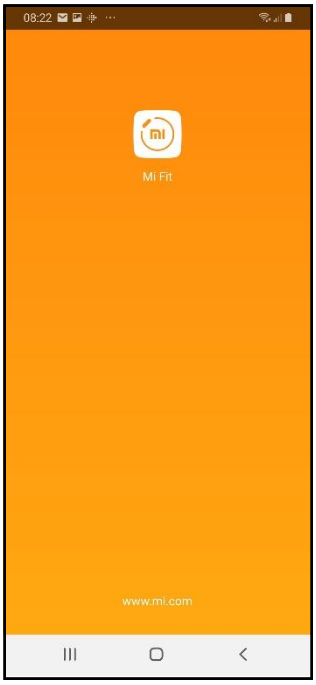
The Mi band is water resistant but not waterproof. Therefore, splashes of water from handwashing will be ok, but you are advised NOT to wear your Mi band in the shower, bath, or if you go swimming. Please also not wear the device when in a sauna or steam room.

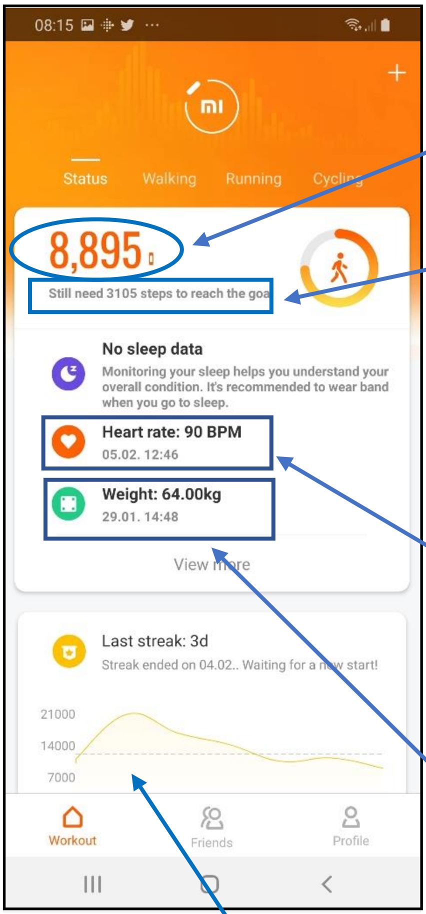
Cleaning your Mi Band:

Remove the sensor from the band, and wash the band in warm soapy water, and dry off with a tea towel. The sensor itself should not be submerged in water, if this requires cleaned, please do so with a damp cloth and dry afterwards.

Using the Mi Band App

Tapping the Mi Fit App will take you to a page like this, which will then refresh and open the page detailed below.





8,895

Still need 3105 steps to reach the goa

No sleep data

Monitoring your sleep helps you understand your overall condition. It's recommended to wear band when you go to sleep.

Heart rate: 90 BPM
05.02. 12:46

Weight: 64.00kg
29.01. 14:48

View more

Last streak: 3d
Streak ended on 04.02.. Waiting for a new start!

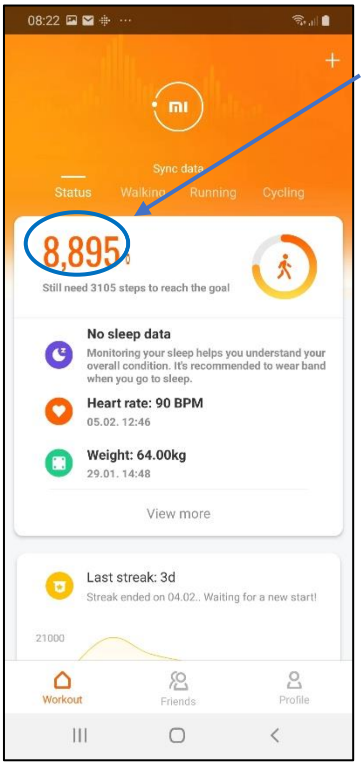
This illustrates the number of steps completed on this day at this time.

This states how many more steps that need to be undertaken to achieve your daily step goal, which in this example is set as 12, 000. When this goal has been achieved the orange circle surrounding the stick man will be entirely orange.

This provides information about heart rate in beats per minute (Bpm). In this example it was recorded on the 5th of february (05.02), at 12.46.

This is the last recorded weight, which in this example was logged at 64kg.

This illustrates graphically the total daily step count over the last 3 days.



08:22

Sync data

Status Walking Running Cycling

8,895

Still need 3105 steps to reach the goal

No sleep data

Monitoring your sleep helps you understand your overall condition. It's recommended to wear band when you go to sleep.

Heart rate: 90 BPM

05.02. 12:46

Weight: 64.00kg

29.01. 14:48

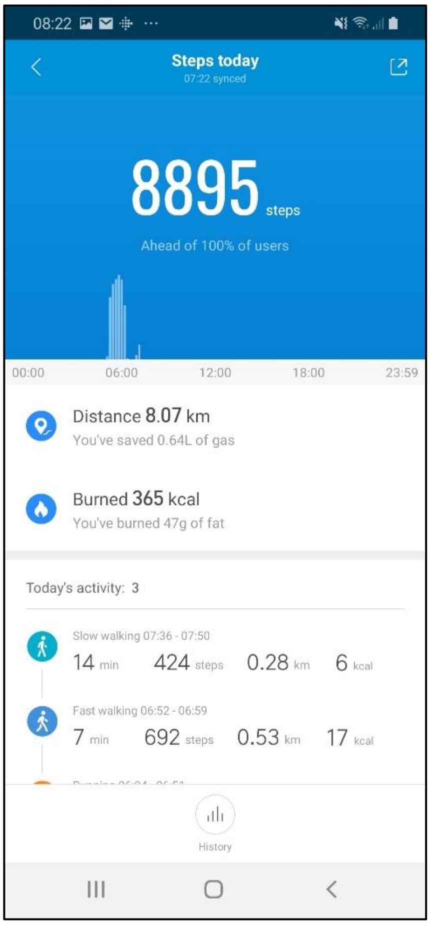
View more

Last streak: 3d

Streak ended on 04.02.. Waiting for a new start!

21000

Taping your current daily step count here, takes you to this display



08:22

Steps today

07:22 synced

8895 steps

Ahead of 100% of users

Distance 8.07 km

You've saved 0.64L of gas

Burned 365 kcal

You've burned 47g of fat

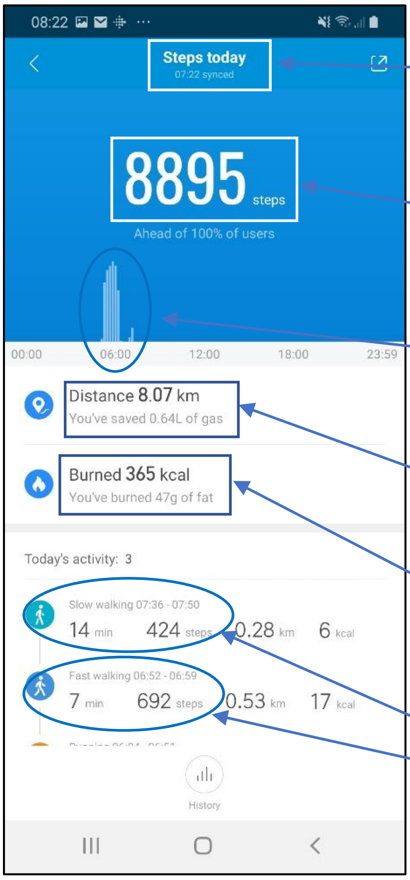
Today's activity: 3

Slow walking 07:36 - 07:50

14 min 424 steps 0.28 km 6 kcal

Fast walking 06:52 - 06:59

7 min 692 steps 0.53 km 17 kcal



08:22

Steps today

07:22 synced

8895 steps

Ahead of 100% of users

Distance 8.07 km

You've saved 0.64L of gas

Burned 365 kcal

You've burned 47g of fat

Today's activity: 3

Slow walking 07:36 - 07:50

14 min 424 steps 0.28 km 6 kcal

Fast walking 06:52 - 06:59

7 min 692 steps 0.53 km 17 kcal

Time, which Mi band data synchronised with the Mi Fit app 7.22,

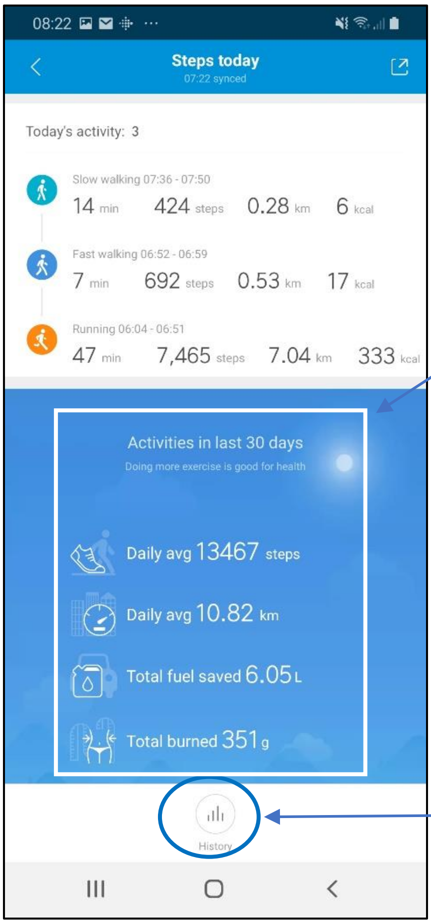
Number of steps taken on this point of time.

Timeline of stepping activity. In this activity, all activity occurred between 6 and 7am

Distance travelled in this example – 8.07km

Amount of energy spent by stepping activity on this day

The Mi band, categories stepping into slow, fast walking, light activities or



Steps today
07:22 synced

Today's activity: 3

Slow walking 07:36 - 07:50
14 min 424 steps 0.28 km 6 kcal

Fast walking 06:52 - 06:59
7 min 692 steps 0.53 km 17 kcal

Running 06:04 - 06:51
47 min 7,465 steps 7.04 km 333 kcal

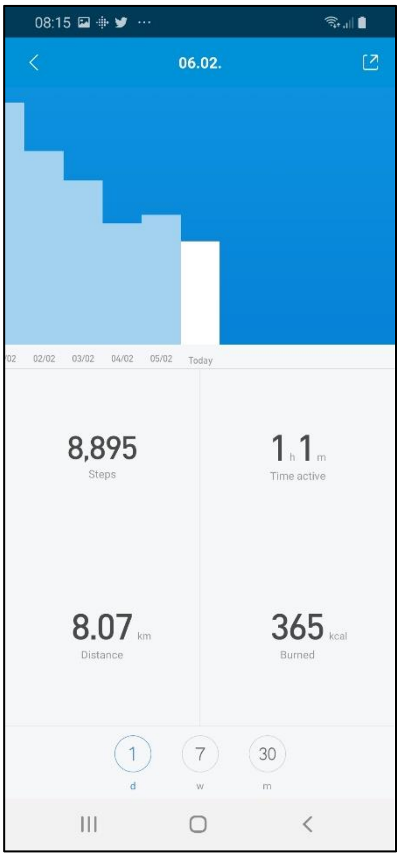
Activities in last 30 days
Doing more exercise is good for health

Daily avg 13467 steps
Daily avg 10.82 km
Total fuel saved 6.05 L
Total burned 351 g

By scrolling down this page, you will be able to see cataloguing of other activities you have done on this day, but also the app summaries conducted over the last 30 days

Tapping this history icon takes you to your activity history and illustrates this in a bar graph format as is shown below.

This display illustrated your total step count on the prior days. In this example, you can see the last 6 days total steps



06.02.

8,895
Steps

1 h 1 m
Time active

8.07 km
Distance

365 kcal
Burned

PDConnect

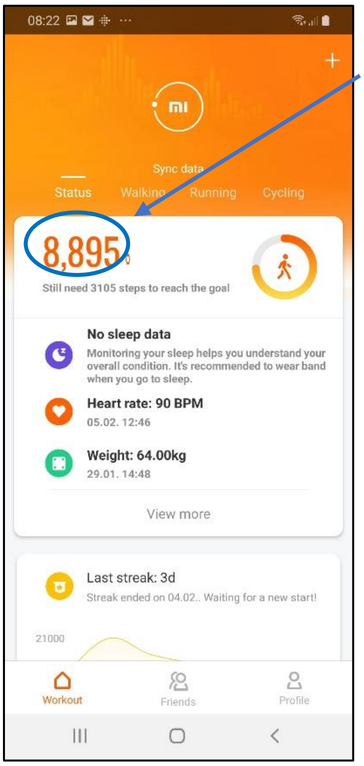
Recording your physical activity information

When the study starts you will need to share the information collected on your tracker. It is advisable that you write down each day your total activity within your activity diary which will be provided. It would be best to do this last thing at night or first thing in the morning where you record the prior day's activity.

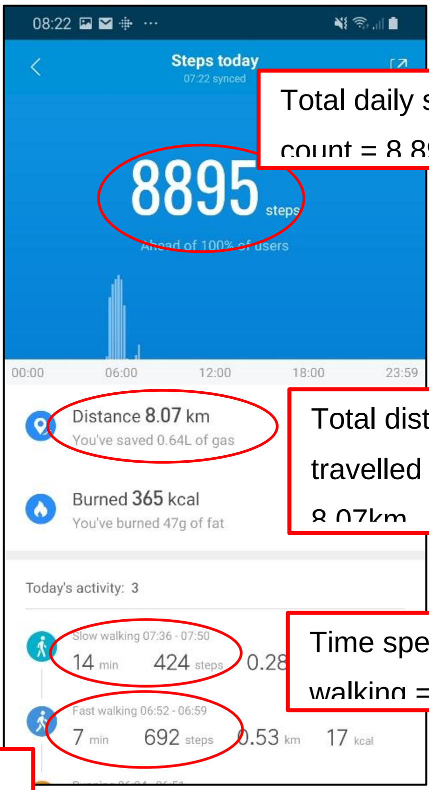
The information we wish you to record is:

- Total step count for that day
- Total distance travelled
- Time spent slow walking
- Time spent fast walking

This information can be found by:



Taping your current daily step count here, takes you to this display



Total daily step count = 8,895

Total distance travelled = 8.07km

Time spent slow walking = 14

Time spent fast walking = 7mins

FREQUENTLY ASKED QUESTIONS

What happens if I forget to wear my device?

As soon as you realise that you have not worn it, put it on. Even if it is half way through the day, please put the device on. Please keep a note in your diary if there is a day, which you forgot to wear the device, and let Julie know at the next assessment appointment.

What happens if I get the device wet?

Take the device off and remove the sensor from the band, and dry both the band and the sensor thoroughly. Once you have dried it, tap the screen and see if it is working. If not contact Julie. 01224 263282, or j.c.jones@rgu.ac.uk

What happens at the end of the study?

You will be sent a pre-paid envelope for you send back your activity tracker and you Smart phone should you have borrowed one. All we ask is that you put the device(s) the device, fastening it securely envelope and pop it in the post. Thank you.

Any problems or issues contact Julie on:

☎ 01224 263282

✉ j.c.jones@rgu.ac.uk

8.10 APPENDIX 10: PHYSIOTHERAPIST INFORMATION SHEET

PDConnect

Physiotherapist Participant Information Sheet

Study Title: Exercise for people with Parkinson's -the PDConnect study

You are being invited to take part in a research study. Before you decide whether you wish to take part, it is important for you to understand why the research is being done, and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear, or should you require any further information, please do not hesitate to contact the researcher. The contact details are available on the last page of this document. Take time to decide whether you wish to take part. Thank you for reading this.

Introduction:

The benefits of exercise for people with Parkinson’s are widely known; however, over 70 per cent of people with Parkinson’s are regarded as sedentary. Therefore, services need to be designed to support people with Parkinson’s to be more active and promote long-term engagement in exercise. This study aims to explore the feasibility and acceptability of a new exercise intervention called PDConnect. PDConnect is an exercise-based intervention, which in addition to exercise provides participants with education, and practical behaviour change interventions to promote self-management which will be delivered online via Microsoft Teams. People participating in PDConnect will receive one to one physiotherapy followed by group-based exercise delivered by fitness instructors. This study, aims to explore the feasibility and acceptability of this intervention, comparing it to physiotherapy care delivered online.

Why have I been chosen?

You have been chosen because you are a band 6 or above Physiotherapist working in NHS Grampian who has two or more years clinical experience. This study is looking at a collaborative approach to exercise between the NHS and community-based exercise provision for people with Parkinson’s. This study will be conducted by Julie Jones from the School of Health Sciences, Robert Gordon University (RGU) and will be conducted within NHS Grampian and RGU:SPORT.

Do I have to take part?

No, it is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet and will be asked to sign a consent form. You will be given a copy of both forms to keep. If you decide to take part, you are still free to withdraw at any time and without giving a reason.

Taking part in the study.

If you decide to take part, you will be randomised to provide either:

- Six sessions of physiotherapy care delivered to people with Parkinson's following standard practice but delivered via Microsoft Teams (control arm).
- Six sessions of home-based Physiotherapy following the PDConnect Programme delivered via Microsoft Teams (Intervention arm).

Randomisation to either group will not require any additional working hours, as therapy will be delivered within your current employment. Time away from your current role will be back-filled by another Physiotherapist, so your current caseload of patients will not be disadvantaged. The study has been discussed with the lead physiotherapist from Aberdeen city, who has confirmed that the back filling of your role will be arranged to allow you to participate in the study.

PDConnect is a health intervention which encompasses education, exercise and behaviour change strategies with the aim of promoting self-management in exercise participation. If you are randomised to deliver the PDConnect programme, you will be required to undertake and engage with a blended learning package. This is nominally 12-hours of directed study to provide you with a deeper understanding of the pathophysiology of Parkinson's, exercise prescription for this population, and delivery of behaviour change interventions to promote self-management for people with Parkinson's. Theoretical-based learning will be complemented by a one-day practical course delivered over Microsoft teams.

At the end of the study, you will be invited to participate in a semi- structured interview, to explore your perceptions of the training, and the delivery of the intervention. This should take approximately 30-minutes and will be undertaken using Microsoft Teams. These interviews will be audio-recorded so all your responses can be transcribed for accuracy.

What are the possible disadvantages and risks of taking part?

The research team do not perceive any disadvantages with being involved in this study. To minimise the risks associated with online exercise delivery standard operating procedures for online delivery of exercise developed by The Chartered Society of Physiotherapy and Parkinson's UK will be followed.

What are the possible benefits of taking part?

There are no personal benefits for you, however, you will be contributing to the evidence-base for the management of people with Parkinson's. For those randomised to deliver PDConnect will receive specialist continued professional development, enhancing professional knowledge and skills in the management of Parkinson's. On completion of the study, online learning material will be made available to the Physiotherapists who were randomised to deliver usual physiotherapy care should they wish.

What happens when the research study stops?

Your involvement will be for the first 6-weeks, with the total duration of the study lasting 30-weeks. Once the study has been completed, the principal researcher will analyse the data and write up the study findings. The study write up will be submitted as the principal researcher's Doctoral thesis and the study findings will also be submitted for publication within a scientific journal. You will receive a written lay summary of the study findings and notified of any publications within scientific journals.

Photography and Videoing:

During the course of the study, the research team may wish to take some photographs, which will be used by the research team when compiling reports for publication, or for use within presentations to the Parkinson's community and at professional conferences. If you do not wish your photograph taken, you may still participate in the study, we will ensure that we do not take any photos of you during the course of the study. All photographs will be stored in line with data protection guidelines and will be kept for five years following completion of the study.

A small number of the physiotherapy and group-based exercise sessions will be video recorded, this is so that the researchers can review how the intervention was delivered. This video footage will be used solely for research purposes and will not be shared out with the research team. This video footage will be destroyed data analysis has been completed.

What if something goes wrong?

In the unlikely event of an accident/injury, the standard operating procedure for online exercise provision should be followed. If any participants fall during the time you are involved in their care, this should be documented as per standard physiotherapy practice, but Julie Jones should also be informed of all falls which occur during the study period.

If you have any complaints about the conduct of this study, you should contact The Convenor, School of Health Sciences Research Ethics Committee, Robert Gordon University, 01224

263250 (SREC@rgu.ac.uk), Or Laura Binnie, Head of School of Health Sciences 01224 263251(l.m.binnie@rgu.ac.uk). The convenor of the ethics committee and Head of School have a responsibility to ensure that research is conducted in a lawful and ethical manner.

Will my taking part in the research be kept confidential?

Yes, all the information you share will be kept confidential. All the data we collect from you will be anonymised i.e., your name will not be able to be linked with transcribed interview content. In addition, your participation in this study will be kept confidential and we will not disclose the names of those involved in delivery of the programme. The researcher and their research supervisor will only see your interview responses and no individuals will be identified in any reports. All information will be collected and stored within the requirements of General Data Protection Regulation Act (GDPR, 2018) and in accordance with RGU policies and procedures relating to the collection, storage and retention of research data.

What will happen to the results of the research study?

The results will be written up by the researcher and submitted as their doctoral research thesis. The results will be published in appropriate academic journals and presented at local and national conferences. All data will be anonymised therefore, you will not be identified in any reports or publications.

Who is organising and funding the research?

Julie Jones, (Principal investigator and doctoral student), is conducting the research under the supervision of Professor Kay Cooper who will also monitor the study's progress. The study is being jointly funded by the Chief Scientist Office and Parkinson's UK.

Who has reviewed the study?

The study has been approved by the School of Health Sciences Research Ethics Committee, RGU (SHS 20/21) research ethics committee (280159) and by NHS Grampian Research & Development

What do I do now?

If you are interested in taking part or would like to discuss the study further before deciding, please contact Julie Jones, ✉ j.c.jones@rgu.ac.uk or ☎ 01224 263282

Thank you for considering taking part in this research study. Please discuss this information with anyone you wish prior to making a decision.

8.11 Appendix 11: Fitness Instructor information sheet

PDConnect

Fitness Instructor Participant Information Sheet

Study Title: Exercise for people with Parkinson's -the PDConnect study

You are being invited to take part in a research study. Before you decide whether you wish to take part, it is important for you to understand why the research is being done, and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear, or should you require any further information, please do not hesitate to contact the researcher. The contact details are available on the last page of this document. Take time to decide whether you wish to take part. Thank you for reading this.

Introduction:

The benefits of exercise for people with Parkinson’s are widely known; however, over 70 per cent of people with Parkinson’s are regarded as sedentary. Therefore, services need to be designed to support people with Parkinson’s to be more active and promote long-term engagement in exercise. This study aims to explore the feasibility and acceptability of a new exercise intervention called PDConnect. PDConnect is an exercise-based intervention, which in addition to exercise provides participants with education, and practical behaviour change interventions to promote self-management, which is delivered online via Microsoft Teams. People participating in PDConnect will receive one to one physiotherapy followed by group-based exercise delivered by fitness instructors. This study, aims to explore the feasibility and acceptability of this intervention, comparing it to usual physiotherapy care.

Why have I been chosen?

You have been chosen because you are a Fitness Instructor working at RGU:SPORT holding a level 3 Personal Training qualification, which is Register of Exercise Professionals (REPS) accredited or equivalent. This study is looking at a collaborative approach to exercise between the NHS and community-based exercise professionals for people with Parkinson’s. This study will be conducted by Julie Jones from the School of Health Sciences, Robert Gordon University (RGU) and will be conducted within NHS Grampian and RGU:SPORT.

Do I have to take part?

No, it is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet and you will be asked to sign a consent form. You will be given a copy of both forms to keep. If you decide to take part, you are still free to withdraw at any time and without giving a reason.

Taking part in the study.

If you decide to take part, you will be responsible for the group-based exercise programme which forms part of the PDConnect programme which will be delivered on the Microsoft Teams platform. PDConnect is a health intervention, which encompasses education, exercise, and behaviour change strategies with the aim of promoting self-management in exercise participation. The programme involves the delivery of specialist physiotherapy, followed by group-based exercise and self-management. By participating in the study, you will be responsible for the delivery of group-based circuit training classes for people with Parkinson's.

Prior to delivering the group-based classes, you will be required to undertake and engage with a blended learning package. This is nominally 12-hours of directed study to provide you with a deeper understanding of the pathophysiology of Parkinson's, exercise prescription for this population, and delivery of behaviour change interventions to promote self-management for people with Parkinson's. Theoretical-based learning will be complemented by a one-day practical course delivered over Microsoft Teams.

You will be required to oversee the delivery of 12-weeks of group-based exercise, based on current evidence and allowing participants to work at their individual level. Each exercise session will last one hour, followed by 30-minutes of discussion on pre-determined topics, which you will also facilitate. You will be provided with all the required materials and resources to deliver the exercise and discussion components of the class. You will also be required to refresh participants home exercise programmes during the 12 weeks as required and will be given access to an online exercise library so you can provide participants with relevant information to guide safe exercise at home.

On completion of the 12-week class, you will be required to contact each participant once a month, for three months, on the phone or via Microsoft Teams to discuss exercise participation and modify their home exercise programme as appropriate. Each call is anticipated to last 20-minutes.

At the end of the study, you will be invited to take part in a semi- structured interview, to explore your perceptions of the training, and the delivery of the intervention. This should take approximately 60 minutes and will be undertaken using Microsoft Teams. The interview will be audio-recorded so all your responses can be transcribed for accuracy.

What are the possible disadvantages and risks of taking part?

The research team do not perceive any disadvantages with being involved in this study or any risks to you personally. The risks associated with being involved in this study surround the potential for injury or accidents associated with the participants. People with Parkinson's have complex physical and non-physical symptoms, which can vary over the course of a day. Therefore, careful supervision will be required of this group while they are exercising. Education on the Parkinson's is provided in the training provided so that you will be aware of how to support people with Parkinson's to exercise safely.

What are the possible benefits of taking part?

You will receive specialist continued professional development, enhancing professional knowledge and skills in the management of Parkinson's.

What happens when the research study stops?

Your involvement will be for the 24-weeks (12-week group-based circuit class + 12-weeks self-management phone calls), with the total duration of the study lasting 30 weeks. Once the study has been completed, the principal researcher will analyse the data and write up the study findings for publication within a scientific journal. You will receive a written summary of the study findings, and will be notified of any publications within scientific journals.

Photography and Videoing:

During the course of the study, the research team may wish to take some photographs, which will be used by the research team when compiling reports for publication, or for use within presentations to the Parkinson's community and at professional conferences. If you do not wish your photograph taken, you may still participate in the study, we will ensure that we do not take any photos of you during the course of the study. All photographs will be stored in line with data protection guidelines and will be kept for five years following completion of the study.

A small number of the physiotherapy and group-based exercise sessions will be video recorded, this is so that the researchers can review how the intervention was delivered. This video footage will be used solely for research purposes and will not be shared out with the research team. This video footage will be destroyed data analysis has been completed.

What if something goes wrong?

In the unlikely event of an accident/injury, appropriate first-aid measures should be delivered to participants. If any participant falls during the time you are involved in their care, Julie Jones should also be informed immediately so this can be recorded and investigated further. As an employee of RGU, you will be covered by RGU indemnity policy.

If you have any complaints about the conduct of this study, you should contact The Convenor, School of Health Sciences Research Ethics Committee, Robert Gordon University, 01224 263250 (SREC@rgu.ac.uk), Or Laura Binnie, Head of School of Health Sciences 01224 263251(l.m.binnie@rgu.ac.uk). The convenor of the ethics committee and Head of School have a responsibility to ensure that research is conducted in a lawful and ethical manner.

Will my taking part in the research be kept confidential?

Yes, all the information you share will be kept confidential. All the data we collect from you will be anonymised i.e. your name will not be able to be linked with transcribed interview content. In addition, your participation in this study will be kept confidential and we will not disclose the names of those involved in the delivery of the programme. The researcher and their academic research supervisors will only see your interview responses and no individuals will be identified in any reports. All information will be collected and stored within the requirements of General Data Protection Regulation Act (GDPR, 2018) and in accordance with RGU policies and procedures relating to the collection, storage and retention of research data.

What will happen to the results of the research study?

The results will be written up by the researcher and submitted as their doctoral research thesis. The results will be published in appropriate academic journals and presented at local and national conferences. All data will be anonymised therefore, you will not be identified in any reports or publications.

Who is organising and funding the research?

Julie Jones, (Principal investigator and doctoral student), is conducting the research under the supervision of Professor Kay Cooper who will also monitor the study's progress. The study is being jointly funded by the Chief Scientist Office, and Parkinson's UK.

Who has reviewed the study?

The study has been approved by the School of Health Sciences Research Ethics Committee, RGU (SHS 20/21) research ethics committee (280159) and by NHS Grampian Research & Development.

What do I do now?

If you are interested in taking part or would like to discuss the study further before deciding, please contact Julie Jones, ✉ j.c.jones@rgu.ac.uk or ☎ 01224 263282

Thank you for considering taking part in this research study. Please discuss this information with anyone you wish prior to making a decision.

8.12 APPENDIX 12: PHYSIOTHERAPIST AND FITNESS INSTRUCTOR CONSENT FORM

PDConnect

CONSENT FORM

SRRG reference number: **SHS/20/21 IRAS No: 280159**

Study title: *A* collaborative approach to exercise provision for people with Parkinson’s – a feasibility study of the PDConnect programme

Name of Researchers: Julie Jones (Principal Investigator)

Please initial box

1. I confirm that I have read and understand the information sheet dated 10/09/2020 (Version 1.1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. ☐

3. I understand that individuals will look at data collected during the study from The Robert Gordon University, where it is relevant to my taking part in this research. I give permission for these individuals to have access to the data. ☐

4. I consent for any pictures to be taken during the study to be shared for promotional purposes and within publications and presentations associated with the study. ☐

   If you do not consent to photography, you can still take part in the study and the researcher will ensure that pictures of you are not used for these purposes. ☐

5. I consent for video footage to be taken during the study to be used research purposes only. I understand that this video footage will be destroyed by the research team on completion of the analysis ☐

6.. I give permission for the 1-1 interview to be audio-recorded and for anonymised quotes to be used in study reports and conference presentations. ☐

7. I understand my role in the study and have had the opportunity to ask questions in relation to this. ☐

8. I agree to take part in the above study. ☐

Name of participant: Date:
Signature: Date:

Name of person taking consent: Date:
Signature: Date:

Two copies to be retained: one for researcher and one for participant.

8.13 APPENDIX 13: HOME RISK ASSESSMENT FORM

8.14 APPENDIX 14: PARTICIPATION STATEMENT

PDConnect

Participation Statement

As this study is being delivered entirely online using Microsoft Teams, your will be engaging with the staff delivering the study over video conferencing as opposed to face-to-face. Therefore, in the event of a fall, trip, or injury during the course of any of the sessions, we require you to provide us with two emergency contact details, whom we can contact only if required.

This information will be treated strictly confidentially and is protected in accordance with GDPR and the Data Protection Act 2018 and will only be accessible to the researcher team and only used in the event of an emergency.

Your Name:	
Your home phone number	
Your mobile phone number	
Emergency Contact Name (1):	
Relationship	
Emergency contact home phone number	
Emergency contact mobile phone number	
Emergency Contact Name (2):	
Relationship	
Emergency contact home phone number	
Emergency contact mobile phone number	

8.15 APPENDIX 15: ROLES AND RESPONSIBILITIES

Roles and responsibilities.

Researchers responsibilities:

- To act as a co-ordinator between all parties involved in the study
- To act as a trouble shooter in the event of any issues (e.g. technology issues) which arise during the study
- To ensure the study is conducted as planned.
- Conduct all measurement during the course of the study (baseline, 6, 18 and 30 weeks)
- Conduct initial risk assessment of participants homes in preparation for remote delivery of exercise
- Provide all participants with an induction and trial run of using Microsoft teams and the use of the Mi Band activity tracker
- Instructors are also required to provide participants with an opportunity to trial the use of the online platform out-with the class setting.

Physiotherapist and Fitness Instructors Responsibilities

- Physiotherapist and Fitness Instructors will provide a safe, effective, and enjoyable interactive online exercise class. It may be necessary for instructors to demonstrate, adapt and provide alternative exercises for individuals with specific needs.
- Prior to the start of the sessions, Physiotherapist and Fitness Instructors are responsible for ensuring the space they are using for delivery is suitable for the activity and clear of any hazards (e.g., trips, slips, falls).
- Physiotherapist and Fitness Instructors are required to remind participants of the need to ensure the environment they are participating from is clear of any potential hazards (e.g., trips, slips, falls) prior to commencing each session.
- Physiotherapist and Fitness Instructors are required to undertake ongoing dynamic risks assessments in relation to instructor to participant ratio and class content. Risk assessments should consider various factors including equipment and participant ability.
- Physiotherapist and Fitness Instructors are responsible for ensuring all Participation Statements are completed correctly for all participants prior to starting the

programme. The Physiotherapist and Fitness instructors must not allow anyone to take part without a participation statement being completed. Participation statements must be stored in locked channels within the Microsoft Teams platform. Instructors must have participation statements at hand (for quick access to individual contact details) for any possible emergency contact details being required during the class.

Your commitment to us:

- You should not exercise beyond your abilities and if you know or are concerned that you have a medical condition which might interfere with you exercising safely you should get advice from a relevant medical professional and follow that advice.
- Any exercise carries its own risks. You should not carry out any activities which you have been told are not suitable for you.
- You should let us know immediately if you feel ill when participating in our class.
- You should ensure the exercise environment is free from obstacles and you wear suitable clothing and footwear. To help you feel as safe as possible while attending this class, you will make sure the area you will be exercising in has no trip hazards, has good lighting, a seat within reach and a table or kitchen work surface to hold onto, also within reach (support maybe be required for some of the standing exercises).
- A family member or carer would be welcome to be present, as required.
- You should keep a phone close to where you are exercising and water for hydration.
- You should inform the instructor and complete a new participation statement for any changes to your contact details, emergency contact person, home address or the address from which you are participating in the class from.

- Follow the safety checklist (below) prior to each session.

Safety Checklist for participants

- Please remember to only exercise if you are feeling well and able to take part. Stop if you feel unwell at all during the exercise; feeling dizzy, have chest pain, feel sick, feel unusual bone or muscle pain.
- Please have medication to hand (eg inhalers or chest pain sprays)
- Wear comfortable, flat shoes even if this is in the house to support your feet and balance.
- Always complete a warm-up before doing any exercise, particularly if you have been sitting for a period of time beforehand.

- Ensure your space is clear and suitable for exercising at home, the floor space is clear and free of trip hazards like cables or the corners of rugs.
- Keep water nearby and drink before, during and after exercise to prevent dehydration and ensure the room is adequately ventilated during hot weather.
- Please work at your own pace
- Where possible, please have a partner/carer or person from your social bubble present within your house while exercising.
- If it is not possible to have someone with you, please ensure that you have a phone in the same room as you are exercising, for use in the event of an injury.

8.16 APPENDIX 16: USUAL CARE PARTICIPANT MANUAL

PDConnect

Study Name: Exercise for people with Parkinson’s -the PDConnect study.

Study Number:_______________

Participant ID:________________

Physiotherapy Group Manual

This study is funded by:

PARKINSON'S UK
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.

CHIEF
SCIENTIST
OFFICE

PDConnect

Study Manual

Thank you for agreeing to participate in this study. Your time and support is very much appreciated. You have been randomised to receive standard physiotherapy care for your Parkinson’s.

So, what happens next?

Physiotherapy:

You will see an NHS Physiotherapist who will arrange with you six, one-hour weekly appointments with you, which will be delivered online via Microsoft Teams. In these appointments, the Physiotherapists will review your needs with you and will design a treatment plan in conjunction with you that addresses your needs. This may involve exercises, which you conduct during the hourly appointment, as well as exercises, which you are requested to do at home on your own.

Measurements:

You will have had some measurements taken by Julie prior to starting. These baseline measures will be repeated when you complete your physiotherapy, and again at 18 weeks, and 30 weeks. Julie will contact you to arrange to repeat these measures, which are conducted on Microsoft Teams. These measures will require Julie to observes you doing some functional tasks within your home as well as asking you to complete some questionnaires about how Parkinson’s impact your everyday life.

Contact Details: ☎ 01224 263282 ✉ j.c.jones@rgu.ac.uk

Activity Tracker (Mi Band):

Julie has already given you a Mi Band and set this up for you. We would like to ask that you wear this from now and for the next thirty weeks of the study. In the next few pages of this manual there is some information about the Mi Band should you need to refer to this during the course of the study. In the event of any problems, please contact Julie Jones.

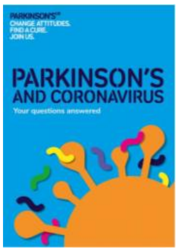
Activity Diary:

During the course of the study, we would like you to complete an activity diary. Within this manual, there is further information on this for you, and some blank copies for you to complete.

Coronavirus (Covid-19)

The researchers recognise that COVID-19 has had a dramatic impact on everyone's lives. In designing this study, the research team has sought guidance from the NHS, Scottish Government and Parkinson's UK to ensure that they are taking the necessary steps to ensure your safety and that of your family during the course of this study.

With this study being delivered online, this dramatically reduces the risk associated with transmission, as staff delivering the intervention will not see you in person, as it will all be delivered online. Even the measurements will be done online using Microsoft Teams. These measurements will be conducted right at the beginning of the study, and repeated at week 6, 18 and 30. You will receive support on how to get started using Microsoft Teams so that you are familiar with this prior to starting the study. If you should develop Covid-19 during the time of the study please contact Julie Jones to let her know. It maybe that your symptoms are minimal and it does not influence your ability to participate in exercise or it may mean that you need to take some time off exercise.



PARKINSON'S AND CORONAVIRUS

Your questions answered

Parkinson's UK have compiled a document about Parkinson's and Covid. This is available online, or if you would like a paper copy please email Julie and this can be posted to you.

Recognising that the Covid-19 situation is ever evolving, and as a result guidance and recommendations also change with time. Please visit the Parkinson's UK webpages for up to date Covid-19 guidance. https://www.parkinsons.org.uk/news/understanding-coronavirus-and-parkinsons

PDConnect

Coronavirus (Covid-19)

What happens if you get Covid-19 during the study?

Covid-19 effects different people in different ways. In the event that you were to contract Covid-19 it is very difficult to predict the impact it will have on your and your ability to participant in everyday tasks as well as exercise.

The key symptoms that people report when they develop Covid-19 include:

- High temperature
- A new and continuous cough,
- Shortness of breath,
- Fatigue,
- Loss of appetite,
- Loss of smell
- Loss of taste

If you develop any of these symptoms you are required to self-isolate for up to 10 days, and it is recommended that you get tested. You may also be required to self-isolate if the person you live with, or those in your "bubble" have symptoms or have tested positive.

NHS

To book a test follow this link for further information:

https://www.nhs.uk/conditions/coronavirus-covid-19/testing-and-tracing/get-a-test-to-check-if-you-have-coronavirus/

If you have variable internet access call 119

PDConnect

Coronavirus (Covid-19)

Up-to-date guidance on Covid-19 can be found on the NHS webpages: https://www.nhs.uk/conditions/coronavirus-covid-19/

If you develop Covid-19 symptoms or become unwell as a result of any other conditions during the course of the study, please inform Julie Jones

☎ 01224 263282 ✉ j.c.jones@rgu.ac.uk

PDConnect

Roles and responsibilities

This part of the manual will provide further details about what you can expect from participating within this study. You will receive six sessions delivered by a Physiotherapist from within NHS Grampian. Below is a summary of the researchers and the physiotherapists responsibilities, as well as what your role within the study entails.

Researchers responsibilities:

- To act as a co-ordinator between all parties involved in the study.
- To act as a trouble shooter in the event of any issues (eg technology issues) which arise during the study
- To ensure the study is conducted as planned.
- Conduct all measurement during the course of the study (baseline, 6, 18 and 30 weeks)
- Conduct initial risk assessment of participants homes in preparation for remote delivery of exercise
- Ensuring all Participation Statements are completed correctly for all participants prior to starting the programme.
- Ensure that all participants have completed as participation statement
- Provide all participants with an induction and trial run of using Microsoft teams and the use of the Mi Band activity tracker
- Researcher’s are also required to provide participants with an opportunity to trial the use of the online platform out-with the class setting.

9.0 GETTING STARTING WITH PDCONNECT

Physiotherapists Responsibilities

- Physiotherapists will provide a safe, effective and enjoyable interactive online exercise class. It may be necessary for instructors to demonstrate, adapt and provide alternative exercises for individuals with specific needs.
- Physiotherapists are required to discuss your exercise programme with you to ensure it meets your individual needs
- Review and refresh your home exercise programme and goals as required
- Prior to the start of the sessions, Physiotherapists are responsible for ensuring the space they are using for delivery is suitable for the activity and clear of any hazards (e.g. trips, slips, falls).
- Physiotherapist are required to remind participants of the need to ensure the environment they are participating from is clear of any potential hazards (e.g. trips, slips, falls) prior to commencing each session.
- Physiotherapists are required to undertake ongoing dynamic risks assessments in relation to instructor to participant ratio and class content. Risk assessments should consider various factors including equipment and participant ability.
- Physiotherapists must have participation statements at hand (for quick access to individual contact details) for any possible emergency contact details being required during the class.

PDConnect

Roles and responsibilities

Your commitment to us:

- You should not exercise beyond your abilities and if you know or are concerned that you have a medical condition which might interfere with you exercising safely you should get advice from a relevant medical professional and follow that advice.
- Any exercise carries its own risks. You should not carry out any activities which you have been told are not suitable for you.
- You should let us know immediately if you feel ill when participating in our class.
- You should ensure the exercise environment is free from obstacles and you wear suitable clothing and footwear.
- To help you feel as safe as possible while attending this class, you will make sure the area you will be exercising in has no trip hazards, has good lighting, a seat within reach and a table or kitchen work surface to hold onto, also within reach (support maybe be required for some of the standing exercises).
- A family member or carer would be welcome to be present, as required.
- You should keep a phone close to where you are exercising and water for hydration.
- You should inform the instructor and complete a new participation statement for any changes to your contact details, emergency contact person, home address or the address from which you are participating in the class from.

- Complete you daily activity diary, and weekly activity planners

- Wear your activity tracker for the duration of the study

- Follow the safety checklist (below) prior to each session

9.0 GETTING STARTING WITH PDCONNECT

Safety First

Participation in exercise can cause injury, therefore working at a rate and pace that you are comfortable is important. As this study is being delivered online, staff will not be with you during appointments so below is a list of additional health and safety information and guidance drawn from the Parkinson's Excellence Network Exercise Hub information "staying active at home when you have Parkinson's".

Before you start exercising you need to prepare your environment making sure that your living space is safe and comfortable for exercise. A risk assessment of your house will have been conducted prior to starting the exercise programme, with recommendations made as appropriate. However, prior to starting any online exercise session, you must follow the points below.

Health and Safety Checklist for participants

- Please remember to only exercise if you are feeling well and able to take part. Stop if you feel unwell at all during the exercise; feeling dizzy, have chest pain, feel sick, feel unusual bone or muscle pain.
- Please have medication to hand (eg inhalers or chest pain sprays)
- Ensure your space is clear and suitable for exercising at home, the floor space is clear and free of trip hazards like cables or the corners of rugs.
- Keep sturdy chairs ready to hold onto, or to sit and rest on.
- Make sure your room is at a comfortable temperature, or adequately ventilated - don't exercise in a room that's too hot. Open a window if you need to.
- Wear comfortable, flat shoes even if this is in the house to support your feet and balance. Check that your shoes and any equipment you're using are in a good condition and right for the activity.
- Always complete a warm-up before doing any exercise, particularly if you have been sitting for a period of time beforehand.
- Keep water nearby and drink before, during and after exercise to prevent dehydration. Don't forget to drink your water. You can lose around one and a half

litres of fluid for every hour of vigorous exercise, so drink water before, during and after a session.

- Please work at your own pace
- Where possible, please have a partner/carer or person from your social bubble present within your house while exercising.
- If it is not possible to have someone with you, please ensure that you have a phone in the same room as you are exercising, for use in the event of an injury.
- Have a telephone or mobile nearby in case of an emergency. If you live alone, please ensure that someone is knows that you are exercising at home and check in with them after you have finished.
- Don’t forget to drink water. You can lose around one and a half litres of fluid for every hour of vigorous exercise, so drink water before, during and after a session.

PDConnect

Participation Statement

As this study is being delivered entirely online, in the event that you have a fall or an injury during the online session, we need to have access to an emergency contact, whom we can contact should such an event arise. This information will be kept securely by the staff, and these people will ONLY be contacted in the event of an emergency.

PDConnect

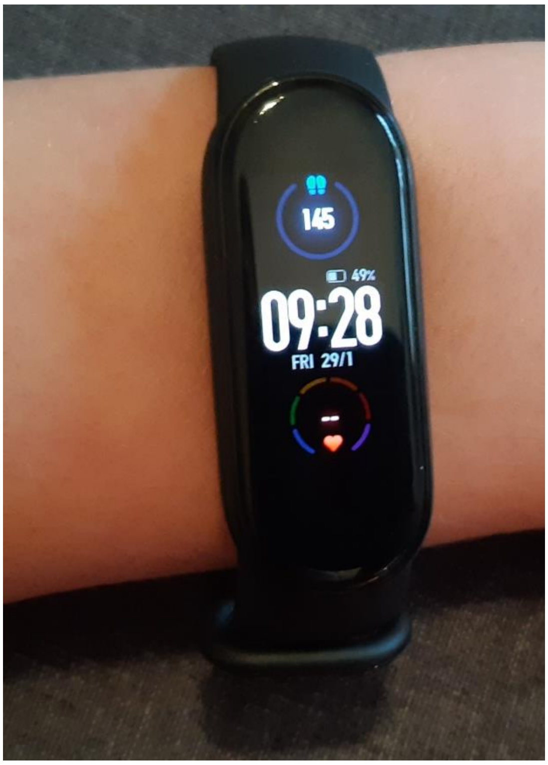
Mi Band -Activity Tracker

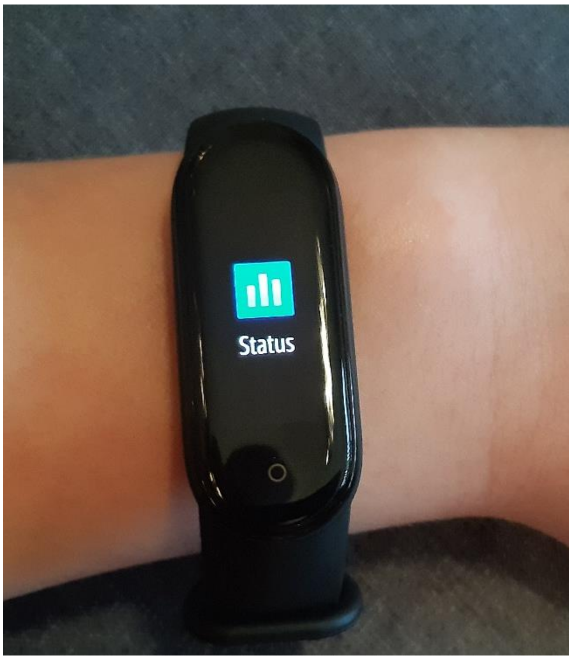
As part of the study, you will receive a Mi band, which is a wrist worn activity tracker. Everyone who is part of this study will receive one for the duration of the study. We would very much like it if you could wear this device every day for the entirety of the study, which is approximately 30 weeks.

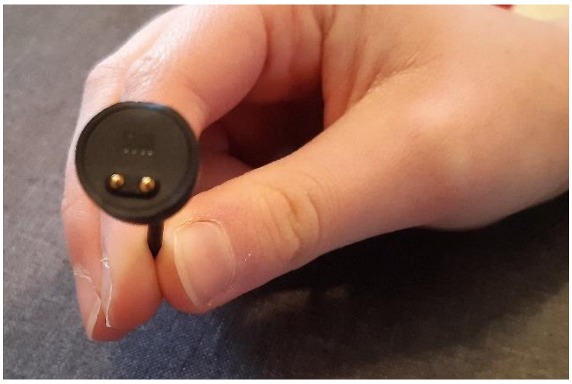
Julie who is one of the researchers will set you up with the tracker after she has taken your baseline measurements. Julie will show you how to use the tracker, set you up a Mi account through the Mi Smart Phone app or on your PC, so that you are all set up and good to go. This guide has been put together for your information, so you can refer back to it as required during the study, in case you run into any issues during the course of the study. In the event of any queries please do not hesitate to contact Julie on 01224 263282, or j.c.jones@rgu.ac.uk

Preparing to use your Mi Band

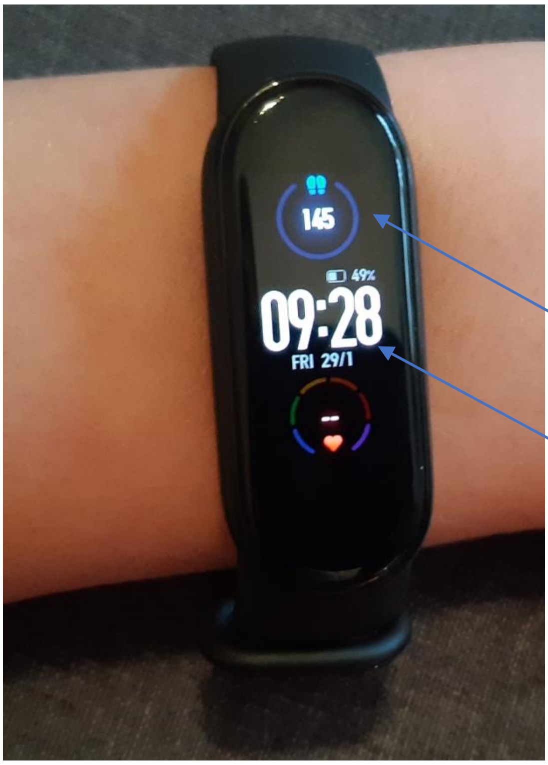
Getting to know your Mi Band.







Wearing the Mi Band



When wearing the Mi band, to conserve power the screen will automatically switch off. However, it will still be recording information. To see the time on the watch tap the

Cumulative daily step count

Date, time, battery level

Any activity that you undertake will be counted. At midnight, the device resets itself and it will return to 0. You will be able to view prior days step count through the Mi Fit phone

By touching the bottom of the screen and sliding your finger up the face of the watch, you can see other features on the watch. Tapping the status icon as shown in the picture will tell you your total

Fastening your Mi Band

Charging your Mi Band:

You can check your battery level by touching the bottom of the watch face and the battery life is illustrated on the watch face. When the battery is low, please charge it. The battery normally lasts 5 days without charging.

To charge: Take the watch off. Connect the charger head to the back of the watch, aligning it with the two emtal spots on the back of the watch. It is magnet so it will click on. Then plug the USB post into a plug or charging unit. To check when complete- all bars should be full.

Battery charging points

Attach the charging cable to the back of the watch as shown

Attach the sensor and cable to a USB plug or point, and switch on to charge. Disconnect when battery is 100% full.

The Mi band is water resistant but not waterproof. Therefore, splashes of water from handwashing will be ok, but you are advised NOT to wear your Mi band in the shower, bath, or if you go swimming. Please also not wear the device when in a sauna or steam room.

Cleaning your Mi Band:
Remove the sensor from the band, and **wash the band** in warm soapy water, and dry off with a tea towel. The sensor itself **should not be submerged** in water, if this requires cleaned, please do so with a damp cloth and dry afterwards.

Getting started with your Mi band

When to wear your Mi Band:

This study is primary interested in your physical activity levels so you are only required to wear the tracker when you get up in the morning, until you go to bed in the evening. We wish to collect this data for the 30 weeks, which the study lasts for. You may wear it while in bed at night but this is not essential, only during the times you are awake. Please take it off when bathing, and should you go swimming.

The Mi band will start collecting data as soon as you put the device on. There is no need to press any buttons. The Mi band has a built in energy saving feature, so unless you tap the bottom located on the screen it will be blank. It is still working even with screen blank. If you wish to see the information, being collected tap the button, and for more in detail information slide your finger up and tap on the other features to see the information.

Further information about your activity can be found on the Mi app on your phone, which we will explore on the next few pages.

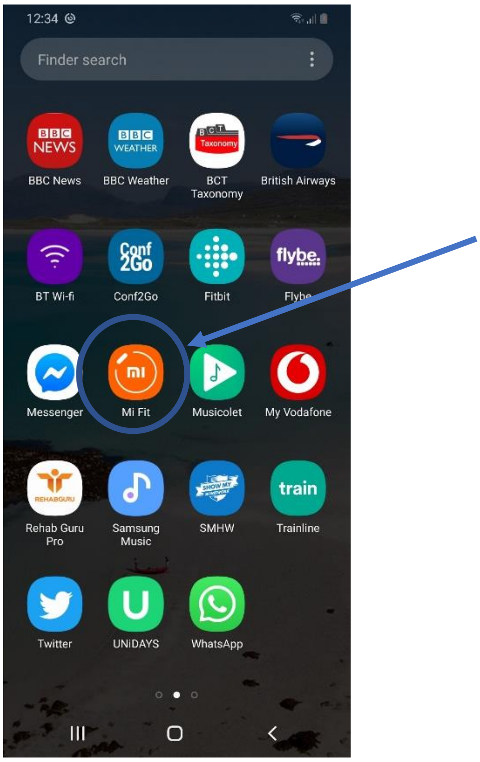
Just tap the mi icon, and it will take you to your information.

The Mi Band Phone App

When setting your phone and band up, Julie will download an app to your phone called Mi Fit app. The icon is opposite. By tapping this icon, you will be able to see all you physical activity data.

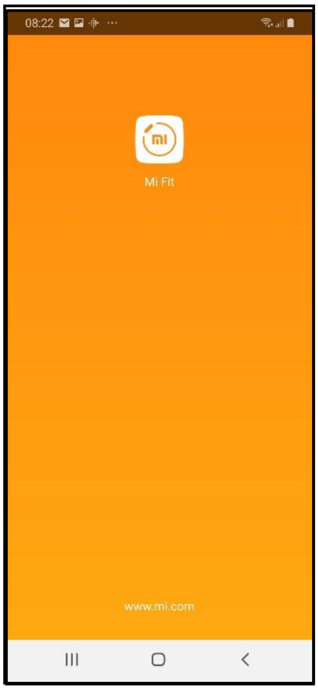
Getting started:

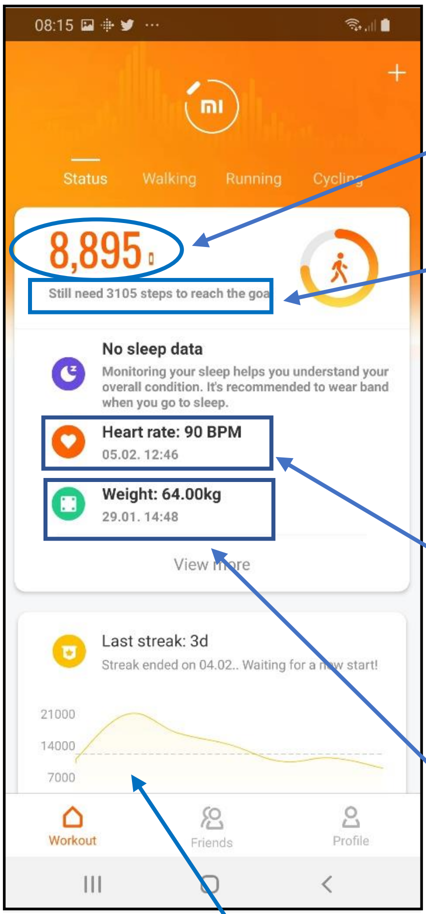
Start by opening up your phone, to your normal home page. All apps are normally listed alphabetically, so may need to swipe the screen depending on how many apps you have.



When you open your phone on the home page, you will see the Mi Fit app listed amongst your other apps that you have on your phone.

Tapping the Mi Fit App will take you to a page like this, which will then refresh and open the page detailed below.





8,895

Still need 3105 steps to reach the goa

No sleep data

Monitoring your sleep helps you understand your overall condition. It's recommended to wear band when you go to sleep.

Heart rate: 90 BPM
05.02. 12:46

Weight: 64.00kg
29.01. 14:48

View more

Last streak: 3d

Streak ended on 04.02.. Waiting for a new start!

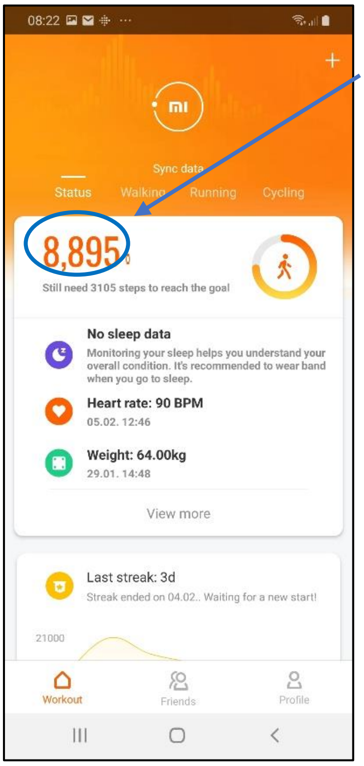
This illustrates the number of steps completed on this day at this time.

This states how many more steps that need to be undertaken to achieve your daily step goal, which in this example is set as 12, 000. When this goal has been achieved the orange circle surrounding the stick man will be entirely orange.

This provides information about heart rate in beats per minute (Bpm). In this example it was recorded on the 5th of february (05.02), at 12.46.

This is the last recorded weight, which in this example was logged at 64kg.

This illustrates graphically the total daily step count over the last 3 days



8,895

Still need 3105 steps to reach the goal

No sleep data

Monitoring your sleep helps you understand your overall condition. It's recommended to wear band when you go to sleep.

Heart rate: 90 BPM

05.02. 12:46

Weight: 64.00kg

29.01. 14:48

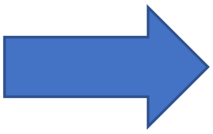
View more

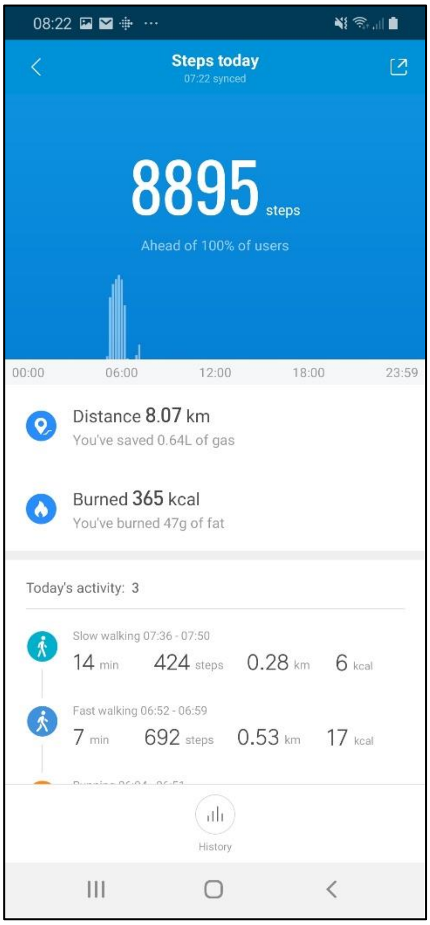
Last streak: 3d

Streak ended on 04.02.. Waiting for a new start!

21000

Taping your current daily step count here, takes you





8895 steps

Ahead of 100% of users

Distance 8.07 km

You've saved 0.64L of gas

Burned 365 kcal

You've burned 47g of fat

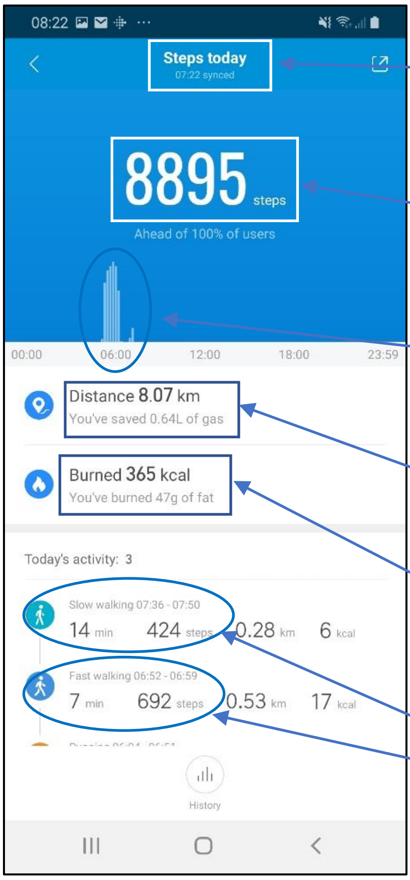
Today's activity: 3

Slow walking 07:36 - 07:50

14 min 424 steps 0.28 km 6 kcal

Fast walking 06:52 - 06:59

7 min 692 steps 0.53 km 17 kcal



Time which Mi band data synchronised with the Mi Fit app -7.22am.

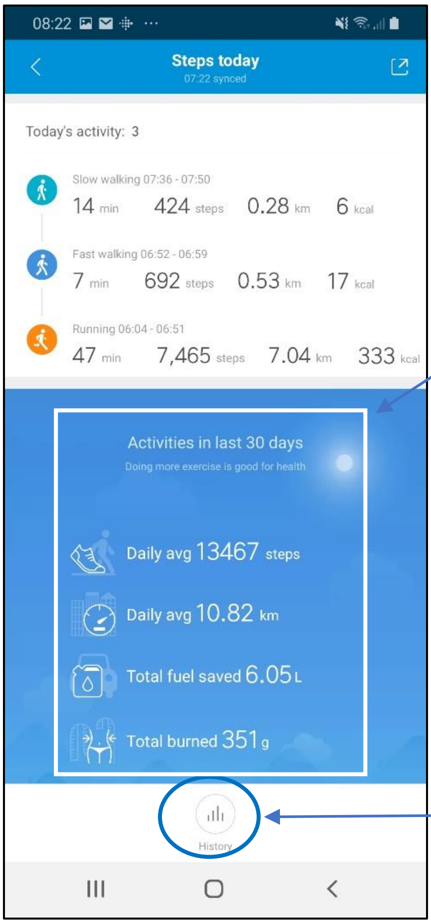
Number of steps taken on this point of time.

Timeline of stepping activity. In this example, all activity occurred between 6 and 7am

Distance travelled in this example – 8.07km

Amount of energy spent by stepping activity on this day

The Mi band, categories stepping into slow, fast walking, light activities or running



Steps today

07:22 synced

Today's activity: 3

Slow walking 07:36 - 07:50

14 min 424 steps 0.28 km 6 kcal

Fast walking 06:52 - 06:59

7 min 692 steps 0.53 km 17 kcal

Running 06:04 - 06:51

47 min 7,465 steps 7.04 km 333 kcal

Activities in last 30 days

Doing more exercise is good for health

Daily avg 13467 steps

Daily avg 10.82 km

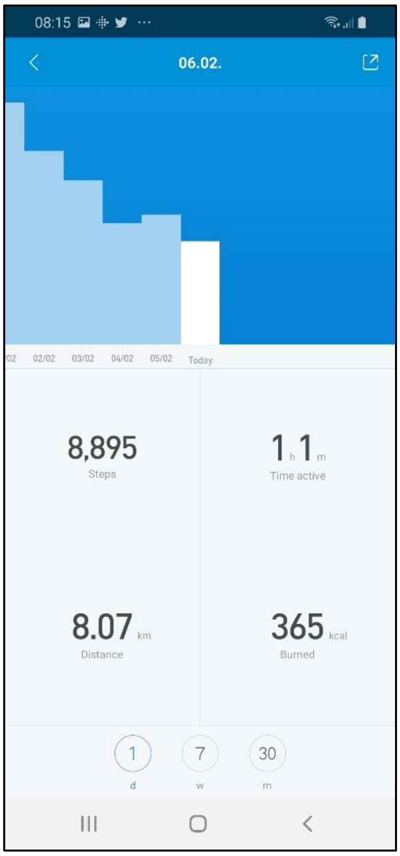
Total fuel saved 6.05 L

Total burned 351 g

By scrolling down this page you will be able to see cataloguing of other activities you have done on this day, but also the app summaries conducted over the

Tapping this history icon takes you to your activity history and illustrates this in a bar graph format as is shown below.

This display illustrated your total step count on the prior days. In this example you can see the last 6 days total steps



8,895 Steps

1 h 1 m Time active

8.07 km Distance

365 kcal Burned

PDConnect

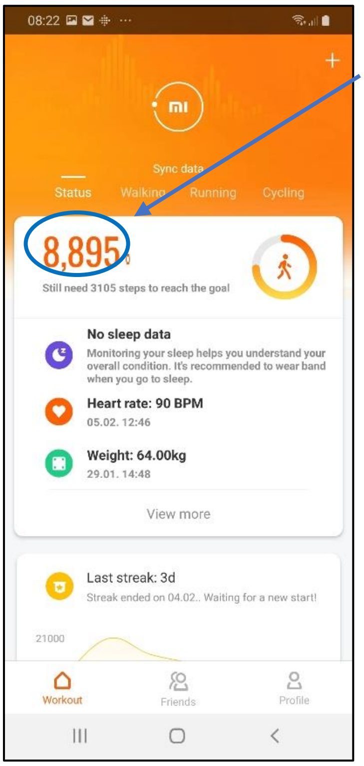
Recording your physical activity information

So we can review your physical activity, you will need to share the information collected on your tracker. It is advisable that you write down each day your total activity within your activity diary. It would be best to do this last thing at night or first thing in the morning where you record the prior day's activity. The activity diary is discussed on page 17.

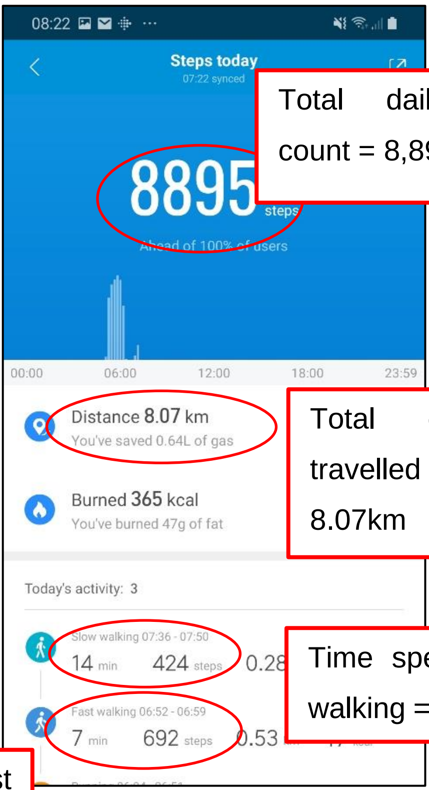
The information we wish you to record is:

- Total step count for that day
- Total distance travelled
- Time spent slow walking
- Time spent fast walking

This information can be found by:



Taping your current daily step count here, takes you



Total daily step count = 8,895

Total distance travelled = 8.07km

Time spent slow walking = 14 mins

Time spent fast walking = 7mins

PDConnect

Frequently asked questions.

What happens if I forget to wear my device?

As soon as you realise that you have not worn it, put it on. Even if it is half way through the day, please put the device on. Please keep a note in your diary if there is a day, which you forgot to wear the device, and let Julie know at the next assessment appointment.

What happens if I get the device wet?

Take the device off and remove the sensor from the band, and dry both the band and the sensor thoroughly. Once you have dried it, tap the screen and see if it is working.

What happens at the end of the study?

You will be sent a pre-paid envelope for you send back your activity tracker and you Smart phone should you have borrowed one. All we ask is that you put the device(s) the device, fastening it securely envelope and pop it in the post. Thank you.

Any problems or issues contact Julie on:

☎ 01224 263282

✉ j.c.jones@rgu.ac.uk

PDConnect

Activity Diary

Below is a completed example of an activity diary to guide what you need to record within your activity diary. Please could this be completed each day for the duration of the study.

Week 1 Week beginning:___________________________

	Total step count for that day	Total distance travelled	Time spent slow walking	Time spent fast walking
Example	**8.895**	**8.07km**	**14 mins**	**7 mins**
Monday				
Tuesday				
Wednesday				
Thursday				
Friday				
Saturday				
Sunday				

Notes: Please make any notes that you may feel are relevant eg I was on holiday this week, I had a cold symptoms on Monday.

PDConnect

Falls record

⚠ Falls: Unfortunately sometimes falls do occur. A falls is defined as an event whereby a person comes to rest on the floor inadvertently. We would like you to record ant falls which occur during the course of this study in the following study. if you experience a falls we would also like you to report this to the researcher

Julie Jones ☎ 01224 263282 ✉ j.c.jones@rgu.ac.uk

Completed example:

Date and Time	***24th January 2020, at 7.55pm***
Was the fall seen	**NO**
Location of fall	**Bthroom**
State the cause of falls	**Tripped on the bath mat**
Please state any injury yes or no. If yes	**Yes, bumped knee**
Did you need to call your GP?	**No**
Did you need to go to hospital?	**No**
Actions after falls	***Hung mat up over bath***

PDConnect

Falls record

Falls Diary: We would like you to record ant falls which occur during the course of this study in the following study. if you experience a falls we would also like you to report this to the researcher Julie Jones ☎ 01224 263282 ✉ j.c.jones@rgu.ac.uk

Date and Time	
Was the fall seen	
Location of fall	
State the cause of falls	
Please state any injury yes or no. If yes	
Did you need to call your GP?	
Did you need to go to hospital?	
Actions after falls	

Date and Time	
Was the fall seen	
Location of fall	
State the cause of falls	
Please state any injury yes or no. If yes	
Did you need to call your GP?	
Did you need to go to hospital?	
Actions after falls	

PDConnect

Thank you

Thank you very much for your time during the course of this study, it is very much appreciated. Should you experience any problems during the course of the study or wish to feedback on the experience please feel free to contact Julie Jones, who is the principal researcher in confidence, or you may also contact the convenor of the RGU Ethics committee or Mrs Laura Binnie, Head of the School of Health Sciences.

Julie Jones	☎ 01224 263282	✉ j.c.jones@rgu.ac.uk
Convenor	☎ 01224 263250	✉ SREC@rgu.ac.uk
Laura Binnie	☎ 01224 263251	✉ l.m.binnie@rgu.ac.uk

Now that the study is complete, please could you return the activity tracker, and the Smart Phone if you have borrowed one. You have been provided with a prepaid envelope so that the devices can be returned to the research team through the Royal Mail special delivery service. If you have any questions, please contact Julie Jones, contact details above.

8.17 APPENDIX 17: PHYSIOTHERAPY HANDOVER SHEET

PDConnect

Physiotherapy Summary handover sheet

Participant Name:		**DoB:**	
Email:		**Phone:**	
Parkinson's Dx Date:		**Consultant:**	
Medication:		**GP**	
Address:			
PMH:		**Main problems:**	

8.18 APPENDIX 18: PHYSIOTHERAPY ATTENDANCE SHEET

PDConnect

Physiotherapy Attendance Record

Name	1	2	3	4	5	6
e.g. Julie Jones	✓	✓				

Physiotherapist Signature.

8.19 APPENDIX 19: PHYSIOTHERAPY NOTES TEMPLATE

PDConnect

PDConnect Physiotherapy Notes

Name:		DoB:
Email:		
Phone Number		
Dx date		
PMH:		

Session 1	
Date	
S	
O	
A	
P	
Short term goals	
1.	
2.	
3.	
Long term goal	
1	
Activity planner complete: YES/NO HEP provided: YES/NO BCTs: YES/NO	
Additional notes	
Signature:	

Session 2	
Date	
S	
O	
A	
P	
Short term goals	
1.	
2.	
3.	
Long term goal	
1	
Activity planner complete: YES/NO HEP provided: YES/NO BCTs: YES/NO	
Additional notes	
Signature:	

8.20 APPENDIX 20: PDCONNECT PARTICIPANT MANUAL

PDConnect

Study Name: Exercise for people with Parkinson's -the PDConnect study.

Study Number:_______________

Participant ID:________________

PDConnect Programme Manual

This study is funded by:

PARKINSON'S UK
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.

CHIEF
SCIENTIST
OFFICE

PDConnect

Study Manual

Welcome to the PDConnect study manual, which has been designed to be an interactive resource, which you can dip in and out of as you participate in the programme. The manual been produced as part of a research project jointly funded by the Chief Scientist Office, and Parkinson's UK.

CHIEF SCIENTIST OFFICE

PARKINSON'S UK
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.

The chapters have been carefully selected, and informed by the views of people with Parkinson's, and aims to provide you with the tools and confidence to embrace a more physically active lifestyle. The manual provides information supporting the value of exercise for your Parkinson's, as well as the wider health and well-being benefits. It should serve as a resource to complement the guidance you receive from the staff delivering PDConnect, providing reference for further reading, and sources of information. All of us could be more active, and developing good exercise habits is not easy at any stage of life, therefore a key aspect of this manual discusses and explores tried and tested strategies that promote changes to behaviour. As such, this manual alongside the intervention aims to equip participants with the knowledge, skills and confidence to self-direct and manage their own physical activity and foster a sense of taking control.

We recognise the importance of your support network so this manual can be shared with family and friends so they can support you in your exercise journey, and even better join you in regularly exercising.

PDConnect

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1.0 WELCOME

Welcome to the PDConnect programme. Your journey to leading a more physically active lifestyle lies ahead. The inspiration for this programme has arisen from my experiences of working with the Parkinson's community listening to their needs, and their views on the shortcomings of current service provision, and the impact this has on their ability to engage in exercise in the short and longer term. Similarly, working with clinical colleagues, I am mindful of the challenges they face in providing services that meet the diverse needs of people with Parkinson's, and the barriers they encounter providing flexible and sustainable exercise opportunities for the Parkinson's population. Finally, the arrival of Covid-19 has also influenced and challenged how we deliver service to those living in towns, cities and in remote and rural environments. The PDConnect programme is a culmination of these experiences, combined and informed by current research on exercise prescription, national and international guidelines, with the intention of providing an evidenced based programme, which is tailored to meet the individual needs of people with Parkinson's, and enable them to continue to lead active and fulfilling lives.

I hope you enjoy your journey.

2.0 THE PDCONNECT PROGRAMME

Why the programme was designed?

There is global recognition of the value that exercise offers to people living with Parkinson's. Research studies which have captured the views of people with Parkinson's, which suggest that they want to be more active, and value participation in exercise as it provides them with a sense of taking control of their own health needs. Overwhelmingly, there is a sense that the Parkinson's community wants to be more active, so that they can continue to lead full lives. However, what is lacking is access to specialist professionals who understand the complexity of the condition, provide advice on getting started, who can tailor exercise to meet their needs, and provide long-term support to progress exercise, and adoption of a more active lifestyle. Consequently, many people with Parkinson's do not feel able to exercise, therefore, either do not exercise or do exercises, which do not target their specific needs.

From listening to the Parkinson's community, and from reviewing the literature, a number of needs were identified to overcome limited engagement in exercise:

- Specialist Parkinson's Physiotherapists who can tailor treatment to meet needs.
- Appreciation of the diverse needs of people with Parkinson's
- Long term access to physiotherapy available on the NHS
- Accessibility to community-based exercise opportunities
- Support to get started with exercise, and knowledge of what exercise is best.
- Support to maintain good exercise habits, to support long term exercise engagement.
- Focus on actively involving people with Parkinson's in their own management, and promotion of self-management.

2.0 PDCONNECT PROGRAMME

Addressing the needs identified above, the PDConnect the key themes of this programme are as follows:

- Programme delivered by specially trained professionals
- Delivery of exercise which is tailored to the individual needs of participants
- Education in relation to exercise enegagement, and propssed benefits of exercise delivered alongside exercise prescription
- Practical strategies to support becoming more physically active
- Support in the development of self management strategies

PDConnect

2.0 PDCONNECT PROGRAMME

Ethos and Values of PDConnect

This programme is about more than just simply prescribing exercise. This programme aims to give participants a sense of control of their condition, which is frequently lacking in current service provision. Parkinson's results in a range of symptoms influencing all aspects of life, and those around them. Consequently, having Parkinson's requires an ability to make informed decisions and choices in relation to the direction of their care, and becoming active partners in their own care. This ethos of active partnership, to empowering informed decision making, is central to the aims of PDConnect.

PDConnect aims to empower participants to make informed decisions about their own healthcare. It focuses upon exercise participation and resuming control of their lives, through practical education and everyday strategies to enable them to live more active, fulfilled, and meaningful lives.

PDConnect

2.0 PDCONNECT PROGRAMME

Key Ingredients of the PDConnect programme

Active partnership between participants and exercise professionals

Targeted education on the benefits and effects of exercise

Individually tailored 1:1 and group based exercise programmes

Delivered by staff with specialist training in Parkinson’s

Provision of functional strategies to enable and promote self-management. Develop a supportive exercise community

To develop self-confidence in engaging in exercising and building this into everyday life.

2.0 PDCONNECT PROGRAMME

Changing established behaviours

All of us are aware that there are things we could do to improve our health and well-being, but moving from this awareness to actually doing something and putting a change in place is challenging. Furthermore, for those who do successfully make a change, such as being more active, maintaining being this active is equally challenging. PDConnect aims to support participants getting started engaging in exercise and sustaining this long term.

Current guidelines, which are supported by Parkinson's UK, advocate that people with Parkinson's should be exercising a minimum of 2.5 hours per week. Indeed, it is now recognised exercise is a key ingredient to your treatment just like taking medication.

Taking part in exercise is as important as taking your medication

PDConnect

2.0 PDCONNECT PROGRAMME

How PDConnect aims to support you to become more active:

When we are thinking about changing a behaviour, we go through a variety of stages, detailed below. PDConnect aims to help you move from contemplating starting exercise to maintaining exercise as part of everyday life.

Contemplation-people are aware of the benefits of and the need to be more active. But often dont know where to start.

Preparation- people realise that change is beneficial and possible to achieve, and start to make concrete plans to change.

Action- where the change actually happens. people start participating in exercise

Maintainence - keeping up exercise programme, and developing strategies to avoid barriers

Relapse -sometimes people revert back to old way of being inactive

PDConnect

2.0 PDCONNECT PROGRAMME

Readiness to exercise questionnaire

Regular physical activity means meeting or exceeding 150 minutes of moderate physical activity per week.

Date Completed:________________________________

		YES	NO
1	I am currently physically active (at least 30 minutes per week).	☐	☐
2	I intend to become more physically active in the next 6 months.	☐	☐
3	I currently engage in regular physical activity.	☐	☐
4	I have been regularly physically active for the past 6 months.	☐	☐
		☐	☐

PDConnect

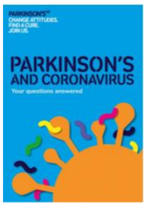
3.0 STAFF CONTACT DETAILS

Julie Jones Principal Investigator, and Physiotherapist j.c.jones@rgu.ac.uk 01224 263282 **Contact Julie if your query involves:**	
Study Physiotherapists Band 6 Physiotherapist Email address Contact number **Contact X if your query involves:**	**TBC**
Study Physiotherapists Band 6 Physiotherapist Email address Contact number **Contact X if your query involves:**	**TBC**
Study Fitness Instructor Email address Contact number **Contact X if your query involves:**	**TBC**
Study Fitness Instructor Email address Contact number	**TBC**

Coronavirus (Covid-19)

The researchers recognise that COVID-19 has had a dramatic impact on everyone's lives. In designing this study, the research team has sought guidance from the NHS, Scottish Government and Parkinson's UK to ensure that they are taking the necessary steps to ensure your safety and that of your family during the course of this study.

With this study being delivered online, this dramatically reduces the risk associated with transmission, as staff delivering the intervention will not see you in person, as it will all be delivered online. Even the measurements will be done online using Microsoft Teams. These measurements will be conducted right at the beginning of the study, and repeated again at week 6, 18 and 30. You will receive support on how to get started using Microsoft Teams so that you are familiar with this prior to starting the study. If you should develop Covid-19 during the time of the study please contact Julie Jones to let her know. It maybe that your symptoms are minimal and it does not influence your ability to participate in exercise or it may mean that you need to take some time off.



PARKINSON'S AND CORONAVIRUS

Parkinson's UK have compiled a document about Parkinson's and Covid. This is available online, or if you would like a paper copy please email Julie and this can be posted to you

Recognising that the Covid-19 situation is ever evolving, and as a result guidance and recommendations also change with time. Please visit the Parkinson's UK webpages for up to date Covid-19 guidance. https://www.parkinsons.org.uk/news/understanding-coronavirus-and-parkinsons

PDConnect

Coronavirus (Covid-19)

What happens if you get Covid-19 during the study?

Covid-19 effects different people in different ways. In the event that you were to contract Covid-19 it is very difficult to predict the impact it will have on you and your ability to participant in everyday tasks as well as exercise.

The key symptoms that people report when they develop Covid-19 include:

- High temperature
- A new and continuous cough,
- Shortness of breath,
- Fatigue,
- Loss of appetite,
- Loss of smell
- Loss of taste

If you develop any of these symptoms you are required to self-isolate for up to 10 days, and it is recommended that you get tested. You may also be required to self-isolate if the person you live with, or those in your "bubble" have symptoms or have tested positive.

To book a test follow this link for further information:
https://www.nhs.uk/conditions/coronavirus-covid-19/testing-and-tracing/get-a-test-to-check-if-you-have-coronavirus/
If you have variable internet access call 119

PDConnect

Coronavirus (Covid-19)

Up-to-date guidance on Covid-19 can be found on the NHS webpages: https://www.nhs.uk/conditions/coronavirus-covid-19/

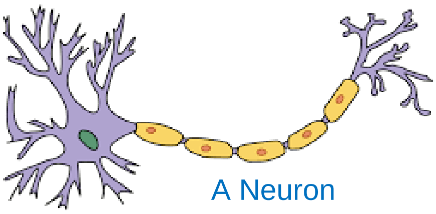
If you develop Covid-19 symptoms or become unwell as a result of any other conditions during the course of the study, please inform Julie Jones

☎ 01224 263282 ✉ j.c.jones@rgu.ac.uk

5.0 UNDERSTANDING PARKINSON'S

What is Parkinson's, and why do the symptoms occur?

Parkinson's is a complex condition, with over forty different recognised symptoms, which means that no two people with Parkinson's are affected in the same way. As you may know, the symptoms of Parkinson's are a result of a loss of dopamine in the brain. The exact reason why dopamine levels decline in Parkinson's is not yet known although, a number of mechanisms are thought to contribute to this loss. Dopamine is a neurotransmitter, which is a chemical messenger, which allows the transmission of signals to travel from cell to cell within the brain. It is this communication network that allows us to function, controlling voluntary and non-voluntary movements. Due to the loss of dopamine, the symptoms of Parkinson's such as slowness of movement rigidity, tremor and postural changes occur. Parkinson's symptoms arise when 70 per cent of the dopamine producing cells located in the substantia nigra become damaged and die.



A Neuron

A Mitochondrion

Parkinson's is thought to affect the mitochondria within neurones. Mitochondria are the power supply of the cells, and if these become damaged the cell dies. Healthy mitochondria produce power to drive biological processes and

play a role in the maintenance of cellular health and regulation of cell's function. In Parkinson's, mitochondria appear less efficient, but there is also problems associated with how the body recycles and replaces these cells. Like batteries, mitochondria run out, and need replacing; in Parkinson's this replacement system is slowed, resulting in old mitochondria existing in cells for longer than they should. These old cells are inefficient, and produce toxins called free radicals and start-off a process called oxidative stress, which leads to the destruction of cells, and ultimately cell death.

So why do problems occur in the mitochondria?

A-synuclein is a protein, which is produced in variety of places including the brain. For reason’s yet to be determined fully by scientists these proteins become misfolded and clump together to form Lewy Bodies. Lewy bodies can occur anywhere in the brain, but in Parkinson’s they form within the Basal Ganglia, in particular the Substantia Nigra. It is thought that these sticky clumps of a-synuclein effect the integrity of the inside of the cell, disrupting the normal recycling of proteins, effecting mitochondrial health, and activity, and the release of the neurotransmitter dopamine. Evidence would also suggest that Lewy bodies effecting one cell, can spread into neighbouring cells causing widespread disruption, which starts of a chain of reactions within the new cells causing damage and ultimately cell death. This ability of Lewy bodies to migrate to other cells is believed to be responsible for the progression of symptoms seen in Parkinson’s.

Read and find out more

- https://www.parkinsons.org.uk/information-and-support/what-causes-parkinsons
- https://www.michaeljfox.org/parkinsons-101

Listen and learn

- https://www.youtube.com/watch?v=PJBKFlOtgq8
- https://parkinsonsnewstoday.com/2017/01/09/dopamine-affect-parkinsons-disease/
- https://www.michaeljfox.org/podcast/podcast-what-protein-anyway

PDConnect

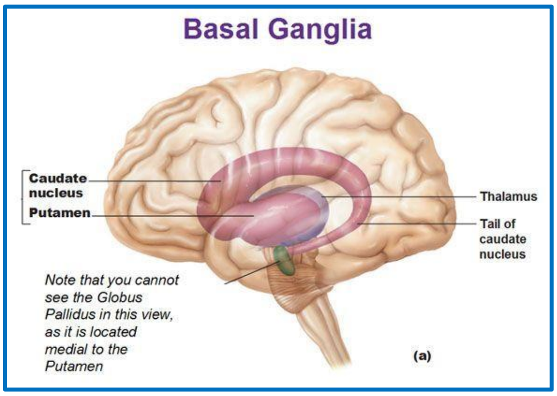
5.0 UNDERSTANDING PARKINSON'S

So why is this all important?

The Basal Ganglia is the part of the brain where the blueprints or motor programmes are stored. As an infant, you learnt to walk; by the time, you were a small child it was something you did not need to concentrate it is something you do without even thinking about it. That is because the movement programme to walk was stored in the Basal Ganglia. So, when you wish to walk, messages are sent from the Basal Ganglia to other parts of your brain, which then send messages activating the correct muscles in the correct sequence enabling you to walk. However, this is all dependent on communication getting from the brain to other parts of the brain, and then to the muscles. For messages to be transmitted they need dopamine. So in Parkinson's where dopamine levels are lower this interrupts the speed, which messages, are sent, resulting in alteration in control of movement.

Position of the Basal Ganglia in the brain

Cross section of the basal ganglia and its component parts



5.0 UNDERSTANDING PARKINSON'S

Key motor symptoms of Parkinson's:

- Slowness of movement – Bradykinesia
- Rigidity – meaning stiff or inflexible muscles
- Tremor –this is an involuntary quivering movement or shake. Characteristically occurring at rest, in a classic slow, rhythmic manner
- Postural instability - tendency to be unstable when standing

Key non-motor symptoms of Parkinson's

- Depression
- Anxiety
- Apathy
- Loss of smell

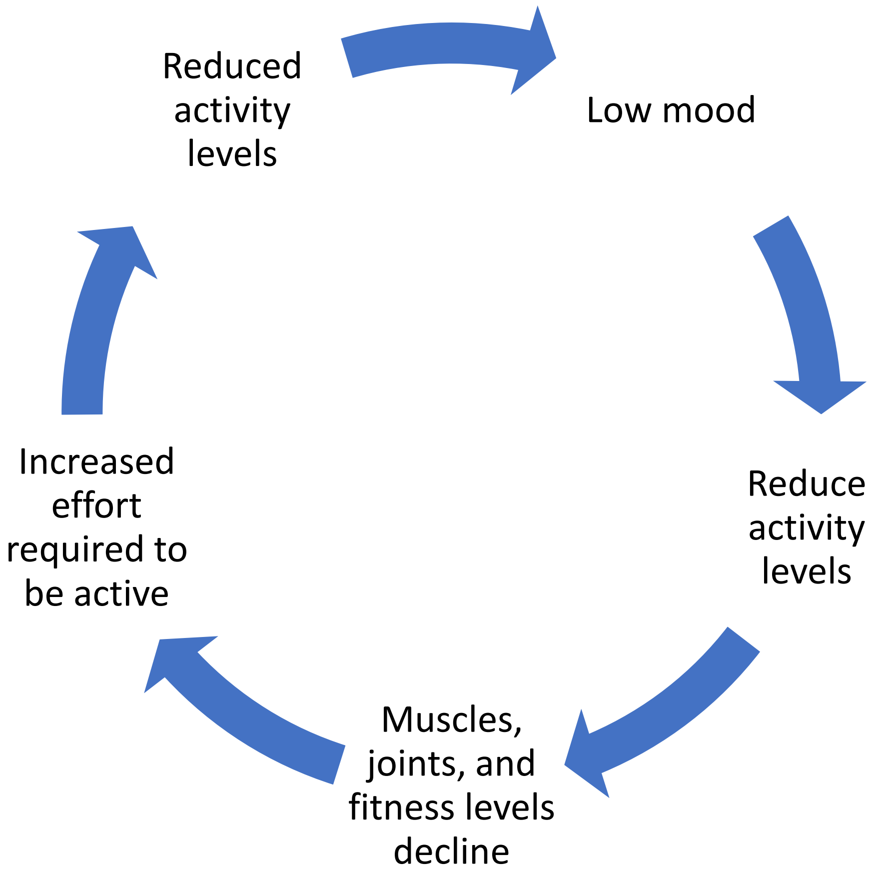
- Constipation
- Sleep disorders
- Restless legs
- Hallucinations and delusions
- Mild memory and thinking problems

- Speech problems
- Fatigue

Impact of inactivity.

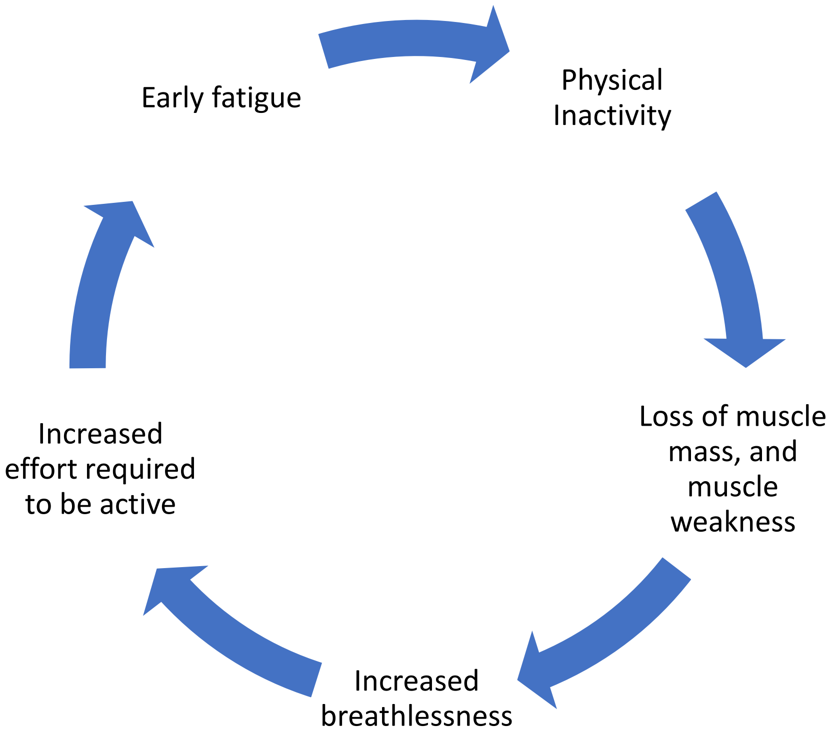
Being active is very important for your Parkinson's and here is why:

1. Due to the low mood and fatigue that can be associated with Parkinson's, people often do not feel motivated to be physically activity. The problem for anyone who becomes physically inactive is that your muscles start to become weaker as you are not using them, your joints begin to get stiff as you are not moving them, and it takes more effort to move as your body becomes deconditioned to higher levels of activity. As a result, a vicious cycle starts whereby the effort to be more active becomes more and you do less.



Impact of inactivity.

At the same time as the cycle described above is happening due to the Parkinson’s symptoms, we are also getting older. Research has shown that people with Parkinson’s are 70 per cent less active than those of a similar age without Parkinson’s. The consequences of this inactivity initiate a vicious cycle of events. Due to the effects of Parkinson’s, people tend to be less motivated to exercise and be active owing to apathy and depression, which are common non-motor symptoms. In addition, the combined effect of the motor symptoms, in particular bradykinesia and rigidity mean people are less likely to move their limbs through full range. Therefore, they experience muscle stiffness and weakness, making it harder to move. In addition the postural instability can affect balance, reducing confidence when walking, all of which compound to reduce motivation to be active. Thus having Parkinson’s predisposes people to loos muscle strength, which is worsened by inactivity.



PDConnect

5.0 UNDERSTANDING PARKINSON’S

Please write below any questions you may have that you wish to address with staff at your next appointment.

6.0 BENEFITS OF EXERCISE

Differences between Physical Activity and Exercise

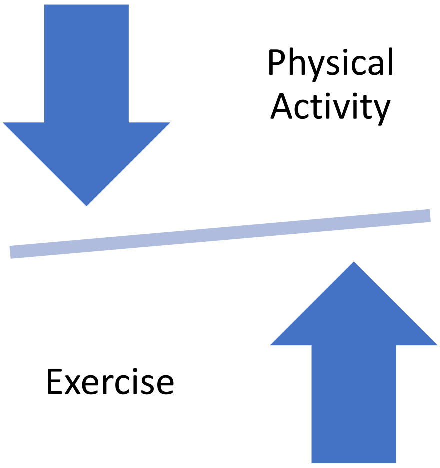
We all know that we could do with being a bit more active, with the terms physical activity, fitness, and exercise all used interchangeably to mean the same thing. However, there is a distinct difference between being physically active and engaging in exercise. The definitions of Physical Activity and Exercise as defined by the American College of Sports Medicine are detailed below.

Physical Activity:

Is defined as any bodily movement produced by skeletal muscles that requires energy expenditure.

Exercise:

Is planned, structured, and repetitive bodily movement done to improve and/or maintain one or more components of physical fitness



Physical Activity


Dog walking


Gardening


Housework

Targeted exercise


Group exercise


Strength Training


Swimming

6.0 BENEFITS OF EXERCISE

Differences between Physical Activity and Exercise

Physical activity is associated with adopting an active lifestyle, and incorporates activities such as housework, dog walking, and gardening. Being physically active results in burning off energy and is about general levels of activity. Therefore, being physically activity is good for general health and well-being, but it will not address the specific issues, which people with Parkinson's have. **All types of exercise and activity are beneficial, but only specific physically targeted exercise will help you control the symptoms of Parkinson's, for example targeting strength or fitness levels and therefore the goals is more than just burning off energy.**

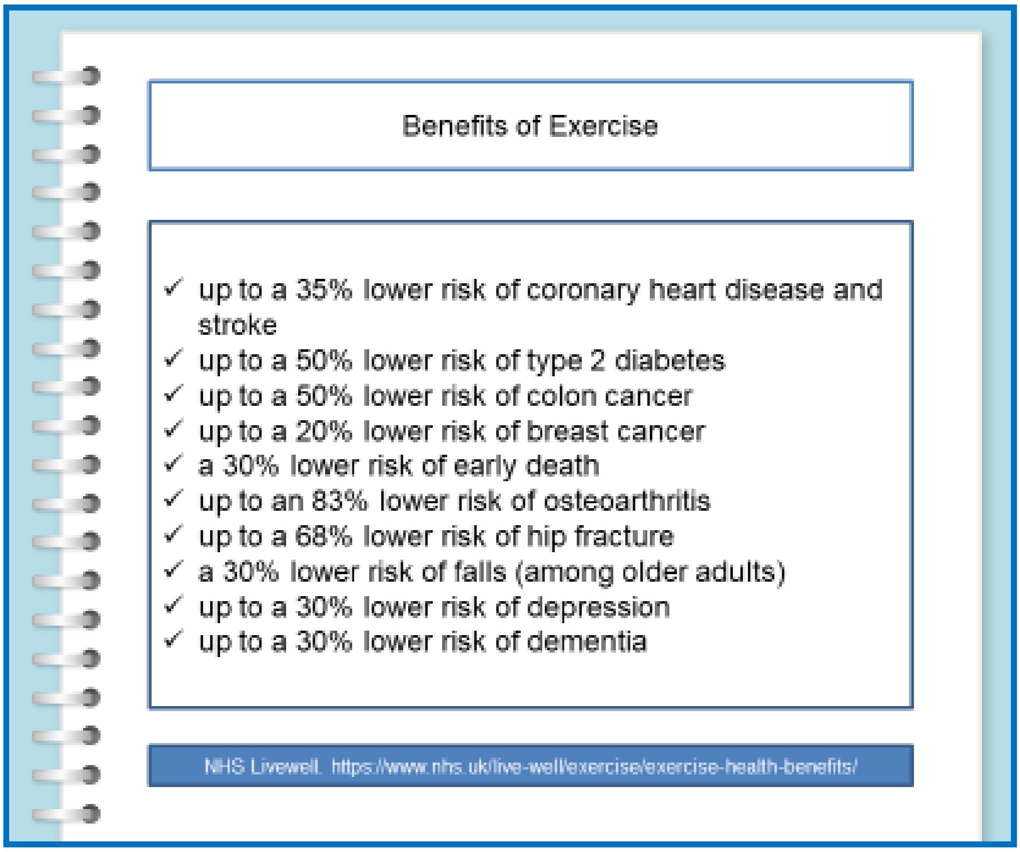
Being just physically active is not enough. In order to be effective at controlling the symptoms of Parkinson's and ultimately slowing down the progression of the disease, you need to be doing the right type of exercise and there are certain elements that the exercise must contain which we will explore in the next section. PDConnect is an exercise programme specifically designed to target the needs of people with Parkinson's.

Engaging in exercise is as important as taking your medication

6.0 BENEFITS OF EXERCISE

General benefits of engaging in exercise

The NHS advocates the involvement in more physical activity and exercise for all adult age groups: They highlight the following as the key benefits:



Benefits of Exercise

- ✓ up to a 35% lower risk of coronary heart disease and stroke
- ✓ up to a 50% lower risk of type 2 diabetes
- ✓ up to a 50% lower risk of colon cancer
- ✓ up to a 20% lower risk of breast cancer
- ✓ a 30% lower risk of early death
- ✓ up to an 83% lower risk of osteoarthritis
- ✓ up to a 68% lower risk of hip fracture
- ✓ a 30% lower risk of falls (among older adults)
- ✓ up to a 30% lower risk of depression
- ✓ up to a 30% lower risk of dementia

NHS Livewell. https://www.nhs.uk/live-well/exercise/exercise-health-benefits/

Benefits of exercise for Parkinson's

The benefits of exercise for people with Parkinson's can be classified into four categories:

- General health and well-being benefits noted above
- Impact on Parkinson's motor
- Impact Parkinson's non-motor symptoms
- Impact at a neurophysiological level i.e. within the Brain.

Benefits of exercise – getting started,
https://www.youtube.com/watch?v=mRHmGJpGIRY

PDConnect

6.0 BENEFITS OF EXERCISE

The impact of exercise on motor symptoms:

Improved Balance

Increased Strength

Improved mobility, including walking

Improved Endurance

Improved speed

Improved performance

I can do more for myself now that I have been exercising, it is the simple things like having the confidence

I have started doing things that I have been avoiding

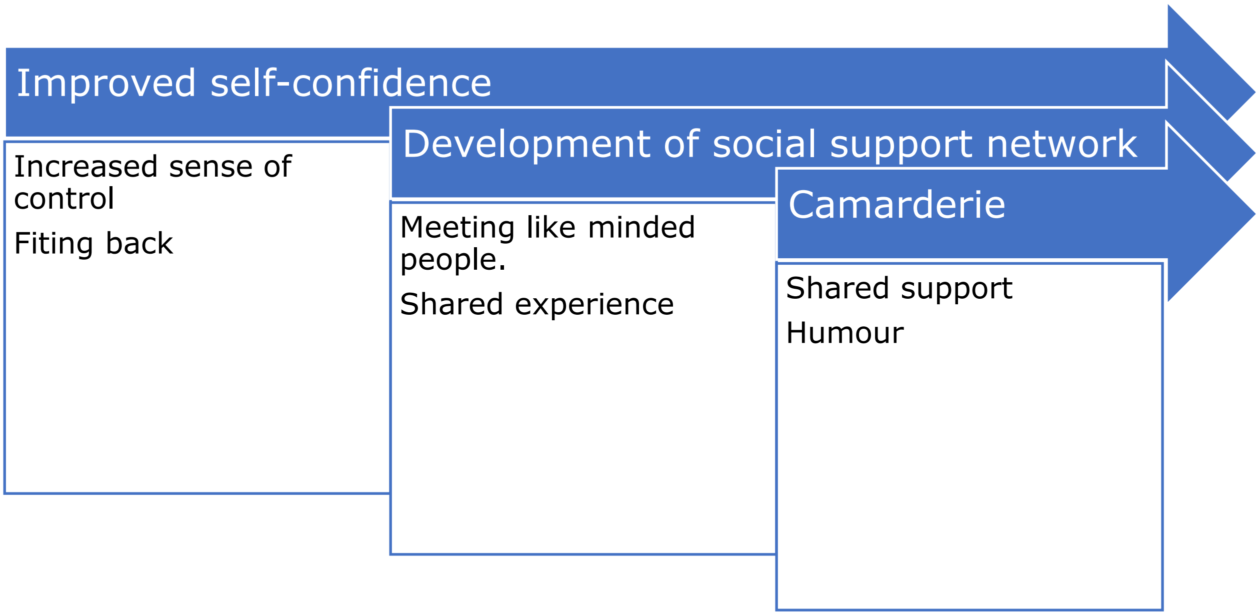
6.0 BENEFITS OF EXERCISE

The impact of exercise on non-motor symptoms:

Research studies have shown that participation in regular exercise can have a positive effect also on the non-motor Parkinson’s symptoms. In particular:

- Cognition or thinking and thought processing
- Mood, in particular improvements in depression
- Improve quality of sleep
- Reduce levels of fatigue
- Relieve constipation

In addition, people with Parkinson’s have reported that participation in exercise increase their sense of control over their condition. The feel that they are doing something to help themselves.



6.0 BENEFITS OF EXERCISE

The impact of exercise at a neurophysiological level.

Evidence is emerging from scientists that participation in regular exercise particularly high intensity exercise, can result in changes within the brain. This is potentially an exciting development for people with Parkinson's, as high intensity exercise has been associated with improvements in substances called BDNF and GDNF. You may have heard of **GDNF** (Glial Derived Neurotrophic Factor). The role of this substance in the brain is to promote the survival of neurones within the brain. In Parkinson's, we know that neurones die, so promotion of a substance which may slow down the rate of decline of neurones and therefore the number which die is a positive finding. This has led to scientists proposing that exercise may have a **neuroprotective** effect, as it could potentially slow the rate of death of neurones within the brain.

Read and find out more about GDNF

- ❖ https://medium.com/parkinsons-uk/could-growth-factors-be-the-key-to-new-treatments-for-parkinsons-68f5cc96e71e

Emerging research is also suggesting that exercise could cause a **neuro-restorative** effect, prompting repair of the damaged neurones and returning function to the existing pathways. In animal studies, exercise has been linked with neurogenesis (growth of new neurones). As Parkinson's is caused by a loss of neurones, in particular dopaminergic neurones, this is why exercise is seen as such as valued treatment approach for people with Parkinson's. Participation in exercise improves the efficiency of blood supply to the brain. Improved blood supply brings with it all the essential nutrients and oxygen, which cells need in order to prosper.

6.0 BENEFITS OF EXERCISE

The impact of exercise at a neurophysiological level.

Regular high intensity exercise

=

Improved brain health

Key messages:

Exercise has the potential to improve the health of neurones within the brain as well as increase the number produced. Research is emerging which would suggest that people who regularly participate in exercise experience a **slower rate of decline of their Parkinson's.**

Hear from people with Parkinson's on their experiences with exercise

- https://www.parkinsons.org.uk/information-and-support/exercise
- https://www.parkinsons.org.uk/information-and-support/exercise-progressing-symptoms
- https://www.youtube.com/watch?v=vbilR8S3ZhQ&feature=emb_rel_pause
- https://www.youtube.com/watch?v=gafYP1eKIdw

6.0 BENEFITS OF EXERCISE

Advocates of Exercise

Engagement in regular exercise for people with Parkinson is supported by many associations.

PARKINSON'S UK
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.

The Cure Parkinson's Trust

European Physiotherapy Guideline for Parkinson's Disease
Developed with nineteen European professional associations

NHS

THE MICHAEL J. FOX FOUNDATION
FOR PARKINSON'S RESEARCH

UK PARKINSON'S
Excellence Network

The Scottish Government
Riaghaltas na h-Alba

PDConnect

6.0 BENEFITS OF EXERCISE

Challenges with exercise engagement:

Now that we have covered the benefits of exercise, we need to tackle why we are not being more active and engaging in exercise. It is easy for us to put up barriers to starting anything new, and exercise is no different. However, it is all too easy just to say I cannot do it, and in order to make a successful change to being more active you need to address these barriers.

Common challenges to exercise

- Do not know where to start?
- Too tired
- Lack of specialist help
- Not enough time
- Don’t like gyms
- Fear
- Lack of confidence

Please write in below what you perceive are your biggest challenges to participating in exercise

6.0 BENEFITS OF EXERCISE

Please write below any questions you may have that you wish to address with staff at your next appointment.

7.0 TYPES OF EXERCISE

There are lots of different types of exercise, what is important is selecting something that your enjoy, that will be fun, and which target your particular symptoms. The PDConnect programme will help guide you with your exercise choices, provide advice and guidance as well as get your started. Below is a list of just some of the exercise types people with Parkinson's across the UK are involved in.

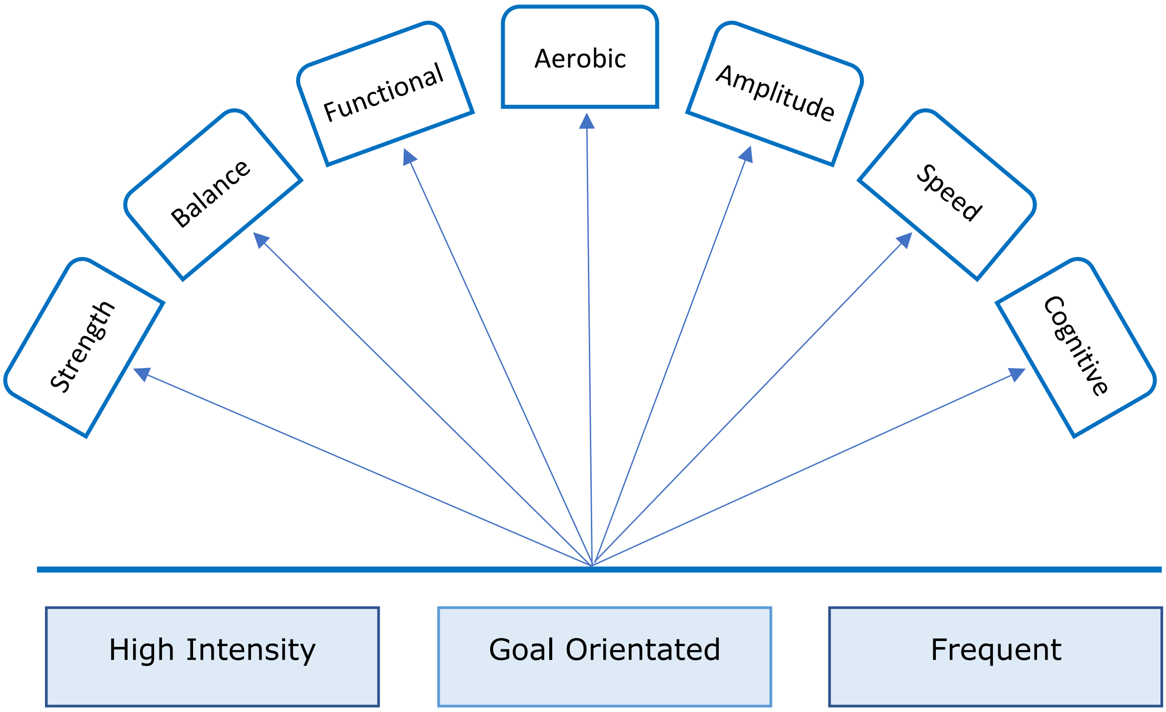
- Dancing
- Aerobic
- Tai Chi
- Pilates
- Yoga
- Strength training
- Cycling
- Nordic walking
- Exerogaming
- Treadmill walking
- Circuit training
- Hydrotherapy
- Box-exercise
- PD Warrior
- Lee Silverman Big Programme
- Gym based programmes
- Swimming
- Walking

7.0 TYPES OF EXERCISE

Types of exercise

People with Parkinson's share similar symptoms they are all different therefore, a one size fits all approach to exercise prescription is not possible. Your exercise needs to be prescribed to meet your needs. While all types of exercise and activity are beneficial, specific physically targeted exercise can help you control the symptoms of Parkinson's.

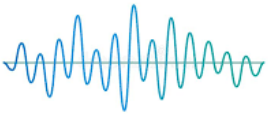
In order to be effective at controlling the symptoms of Parkinson's and ultimately slowing down the progression of the disease, you need to be doing the right type of exercise and there are certain elements that the exercise must contain as shown in the diagram below.



No one type of exercise is enough so a combination of all the boxes above is required, with the aim at progressing to working at high intensity exercise which are focussed on your goals which can become part of your everyday activities. During PDConnect, we will help you develop an exercise programme incorporating all these elements.

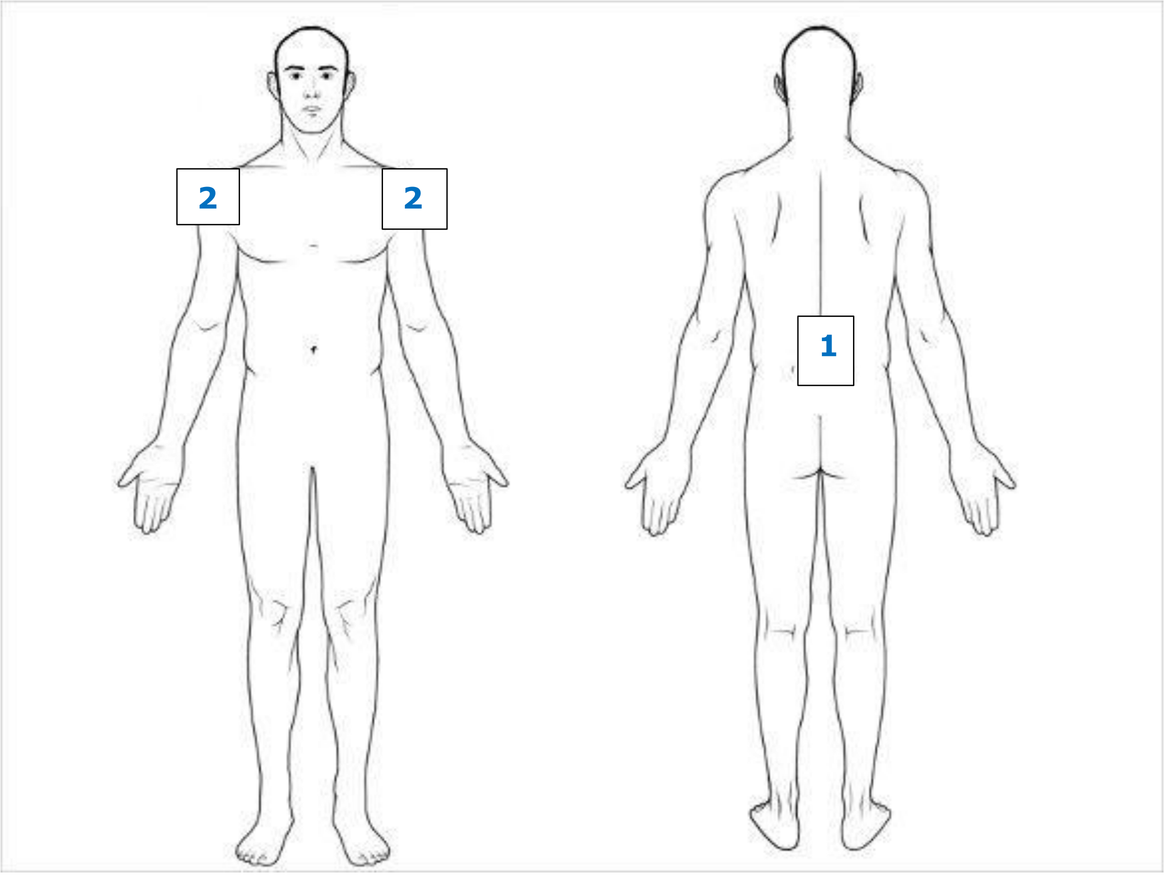
PDConnect

7.0 TYPES OF EXERCISE

Exercise Type		Definition
Strengthening exercise		Targets specific muscle groups and is normally against a form of resistance with weights, resistance bands or our own body weight.
Balance exercise		These exercises challenge your balance reactions by narrowing your base of support, which leads to improvements in balance during functional tasks such as walking
Functional exercise		These exercise focus on exercising during tasks that you would encounter within the home, such as sit to stand.
Aerobic exercise		These exercises increase your heart, and breathing rate, with the aim of improving your fitness levels.
Amplitude exercise		This involves exercising using large often-overstated movements. Where the emphasis is moving your arms of legs through full range of movement.
Speed based exercises		These exercises encourage you and build your confidence in changing the speed. For example sudden changes in direction
Cognitive based exercises		This is where a thinking task is integral part of the exercise, as we are commonly required to do two things at the same time. Therefore, this may involve counting backwards while throwing a ball.

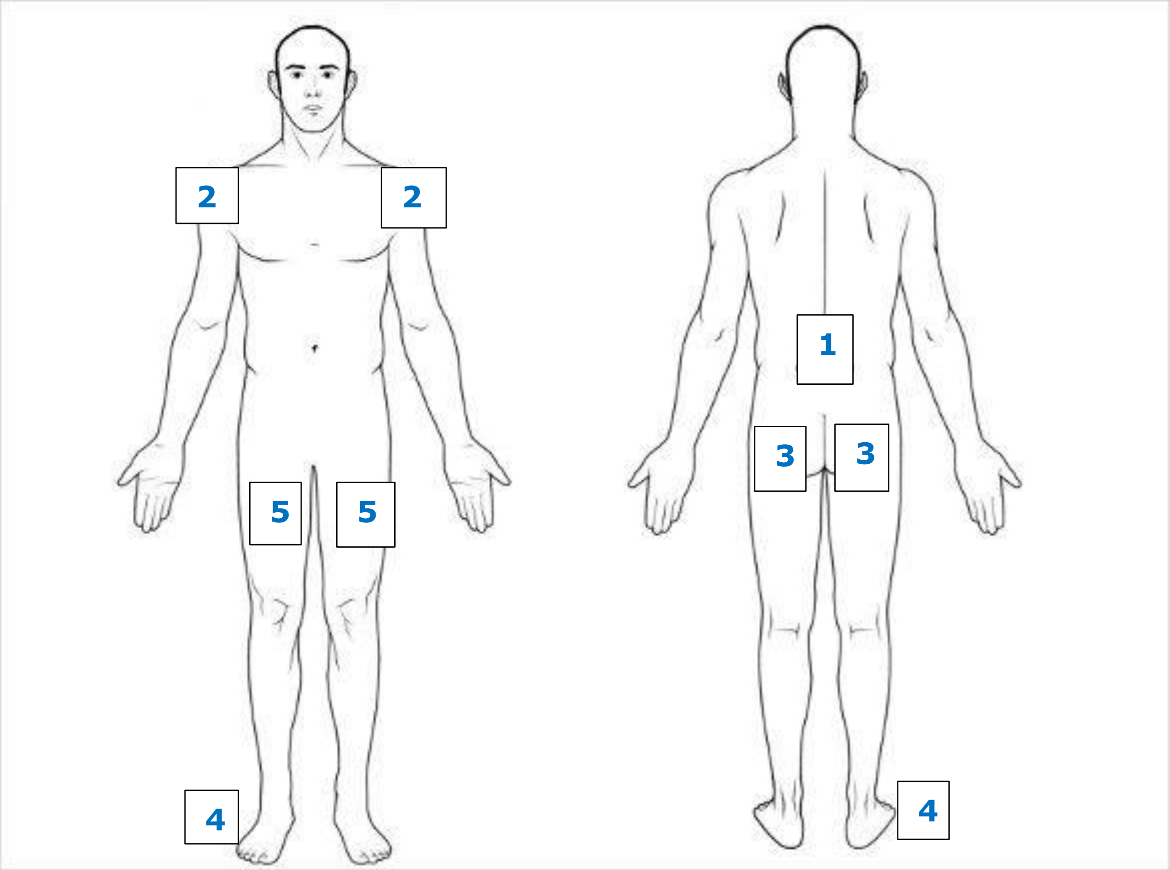
7.0 TYPES OF EXERCISE

Target areas for exercise



1	**Spine.** Many people with Parkinson's experience stiffness in their spine. This impact of a loss of movement here is that people find it difficult to roll over in bed, reach for objects, but it also effects their balance and walking. Further, with progression of Parkinson's, people often become stooped. So exercises need to focus on maintain flexibility in the spine, and strengthening of muscles to help maintain an upright posture.
2	**Shoulders:** Many people experience stiffness in their shoulders, and a loss of arm swing early in Parkinson's. This causes functional problems with washing and dressing but more importantly, effects stability when walking, as arm swing is important for momentum, and stability of walking.

Target areas for exercise



3	**Bottom or Gluteal muscles:** These muscles provide stability around this hips and pelvis. These muscles are essential for tasks such as getting out of a chair, walking, and balance.
4	**Ankle joints and muscles:** flexibility in the ankle joint is essential to ensure foot clearance when walking, with strong muscles in the calf to provide propulsion when walking. Having a strong ankle joint is also importance for the maintenance of balance.
5	**Thighs:** The muscles on the front of you thighs are needed for functional tasks such as sit to stand, stair climbing and walking. Strong muscles are required to provide stability around the knee, which offers stability when upright.

7.0 TYPES OF EXERCISE

Key features of exercise

A key feature of PDConnect will be getting you going with an exercise programme which meets not only your Parkinson's needs but will also accommodate any other conditions you may have alongside your Parkinson's exercise. We will discuss with you what your goals and aspirations are, and from that together we will design an bespoke exercise programme for you, do doing during your time within the PDConnect staff as well as independently at home. You will receive information on your exercise programme through an online app called REHABGuru, which we will talk about in section X of this manual, so you will not be expected to remember all your exercises.

Key to the success of your exercise will be:

Power:

Maximal Effort and Energy to Produce Purposeful Movement

Amplitude

Maximal Range of Purposeful Movement

Accuracy

Correct and Precise Purposeful Movement

PDConnect

7.0 TYPES OF EXERCISE

Frequency, intensity and duration of exercise:

So how much exercise should you be doing? Current evidence suggests that you should be doing 2.5 hours of exercise per week as this is thought to keep you fit and healthy but can potentially slow the progression of Parkinson's symptoms.

Your aim should to undertake:

- Moderate or Vigorous Exercise - 30mins, 5 times/week
- Progressive Resistance Exercise – Twice Weekly
- Parkinson’s specific exercise - Twice Weekly

This may seem like a challenge is you are new to exercise, but we are here to help, and support you to reach this target. Intensity of your exercise is important, and you need to be aiming at moderate to high intensity. When exercising it is difficult to gauge your intensity, but at this intensity you should be able to talk but perhaps not in full sentences. As a guide, you can also use the rate of perceived exertion scale or RPE for short (copy on the following page). This scale allows you to estimate how hard you are working. Perceived exertion is how hard you think your body is exercising. Using this scale is also a good way to see how you are progressing with your exercise, as it is a measure the amount of effort it takes to do an activity. Over time, the amount of effort it takes should decrease. Once you have reached this point, you can gradually move on to more challenging activities.

Moderate intensity on the RPE scale would be 13.

Rating of Perceived Exertion (RPE)

Number Rating	Verbal Rating	Example
6		No effort at all. Sitting and doing nothing
7	Very, very light	Your effort is just noticeable.
8		
9	Very light	Walking slowly at your own pace.
10		Light effort.
11	Fairly light	Still feels like you have enough energy to continue exercising.
12		
13	Somewhat hard	
14		Strong effort needed
15	Hard	
16		Very strong effort needed.
17	Very Hard	You can still go on but you really have to push yourself. It feels very heavy and you are very tired.
18		
19	Very, very hard	For most people, this is the most strenuous exercise they have ever done. Almost maximal effort.
20		Absolute maximal effort (highest possible). Exhaustion.

7.0 TYPES OF EXERCISE

Making time to exercise

Making time for exercise is a challenge for everyone, especially if exercise has never really featured in your life before now. However, think of exercise as part of your medication. You wouldn't miss a dose of your medication, so why miss a dose of your exercise? There are 24 hours in a day and all we ask of you is to dedicate a minimum of 30 minutes of that day, 5 times a week to treating your Parkinson's.

We also know that the 'right time' for one person is completely different to the next. That 'right time' for any individual may change from day to day and week to week. Parkinson's is a complex disorder with multiple motor and non-motor symptoms that can fluctuate. For you to get the best out of your exercise, you need to be at your best. That means it has to be at a time of day when your medication is at its most effective, when you are at your most focused and when you have your best energy levels. Also, remember some days you may have an off day and this is ok.

Take control of your own exercise schedule. You can choose to do your daily dose at a different time every day, if that suits you best. Whatever works best for you? To help you with this we have designed an activity diary so you can record your activity and monitor your own progress. There is also a weekly activity planner so you can plan ahead and schedule in your exercise to fit round your other commitments.

7.0 TYPES OF EXERCISE

Walking:

Waking is a form of exercise which everyone can do. Walking briskly can help you build stamina, and it can be done indoors or outdoors. There are many reasons why walking is such a good form of exercise.

- It is free, except for the need for a good pair of supportive shoes
- You can do it anytime, anywhere so it is flexible
- You can go on your own, or walk with friends
- It is a low impact form of exercise, so it is something that most people can do
- Walking outside has been shown to for our mental health too.
- By increasing the speed and duration of walking we can increase our endurance and overall fitness

As part of PDConnect you will be participating in supervised exercise, and will have a home exercise plan, but we would also like to add walking to your daily dose of activity. We will support you to build up so that you are confident walking up to five times a week.

REMEMBER:

Just like your daily Parkinson’s medications. **You need to have a daily dose of exercise**

7.0 TYPES OF EXERCISE

Many different types of walking exist:

Nordic Walking: This type of walking involves walking with tall poles. The use of the poles encourages people with rotate their spine when walking, as well as maintain an upright posture.

Brisk walking: Walking at a good pace (so you can still speak but maybe would not manage long sentences). To benefit you need to build up how long you can maintain this brisk pace for. You can start by walking at a brisk pace for one lamp post and then return to normal pace. Then progress to keep up the brisk pace between 2 lamp posts and so on. A nice introductory way to develop your stamina and confidence walking faster outdoors.

Hill walking, or trail walking: This walking involved walking on uneven ground and of different levels of inclines and declines which is good for developing stamina as well as balance and spatial awareness. Requires a good level of fitness initially.

Recreational walking: Walking for example with your dog allows you to walk at you own pace, and on a surface that you feel comfortable and confident on. To be of benefit you need to think or walking for a minimum of 15 minutes at any one time, or you could consider altering your pace.

Treadmill walking: Research has looked at the benefits of treadmill walking for people with Parkinson's. Treadmill walking has the advantage that you walk in a straight on an even surface. Your walking speed and level of incline can be controlled. Treadmill walking is good for developing rhythm, confidence and stamina, but perhaps does not prepare you for walking in the real world, like negotiating kerbs, and sudden changes of direction.

7.0 TYPES OF EXERCISE

So far, we have covered the positive aspects of exercise. So far, we have covered the positive aspects of exercise. However, for some people especially if they are new to exercise can often feel a bit of muscle soreness after exercise. Some people report feeling a stiffness or cramp like feeling in their muscles 24-72 hours after exercising, this is commonly referred to as delayed onset of muscle soreness or DOMs for short. Typically, this soreness is only felt when the muscles are moving not at rest, and results in muscle stiffness plus tenderness. Passive stretching will increase your symptoms, which is one of the reasons why you feel stiff. DOMs normally occurs when people exercise who are unaccustomed to it. IT should pass within 72 hours, if it does not, please contact your physiotherapist.

Things to limit muscle soreness, and injury while exercising:

- Warm up before exercise
- Gradually build up your exercise programme
- Ensure your do a cool down following exercising.

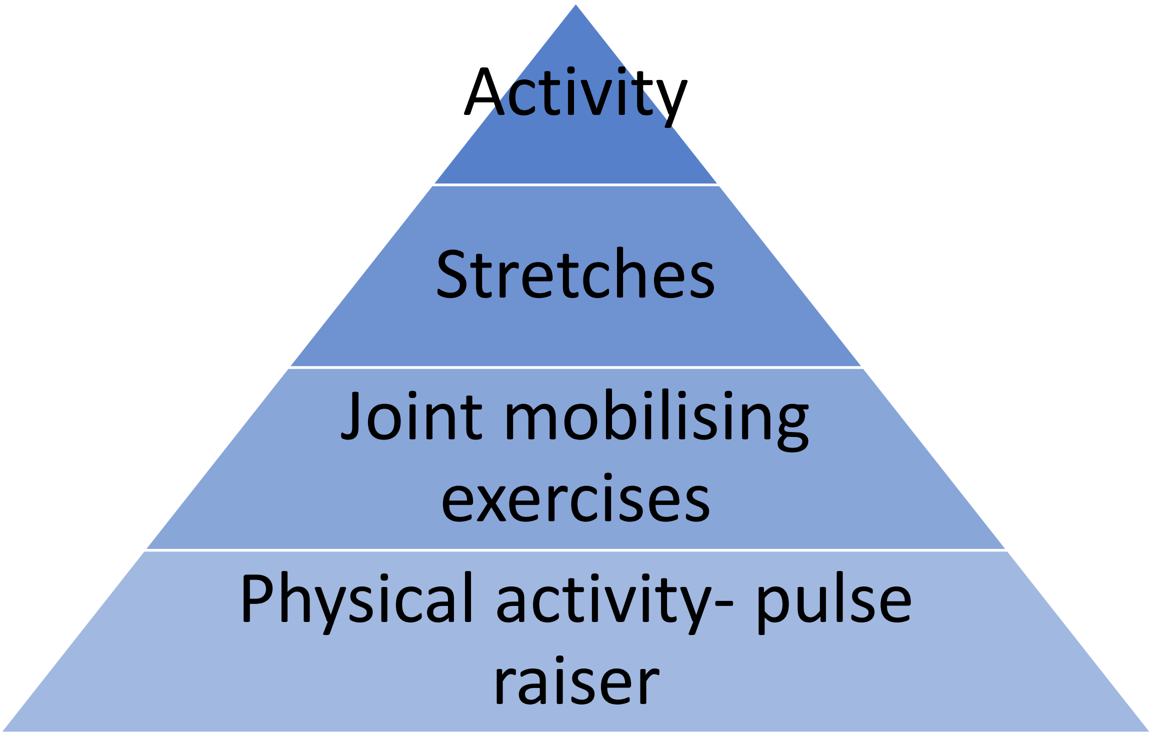
Warming up:

You should always warm up before exercise, even before you undertake excise at home. The purpose of the warm is to prepare your body for exercise, and it has the added advantage of reducing the likelihood of injury. Why warm up?

- Improve flexibility of your muscle so you can move more effectively when you are exercising
- Increase blood flow and oxygen – this is required for your muscle to work effectively
- Improved performance during eh exercise programme
- Less muscle pain and tension

7.0 TYPES OF EXERCISE

What should your warmup consist off?



Pulse raiser:

The intensity should be gradually increases. Consider marching on the spot, or if you are less confident, march on the spot when sitting. Aim for doing at least 3 minutes. To increase the intensity, punch your hand s up into the air above your head while marching

Joint Mobilising exercises:

This should involve moving all your limbs and body through their available range of motion. Make sure you do this on both your left and right side. See the photos for guidance.

Stretches:

You should run through some stretches of the main muscle groups in particular the arms, legs, ankles, and back. Stretches should be nice, smooth, and controlled movements, not fast and jerky as this can cause injury.

7.0 TYPES OF EXERCISE

Warm up exercise examples

- ❖ Ensure that the chair you use is sturdy and stable.
- ❖ Wear comfortable clothes and supportive footwear.
- ❖ Ensure that you have enough space
- ❖ Have some water to hand for during and after exercising
- ❖ While exercising, if you experience chest pain, dizziness or severe shortness of breath, **stop immediately** and contact your GP (or call an ambulance if you feel very unwell and your symptoms do not go away when you stop exercising).
- ❖ If you experience pain in your joints or muscles, stop, **check your position** and try again. If the pain persists, seek advice from your physiotherapists or fitness instructor.

The following are some simple warm up exercises to do prior to doing your home exercise programme. **Please complete them all.** If you have any questions about these please ask your physiotherapist or fitness instructor

7.0 TYPES OF EXERCISE

Warm up exercise examples

Marching

This can be done in **sitting** or in **standing**. Aim to march on the spot for **1 minute.**

Sitting: Ensure that your back is up nice and straight, and not resting on the back of the chair. Looking straight ahead, lift your knees up towards your chest, marching on the spot. If possible, swing your arms while you march as this will increase the intensity of the exercise

Standing: Hold onto the chair, if required. Alternatively, if you feel confident, let go of the chair but keep it close to hand should you need it to steady yourself. Focus on keeping your back up straight, looking straight ahead (not at your feet), and march on the spot. If you can swing your arms as you march on the spot

Neck Movements

These exercises can be done in sitting or standing.

If standing have the chair in front for support as required. Looking straight in front, turn your head to the left slowly and hold for a count of **5**, then turn your head back to the front, and turn to the right, hold for a count of **5** and turn back to the middle. **Repeat this 5 times to each side.**

Back Rotations

This exercise aims to loosen off your back before exercising. This is a slow and controlled exercise.

Sitting up straight, arms raised to shoulder height. Slowly turn your body to the **left** and hold for a count of **5.** Turn back to the middle and rotate to the **right** and hold for a count of **5**. Repeat **five times** to each side.

Back Extensions

This exercise aims to loosen off your back before exercising. This is a slow and controlled exercise.

This can be done in sitting or standing. In either start position, raise your arms to shoulder height and lift them as high as you can above your head, and hold for a count of **5** and slowly lower. **Repeat 10 times.**

Leg Stretches

These are slow and controlled movements, designed to stretch your thigh muscles

Keeping your back as straigh as possible, point your toes up to the celing and raise your lower leg so that your knee is stright. Hold for a count of **5** and slowly lower. Repeat **5** times on each leg.

Ankle Mobility.

These exercise are designed to loosen the ankle joint

Sitting tall, with your back straight, point your toes up towards the ceiling and then point your toes to the floor. Move your ankle up and down **5** times on the **left** ankle then repeat on the right.

Ankle Circles

These exercise are designed to loosen the ankle joint

Sitting up tall, point your toes up to the ceiling and circle your ankles in a clockwise direction, 5 times. Then repeat on the other ankle.

Side Stepping

This is preferably done in standing but could be done in sitting

Standing up tall, looking straight ahead. Hold onto the chair for support as required. Step out to the left and back in. Step in and out to the **left** for **1-2 minutes** before swapping to do the same on the **right side.**

If you feel steady, as you step out you could raise your arm also out to the side, to shoulder height and back down.

Small Knee Bends

Standing holding onto the back of a chair as required. Keeping your back straight, bend your knees until your knees are just over your toes, and push back up through your legs. This should be a slow controlled movement. Repeat **5** times

If you are able when you bend your knees down, try to raise your arms to shoulder height.

Toe Raises

Holding onto the back of the chair as required. Raise your heels of the floor and slowly lower. Repeat **10** times.

Toe Raises

Holding onto the back of the chair as required. Raise your toes of the floor and slowly lower. Repeat **10** times.

Step Standing



In standing, holding on as required. Take your left leg forwards heel leading then swing behind you point your toes. Keep your back nice and straight, so that it is only your leg that is moving. Repeat for 1 minute on left leg, before doing the same on the right.

Repeat Marching

This can be done in **sitting** or in **standing**. Aim to march on the spot for **1 minute.**



PDConnect

7.0 TYPES OF EXERCISE

Summary

To key learning points from this section:

- Physical activity is associated with an active lifestyle
- Exercise is a targeted approach to activity, focussing on specific areas of the body
- Research suggests that exercise benefits motor and non motor symptoms of Parkinson’s
- Exercise need to be tailored to individual needs
- Engaging in one type of exercise only will not be sufficient
- Parkinson’s has many different symptoms therefore a range of different exercise
- The key areas that need to be worked on are: amplitude of movement, the spine, hips, thighs, and ankles
- Exercise programmes should incorporate the following elements:
    - Strengthening exercises
    - Balance exercises
    - Functional based exercises
    - Aerobic exercise
    - Cognitive/thinking aspect
- Exercise needs to be done for a minimum of 30 minutes five times a week
- The intensity of training is important, aiming for exercising at RPE level 13, or a little out of breath.
- **Effective exercise is enjoyable**

7.0 TYPES OF EXERCISE

Please write below any questions you may have that you wish to address with staff at your next appointment.

8.0 EXERCISE FRAMEWORKS AND GUIDANCE

Parkinson’s UK Exercise framework

In 2018, Parkinson’s UK published an exercise framework, which was created by a group of specialist exercise professionals. This framework was designed to provide guidance and recommendations about exercise participation at each stage of Parkinson’s. The ethos of the Exercise Framework is about the importance of investing in exercise from diagnosis and embedding exercise as part of your everyday life. The ethos was to promote an exercise-based lifestyle.

European Physiotherapy Guideline for Parkinson’s

European Physiotherapy Guideline for Parkinson’s Disease

Developed with nineteen European professional associations

Key points from these guidelines include:

- ❖ Exercise prescription should be based upon people with Parkinson’s treatment goals, abilities, motivation and preferences, as well as external factors such as the availability of exercise group
- ❖ Minimum of 45 minutes three times a week
- ❖ Varied approach to exercise prescription
- ❖ Delivery by specialist therapists
- ❖ Exercise can be delivered individually or as a group.

8.0 EXERCISE FRAMEWORKS AND GUIDANCE

National Institute for Health and Care Excellence (NICE)

Key points from these guidelines in relation to exercise include:

- Early referral to physiotherapists with experience in Parkinson's to provide, advice, education and support in relation to Physical activity and exercise.
- Parkinson's specific physiotherapy should be provided for those with balance and motor function problems
- www.nice.org.uk/guidnace/nh71

Scottish Government recommendations – Neurological Care and Support in Scotland 2020.

Key points from this policy:

- Support people to manage their condition
- Develop integrated and co-ordinated models of care
- Ensure people are active partners in their care.
- Ensure equitable and timely access to services
- Ensure high standards of effective, person centred and safe care and support

PDConnect

8.0 EXERCISE FRAMEWORKS AND GUIDANCE

Parkinson’s UK Exercise Framework

	Investing in exercise from diagnosis onwards	**Staying Active**	**Managing Complex (physical) Challenges**
FOCUS	**Emerging evidence suggests that increasing exercise to 2.5 hours a week can slow the progression of Parkinson’s symptoms, so**: - seek referral to an informed professional to discuss exercise and its benefits, the individual’s physical state and motivation - exposure to an exercise-focused lifestyle, using family, friends or Parkinson’s networks, supports regular exercise behaviour - if symptoms are mild, this is the optimal time to improve physical condition to remain well, prevent inactivity and the complications of sedentary behaviour	**Keeping moving is important for people with Parkinson’s, so:** - stay as (or more) active than at diagnosis and increase exercise targeting Parkinson’s-specific issues such as balance and doing two things at once - continue to keep the progression of symptoms to a minimum by exercising both the body and the mind - use the positive effects of exercise to better manage non-motor symptoms such as mood and sleep	**Movement, ability and motivation change over time, so:** - pay attention to specific physical functions that focus on daily activities such as getting up out of a chair, turning or walking safely - continue to maintain general fitness for physical wellbeing, finding ways to make sure this is kept up - prevent discomfort related to postural changes

	Investing in exercise from diagnosis onwards	Staying Active	Managing Complex (physical) Challenges
Exercise style	**Target postural control, balance, large movement and coordination through**: • Moderate and vigorous intensity exercise to get the best performance from the body. Best done 5 x week in 30 minute bouts • Progressive resistance exercise to build muscle strength and power. Best results if done 2 x week • Parkinson's-specific exercise prescribed by health professionals such as dual-tasking and stretching for flexibility.	**Target flexibility plus slower exercise to control postural muscles for balance through:** • Maintaining effortful exercise that pushes people according to their fitness levels • Continuing resistance exercises • Increasing balance exercises • Increasing postural exercises • Parkinson's-specific review by health professionals	**Target better movement through:** • Functional exercise (chair-based with the use of resistance bands) • Supervised classes with a professional reviewing safety to perform exercise • Home programmes to stay moving, avoid sedentary behaviour, reduce flexed position and the secondary effects of being less mobile
Examples	• Sport: racket sport, cycling, jogging, running and swimming • Leisure centre and other classes: aerobics, vigorous intensity training. Nordic walking • Home DVDs • Parkinson's-specific exercise such as PD Warrior	• Golf, bowling, (paired) dance, health walks, swimming • Flexibility with strength: tai chi, Pilates and yoga • Specific classes for people with Parkinson's such as LSVT BIG and balance and walking classes (run by the Parkinson's UK network)	• Specific classes for people with mobility and balance challenges, especially dance • Pedal exerciser • Resistance band workouts • Supervised balance and mobility challenge tasks • Seated exercise groups

9.0 GETTING STARTING WITH PDCONNECT

This part of the manual will provide further details about what you can expect from participating within the PDConnect programme. The PDConnect study is being delivered by a group of researchers from RGU, and is being delivered by Physiotherapists from NHS Grampian and Fitness Instructors from RGU:Sport. Below is a summary of the researchers and staff delivering PDConnect responsibilities, as well as what your role within the study entails.

Researcher's responsibilities:

- To act as a co-ordinator between all parties involved in the study
- To act as a trouble shooter in the event of any issues (eg technology issues) which arise during the study
- To ensure the study is conducted as planned.
- Conduct all measurement during the course of the study (baseline, 6, 18 and 30 weeks)
- Conduct initial risk assessment of participants homes in preparation for remote delivery of exercise
- Ensuring all Participation Statements are completed correctly for all participants prior to starting the programme.
- Ensure that all participants have completed as participation statement
- Provide all participants with an induction and trial run of using Microsoft teams and the use of the Mi Band activity tracker
- Instructors are also required to provide participants with an opportunity to trial the use of the online platform out-with the class setting.

9.0 GETTING STARTING WITH PDCONNECT

Physiotherapist and Fitness Instructors Responsibilities

- Physiotherapist and Fitness Instructors will provide a safe, effective and enjoyable interactive online exercise class. It may be necessary for instructors to demonstrate, adapt and provide alternative exercises for individuals with specific needs.
- Physiotherapist and Fitness Instructors are required to discuss your exercise programme with you to ensure it meets your individual needs
- Review and refresh your home exercise programme and goals with you every three weeks
- Prior to the start of the sessions, Physiotherapist and Fitness Instructors are responsible for ensuring the space they are using for delivery is suitable for the activity and clear of any hazards (e.g. trips, slips, falls).
- Physiotherapist and Fitness Instructors are required to remind participants of the need to ensure the environment they are participating from is clear of any potential hazards (e.g. trips, slips, falls) prior to commencing each session.
- Physiotherapist and Fitness Instructors are required to undertake ongoing dynamic risks assessments in relation to instructor to participant ratio and class content. Risk assessments should consider various factors including equipment and participant ability.
- Instructors must have participation statements at hand (for quick access to individual contact details) for any possible emergency contact details being required during the class.

9.0 GETTING STARTING WITH PDCONNECT

Your commitment to us:

- You should not exercise beyond your abilities and if you know or are concerned that you have a medical condition which might interfere with you exercising safely you should get advice from a relevant medical professional and follow that advice.
- To undertake your home exercise programme five times a week
- Work up to walking outside four times a week
- Any exercise carries its own risks. You should not carry out any activities which you have been told are not suitable for you.
- You should let us know immediately if you feel ill when participating in our class.
- You should ensure the exercise environment is free from obstacles and you wear suitable clothing and footwear.
- To help you feel as safe as possible while attending this class, you will make sure the area you will be exercising in has no trip hazards, has good lighting, a seat within reach and a table or kitchen work surface to hold onto, also within reach (support maybe be required for some of the standing exercises).
- A family member or carer would be welcome to be present, as required.
- You should keep a phone close to where you are exercising and water for hydration.
- You should inform the instructor and complete a new participation statement for any changes to your contact details, emergency contact person, home address or the address from which you are participating in the class from.

- Complete you daily activity diary, and weekly activity planners

- Wear your activity tracker for the duration of the study

- Follow the safety checklist (below) prior to each session

9.0 GETTING STARTING WITH PDCONNECT

Safety First

Participation in exercise can cause injury, therefore working at a rate and pace that you are comfortable is important. Furthermore, as the PDConnect study is being delivered online, staff will not be with you during appointments so below is a list of additional health and safety information and guidance drawn from the Parkinson's Excellence Network Exercise Hub information "staying active at home when you have Parkinson's".

Before you start exercising you need to prepare your environment making sure that your living space is safe and comfortable for exercise. A risk assessment of your house will have been conducted prior to starting the exercise programme, with recommendations made as appropriate. However, prior to starting any online exercise session, you must follow the points below.

Health and Safety Checklist for participants

- Please remember to only exercise if you are feeling well and able to take part. Stop if you feel unwell at all during the exercise; feeling dizzy, have chest pain, feel sick, feel unusual bone or muscle pain.
- Please have medication to hand (eg inhalers or chest pain sprays)
- Ensure your space is clear and suitable for exercising at home, the floor space is clear and free of trip hazards like cables or the corners of rugs.
- Keep sturdy chairs ready to hold onto, or to sit and rest on.
- Make sure your room is at a comfortable temperature, or adequately ventilated - don't exercise in a room that's too hot. Open a window if you need to.
- Wear comfortable, flat shoes even if this is in the house to support your feet and balance. Check that your shoes and any equipment you're using are in a good condition and right for the activity.
- Always complete a warm-up before doing any exercise, particularly if you have been sitting for a period of time beforehand.
- Keep water nearby and drink before, during and after exercise to prevent dehydration. Don't forget to drink your water. You can lose around one and a half

litres of fluid for every hour of vigorous exercise, so drink water before, during and after a session.

- Please work at your own pace
- Where possible, please have a partner/carer or person from your social bubble present within your house while exercising.
- If it is not possible to have someone with you, please ensure that you have a phone in the same room as you are exercising, for use in the event of an injury.
- Have a telephone or mobile nearby in case of an emergency. If you live alone, please ensure that someone is knows that you are exercising at home and check in with them after you have finished.
- Don’t forget to drink water. You can lose around one and a half litres of fluid for every hour of vigorous exercise, so drink water before, during and after a session.

PDConnect

9.0 GETTING STARTED WITH PDCONNECT

Participation Statement:

As this study is being delivered entirely online, in the event that you have a fall or an injury during the online session, we need to have access to an emergency contact, whom we can contact should such an event arise. This information will be kept securely by the staff, and these people will ONLY be contacted in the event of an emergency. This form will be completed at the beginning of the study. If any of your details change, please let Julie know immediately.

9.0 GETTING STARTING WITH PDCONNECT

Six sessions of 1:1 Specialist Physiotherapy

12 weeks of circuit group-based exercise

12 weeks of independently managed exercise

This will include:

- 12 sessions of group-based circuit exercise delivered by a Parkinson's Trained Fitness Instructor using Microsoft Teams.
- One hour of exercise including a warmup and cool down. In a addition there will be 30 minutes of group discussion.
- Includes 10 different exercise stations. Each station has four levels of difficulty to allow exercise to be tailored to individual need.
- Spending 4 minutes at each station.
- Exercises are selected from current research and will target key areas of Parkinson's.
- Regular review of your exercise goals and home exercise programmes to ensure these remain challenging and appropriate to meet your needs.
- Opportunity within discussion sessions will be given to address any questions (more info on next page)
- Development of strategies to develop and maintain exercise habits.
- Wearing a physical activity tracker (Mi Band), keeping an activity diary, and development activity planner.
- Repeating of baseline measures

9.0 GETTING STARTING WITH PDCONNECT

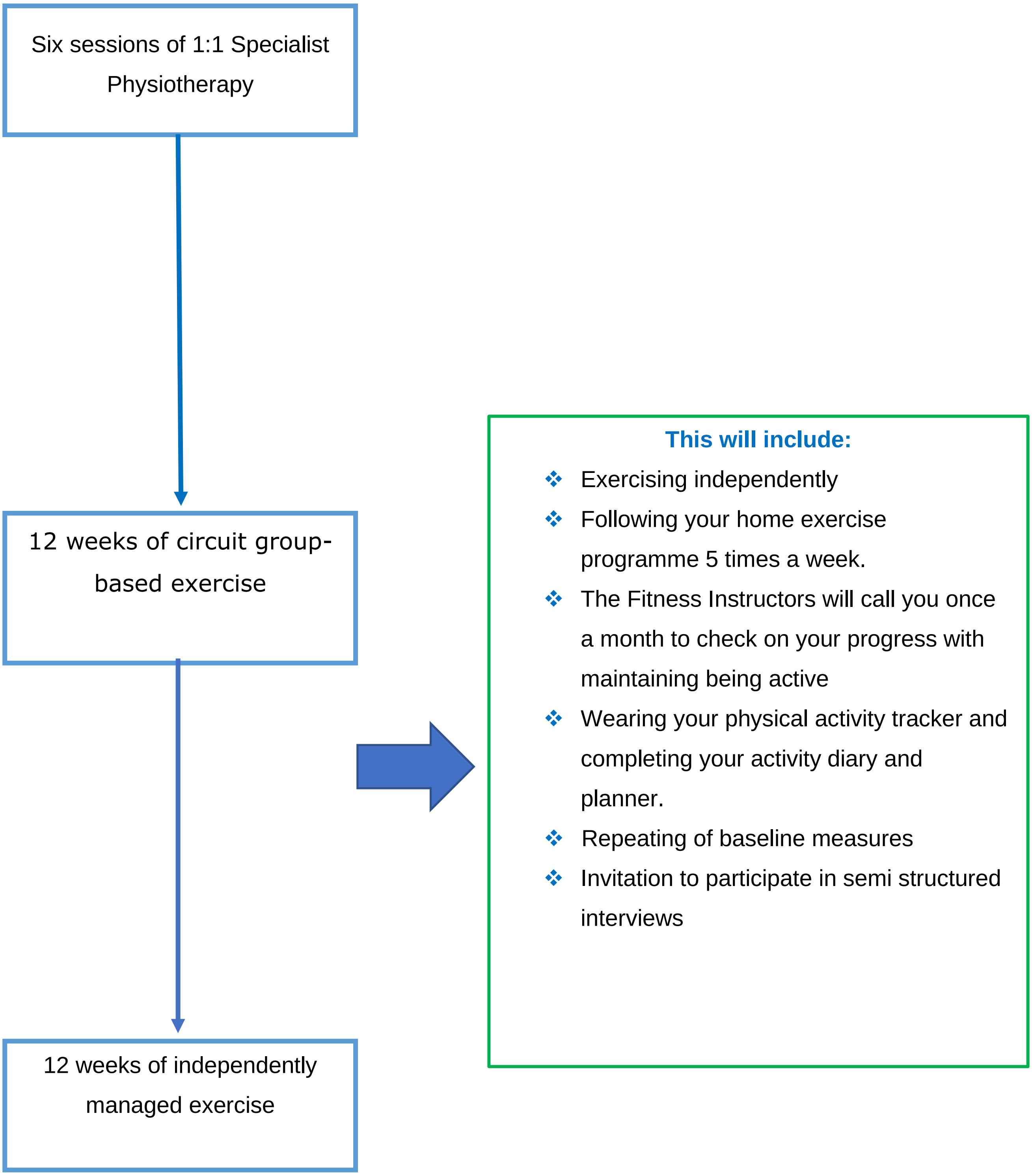
Group Based Exercise Sessions

Using Microsoft teams everyone will participate in the exercise session together. So, on screen you will be able to see the other participants. We are mindful that meeting people online is a different experience for everyone. So, on the first group session, we will some general introductions so everyone knows who each other are, and we would hope during the course of the following 12 weeks you will all get to know each other better.

The group-based sessions will include a warm up and a cool down, these will be guided by the fitness instructor. Once the warm has been completed the fitness instructor will guide you through the next 10 exercises. Mindful that there may be differing abilities within the group, each of the 10 exercises has 4 levels of complexity. Which level you will do will be based on joint discussions had between you and the physiotherapist within the 1:1 sessions. During this phase of the study, the fitness instructor will demonstrate each exercise in turn, and will provide key points to ensure that you are all engaging in the exercises correctly and adopting the correct technique, while also maintaining high effort.

During these sessions, we would welcome open communication so any comments, or questions, humour, will be welcomed. Following the exercise, there will be time for discussion. We have suggestions of discussion topics for the first 6 weeks. We will be looking the group to make some suggestions of things that you would like to raise for the following weeks. This group is to support you, so we are keen to hear what you would find most beneficial to discuss.

9.0 GETTING STARTING WITH PDCONNECT



Six sessions of 1:1 Specialist Physiotherapy

12 weeks of circuit group-based exercise

12 weeks of independently managed exercise

This will include:

- Exercising independently
- Following your home exercise programme 5 times a week.
- The Fitness Instructors will call you once a month to check on your progress with maintaining being active
- Wearing your physical activity tracker and completing your activity diary and planner.
- Repeating of baseline measures
- Invitation to participate in semi structured interviews

PDConnect

9.0 GETTING STARTING WITH PDCONNECT

Study Expectations

What you can expect of PDConnect Staff

- ✓ Specialist knowledge of Parkinson's.
- ✓ Experts in exercise prescription
- ✓ Experienced in supporting change
- ✓ Working collaboratively
- ✓ Open communication
- ✓ Supportive
- ✓ Motivational
- ✓ Active listeners

Your contribution

- ➢ Open communication
- ➢ Active participation
- ➢ Motivated to adopt a more active lifestyle
- ➢ Confidence to ask questions
- ➢ Work collaboratively with staff
- ➢ Complete home exercises
- ➢ Complete activity diary
- ➢ Wear activity tracker –Mii Band

PDConnect

9.0 GETTING STARTING WITH PDCONNECT

Health Agreement

Health contracts have been used for some time with healthcare as an agreement between staff and patients. The advantages of having an agreement or contract makes clear from the outset as to roles, responsibilities of each parties, which is important when people are working together. By asking you to complete this, it is hoped that you will feel more actively involved in the direction of your exercise journey. The theory being if you have been involved from this from the outset you will feel more in control and are more likely to keep to what they have written within the contract.

Below are some examples of what some patients have put in health contracts before:

- I will always take the stairs instead of using lifts.
- I will go out for a walk with my husband twice a week
- I will walk to collect the paper each day and not take the car.

Write down some ideas of things that you may like to include in your health contract that are related to exercise and physical activity

PDConnect

9.0 GETTING STARTING WITH PDCONNECT

Health Agreement

Following discussion with your Physiotherapists, complete the following contract.

Date or agreement:____

Review Date:____

1	
2	
3	
4	
5	

Signed:_____________________________________ (Participant)

Signed:_____________________________________ (Physio)

9.0 GETTING STARTING WITH PDCONNECT

Readiness to exercise:

On a scale of 1-10 below. Can you rate on the scale below how confident you feel engaging in exercise, if 10 was very confident, and 0 being no confidence at all. Please circle.

---

1 2 3 4 5 6 7 8 9 10

Changing our behaviour is not easy, as our behaviour is influenced by many factors, such our family, where we live, our perceptions and values, finance, and these are just a few. Before we can successfully change our behaviour, we need to identify and understand potential barriers to changing behaviour so that they can be addressed, and broken down. Without addressing these barriers, change is often short lived, with people reverting back to old habits, as the barriers are just too significant.

When we think about changing our behaviour, there are many different approaches we can take, and some approaches will work better for some more than others. A huge amount of theoretical literature has been written about behaviour change. This body of literature was reviewed when designing the PDConnect programme, and we have drawn from a particular model called the Behaviour Change Wheel which was designed and developed by Susan Michie and colleagues, and has been used successfully in a number of other long term conditions. Within this evidenced based model, they detail several strategies, in order to inform which ones will work best for you, we need to explore in a little detail your thoughts and perceptions of exercise

9.0 GETTING STARTING WITH PDCONNECT

Changing behaviours.

Either on your own, or with someone who knows you well, consider the following points, writing your ideas in the box. The more open and honest you can be the better, as this will be useful when we discuss strategies to support you embracing being more physically active as part of the PDConnect programme. .

In the box below, please write below what you think is the hardest thing about getting started or keeping doing with exercise

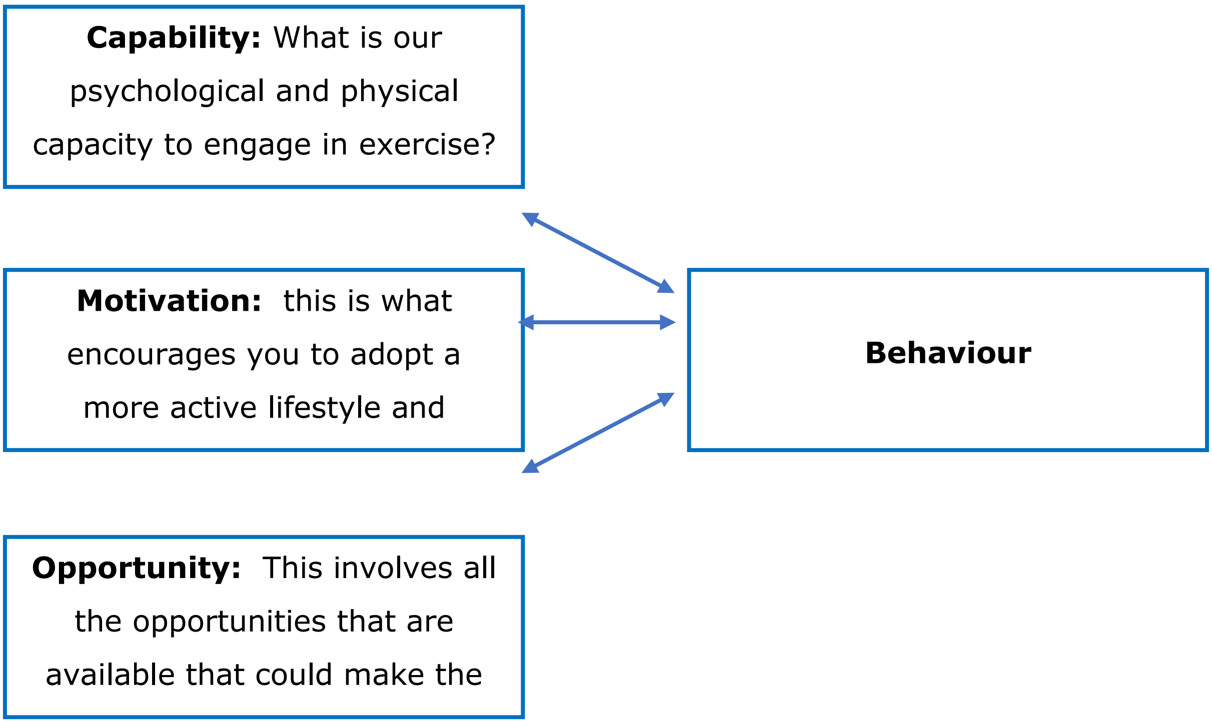
What are your feelings towards exercise and being more active?

PDConnect

10.0 GETTING GOING WITH EXERCISE

Changing behaviours, and action planning.

Michie and colleagues proposed that our behaviour is shaped by our capacity, motivation, and the opportunities, which arise.



Capability: What is our psychological and physical capacity to engage in exercise?

Motivation: this is what encourages you to adopt a more active lifestyle and

Opportunity: This involves all the opportunities that are available that could make the

Behaviour

Getting going with exercise:

We have already explored what you think are the barriers to exercise. What do you think your key motivators are to start and continue exercising?

10.0 GETTING GOING WITH EXERCISE

Changing behaviours, and action planning.

How best to motivate you?

Which of the following strategies do you think would help motivate you to be more active? Please tick in the boxes as appropriate. We will use this information to guide the delivery of your exercise programme.

	YES		**NO**
Setting goals and targets			
Getting feedback on your performance			
Monitoring your own performance			
Support from family and friends			
Guidance from professionals			
Education on exercise			
Demonstration of exercises			
Hearing about others exercise experiences			
Practicing			
Reading about exercise from credible source			
Exercising with others			

PDConnect

10.0 GETTING GOING WITH EXERCISE

Changing behaviours, and action planning.

Tips to build activity into your day:

- walk or ride part of your journey to work or the shops
- get off a bus or tube stop before your destination
- if you drive, park further away from your office and walk or ride the rest of the way
- go for a walk or a ride with your friend rather than meeting for coffee
- exercise before or after work, or during your lunch break
- lots of gardening can provide a good workout
- exercise in front of the TV
- try an online video workout

Further info: The NHS has also put some resources some resources together

Green Gyms: Improve your health and the environment at the same time with the outdoor alternative to the gym. Work up a sweat digging, planting, lopping and clearing paths at one of 95 free Green Gyms around the country run by The Conservation Volunteers. Experienced leaders guide volunteers through a range of practical projects, giving you the opportunity to tackle physical jobs outdoors. This can improve your strength and stamina, and boost your practical skills and confidence. There are sessions for all fitness levels, and no previous gardening or conservation experience is necessary. Find a free Green Gym near you

Outdoor gym: Look around you: the world is your gym. With this in mind, the National Trust and outdoor exercise specialists Eco Fitness have produced a free outdoor fitness programme you can follow, whatever the weather. The 31-day plan has been designed to ease people into being active outdoors and make exercise fun rather than a chore. No equipment is needed. Exercises in the challenge include power walking, tree press-ups and "spotty dogs". Find out more about the National Trust outdoor gym programme.

PDConnect

11.0 ACTIVITY DIARY

“Taking exercise is as important as taking your medicine”

By exercising, I am doing something to help myself, and my Parkinson’s.

Exercise has made me feel positive about my future

The activity diary has been put together so that you can record your activity during the course of this study and beyond. Activity diaries and the act of writing down activity has been shown to help people to develop good exercise habits.

PDConnect

11.0 ACTIVITY DIARY

We would like you to record the activity that you participate in each day. Also within this diary, we will record your activity goals, which will be reviewed during the course of the study and progressed as required. We have also produced some areas for you to note things down as you go, which you can then discuss with the Physiotherapist or Fitness Instructor during your sessions with them.

Please bring your diary with you to every exercise session

Things to remember when exercising:

- Try and do a little more each day than you did the day before.
- Discomfort following exercise is common for a few days after exercise and does not mean the activity is physically harmful. If muscle soreness lasts for more than 3 days contact your physiotherapist to discuss this.
- Regular aerobic exercise of any kind is very helpful, for example walking, swimming, stationary bicycling, or treadmill.
- Avoid prolonged sitting, lying down, or leaning in one position.
- Vary the types of exercise you engage in.

Want to know more about exercise?:

On the Parkinson's UK website:

- https://www.parkinsons.org.uk/information-and-support/exercise
- https://medium.com/parkinsons-uk/tagged/exercise
- https://medium.com/parkinsons-uk/the-science-of-exercise-part-1-58c1054b50c6
- https://medium.com/parkinsons-uk/the-science-of-parkinsons-exercise-part-2-2d680afa1a01

PDConnect

11.0 ACTIVITY DIARY

How active should you be?

Aerobic Exercise

- 30-60minutes
- 5x a week
- Moderate to high intensity

Strength Exercise:

- 2-3 times a week
- 10-15 repetitions of any exercise
- 2-3 sets of each exercise

Flexibility or Stretching Exercise

- Daily
- Minimum 10 minutes
- Hold each stretch for 20-30 seconds

Balance Exercises

- 20-30 minutes
- 2-3 times a week

Being Physically Active

- daily

Walking

- daily
- preferably briskly

PDConnect

11.0 ACTIVITY DIARY

How active should you be?

This infographic produced by the Chief Medical Officer in 2019 provides a nice illustration of how much activity is recommended for adults

Physical activity for adults and older adults

- Benefits health
- Improves sleep
- Maintains healthy weight
- Manages stress
- Improves quality of life

Reduces your chance of

Type II Diabetes	-40%
Cardiovascular disease	-35%
Falls, depression etc.	-30%
Joint and back pain	-25%
Cancers (colon and breast)	-20%

Some is good, more is better

Make a start today: it's never too late

Every minute counts

Be active

at least 150 minutes moderate intensity per week
increased breathing able to talk

OR
or a combination of both

at least 75 minutes vigorous intensity per week
breathing fast difficulty talking

to keep muscles, bones and joints strong

Build strength on at least 2 days a week

Minimise sedentary time
Break up periods of inactivity

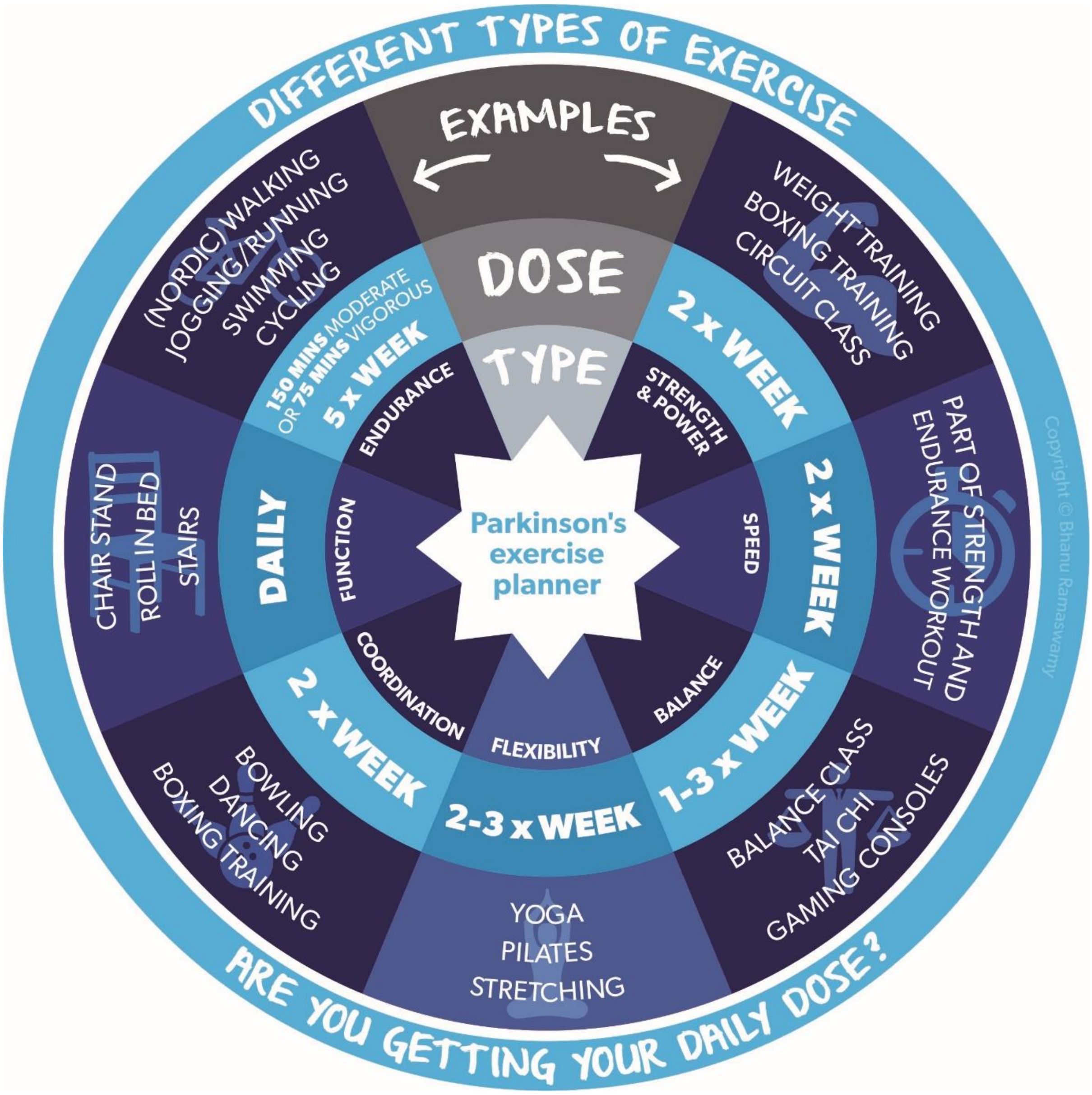
For *older adults*, to reduce the chance of frailty and falls
Improve balance 2 days a week

UK Chief Medical Officers' Physical Activity Guidelines 2019

PDConnect

11.0 ACTIVITY DIARY

Types of Activity



Engaging in a variety of activities is important, one it keeps it fun and interesting but also reduces the likelihood for injury. There is some examples below.

11.0 ACTIVITY DIARY

Making time for exercise each day is difficult for everyone, especially if you are new to exercise.

Fitting exercise into your life five days a week is a challenge. This diary is part of several techniques that we hope will help you fit exercise into to your everyday schedule.

Finding the right time to exercise can be difficult. You will find that your Parkinson’s symptoms fluctuate, and as a result the right time to exercise will likely change from day to day.

For you to get the best out of your exercise, you need to be at your best. That means it has to be at a time of day when your medication is at its most effective, when you feel that you have the most energy.

So planning is required so that you can take control of your own exercise schedule. You can choose to do your daily dose at a different time every day, if that suits you best.

Many barriers exist to exercise, including your disease pattern, your feelings and beliefs towards the benefits of exercise, the design of the programme you take part in, support from people around you and the social and physical environment can all play a part.

11.0 ACTIVITY DIARY

Motivators to engage in exercise:

Improved emotional well-being

Sense of community and social support

Improved energy levels

Improved sense of well-being

Improved sense of control

Enhanced confidence

Potential to slow rate of disease progression

Improved strength and do all the things I want to do

So what are you waiting for?

PDConnect

11.0 ACTIVITY DIARY

Keeping a diary.

Many people find keeping a diary a useful method of keeping track of their progress over time, but also to plan for the week ahead so that activity can be structured in amongst all the other chores, responsibilities and jobs that a normal week demands.

The diary we would like you to keep has three components:

1. Goals setting
2. A weekly activity planner – so you can plan for the week ahead what activities you are going to do and when
3. An activity diary so you can record all the activities that you have under taken

The next few pages will provide guidance on these aspects, and completed examples for you to look at, followed by several blank forms for you to complete during the course of the study. For the first 6 weeks, the physiotherapist will support you in setting goals and developing your planner, and completing your diary, so don't worry, help will be on hand.

The key things that we wish to record in this diary:

- Exercise and physical activity goals
- Time spent being engaging in physical activity
- Types of physical activity and exercise that you participated in
- Whether you experienced any adverse events such as falls.

What do you perceive are the challenges that prevent you being more active and participating in exercise?

What activities have your stopped doing that you would like to do? What would help you to start doing them again?

PDConnect

11.0 ACTIVITY DIARY

Please write in the box the answers to the following questions:

When is the best time for you to exercise?

What factors motivate you most to exercise?

What and who will help to take your daily dose of exercise?

Which of the motivators to exercise means the most to you?

Example - Setting yourself a goal or a target.

Date: **26th March 2020** **Week One**

Participant signature: Julie Jones. **Therapist Signature:** John Ball

Number	My Target or Goal
1	To be able to walk to my daughters house by myself in less than 30 minutes within 6 weeks.
2	To achieve my daily step goal of 8,000 steps per day for a whole week within 3 weeks.
3	To feel confident to meet my friends for coffee in Dobbies in 8 weeks. I want to be able to walk around the garden independently without my stick and be able to carry my own coffee to my table
4	I want to be able to hang my washing up on the drier by myself in 4 weeks
5	I would like to be able to get out of a chair without using my arms in 4 weeks
6	I would like to be able to go on holiday with my abroad with my husband, and feel confident to walk independently to and in the airport in 2 months.

Setting yourself a goal or a target

Date:

Week 1.

Participant signature:

Therapist Signature:

Number	**My Target or Goal**
1	
2	
3	
4	
5	

Copies of these pages were provided for participants to record goals as they progressed through the intervention.

PDConnect

11.0 ACTIVITY DIARY

Activity planner

Below is a completed example of an activity planner to guide what you in completing this each week. As with the goal setting, the physiotherapist will support you in completing this planner at the beginning, so to help you get into the swing of it. **The purpose of the planner, is to help you structure in physical activity into each day, so you get your daily dose of exercise.** It is a just a plan, and somethings may need to change, for example if it is raining, or snowing, an outdoor walk may no longer be possible.

Days	Morning	Afternoon	Evening
Monday	Supermarket shopping Housework	Looking after Emily (grandchild)	30 minute walk outside
Tuesday	Home exercise programme Housework	Looking after Emily	15 minute walk outside
Wednesday	30 minute walk outside Coffee with friends	Pilates exercise class	Home exercise programme
Thursday	Home exercise programme	Walking group	Choir practice
Friday	Gardening	Home exercise programme	Theatre, and dinner

Weekly Activity Planner. This should be completed each week

Week 1.

	Morning	Afternoon	Evening
Monday			
Tuesday			
Wednesday			
Thursday			
Friday			
Saturday			
Sunday			

Participants were provided with a weekly activity planner for the 30 weeks of the study

PDConnect

11.0 ACTIVITY DIARY

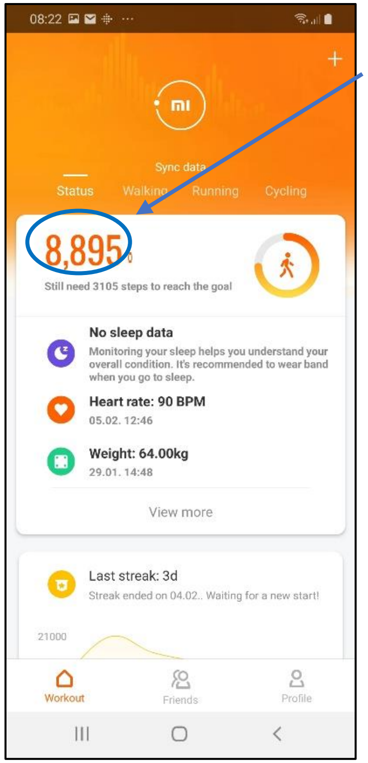
Activity Diary: We would like you to record here what activity you did each day, including how many steps that you have done which are recorded on your Mi band. A completed example can be found below which will help guide you in completing this. As with the goal setting, and weekly activity planners, your physiotherapist will be able to help you get started with this.

EXAMPLE

	Activities undertaken	Total daily step count	Total distance travelled	Time spent slow walking	Time spent fast walking
Monday	• Gardening • Outdoor walk • Home exercise programme	8.895	8.07km	14 mins	7 mins
Tuesday	• Home exercise programme • Shopping • Cleaning the bathrooms	7,966	7.03km	9 mins	6 mins
Wednesday	• Home exercise programme • Supermarket shopping • Played 9 holes of golf	11, 456	10,67km	49 mins	17 mins

The complete the complete the activity table you will need to synchronise you Mi band with the Mi app. Information on this covered within section 11. But I have also put a little information here too. If you click the Mi app on your phone and synchronised it, you will find the day's activity. It is best to do this first thing in the morning where you can record the prior day's steps

This information can be found by:



Still need 3105 steps to reach the goal

No sleep data

Monitoring your sleep helps you understand your overall condition. It's recommended to wear band when you go to sleep.

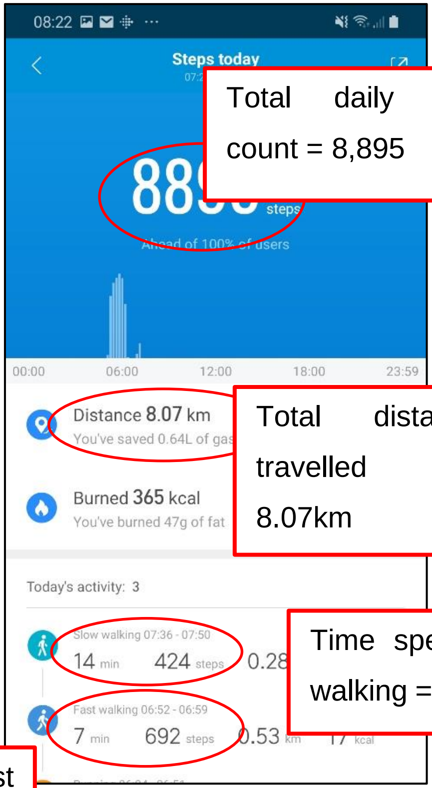
Heart rate: 90 BPM
05.02. 12:46

Weight: 64.00kg
29.01. 14:48

View more

Last streak: 3d
Streak ended on 04.02.. Waiting for a new start!

Taping your current daily step count here, takes you



Ahead of 100% of users

Distance 8.07 km
You've saved 0.64L of gas

Burned 365 kcal
You've burned 47g of fat

Today's activity: 3

Slow walking 07:36 - 07:50
14 min 424 steps 0.28

Fast walking 06:52 - 06:59
7 min 692 steps 0.53 km 17 kcal

Total daily step count = 8,895

Total distance travelled = 8.07km

Time spent slow walking = 14 mins

Time spent fast walking = 7mins

Daily Activity Diary. This should be completed **each day**

Week 1.

	Activities undertaken	Total daily step count	Total distance	Time spent slow walking	Time spent fast walking
Monday					
Tuesday					
Wednesday					
Thursday					
Friday					
Saturday					
Sunday					

Participants were provided with a week diary page to complete each week.

PDConnect

11.0 FALLS DIARY

Recording falls:

Falls: A fall is defined as an event whereby by a person comes to rest on the floor or lower level inadvertently. We would like if possible for you to record any falls during the course of this study. Please could you record **any falls** that occur in the following table. In the event of a fall, please can you also inform Julie Jones

☎ 01224 263282 ✉ j.c.jones@rgu.ac.uk

EXAMPLE:

Date and Time	Was the fall seen?	Location of fall	Cause of fall if known. If known please state	Any injury yes or no. If yes please state injury	Did you need to call your GP?	Did you need to go to hospital?	Actions after falls
e.g. 24th January 2020, at 7.55pm	***NO***	***Bathroom***	***Tripped on bath mat***	***Yes. Bump on the knee***	***NO***	***No***	***Hung mat up over bath***

PDConnect

11.0 FALLS DIARY

Falls Diary: We would like you to record ant falls which occur during the course of this study in the following study. if you experience a falls we would also like you to report this to the researcher Julie Jones ☎ 01224 263282 ✉ j.c.jones@rgu.ac.uk

Date and Time	Was the fall seen?	Location of fall	Cause of fall if known. If known please state	Any injury yes or no. If yes please state injury	Did you need to call your GP?	Did you need to go to hospital?	Actions after falls

12.0 INTRODUCING THE MI ACTIVITY TRACKER

As part of the study, you will receive a Mi band, which is a wrist worn activity tracker. Everyone who is part of this study will receive one for the duration of the study. This guide has been put together for your information, so you can refer back to it as required during the study and in case you run into any issues during the course of the study. In the event of any queries please do not hesitate to contact Julie on 01224 263282, or j.c.cjones@rgu.ac.uk

In this guide you will find the following information

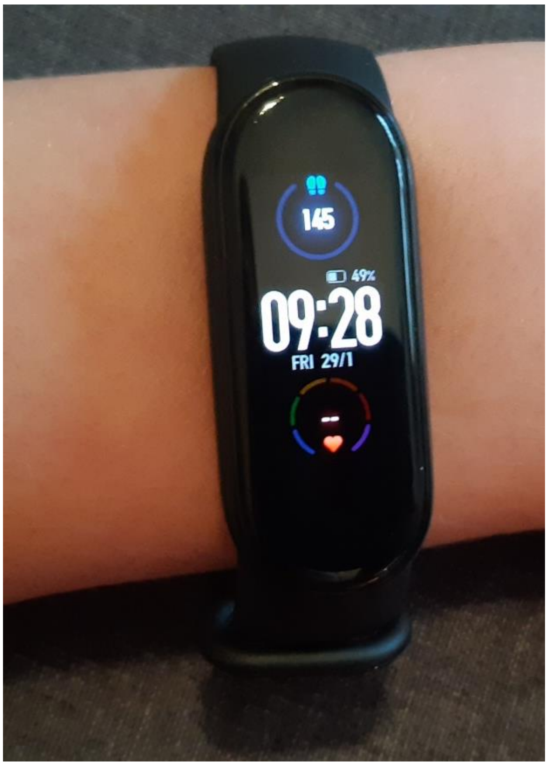
- Preparing to use your Mi Band
- How to maintain your Mi band
- Getting started
- Frequently asked questions

12.0 YOUR MI ACTIVITY TRACKER

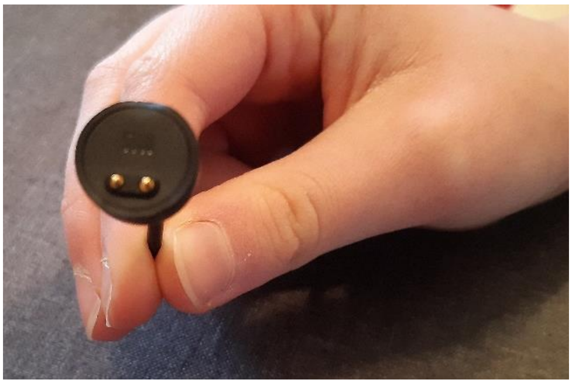
As part of the study, you will receive a Mi band, which is a wrist worn activity tracker. Everyone who is part of this study will receive one for the duration of the study. We would very much like it if you could wear this device every day for the entirety of the study, which is approximately 30 weeks.

Preparing to use your Mi Band

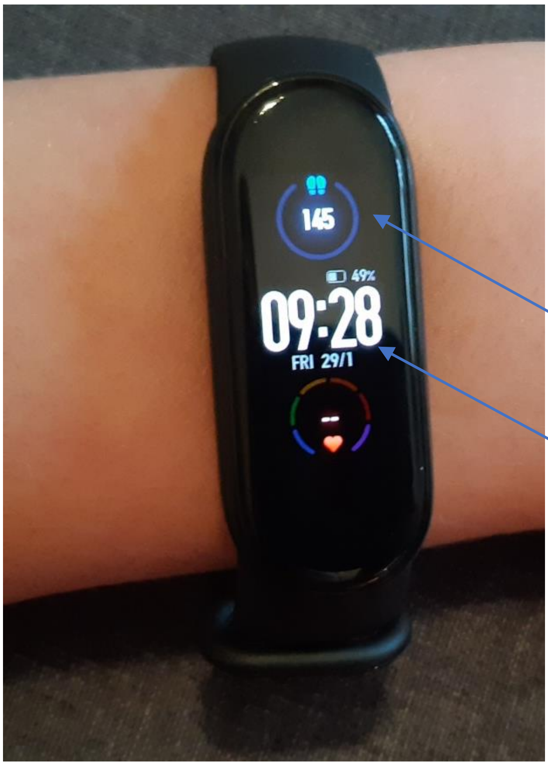
Getting to know your Mi Band.



Mi band Charging components



Wearing the Mi Band



When wearing the Mi band, to conserve power the screen will automatically switch off. However, it will still be recording information. To see the time on the watch tap the

Cumulative daily step count

Date, time, battery level

Any activity that you undertake will be counted. At midnight, the device resets itself and it will return to 0. You will be able to view prior days

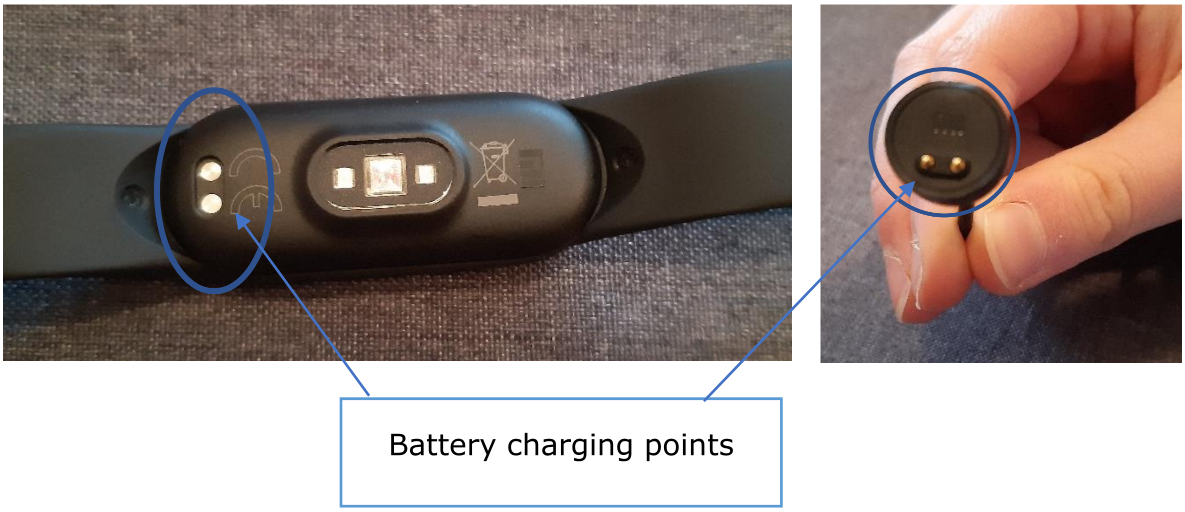
By touching the bottom of the screen and sliding your finger up the face of the watch, you can see other features on the watch. Tapping the status icon as shown in the picture will tell you your total

Fastening your Mi Band

Charging your Mi Band:

You can check your battery level by touching the bottom of the watch face and the battery life is illustrated on the watch face. When the battery is low, please charge it. The battery normally lasts 5 days without charging.

To charge: Take the watch off. Connect the charger head to the back of the watch, aligning it with the two emtal spots on the back of the watch. It is magnet so it will click on. Then plug the USB post into a plug or charging unit. To check when complete- all bars should be full.



Attach the charging cable to the back of the watch as shown

Attach the sensor and cable to a USB plug or point, and switch on to charge. Disconnect when battery is 100% full.

Showering and bathing:

The Mi band is water resistant but not waterproof. Therefore, splashes of water from handwashing will be ok, but you are advised NOT to wear your Mi band in the shower, bath, or if you go swimming. Please also not wear the device when in a sauna or steam room.

Cleaning your Mi Band:

Remove the sensor rom the band, and wash the band in warm soapy water, and dry off with a tea towel. The sensor itself should not be submerged in water, if this requires cleaned, please do so with a damp cloth and dry afterwards.

PDConnect

12.0 YOUR MI ACTIVITY TRACKER

When to wear your Mi Band:

This study is primary interested in your physical activity levels so you are only required to wear the tracker when you get up in the morning, until you go to bed in the evening. We wish to collect this data for the 30 weeks, which the study lasts for. Please take it off when bathing, and should you go swimming.

The Mi band will start collecting data as soon as you put the device on. There is no need to press any buttons. The Mi band has a built in energy saving feature, so unless you tap the bottom of the screen located on the screen it will be blank. It is still working even with screen blank. If you wish to see the information, being collected tap the button, and for more in detail information slide your finger up and tap on the other features to see the information.

Further information about your activity can be found on the Mi app on your phone, which we will explore on the next few pages.

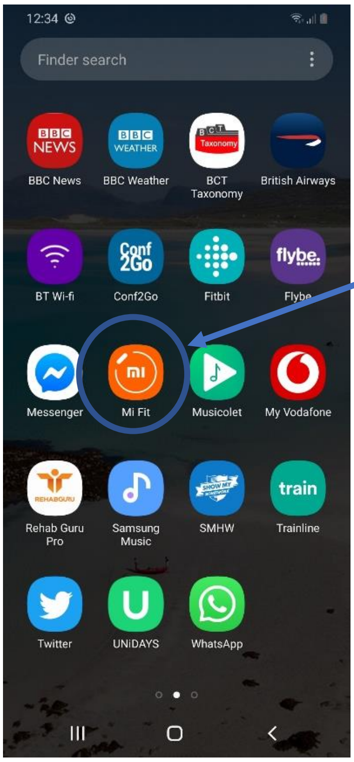
Just tap the mi icon, and it will take you to your information.

The Mi Band Phone App

When setting your phone and band up, Julie will download an app to your phone called Mi Fit app. The icon is opposite. By tapping this icon you will be able to see all you physical activity data.

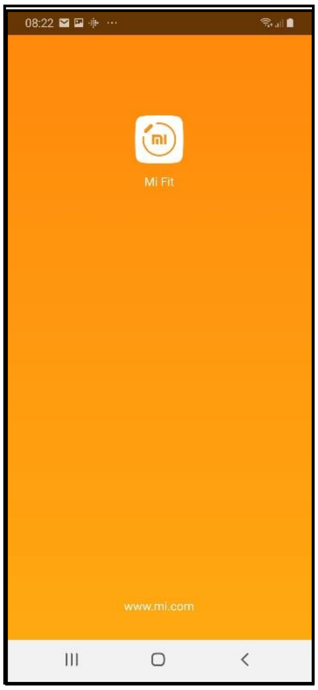
Getting started:

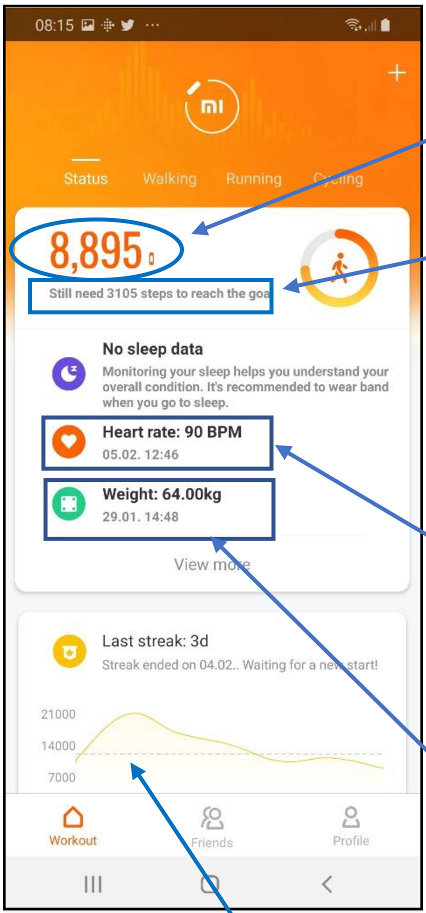
So start by opening up your phone, to your normal home page. All apps are normally listed alphabetically, so may need to swipe the screen depending on how many apps you have.



When you open your phone on the home page, you will see the Mi Fit app listed amongst your other apps that you have on your phone.

Tapping the Mi Fit App will take you to a page like this, which will then refresh and open the page detailed below.





Still need 3105 steps to reach the goa

No sleep data

Monitoring your sleep helps you understand your overall condition. It's recommended to wear band when you go to sleep.

Heart rate: 90 BPM
05.02. 12:46

Weight: 64.00kg
29.01. 14:48

View more

Last streak: 3d

Streak ended on 04.02.. Waiting for a new start!

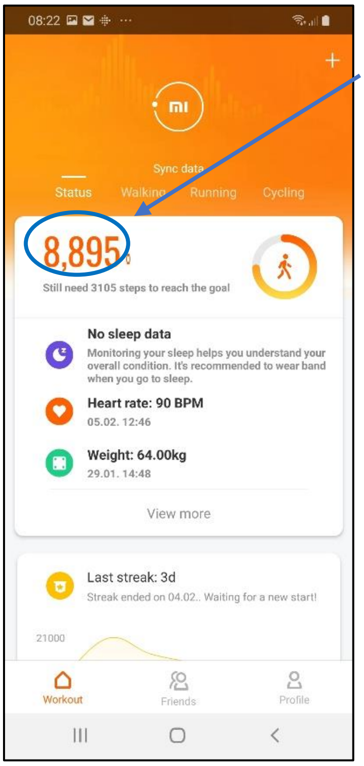
This illustrates the number of steps completed on this day at this time.

This states how many more steps that need to be undertaken to achieve your daily step goal, which in this example is set as 12, 000. When this goal has been achieved the orange circle surrounding the stick man will be entirely orange.

This provides information about heart rate in beats per minute (Bpm). In this example it was recorded on the 5th of february (05.02), at 12.46.

This is the last recorded weight, which in this example was logged at 64kg.

This illustrates graphically the total daily step count over the last 3 days.



8,895

Still need 3105 steps to reach the goal

No sleep data

Monitoring your sleep helps you understand your overall condition. It's recommended to wear band when you go to sleep.

Heart rate: 90 BPM
05.02. 12:46

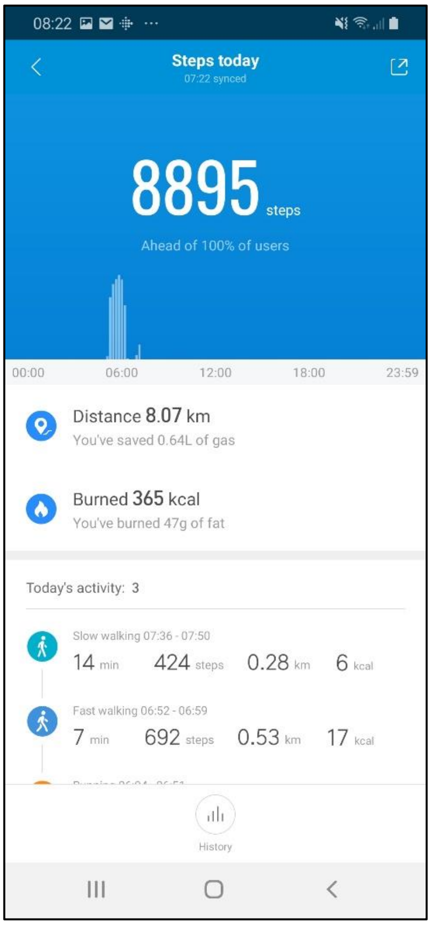
Weight: 64.00kg
29.01. 14:48

View more

Last streak: 3d
Streak ended on 04.02.. Waiting for a new start!

21000

Taping your current daily step count here, takes you to this display



Steps today
07:22 synced

8895 steps

Ahead of 100% of users

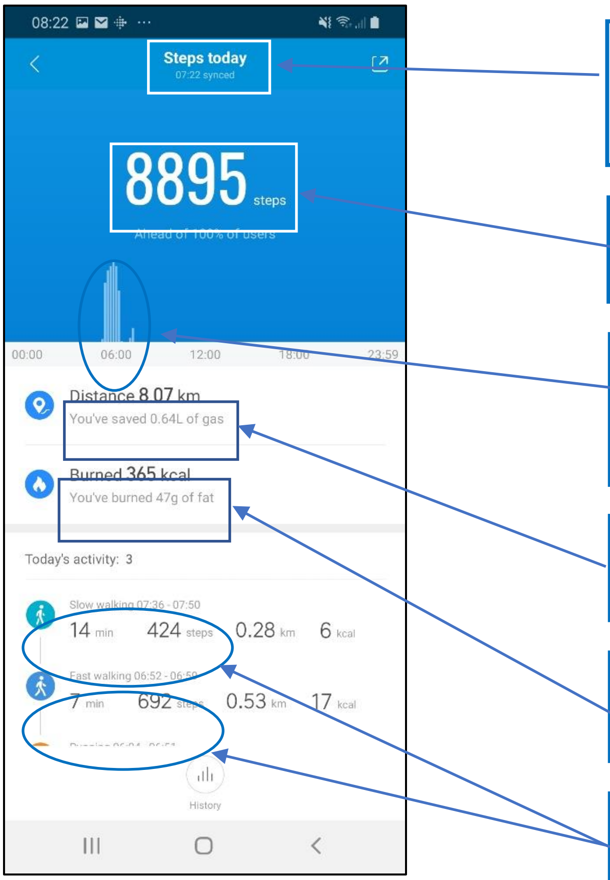
Distance 8.07 km
You've saved 0.64L of gas

Burned 365 kcal
You've burned 47g of fat

Today's activity: 3

Slow walking 07:36 - 07:50
14 min 424 steps 0.28 km 6 kcal

Fast walking 06:52 - 06:59
7 min 692 steps 0.53 km 17 kcal



Steps today
07:22 synced

8895 steps

Ahead of 100% of users

Distance 8.07 km
You've saved 0.64L of gas

Burned 365 kcal
You've burned 47g of fat

Today's activity: 3

Slow walking 07:36 - 07:50
14 min 424 steps 0.28 km 6 kcal

Fast walking 06:52 - 06:59
7 min 692 steps 0.53 km 17 kcal

Time, which Mi band data synchronised with the Mi Fit app 7.22, am

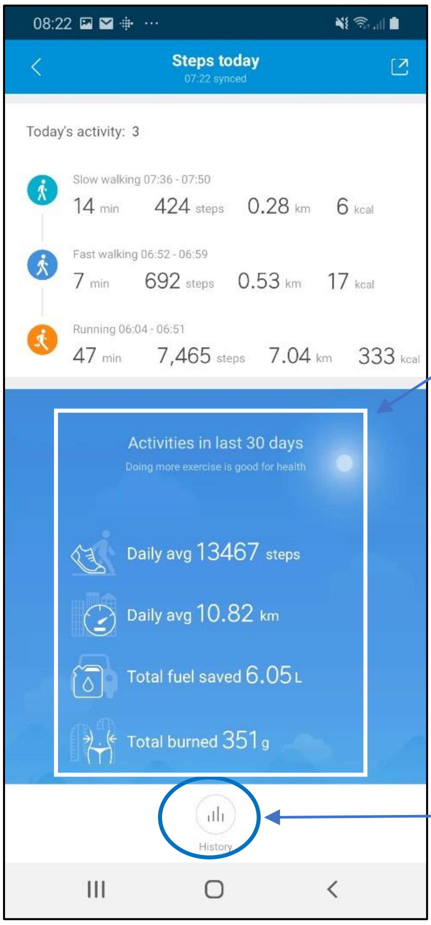
Number of steps taken on this point of time.

Timeline of stepping activity. In this activity, all activity occurred between 6 and 7am

Distance travelled in this example – 8.07km

Amount of energy spent by stepping activity on this day

The Mi band, categories stepping into slow, fast walking, light activities or running



Today's activity: 3

Slow walking 07:36 - 07:50
14 min 424 steps 0.28 km 6 kcal

Fast walking 06:52 - 06:59
7 min 692 steps 0.53 km 17 kcal

Running 06:04 - 06:51
47 min 7,465 steps 7.04 km 333 kcal

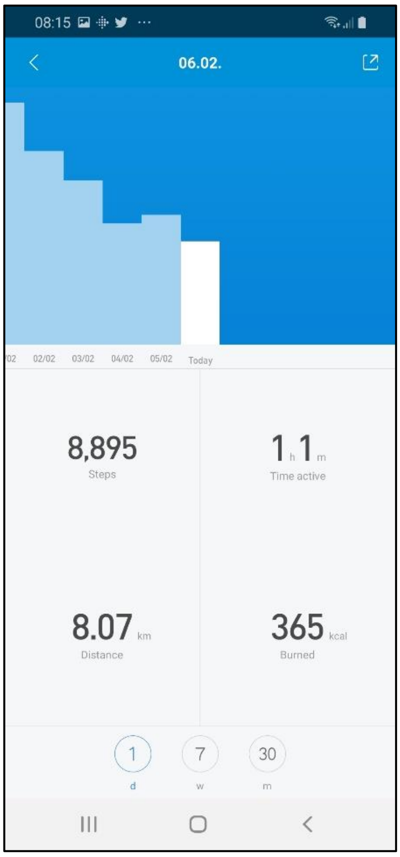
Activities in last 30 days
Doing more exercise is good for health

Daily avg 13467 steps
Daily avg 10.82 km
Total fuel saved 6.05 L
Total burned 351 g

By scrolling down this page, you will be able to see cataloguing of other activities you have done on this day, but also the app summaries conducted over the

Tapping this history icon takes you to your activity history and illustrates this in a bar graph format as is shown below.

This display illustrated your total step count on the prior days. In this example, you can see the last 6 days total steps



8,895 Steps

1 h 1 m Time active

8.07 km Distance

365 kcal Burned

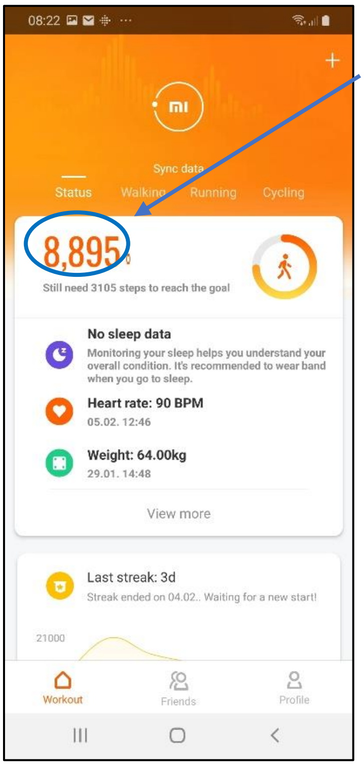
Recording your physical activity information

So we can review your physical activity, you will need to share the information collected on your tracker. It is advisable that you write down each day your total activity within your activity diary. It would be best to do this last thing at night or first thing in the morning where you record the prior day's activity. The activity diary is discussed in section 10.0.

The information we wish you to record is:

- Total step count for that day
- Total distance travelled
- Time spent slow walking
- Time spent fast walking

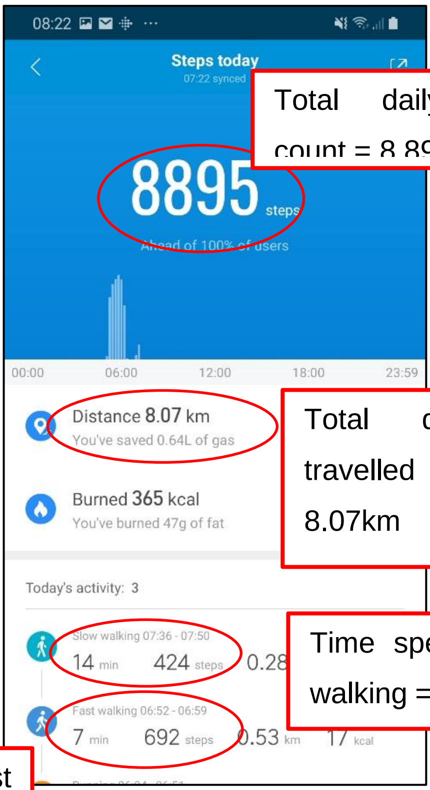
This information can be found by:



Monitoring your sleep helps you understand your overall condition. It's recommended to wear band when you go to sleep.

Streak ended on 04.02.. Waiting for a new start!

Taping your current daily step count here, takes you



Total daily step count = 8,895

Total distance travelled = 8.07km

Time spent slow walking = 14 mins

Time spent fast walking = 7mins

12.0 FREQUENTLY ASKED QUESTIONS

What happens if I forget to wear my device?

As soon as you realise that you have not worn it, put it on. Even if it is half way through the day, please put the device on. Please keep a note in your diary if there is a day, which you forgot to wear the device, and let Julie know at the next assessment appointment.

What happens if I get the device wet?

Take the device off and remove the sensor from the band, and dry both the band and the sensor thoroughly. Once you have dried it, tap the screen and see if it is working. If not contact Julie. 01224 263282, or j.c.jones@rgu.ac.uk

What happens at the end of the study?

You will be sent a pre-paid envelope for you send back your activity tracker and you Smart phone should you have borrowed one. All we ask is that you put the device(s) the device, fastening it securely envelope and pop it in the post. Thank you.

Any problems or issues contact Julie on:

☎ 01224 263282

✉ j.c.jones@rgu.ac.uk

13.0 YOUR HOME EXERCISE PROGRAMME AND REHABGuru

Physiotherapists commonly provide patients with a home exercise programme, because as you will have realised by now, the one exercise session a week is not enough. All the good work that you do in your session needs to be reinforced at home. As part of this study, we would like participants to work toward **completing their home exercise programme (HEP) five times a week**. By completing your HEP, you will meeting the physical activity guidelines but this frequency of exercise engagement is also associated with benefits for your Parkinson's.

Before you start, we need to consider your **safety**

Ensure that you have a chair that is sturdy and stable

Wear comfortable clothes and supportive footwear that allows you freedom to move.

Ensure that you have enough space to exercise, and that there is no hazards which you could trip on while exercising

While exercising, if you experience chest pain, dizziness or severe shortness of breath, stop immediately and contact your GP

If you experience pain in your joints or muscles, stop, check your position and try again. If the pain persists, contact your physiotherapist or fitness instructor

Have some water to hand so that you remain hydrated

13.0 YOUR HOME EXERCISE PROGRAMME AND REHABGuru

Your physiotherapist will get you started with an exercise programme and this will be updated throughout the study to ensure that your programme remains challenging to meets your needs. The content of your HEP, will be informed by discussions with you as to your preferred types of exercise, your goals, and your individual health and Parkinson's needs. Therefore, your HEP is unique to you and will differ from other participants within the study.

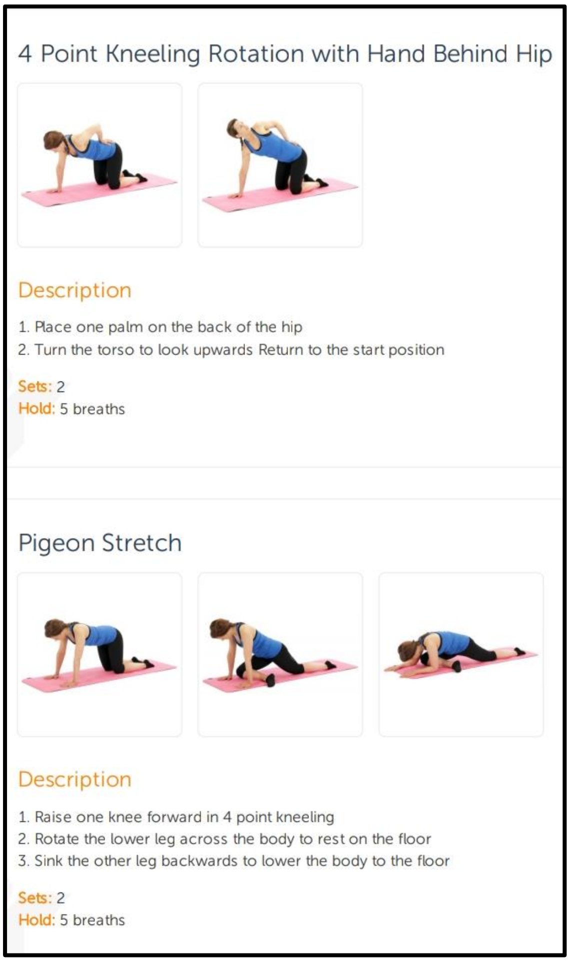
To help with exercising at home, you will receive a list of exercises for you to complete at home. We will be using REHABGuru®, which is an electronic library of exercise, which provides clear pictures, and videos of the exercises that you need to do at home. You will be asked to complete these exercises five times each week at home.

Once we have planned your home exercise programme with you, we will send a copy of this to you via Microsoft teams to your own personal channel. Microsoft teams use the word channel instead of the folder. Your channel can only be accessed by you and members of the research team.

You will be able to view your home exercise programme here, and if you have any questions you can send a message or call to the research team who will be able to answer this for you through this personal channel. The advantages of having access to your home exercises on Microsoft teams is that you can also watch videos of the exercise that you have been prescribed which may help remind you of the correct technique. It also means that you can access you HEP anywhere even if you are away from home.

Julie will take you through how to access your exercise and introduce you to your personal channel at the beginning of the study.

Example of a REHABguru Home Exercise Programme



4 Point Kneeling Rotation with Hand Behind Hip

Description

1. Place one palm on the back of the hip
2. Turn the torso to look upwards Return to the start position

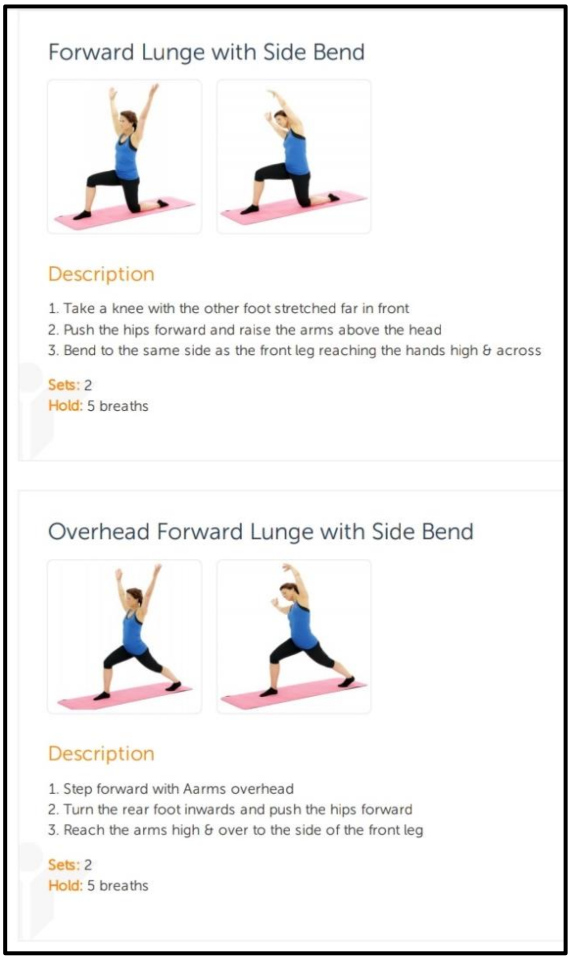
Sets: 2
Hold: 5 breaths

Pigeon Stretch

Description

1. Raise one knee forward in 4 point kneeling
2. Rotate the lower leg across the body to rest on the floor
3. Sink the other leg backwards to lower the body to the floor

Sets: 2
Hold: 5 breaths



Forward Lunge with Side Bend

Description

1. Take a knee with the other foot stretched far in front
2. Push the hips forward and raise the arms above the head
3. Bend to the same side as the front leg reaching the hands high & across

Sets: 2
Hold: 5 breaths

Overhead Forward Lunge with Side Bend

Description

1. Step forward with Aarms overhead
2. Turn the rear foot inwards and push the hips forward
3. Reach the arms high & over to the side of the front leg

Sets: 2
Hold: 5 breaths

PDConnect

13.0 YOUR HOME EXERCISE PROGRAMME AND REHABGuru

Safety considerations when exercising at home and during online sessions

Participation in exercise can cause injury, therefore working at a rate and pace that you are comfortable is important. You will be doing your home exercise programme unsupervised. Therefore as when exercising online, consideration to health and safety is required. Below is a list of additional health and safety information and guidance drawn from the Parkinson’s Excellence Network Exercise Hub information “staying active at home when you have Parkinson’s”.

Before you start exercising you need to prepare your environment making sure that your living space is safe and comfortable for exercise.

- Move loose rugs and unnecessary furniture to clear enough space.
- Keep sturdy chairs ready to hold onto, or to sit and rest on.
- Make sure your room is at a comfortable temperature - don’t exercise in a room that’s too hot. Open a window if you need to.
- Check that your shoes and any equipment you’re using are in a good condition and right for the activity.
- Remember to keep any important medication or inhalers close by.
- Have a telephone or mobile nearby in case of an emergency. If you live alone, please ensure that someone is knows that you are exercising at home and check in with them after you have finished.
- Don’t forget to drink water. You can lose around one and a half litres of fluid for every hour of vigorous exercise, so drink water before, during and after a session.

13.0 YOUR HOME EXERCISE PROGRAMME AND REHABGuru

Frequency of exercising at home

You need to work towards completing your home exercise programme five times a week.

It would be a good idea to put in your activity planner when and what days you plan to do your exercises, as when we are busy exercise is often the first thing to go.

Schedule in some walks outside, and challenge yourself to walk at faster than your normal comfortable pace, for 2 minutes and then slow back down to your comfortable place. When you are feeling more confident, you could consider adding in some hills, as these require more effort. Try to build us your walking to 20 minutes three to four times a week.

Exercising on your own at home can be challenging. Exercising with others can be motivating and keep you at it on those days where you find it a struggle to do your exercises. So, why not get your partner or family member involved too.

14.0 STAYING ACTIVE

Local exercise opportunities:

There is a number of exercise opportunities in Aberdeen city and shire. The ones below are Parkinson's specific to get your started:

Local Parkinson's group: Aberdeen Branch. Alice Hall ☎ 0344 225 3725 ✉ vc.scotland1@parkinsons.org.uk Sheddocksley Baptist Church, Eday Road, Aberdeen This group meets monthly on the third Wednesday of the month. 7.30-9.30pm 🔍 https://localsupport.parkinsons.org.uk/provider/aberdeen-branch
Garioch branch Alice Hall ☎ 0344 225 3725 ✉ vc.scotland1@parkinsons.org.uk Acorn centre**,** West High Street,Inverurie This group meets monthly on the last Tuesday of the month except December, January and July 🔍 https://localsupport.parkinsons.org.uk/activity/garioch-group-meeting
Aboyne Group Alice Hall ☎ 0344 225 3725 ✉ vc.scotland1@parkinsons.org.uk St Margarets Catholic Church, Aboyne This group meets monthly on the first Thursday of every month
Parkinson's UK Online exercise classes, developed and delivered by Parkinson's specialist Physiotherapists and fitness instructors https://www.youtube.com/playlist?list=PL1ixQpbHed3asr5w0qe6ufxNTt1a4KpP

PDConnect

14.0 STAYING ACTIVE

Parkinson's Specific Exercise classes:

Exercise classes: Sheddocksley Baptist Church Eday Road Aberdeen Every Thursday 0945-10.30, and 10.45 until 12. ☎ 0344 225 3742 ✉ aberdeenpsg@gmail.com 🔍 https://localsupport.parkinsons.org.uk/activity/physiotherapy-3	
Exercise classes: Aboyne Community centre Every Friday morning 10.30-11.30 circuit based exercise. 11.30-12.30 chair based exercise ☎ 01339 267702 ✉ steve.russell@aberdeenshire.gov.uk	
Singing group: Sheddocksley Baptist Church, Eday Road,Aberdeen Every Friday 10-11am ☎ 0344 225 3742 ✉ aberdeenpsg@gmail.com	
CityMoves: Dance for Parkinson's His Majesties Muscic Theatre, Rehearsal Studio Tuesday afternoon 2-4pm Booking required ☎ 01224 984161. ✉ citymoves@citymoves.org.uk 🔍 https://www.citymoves.org.uk/class/dance-for-parkinsons/	

PDConnect

14.0 STAYING ACTIVE

Other exercise opportunities in the area:

Aberdeen Sports Village

There is a variety of EVERGREEN exercise classes on each day including badminton, table tennis, exercise to music, pilates, yoga, aqua aerobics, open to those over those age of 60. Click on the website below and have a look at the opportunities available to you.
https://www.aberdeensportsvillage.com/group-exercise

RGU ROBERT GORDON UNIVERSITY ABERDEEN

Group based exercise classes run by University Physiotherapy staff and students. Classes run every Monday, 10-11, and 11-12.
Contact Gavin g.m.thomas@rgu.ac.uk or Chris c.mieklejohn@rgu.ac.uk if you are interested.

15.0 Further reading and information

- National Institute of Health and Care Excellence (NICE) Parkinson’s Guideline, published in 2017. https://www.nice.org.uk/guidance/ng71

- “Gaun Yersel!”: The Self Management Strategy for Long Term Conditions in Scotland 2009 http://www.ltcas.org.uk/index.php?id=47

- Parkinson’s UK information and support site: https://www.parkinsons.org.uk/information-and-support

- Parkinson’s UK – further reading in exercise: https://www.parkinsons.org.uk/information-and-support/exercise

- Listen to this podcast which gives a nice over view of Parkinson’s – 25min listen. https://edhub.ama-assn.org/jn-learning/audio-player/18219124

- All photographs courtesy of Parkinson's UK'

Thank you

Thank you very much for your time during the course of this study, it is very much appreciated. Should you experience any problems during the course of the study or wish to feedback on the experience please feel free to contact Julie Jones, who is the principal researcher in confidence, or you may also contact the convenor of the RGU Ethics committee or Mrs Laura Binnie, Head of the School of Health Sciences.

Julie Jones	☎ 01224 263282	✉ j.c.jones@rgu.ac.uk
Convenor	☎ 01224 263250	✉ SREC@rgu.ac.uk
Laura Binnie	☎ 01224 263251	✉ l.m.binnie@rgu.ac.uk

Now that the study is complete, please could you return the activity tracker, and the Smart Phone if you have borrowed one. You have been provided with a prepaid envelope so that the devices can be returned to the research team through the Royal Mail special delivery service. If you have any questions, please contact Julie Jones, contact details above.

16.0 NOTES

8.21 APPENDIX 21: PDCONNECT STAFF MANUAL

PDConnect

PDConnect: Training and Development Manual

PDConnect

Training and Development Manual Content

Welcome

Welcome to the PDConnect training and development workbook.

This workbook has been designed to be a flexible learning tool combining online learning, with practical based workshops to consolidate learning. The intention was that learning resources would be easy to access, allowing you to fit learning around your work and home life commitments. The training workbook been produced as part of a research project jointly funded by the Chief Scientist Office, and Parkinson's UK.

The sections have been carefully selected, with the content informed by the collective views of Parkinson's specialist exercise professionals in the UK and the Parkinson's community. The aim of the training is to provide you with an advanced understanding of the pathology of Parkinson's, and effective management of this complex long-term condition. In addition, it serves to provide you with further skills in supporting behaviour change, enabling people with Parkinson's to have the tools and strategies available, to effectively manage their own condition. All of us could be more active, and developing good exercise habits is not easy at any stage of life, therefore a key aspect of this training discusses and explores tried and tested strategies that promote changes to behaviour. As such, this training alongside the PDConnect intervention aims to equip people with Parkinson's with the knowledge, skills and confidence to self-direct and manage their own physical activity and foster a sense of taking control.

2.0 About the Training programme

2.1: Origins of the training

The content of this training has been guided and informed by the following:

- Parkinson's Excellence Network Exercise Hub – which is a group of Physiotherapists and Exercise Instructors who are Parkinson's specialists.
- National and local consultations with the Parkinson community, and qualitative research, which has captured the views and perceptions of people with Parkinson's.
- NICE Guidelines for Parkinson's (2017)
- Allied Health Professionals' Competency framework for progressive neurological conditions.
- Physiotherapy Framework. Chartered Society of Physiotherapy 2013
- Standards of conduct, performance and ethics, HCPC 2016.
- Scientific literature published in the last decade.

UK PARKINSON'S Excellence Network

hcpc health & care professions council

CHARTERED SOCIETY OF PHYSIOTHERAPY


Allied Health Professionals' competency framework for progressive neurological conditions

NHS
National Institute for Health and Clinical Excellence


Rate of Progression in Activity and Participation Outcomes in Exercisers with Parkinson's Disease: A Five Year Prospective Longitudinal Study

Exercise-induced increase in brain-derived neurotrophic factor in human Parkinson's disease: a systematic review and meta-analysis

The effects of dual task gait and balance training in Parkinson's disease: a systematic review

Exercise-induced neuroplasticity in human Parkinson's disease: What is the evidence telling us?

Effectiveness of resistance training on muscle strength and physical function in people with Parkinson's disease: a systematic review and meta-analysis

Effects of Exercise on Falls, Balance, and Gait Ability in Parkinson's Disease: A Meta-analysis

Xia Shen, MPT[1,2], Irene S. K. Wong-Yu, MSc[2], and Margaret K. Y. Mak, PhD[2]

PARKINSON'S UK

2.2 The need for education and training

The National Institute for Health and Clinical Excellence (NICE) published the new Parkinson's Guidelines, which recommended that all people with Parkinson's should be seen by a specialist Physiotherapist or exercise professional from diagnosis for assessment, education and advice, including information about physical activity. Similarly, the European Physiotherapy Guidelines published in 2014 highlighted the need for specialist training to meet the diverse and complex needs of people with Parkinson's. Further, this need for specialist training has been voiced by the Parkinson's community. Qualitative research has highlighted that people with Parkinson's value specialists' ability to:

- Tailor exercise to meet individual needs
- Educate on exercise dosage
- Be proactive delivery of therapy
- Provide timely feedback

The use of specialist physiotherapists has been shown to enhance quality of care and cost effectiveness. The evidence therefore suggests that care is optimised and enhanced when delivered by physiotherapists who have undertaken dedicated Parkinson's training. However, in the UK there is no formalised postgraduate training programmes to address this need.

This manual therefore has been designed to address this gap and is designed to be an interactive resource, which you can engage with at home or at work.

PDConnect

2.0: About the training programme

2.3: Learning Outcomes

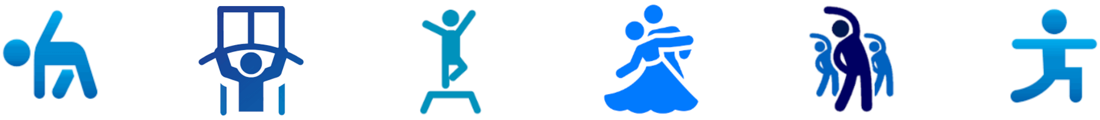
This training programme will the following key areas:

- Pathophysiology of Parkinson’s
- Symptom management
- Exercise prescription for PwP
- Self-management
- Behaviour change interventions
- Developing effective patient partnerships.
- PDConnect programme

Recognition of the difference in prior education and training and professional standards between Physiotherapists and Exercise Professionals, is reflected in the different learning objectives of the training and development, which will be delivered as part of the PDConnect study.

The overall aim of this workbook is to enable you to:

1. Develop specialist knowledge and understanding of Parkinson’s, and the impact this has on everyday life
2. Plan and deliver bespoke evidence informed exercise programmes for people with Parkinson’s
3. Deliver effective behaviour change intervention to support people with Parkinson’s to embed exercise within everyday life
4. Enable and equip you to effectively deliver the PDConnect intervention



2.4: Training and development overview

The training is divided into two main components, an interactive learning workbook that you can access of online or download and print in paper format, which should take up to 12 hours of study, followed by a full day practical workshop. The learning study is full directed, where a range of different resources have been identified to aid your learning. Resources you will encounter include:

📚	Links to Journal articles
🎙	Podcasts
▶ YouTube	YouTube/Videos

Reading resources are highlight by the 📖 icon, with audio-visual resources highlighted by the 🎧 icon. There are also embedded links within the text, which are blue and underlined; clicking these links will also take you to further reading resources. Expectations will be that you work through the online material prior to attending the practical workshop, which will be held on XXXX at RGU. Should you have any problems, please contact Julie Jones

☎ 01224 2632821 ✉ j.c.jones@rgu.ac.uk

2.5: Before you get started

Prior to commencing this learning, it would be useful for you to think of your current line of work and identify what you think below are your key learning requirements in relation to working with people with Parkinson's. This will be useful to review on completion of this workbook, and any learning, which has not been covered within this package, can be addressed within the practical workshop.

Please write in the space below what you perceive are your key learning needs, to effectively manage people with Parkinson's.

3.0: Understanding Parkinson’s

3.1: Learning outcomes

Key Learning outcomes for physiotherapists:

1. To critically discuss the pathophysiology of Parkinson’s and be able to relate and evaluate the impact this has on PwP and their wider support network.
2. To discuss the impact of motor and non-motor Parkinsonian symptoms on movement and function amongst PwP
3. Critically discuss and justify core physiotherapy treatment and assessment approaches and further assessment skills, and safely, effectively, and professionally apply selected physiotherapy techniques.
4. To independently select and apply appropriate assessment techniques to meet individual patient needs

Key Learning outcomes for Fitness Instructors

1. To discuss the pathology of Parkinson’s and the impact this has on everyday function
2. To discuss the range of motor and non-motor symptoms which occur in Parkinson’ and the impact this has upon movement.
3. To develop an awareness of the key measures used to measure performance and ability for PwP.

3.2: Pathophysiology:

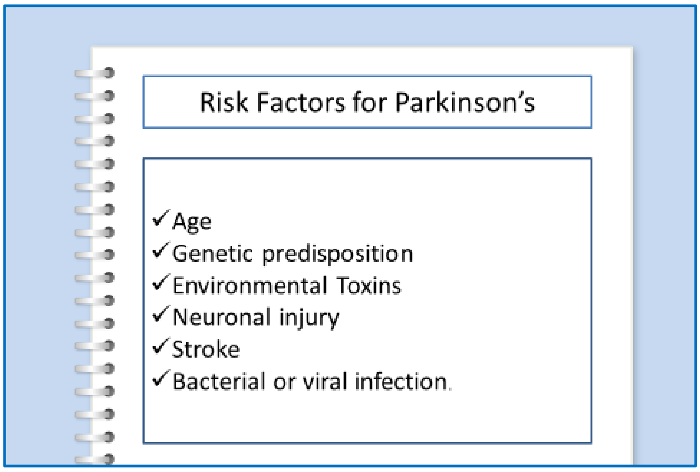
Parkinson's is a complex condition, with over forty different recognised symptoms, with the distribution of these symptoms differing between patients. Parkinson's is a classified as a progressive neurodegenerative disorder, and pathologically it is defined by the selective loss of dopaminergic neurons within the substantia nigra pars compacta of the midbrain and intracellular inclusions called Lewy bodies (LB) in the neurons of affected brain regions. With disease progression, there is degeneration of the neural circuitry within the nigrostriatal pathway, producing motor, cognitive and psychiatric symptoms. Dopamine is a neurotransmitter that allows function, controlling voluntary and non-voluntary movements. Due to the loss of dopamine, the symptoms of Parkinson's such as slowness of movement rigidity, tremor and postural changes occur. The non-motor symptoms are reported to arise when 30% of dopaminergic cells are lost, with motor symptoms becoming more prevalent when70 per cent of the dopamine producing cells located in the substantia nigra become damaged and die[1].

The exact mechanism, which causes dopamine decline, is unknown although a number of mechanisms are thought to contribute to this loss. Although the cause remains undetermined a combination of environmental and genetics interactions is a commonly held view. Up to 10% of cases have a clear genetic origin, while the rest are of idiopathic in nature. The predominant pathogenic processes include protein arrogation, oxidative stress, progressive neurodegeneration, and systemic neuro-inflammation.

Nice introduction to causes of Parkinson's

[Understanding Parkinson's](https://www.parkinsons.org.uk/information-and-support/what-causes-parkinsons)

https://www.parkinsons.org.uk/information-and-support/what-causes-parkinsons

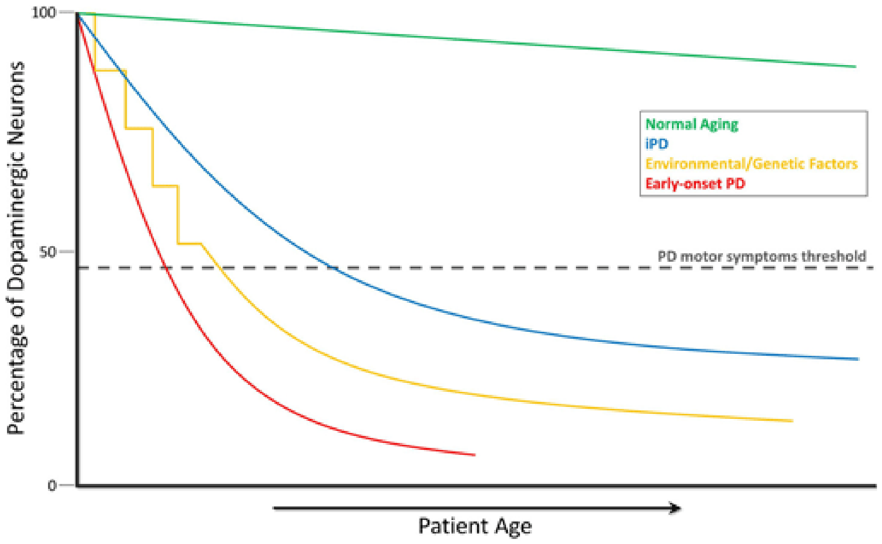


Risk Factors for Parkinson's

- ✓Age
- ✓Genetic predisposition
- ✓Environmental Toxins
- ✓Neuronal injury
- ✓Stroke
- ✓Bacterial or viral infection.

3.3: Age:

Ageing is the most important significant risk factor for developing Parkinson's, with incidence rising sharply at the age of 60's and then exponentially in subsequent decades of life globally[2]. Owing to ageing population, this likely explains in part why the incidence of Parkinson's is predicted to rise by 50% by 2030[3]. Parkinson's is in itself is a challenging condition to manage owing to the diversity of symptoms, but as it most commonly occurs when people are over the age of 60 means that they likely have co-existing conditions e.g. Coronary Heart Disease, which needs to be considered when treatment planning.



3.4: Genetics’ and Parkinson’s.

Genetic changes are seen in both familial and idiopathic Parkinson’s. The most common being the alpha synuclein gene, which encodes the alpha synuclein protein, which is produced in a variety of places in the brain and may in part explain the diversity of symptoms seen in Parkinson’s. For reason yet to be determined fully by scientists, these proteins become misfolded and clump together into form Lewy Bodies. Lewy bodies can occur anywhere in the brain, but in Parkinson’s they form within the Basal Ganglia, in particular the Substantia Nigra. It is thought that these sticky clumps of a-synuclein effect the integrity of the inside of the cell, disrupting the normal recycling of proteins, effecting mitochondrial health, and activity, and the realise of the neurotransmitter dopamine. Evidence would also suggest that Lewy bodies effecting one cell, can spread into neighbouring cells causing widespread disruption, which starts of a chain of reactions within the new cell causing damage and ultimately cells death. This ability of Lewy bodies to migrate to other cells is believed to be responsible for the progression of symptoms seen in Parkinson’s.

Becky Port provides a good overview of the genetics involved in the pathophysiology of Parkinson’s

Shulman et al (2011) article provides and review of genetics in Parkinson’s.

Podcasts on Genetics and Parkinson’s
Michael J Fox Foundation Genetic causes of Parkinson’s
Michael J Fox Foundation Proteins in Parkinson’s
Alpha Synuclein in Parkinson’s- Parkinson’s UK
Khan Academy: Genetics in Parkinson’s

3.5: Environmental Toxins:

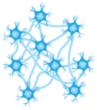
Pesticides are most significant environmental factor associated with Parkinson’s, causing oxidative stress. Oxidative stress occurs when there is imbalance between free radicals and antioxidants in your body. Free radicals have an uneven number of electrons, which means that they react easily with other molecules. As a result, they can form large chain chemical reactions –these reactions - referred to as oxidation; can be either harmful or beneficial to the body.

Oxidative stress in Parkinson’s has been shown to:

- ↑ Lipid Peroxidation
- DNA Damage
- Mitochondrial dysfunction

Causing dopaminergic neuronal dysfunction Substantia Nigra compacta

Nigral dopaminergic neurons are particularly sensitive to oxidative stress. Oxidative stress initiates a number of other chain reactions, which cause neuronal dysfunction and ultimately cell death. Oxidative stress stimulates microglial activation, which precipitates the generation reactive oxygen species (ROS) from microglia, and consequently further dopaminergic neuronal death to ultimately propagate and propel a feed forward cycle of neuronal cell death and inflammation underlying the progression of the disease (see figure 1).



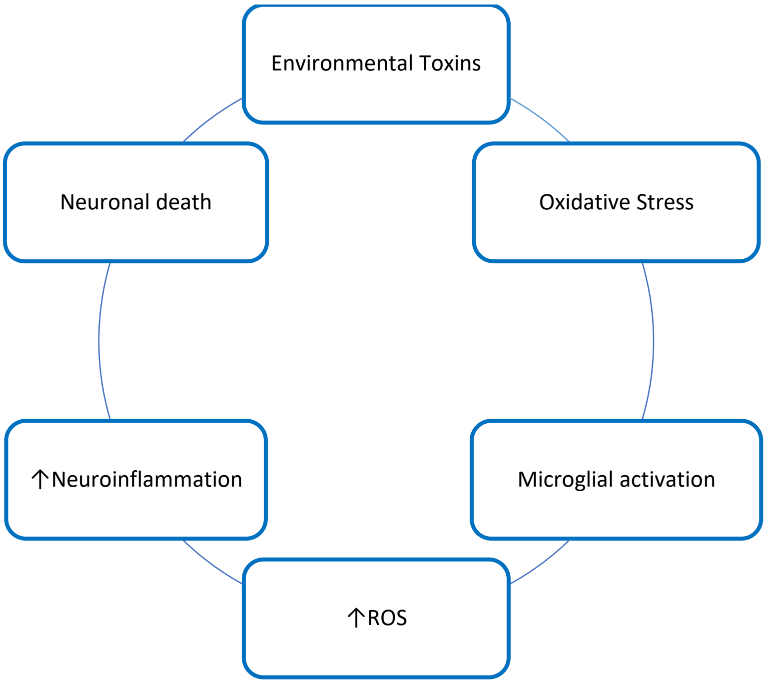


Figure 1.

3.6: Mitochondrial dysfunction:

Mitochondria dysfunction is associated with Parkinson's. Healthy mitochondria produce power to drive biological processes, and maintain the health of cells, and regulating their function. In Parkinson's, mitochondria appear less efficient, in terms of energy production but also mitochondrial biogenesis. Like batteries, mitochondria run out, and need replacing, in Parkinson's this replacement system is slowed (mitophagy), resulting in old mitochondria existing in cells for longer than they should. These old cells are inefficient, and produce ROS, leading to oxidative stress, which initiates the destruction of cells, and ultimately cell death. The complex interplay of the various mitochondrial functions leads to a vicious cycle of progressive cellular dysfunction that ultimately results in neurodegeneration that underlies PD pathogenesis and progression.

Heather Mortiboys talking about the role of mitochondria in the pathogenesis of Parkinson's:
https://www.youtube.com/watch?v=Yamv4v5tUqs&t=40

3.7: Neuro-inflammation:

It remains unknown is neuro-inflammation is a consequence of or a cause of neurodegenerative diseases[4].

Neuro-inflammation can occur when the natural inflammation response is not stopped, which leads to a chronical inflammatory state, or in response to secreted molecules from neurons under degeneration. Postmortem, studies of Parkinson's brains have demonstrated high levels of activated microglial cells, and inflammatory mediators such as cytokines, chemokines, and ROS, implicating neuro-inflammation within the pathology. Further, animal models suggest that neuro-inflammation plays a pivot role in disease progression and is associated with neurotrophic and mitochondrial dysfunction, oxidative stress and protein functions such as alpha synuclein[5].

If you would like to read more about neuro-inflammatory mechanism in Parkinson's- Troncoso-Escudero et al (2018)

Further reading on the causes of Parkinson's:
https://www.parkinsons.org.uk/information-and-support/what-causes-parkinsons
Parkinson's review paper by Kalia and Lang (2015)

Huw Morris talking about causes of Parkinson's and current research. https://www.youtube.com/watch?v=6F-Bx7qjnSo

3.7: Neural Injury:

Neural Injury is another mechanism, which has been known to cause Parkinsonian symptoms. In this instance, this refers to a traumatic brain injury that occurs either in an acute incident of chronically over time. Traumatic Brain injury is linked with breakdown of the blood brain barrier, brain inflammation, impaired mitochondrial function, and α-synuclein accumulation[6]. Similarly, viral and bacterial infection can cause similar effects within the CNS leading to neuronal damage, degeneration and cell death.

3.8: Stroke:

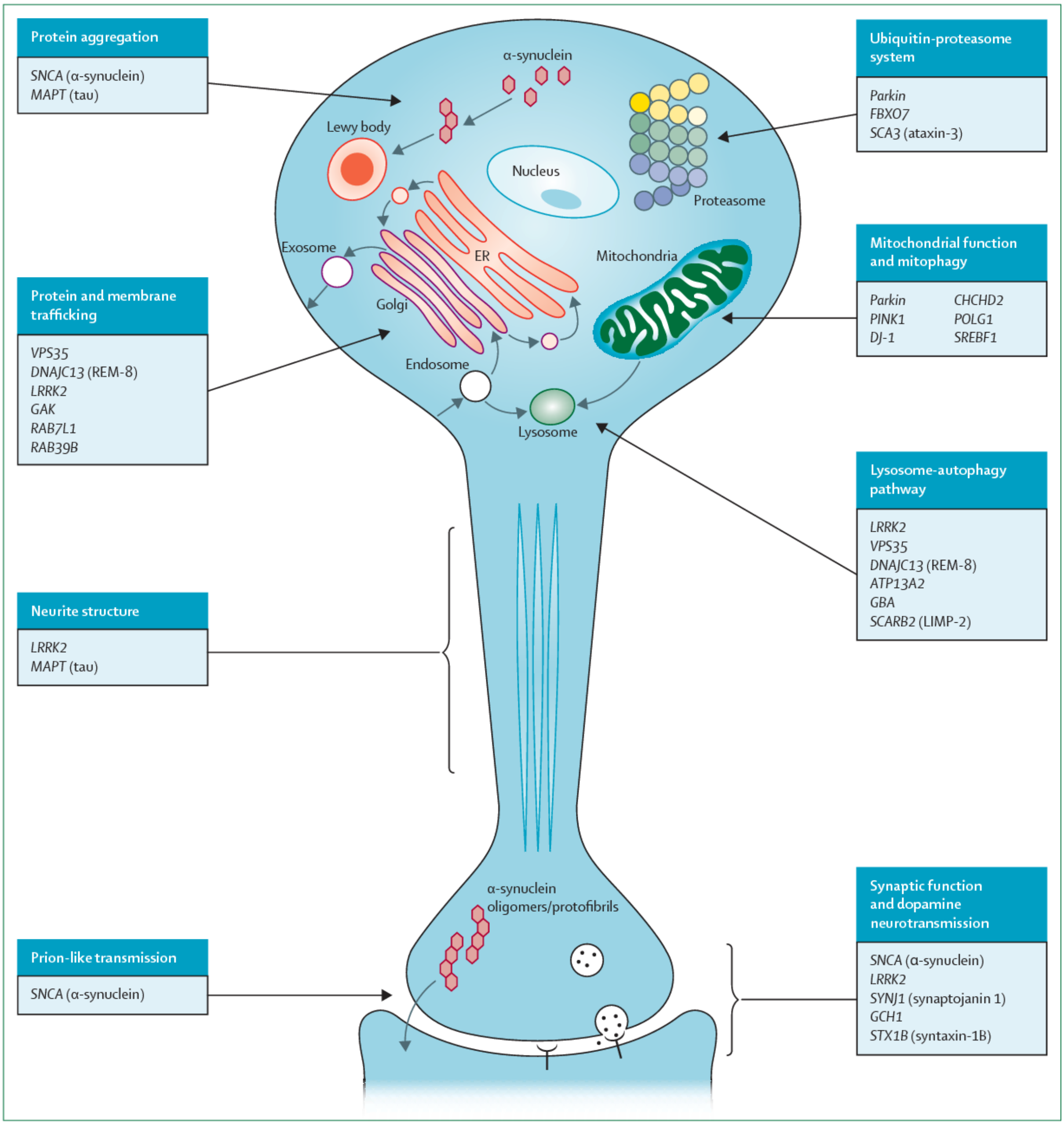
Stroke by its very mechanism of either ischemic or haemorrhagic will result in cell death due to restriction in blood flow to the cells. Therefore, is a person were to have a stroke or repeated TIA's within the Basal Ganglia they will present with Parkinsonian symptoms. However, this would be subtyped, as secondary Parkinson's not idiopathic as the cause can be ascertained.

3.9: Parkinson's outside the Central Nervous System

In recent years there has been much news coverage suggesting that Parkinson's is not solely a central nervous system condition and may have origins outside the brain, for example the gut. Changes in the microorganisms in the gut are believed to play a role in the initiation of Parkinson's, as the promote build up and aggregation of proteins which is linked to Parkinson's.

Parkinson's UK Brief video on the involvement in the gut
Michael J Fox Foundation on the role of the gut in Parkinson's (1hour presentation)

Figure3: Key cellular processes implicated in the pathology of Parkinson’s. Kalia and Lang (2015)[9]



3.0: Understanding Parkinson’s

Key Learning Points:

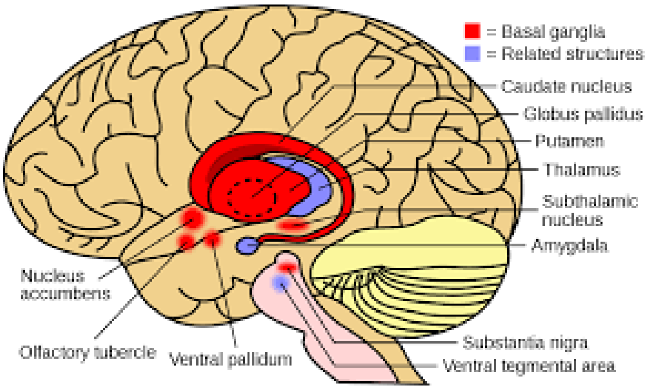
- The causes of Parkinson’s remains undetermined
- Causes are multifactorial in nature and inter-related
- Key causal factors include:
  - Oxidative stress
  - Mitochondrial Dysfunction
  - Neuro-inflammation
  - Protein aggregation
  - Genetics
  - Environmental toxins
  - Age

3.10: What is Parkinson's:

Basic introduction video to Parkinson's (9mins)

Impact of Parkinson's on Movement (13mins)

To understand the symptoms of Parkinson's, you need to revisit your neuroanatomy. The "basal ganglia" is a group of subcortical nuclei responsible primarily for motor control, as well as other roles such as motor learning, executive function and behaviours, and emotions.

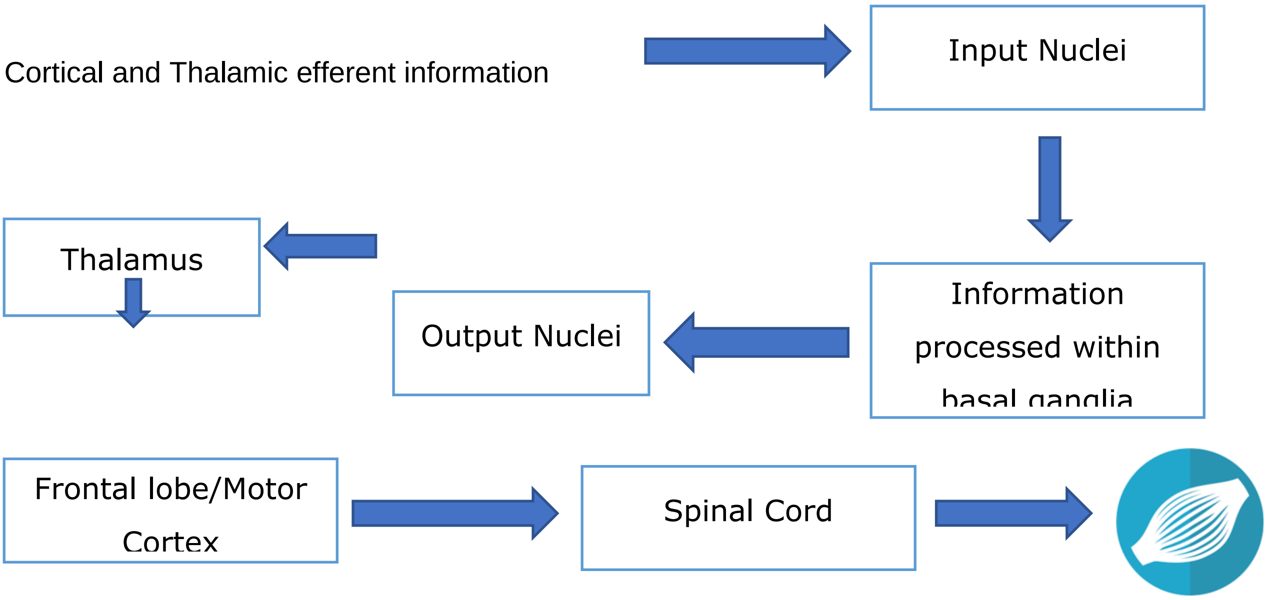


Basal Ganglia nuclei can be classified as: input, output or intrinsic nuclei.

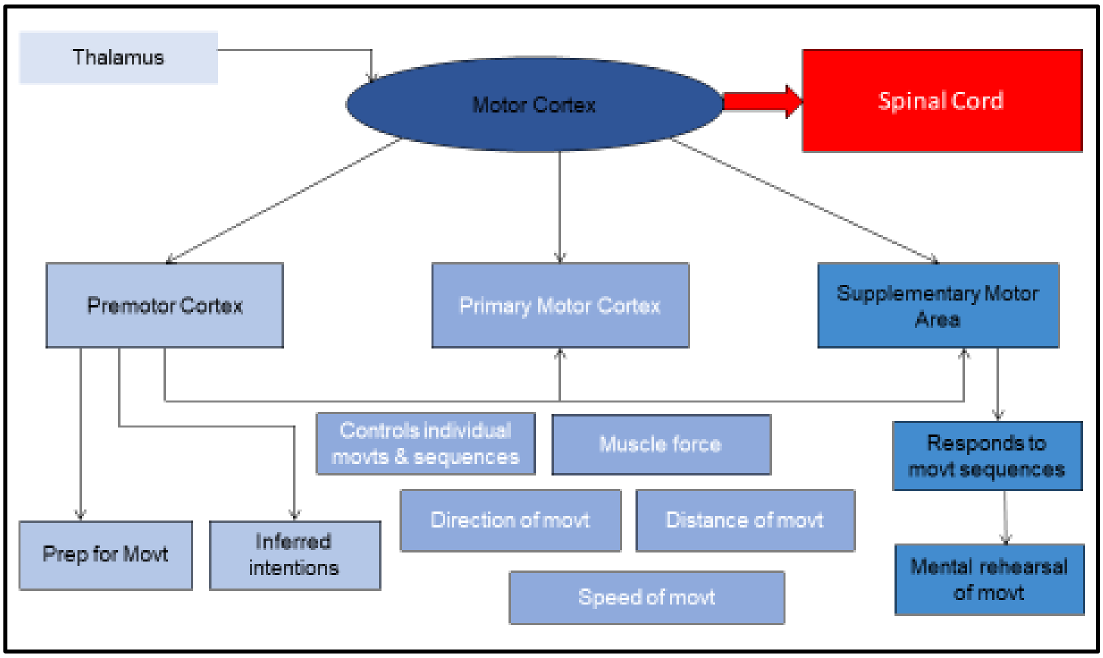
Input	Output	Intrinsic
Receives incoming information from different sources, mainly cortical, thalamic, and nigral in origin: Caudate nucleus (CN) Putamen Accumbens nucleus (AN)	Sends basal ganglia information to the thalamus: Globus Pallidus internus (GPI) Substantia nigra pars reticulate (SNr)	Located between input and output nuclei in the relay of information. Globus pallidus externus(GPe), Subthalmaic Nucleus (STN) Substantia nigra pars compact

Adapted from Lanciego,et al 2012[7]

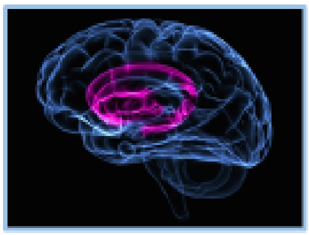
3.11: Role of the Basal Ganglia in Motor control:

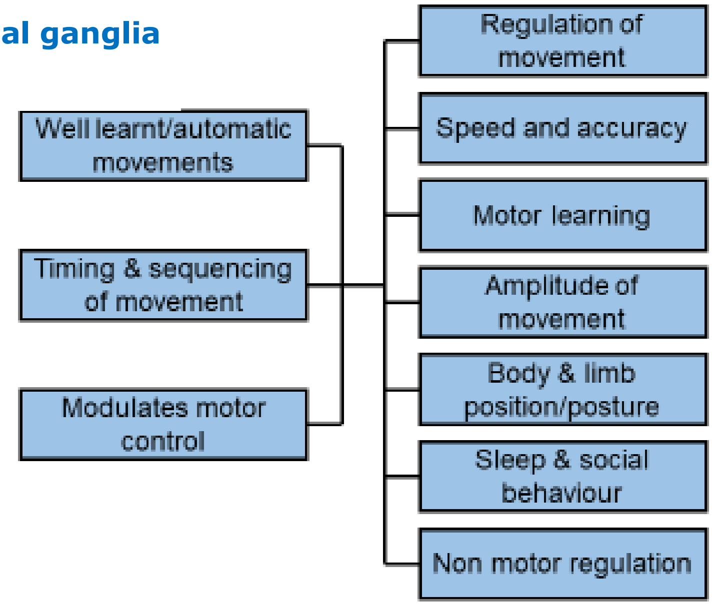


For the basal ganglia to function dopamine is needed to be released at the input nuclei, if not transmission of information is affected. The figure below shows the areas of the frontal lobe and their function, and therefore the symptoms which may arise due to inhibition of the basal ganglia which occurs in the absence of dopamine.



3.12: The role of the basal ganglia in Parkinson's



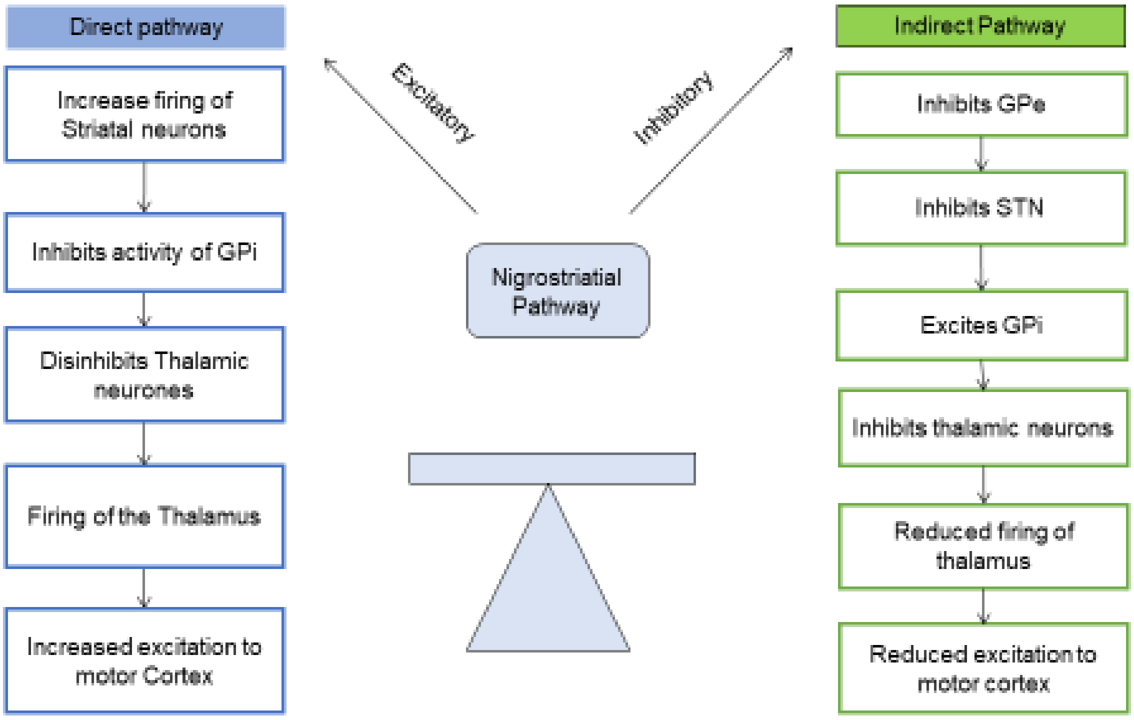


Research has yet to fully understand how dopamine modulates activity of the basal ganglia, however the cortico–basal ganglia–thalamo–cortical loops were proposed in the 1980's[7,8]. This was based upon the concept that neuronal signals from the cortex flow to the striatum, through the GPi and SNr, and project back to the cortex via the thalamus, forming parallel loop. Put simply - Activity in this loop is modulated by the Substantia Nigra, which essentially acts as an accelerator, and the Subthalamic nucleus acting as a break. Therefore, in Parkinson's where there is deficiency of dopamine in the Substantia Nigra, the output of the Substantia Nigra is reduced, and therefore output is reduced to the thalamus and the patient slows down, i.e. the accelerators fails to work.

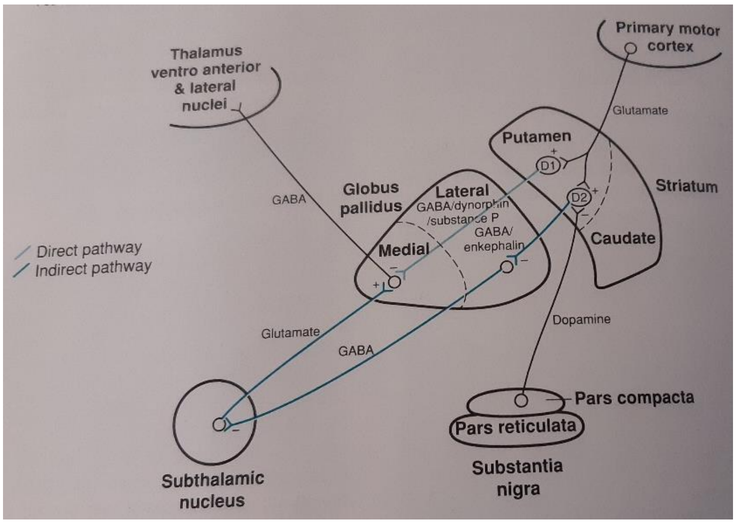
On a more advanced level the basal ganglia output in modulated by two pathways:

- Direct pathway
- Indirect pathway

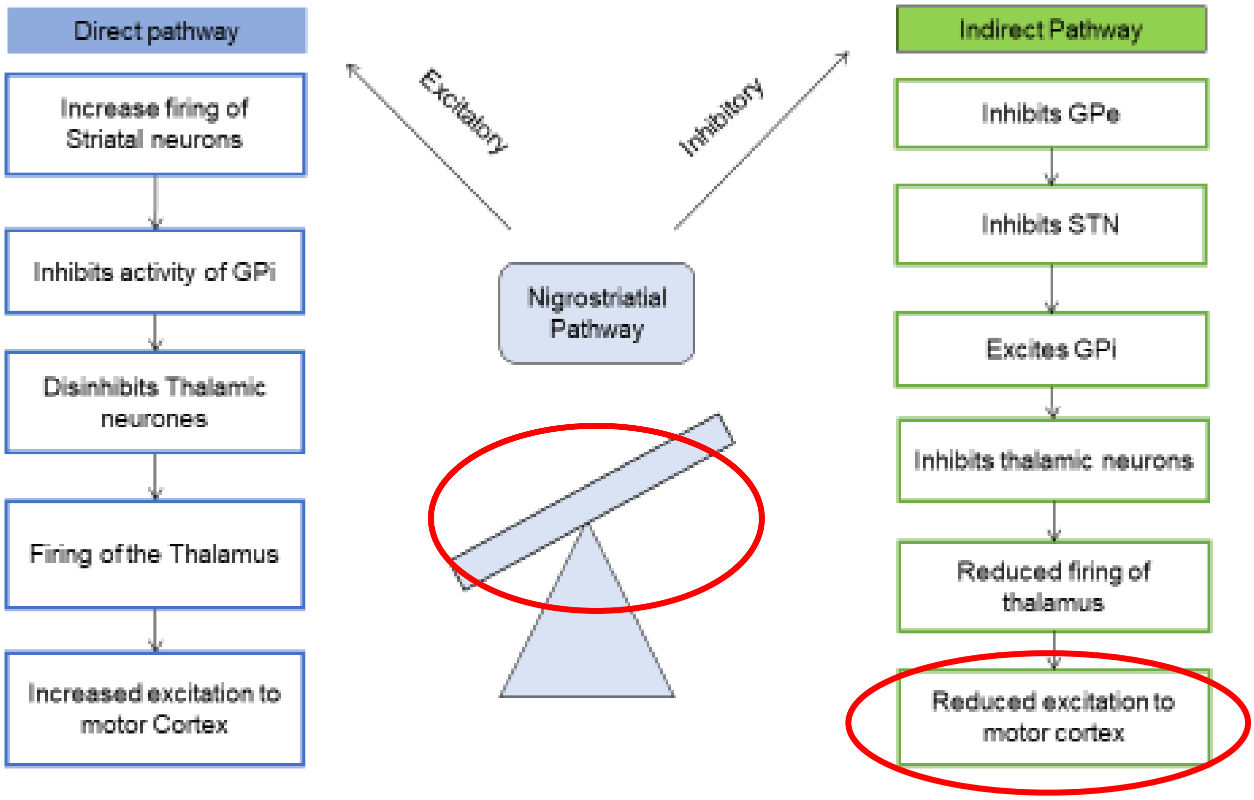
3.13: Direct and indirect pathways



This is a simplified diagram illustrates normal function but does not consider the impact of other neurotransmitters such as glutamate and gaba. The net effect here is **MOVEMENT,** due to communication flowing from the thalamus to the motor cortex.



3.14: Direct and indirect pathways in Parkinson's



The net effect here is one of reduced output via the thalamus and onto the motor cortex. Therefore the motor symptoms seen in Parkinson's in particular lack of modulation of motor control, is that incomplete movement communications can be sent to the cortex affecting performance but also the shifting from one movement segment to another (set shifting) can be negatively affected as the signals to stop one programme prior to commencing another are not conveyed. When this was model was proposed in the 1980's it was perceived that the organisation of the basal ganglia was set up so afferent information was received and modulated within the basal ganglia before it was sent to the motor cortex to either facilitate or inhibit movement as part of a loop. More recently, it has been proposed that there are several loops forming a complex network, ideally designed for selecting and inhibiting simultaneously occurring events and signals.

PDConnect

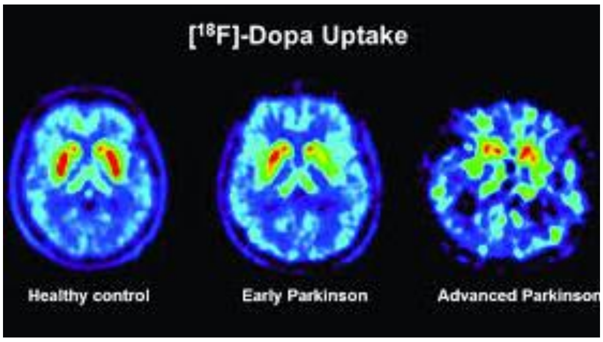
Understanding Parkinson’s

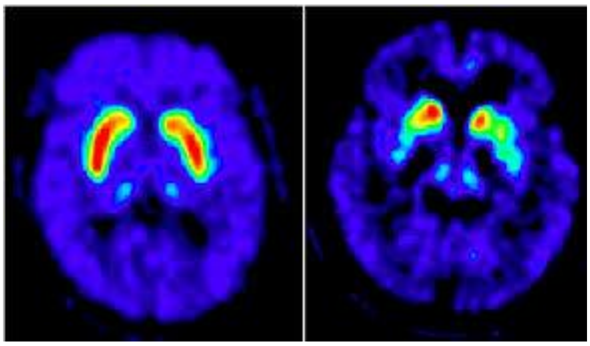
Write in the box below a summary of your learning from the last section. In particular focussing on the influence of the Basal ganglia on motor control in Parkinson’s

3.15: Diagnosis of Parkinson’s:

Research is heavily focussed on establishing biomarkers for Parkinson’s but as yet, there is not a diagnostic test for Parkinson’s. Therefore, diagnosis is based upon clinical features in particular the presence of bradykinesia (slowness of movement), rigidity, and resting tremor. Postural instability, is also regarded as a cardinal feature, however this commonly presents later with disease progression. The UK Brain Bank Criteria[10] is used to improve reliability of diagnosis, with scans and blood test used to rule out any other potential conditions such as tumours and strokes or Parkinson’s plus conditions such as MSA and PSP. As Parkinson’s has over 40 recognised symptoms encompassing both motor and non- motor symptom, patients may require several appointments with their consultant before a diagnosis is confirmed.

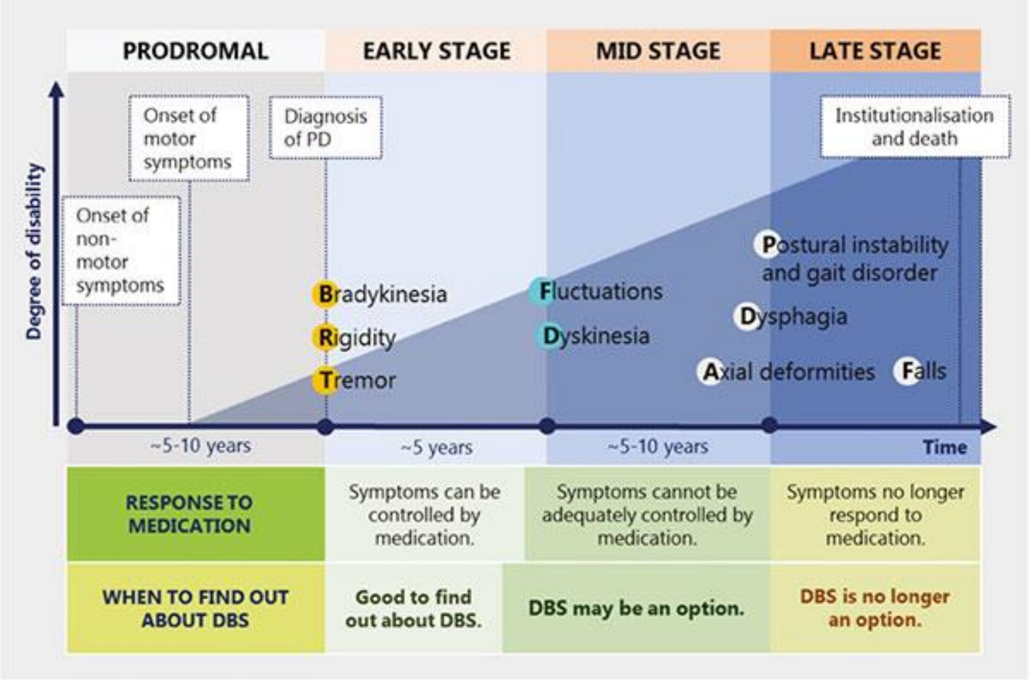
PET scans can be used, which involve injecting a radioisotope, which binds with Dopamine; this allows illustration of dopamine uptake within the brain.



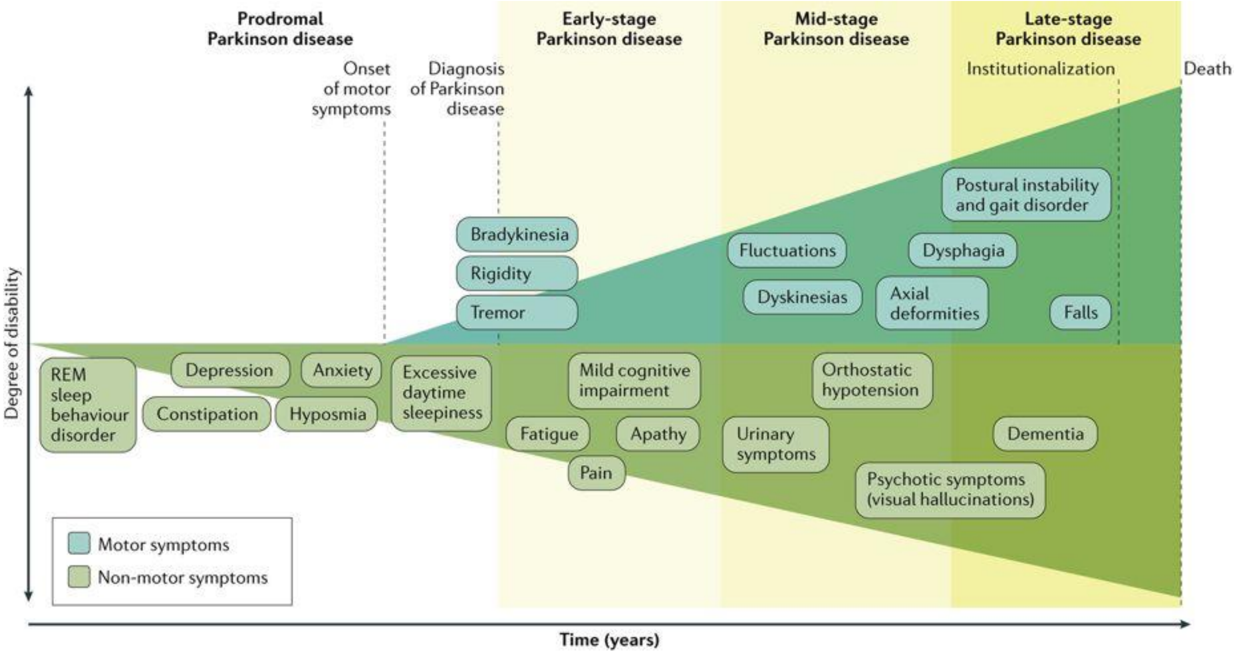


The red areas highlights dopamine uptake areas to in the health controls, you can see two areas highlighted red, with Parkinson’s these progressively get smaller, representing the progressive loss of dopamine

3.16: Progression of Parkinson’s: The progression of Parkinson’s is variable between individuals; however, the chart below provides a guide.



National Heart Centre Singapore



Poewe et al (2017)[11]

Nature Reviews | Disease Primers

Research to date would suggest that Lewy pathology progresses in a standardised approach over the duration of Parkinson’s. Braak[12] proposed six stages whereby Lewy body pathology commences in the periphery, progressing towards the CNS, with cardinal motor features of Parkinson’s emerging only when it effects the CNS at stage 3. This model, while old, is still well regarded although as our knowledge of the condition develops, through emerging research it is increasingly being challenged.

Listen to Dr Alastair Noyce taking about the prodromal phases of Parkinson’s

Stage 1	•Peripheral nervous system (autonomic neurons), olfactory system, medulla.
Stage 2	•Pons, spinal cord grey matter
Stage 3	•Pons, midbrain (substantia nigra pars compacta), basal forebrain, limbic system.
Stage 4	•Limbic system, thalamus, temporal cortex
Stage 5 & 6	•Multiple cortical regions

3.17: What does disease progression look like clinically?

Early stages:

- Unilateral symptoms
- ↓arm swing on one side when walking
- ↓step and stride length, ↓foot clearance
- Fatigues especially on one side of the body
- Difficult conducted repetitive movements
- Difficulties with hand co-ordination esp. on one side
- ↓shoulder ROM, possible adhesive capsulitis
- Hypomimia
- Micrographia

Mid Stages:

- Bilateral symptoms
- Hypophonia
- Dysphagia
- Stooped posture and festinating gait
- Motor fluctuations and dyskinesia's

Late Stages:

- Postural Instability, balance problems and falls
- Gait dysfuntion
- Global rigidity
- Drooling, and Dysphagia

3.18: Parkinson's Symptoms

With over 40 recognised symptoms, Parkinson's is a diverse condition. Further it is a very heterogeneous condition, so there is marked variation in symptom distribution between people, meaning no two people are the present the same.

Symptoms in Parkinson's can be divided into:

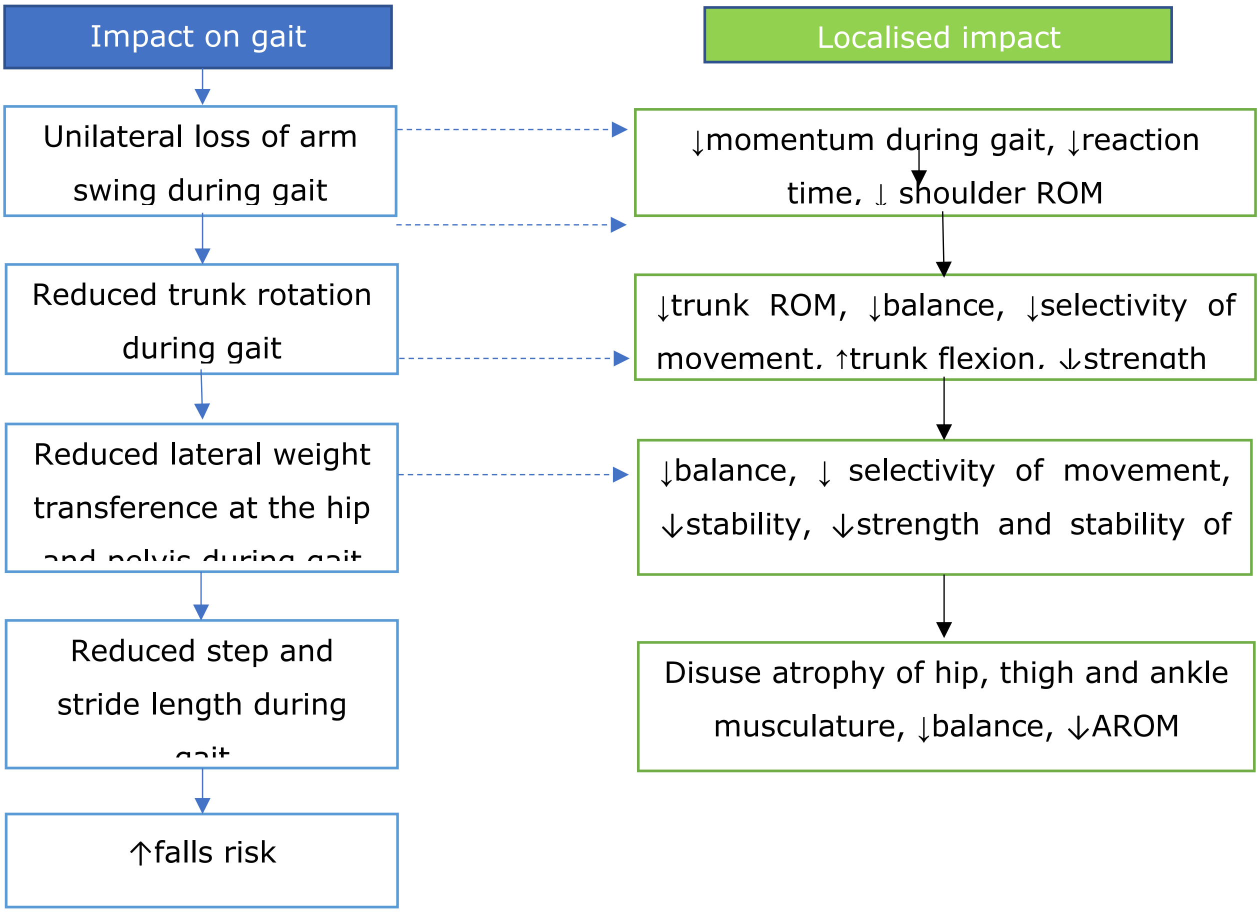
- Motor Symptoms
- Non-Motor symptoms

Davis Phinney Foundation for Parkinson's non-motor symptoms presentation

3.19: Classic Motor Symptom presentation within Parkinson's includes:

- Bradykinesia
- Muscular Ridgity
- Resting Tremor
- Postural &Gait Impairment

Bradykinesia is a slowness of movement, with hypokinesia being a loss of movement. The latter, is commonly seen early in the condition with the unilateral loss of arm swing during walking and the loss of facial expression. Bradykinesia is a primary motor symptom of Parkinson's, however it has wide reaching effects as it causes under-scaled movements and reduction in movement amplitude, which need consideration when designing treatment programmes, the figure below illustrates potential consequences of reduced arm swing, as well as the impact at each local level.



3.20: Rigidity:

Patients report this as stiffness affecting all muscle groups, including limbs and spine. On assessment, this will be felt as resistance during passive movement. When testing for rigidity, it is easiest to recognise when passively moving the elbow or wrist. If the rigidity is mild, asking the patient to actively flex their contralateral shoulder which will emphasise the rigidity –this is known as Froments sign.

Rigidity differs from spasticity. Rigidity in Parkinson’s is commonly referred to as either lead pipe, a smooth resistance through range cogwheeling when it feels more jerky due to superimposed tremor. In rigidity, resistance stay constant throughout the ROM, with spasticity there is a velocity dependent increase in tone followed by relaxation.

Clinical problems associated with rigidity:

- Stiffness
- ↓AROM and PROM
- ↓Strength
- ↓muscle power
- Pain
- Altered biomechanics, and posture
- Altered proprioception
- ↓function
- Learnt non use

3.21: Tremor:

Not all patients will have tremor, up to 20 per cent of people with Parkinson’s never present with a tremor. In Parkinson’s key features of the tremor is that it occurs at rest so differs from essential or action-based tremors. It presents initially in the upper limb, normally unilaterally, before spreading to the ipsilateral leg before progressing bilaterally. The tremor involves intermittent opposition of the thumb and index finger and has been referred to as a pin rolling tremor. Tremor will get worse when patients are stressed, anxious or emotional, and when dual tasking.

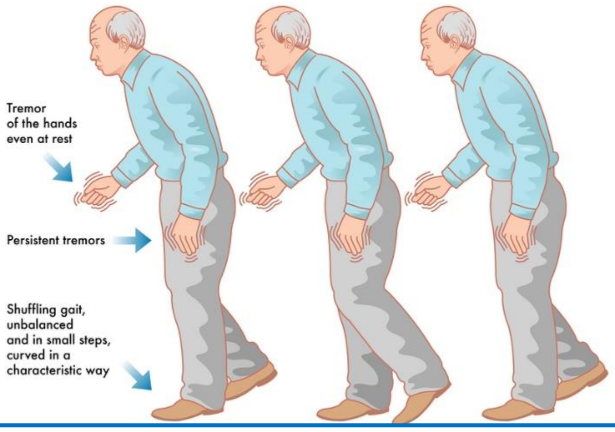
To assess for tremor, ask you patients to sit with their hand resting on their thighs in front of them in sitting. It may well be present straightaway but if not, ask you patient to count backward from 100 in 3’s (i.e. increase cognitive load) and the tremor will become more pronounced.

Clinical problems associated with tremor

- ↓dexterity
- ↓fine motor skills
- ↓ROM
- ↓ muscle strength
- ↓quality of movement
- ↓function

3.22: Postural and gait instability:

This occurs later in the condition therefore is not always a diagnostic criteria. Postural instability is normally associated with trunk flexion, especially in the thoracic and cervical regions. Due to spinal rigidity, patients tend to fall forwards or back. As instability occurs later in the condition, it often co-exists with a shuffling or festinating gait pattern. Postural instability is a culmination of the other cardinal features, which results in a slow gait pattern characterised by reduced step and stride length.



Please list in the box the biomechanical and long-term implications of adopting this posture would be for a person with Parkinson's.

Now that you have worked through the pathology, the role of the basal ganglia and all its interconnections, and the symptoms. Draw a mind map of the symptoms, relating these to the underlying pathology. Include in your map the primary features of Parkinson’s, and how these may link in with other symptoms. Scan you mind map and email this to Julie. Mind map example below on a differ topic

3.23: The impact that Parkinson’s has on people:

Hear the voices of those who live Parkinson’s and how it effects them and those around them.

Emma Lawton, and another from Emma

Sarah and others tell their stories

Paul

Ron and his wife

Janet

PDConnect

3.0: Understanding Parkinson's

STOP

Before we move onto the next section, let's just pause to consolidate all the learning to so far. Please read through the following statements below and tick as applies. If you tick no to any of these, read back through the study materials, and if you have any further questions, please email Julie- j.c.jones@rgu.ac.uk

		YES	NO
1.	Discuss the key causes of Parkinson's, and their contribution to neurodegeneration in Parkinson's		
2.	Discuss the risk factors for Parkinson's and their contribution to symptom generation in Parkinson's		
3.	To be able discuss the role of the basal ganglia in control of movement		
4.	To discuss the impact of dopamine deficiency in the control of movement		
5.	To discuss how Parkinson's is thought to spread within the brain, and how the condition progresses over time		
6.	To be able to identifying key motor features and relate these to the underlying mechanism of the condition		
7.	State the key motor and non-motor features of Parkinson's and how these impact everyday function		
8.	To be able to relate how primary symptoms result in development of secondary musculoskeletal issues		
9.	Articulate the difference between bradykinesia and hypokinesia		
10.	Articulate the impact on Parkinson's on their wider community		

PDConnect

4.0: Medical management of Parkinson’s

4.1: Learning Outcomes:

These learning outcomes adapted from the AHP competency framework for progressive neurological conditions:

1. To demonstrate knowledge and critical understanding of different types of disease specific medical treatments used in PD, including mode of action, aim of intervention, effect on disease, side effects and adverse effects: · Dopamine agonists · Levodopa · MAO-B inhibitors · COMT inhibitors · Glutamate antagonists · Anticholinergics/antimuscarinics

2. To clinical reason and evaluate how medications can affect the physical performance of people with Parkinson’s

Medication forms the mainstay of management for people with Parkinson’s. However, at present, medication can only provide SYMPTOMATIC benefits for patients. It has no effect on slowing the progression of the condition down, as yet no pharmacological therapies exists which are neuroprotective.

To start with watch this video to see why taking medication is so important for people with Parkinson’s.

As mentioned previously no two people with Parkinson’s are the same, and therefore medication types, and dose of medication also vary between people with Parkinson’s. Therefore, an understanding of how they work, and the side effect profile is valuable when managing this group of people.

4.0: Medical management of Parkinson's

There are several classes of medication the people can be on, and people may be on one type or a combination of different classes of drugs. Medications are designed to do one or all of the following:

1. ↑ the amount of dopamine in the brain
2. They act as a dopamine substitute, stimulating the parts of the brain where dopamine works
3. Block the action of other factors (enzymes) that break dopamine, so that dopamine in available for use for longer.

The Parkinson UK webpages provide information about all the differing types of medications and their side effect profiles

The Khan Academy overview video on medication management

Having read and listened to this material you should be able to answer the following questions and be comfortable discussing this with your patients. There is space on the next page to write your answers.

1. What are the key classes of medication used in Parkinson's.
2. What is the mechanism of action of each of the different classes of medication?
3. Why are some people on a combination of medications for those Parkinson's
4. What are the key side effects associated with each class of drug?
5. Define wearing off phenomenon, and the impact this has on motor function
6. Why is it important that people with Parkinson's get their medication on time?

5.0: Assessment of people with Parkinson's

5.1: Learning Outcomes

Key Learning outcomes for physiotherapists:

1. To critically discuss the medical management of Parkinson's
2. To select, plan, justify and apply appropriate treatment approaches and techniques for PwP
3. To critically discuss and justify a range of outcome measures suitable for the use in the management of PwP

Key Learning outcomes for Fitness Instructors

1. To develop an awareness of the common drugs used in the management of Parkinson's and their side effect

PDConnect

5.0: Assessment of people with Parkinson’s

The assessment of a person with Parkinson’s, does not differing hugely for other long term neurological, however consideration need to be given to the objective assessment of the key Parkinsonian symptoms, and the impact of secondary complications and co-existing conditions. Assessment will be focussed in detail on the practical workshop day.

In addition to a standard physiotherapist assessment, assessments should include:

5.2: Subjective:

- When diagnosed, who diagnosed them
- Current disease stage – Hoehn and Yahr
- Motor complications – fluctuations, on/off times, wearing off, dyskinesia’s
- Cognitive complications – cognitive processing, planning, decision making, attention shifting, dual tasking, apathy, fatigue, depression, hallucinations, delusions, compulsive behaviours.
- Pain – diurnal patterns, locations, aggs and eases
- Medication for Parkinson’s including dosage, time since reviewed, all other meds hx
- Current participation levels
- Current knowledge and understanding of Parkinson’s.
- Level of self-efficacy (see measurement tools)
- Readiness to change
- Support Network
- Aims and objectives, goals.

5.3: Objective:

This should include all standard aspects of assessment, AROM, muscle strength, transfers, functional testing, balance, dexterity. The table highlights some addition key areas of focus.

Physical Capacity	**Gait**
Muscle Power in particular: • Hip extensors • Knee extensors • Ankle flexors Muscle Tone in particular: • Hamstrings • Gastroc • Biceps Joint Mobility in particular: • Csp, and Tsp • Shoulder • Hip • Knee • Ankle Exercise Tolerance: • Current physical activity levels • Daily walking distance	• Spatiotemporal gait parameters • Biomechanics of gait • Gait AX with dual tasking • Obstacle negotiation • Acceleration and deceleration of gait • Festination of freezing: • On step initiation • Turning • Obstacle negotiation • Doorways • Forward walking • Backwards walking • Dual tasking • Surface changes
Bradykinesia	**Tremor**
• UL and LL bradykinesia testing	• Indicate on body chart

5.4: Measurement tools used in Parkinson’s.

The European Physiotherapy Guideline for Parkinson’s Disease recommends a number of measurement tools for Parkinson’s. Key measures are summarised below:

Parkinson’s specific measures:

- Unified Parkinson’s Disease Rating Scale (UPDRS)
- **Parkinson Fatigue Scale**
- Parkinson’s Anxiety Scale
- Parkinson’s Disease Questionnaire 39 (PDQ39)

Gait measures:

- 6 minute walk test
- 10M walk test
- Functional Gait Assessment- FGA
- Timed Up and Go- TUAG

Balance Measures:

- MiniBESTest
- Functional Gait Assessment- FGA
- Activities-Specific Balance Confidence (ABC) Scale
- Timed Up and Go- TUAG
- Falls frequency

Physical activity:

- Physical Activity Scale for individuals with Physical Disability (PASIPD)
- Physical Activity Scale for the Elderly (PASE)
- Activity diaries

Activities of daily Living:

- Nottingham Health Profile
- Schwab and England Activities of Daily Living Scale

PDConnect

5.0: Assessment of people with Parkinson’s

Please write below any questions you may have, that you wish to address in regard to assessment at the practical workshop.

PDConnect

6.0: Exercise prescription for PwP

6.1: Learning outcomes

Key Learning outcomes for physiotherapists:

1. To critically justify the benefits of exercise for PwP
2. To critically evaluate the barriers and motivators to exercises for PwP
3. To critically discuss the evidence base in relation to exercise prescription for PwP
4. To select, plan, justify and apply appropriate exercise interventions for PwP

Key Learning outcomes for Fitness Instructors

1. To be able deliver group based exercise programmes for PwP
2. To independently prescribe and deliver bespoke exercise programmes for PwP, accommodating the range of their symptoms
3. To be able to progress and or regress exercise in response to individual performance.

This training will not covering the wider benefits of exercise as this is assumed knowledge, but will focus primarily on the exercise for people with Parkinson’s (PwP). This section is aimed to give you the theory behind exercise prescription in Parkinson’s, which will be revisited in the practical based workshops.

6.2: Differences between Physical Activity and Exercise

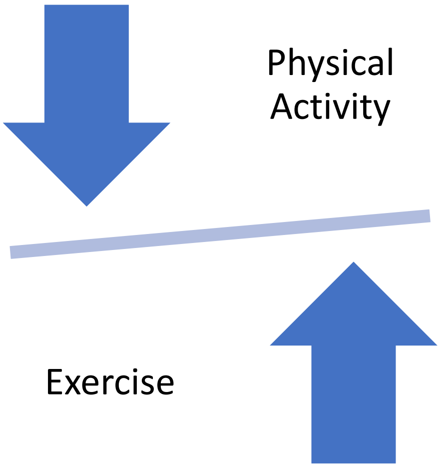
Physical activity, and exercise are often used interchangeably. But, there is a distinct difference between being physically active and engaging in exercise. The definitions of Physical Activity and Exercise as defined by the American College of Sports Medicine are detailed below. PwP need to be physically active but more importantly need to undertake targeted exercise.

Physical Activity:

Is defined as any bodily movement produced by skeletal muscles that requires energy expenditure.

Exercise:

Is planned, structured, and repetitive bodily movement done to improve and/or maintain one or more components of physical fitness



Physical Activity


Dog walking


Gardening


Housework

Targeted exercise


Group exercise


Strength Training


Swimming

PDConnect

6.0: Exercise prescription for PwP

Exercise has been hailed as the new medicine for Parkinson's[13], and is perceived as an integral component of Parkinson's management not solely as complementary to medication, but of equal importance[14]. Strong evidence exists advocating that exercise has a positive impact on Parkinsonian symptoms[15-17], as well as disease progression[18-21].

Interest in exercise has risen exponentially in the last 5 years owing to researchers associating exercise with potential to limit disease progression, and thereby offer a neuroprotective effect[18-21]. As discussed in prior section medication has traditionally been the focus of management, although, as yet medication address only Parkinsonian symptoms, and as yet drug which positively impact on disease progression remain elusive. Furthermore, the effectiveness of drugs is relatively short-lived and are associated with large side effect profiles. Therefore, exercise is very much regarded as the new medicine for Parkinson's.

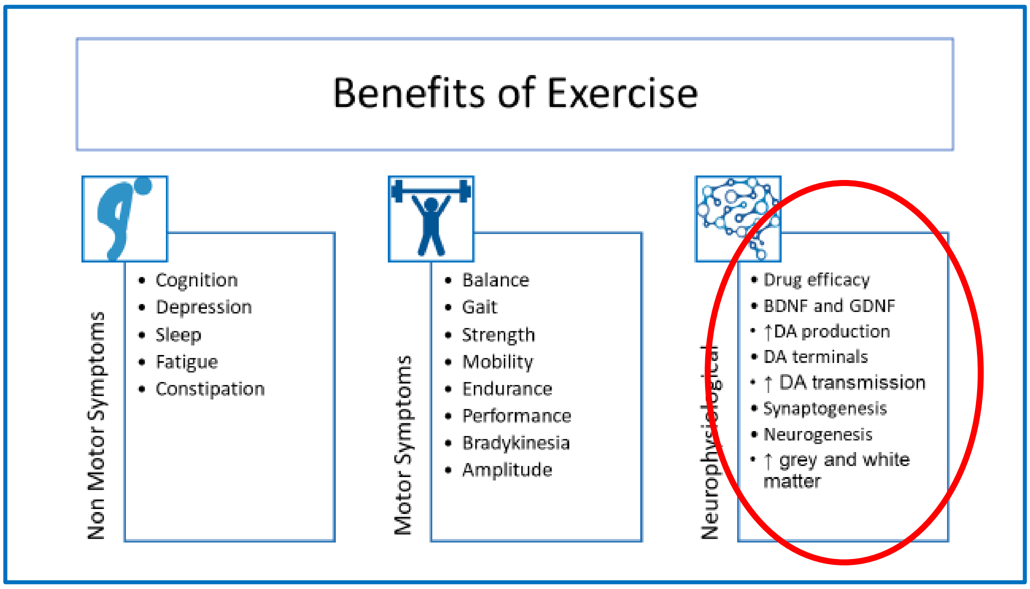
Key message for PwP:

Engaging in exercise is as important as taking your medication

Dr Terry Ellis, presentation of exercise for PwP

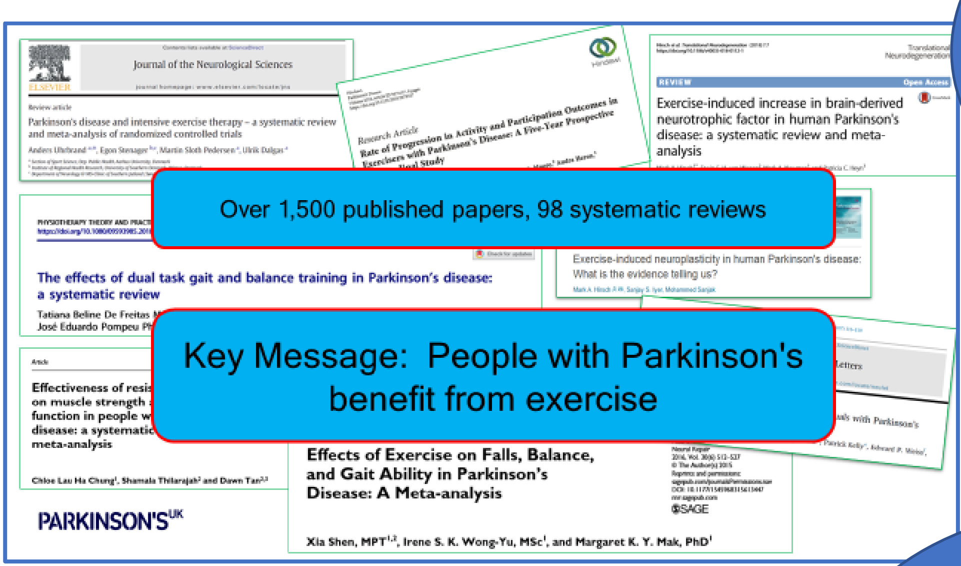
6.3: Neurophysiological Basis for exercise in Parkinson's

The figure below highlights the effects of exercise at a neurophysiological level, which cumulatively lead to enhanced brain health, and limit the rate of decline of the condition. Many of these findings have been demonstrated in animal models, however this is beginning to be replicated in human models. These benefits only occur when people participate in regular high intensity exercise.



High Intensity exercise has been shown increased levels of GDNF and BDNF, which are neurotrophic factors in the brain, which promote the survival of neurones within the brain. This has led to scientists proposing that exercise may have a **neuroprotective** effect, as exercise has potential protect the rate of death of neurones within the brain. Emerging research is also suggesting that exercise could cause a **neuro-restorative** effect, prompting repair of the damaged neurones and returning function to the existing pathways. In animal studies, exercise has been linked with neurogenesis which is the growth of new neurones. Participation in exercise improves the efficiency of blood supply to the brain. Improved blood supply brings with it all the essential nutrients and oxygen which cells need in order to prosper.

6.4: Exercise research in Parkinson's



Over 1,500 published papers, 98 systematic reviews

Key Message: People with Parkinson's benefit from exercise

I have started doing things that I have been avoiding

I can do more for myself now that I have been exercising, it is the simple things like having the confidence

Key messages: Exercise has the potential to improve the health of neurones within the brain as well as increase the number produced. Research is emerging which would suggest that people who regularly participate in exercise experience a **slower rate of decline of their Parkinson's.**

Jane Rideout tells you about her exercise journey.

Jane also talks about the benefits that exercise has brought to her. She has had Parkinson's for 12 years.

Group exercise hear the benefits from PwP

Janet Kerr talks about her experiences of exercise

6.5: The impact of exercise on motor symptoms

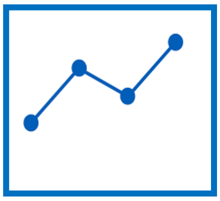
Improved Balance Flynn et al (2019)

Increased Strength Chung et al (2016)

Improved mobility, including walking Meng et al (2018)

Improved Endurance Shu et al (2014)

Improved speed Stuckenschneider et al (2015)



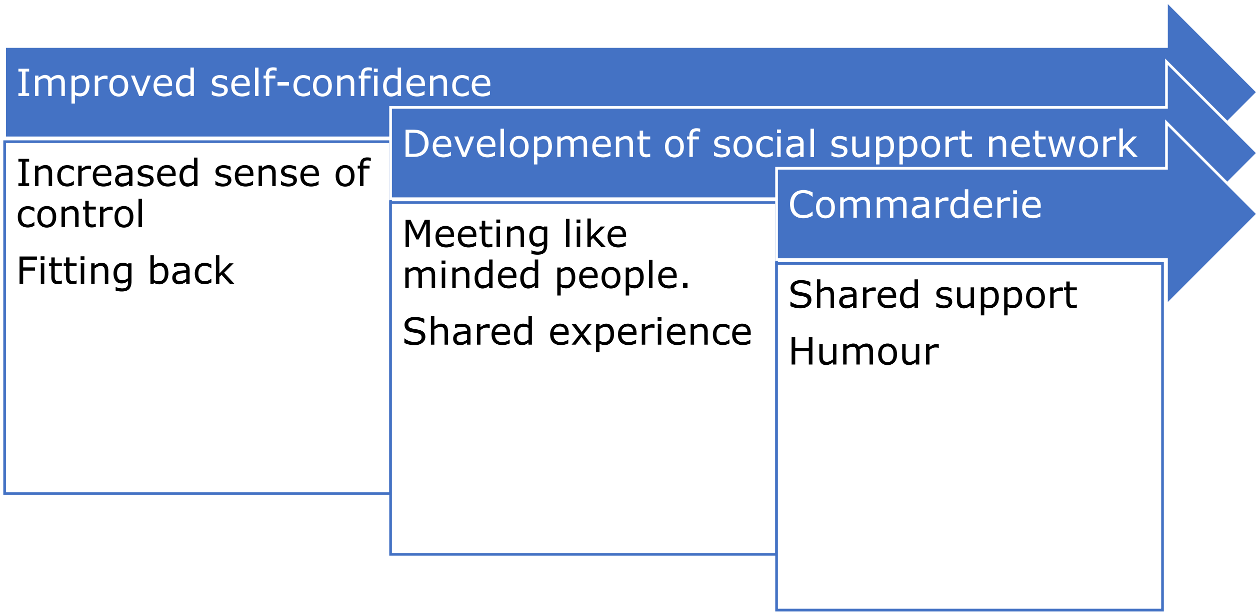
Improved performance Prodoehl et al (2015)

6.6: The impact of exercise on non-motor symptoms:

Research studies have shown that participation in regular exercise can have a positive effect also on the non-motor Parkinson's symptoms. In particular:

- Cognition or thinking and thought processing
- Mood, in particular improvements in depression
- Improve quality of sleep
- Reduce levels of fatigue
- Relive constipation

In addition, PwP have reported that participation in exercise also their sense of control of their condition, as they feel as though they are doing something to help themselves.



Improved self-confidence

Increased sense of control

Fitting back

Development of social support network

Meeting like minded people.

Shared experience

Commarderie

Shared support

Humour

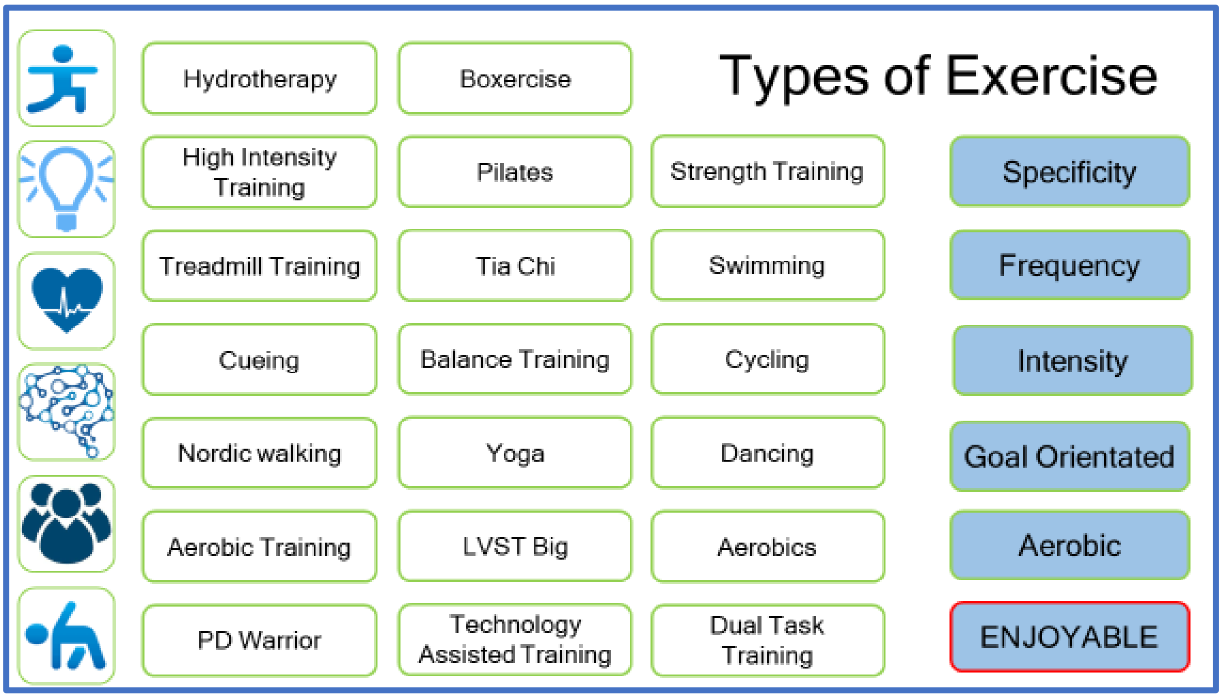
6.7: Prescribing exercise for PwP

Systematic reviews[16,17] indicate that regular exercise correlates with improved Parkinsonian symptoms, citing improvements in strength[22], balance[23] and gait[24] as well ameliorating depression and fatigue[25], when delivered individually or as part of a group[26,27]. Although a large body of evidence exists, owing to heterogeneity in types of exercise prescribed and variation of symptoms between PwP, drawing consensus on the optimal approach to exercise is challenging. Consequently, the optimum type, and dosage of exercise to inform clinical practice remains underdetermined from the systematic reviews[13].

What can be determined from research is that the following key principals need to be considered when prescribing exercise:

Specificity
Intensity
Frequency
Aerobic
Goal Orientated

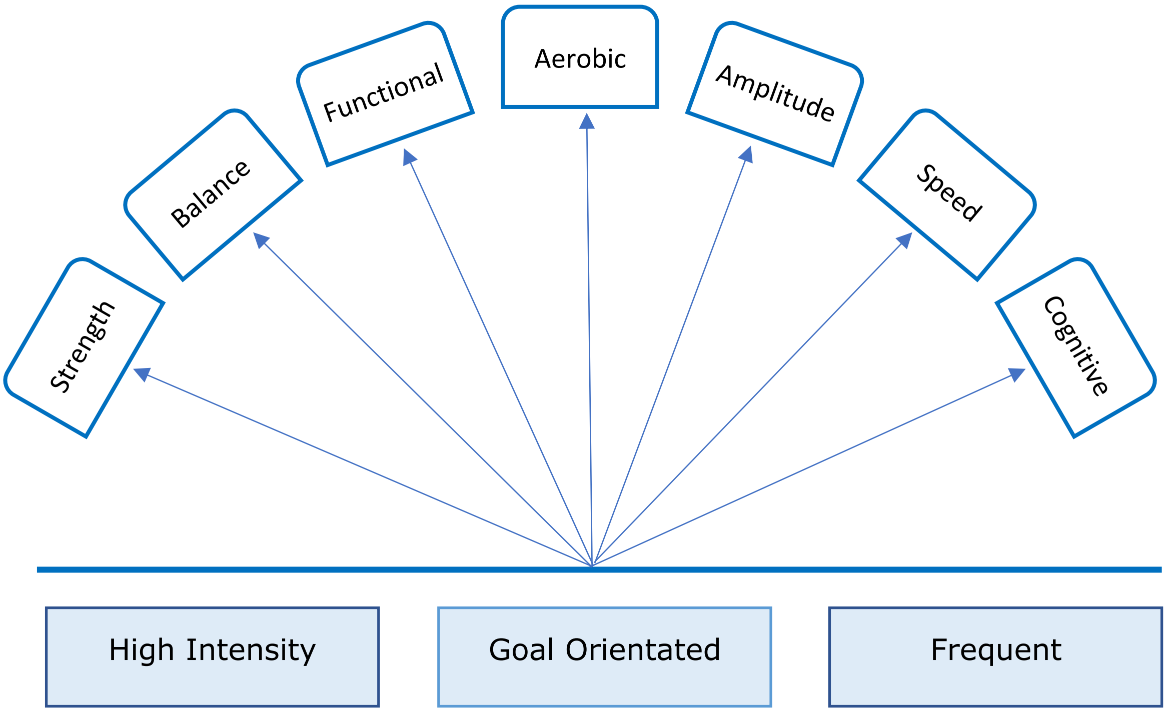
6.8: Types of exercise



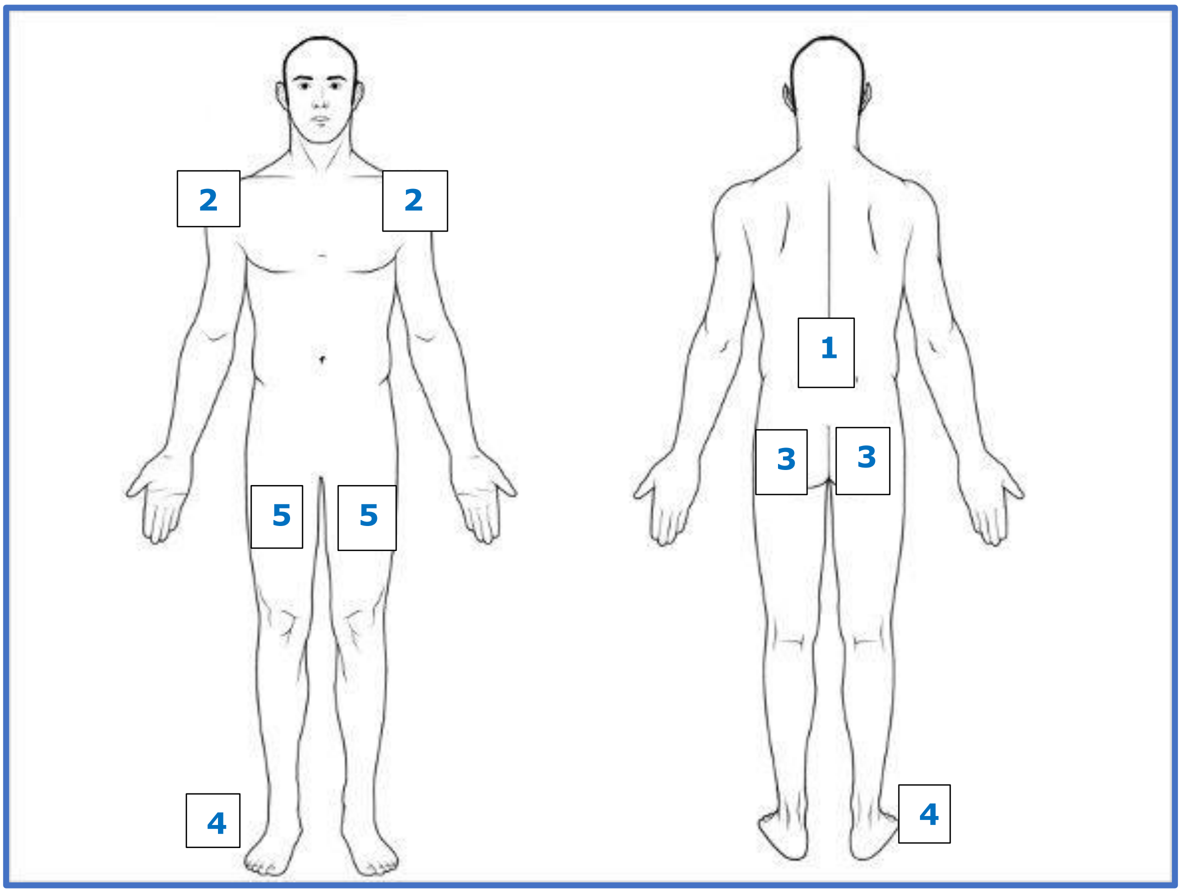
Types of Exercise

Hydrotherapy
Boxercise
High Intensity Training
Pilates
Strength Training
Specificity
Treadmill Training
Tia Chi
Swimming
Frequency
Cueing
Balance Training
Cycling
Intensity
Nordic walking
Yoga
Dancing
Goal Orientated
Aerobic Training
LVST Big
Aerobics
Aerobic
PD Warrior
Technology Assisted Training
Dual Task Training
ENJOYABLE

When prescribing exercise, programmes must include the following components:



6.9: Key areas to focus upon.



6.10: Intensity of exercise:

In order to achieve the neuroprotective effect of exercise, research advocates that exercise must be of moderate to high intensity – working at 60-80% of mHR, or RPE 13. Many PD specific exercise approaches emphasise intensity:

PD WARRIOR

PWR!® Parkinson Wellness Recovery

LSVT® GLOBAL

6.11: Frequency and duration:

Aerobic Exercise

- 30-60minutes
- 5x a week
- Moderate to high intensity

Strength Exercise:

- 2-3 times a week
- 10-15 repetitions of any exercise
- 2-3 sets of each exercise

Flexibility or Stretching Exercise

- Daily
- Minimum 10 minutes
- Hold each stretch for 20-30 seconds

Balance Exercises

- 20-30 minutes
- 2-3 times a week

Being Physically Active

- Daily

Walking

- Daily
- Preferably briskly

6.12: Barriers and Motivators to Exercise

Despite the benefits of exercise being widely reported within research, and widely acknowledged by the Parkinson's community, 70% of people with Parkinson's are known to be sedentary. This is thought to be attributed to a combination of both the motor and non-motor symptoms. Apathy and fatigue reduce motivation, and motor symptoms such as rigidity makes moving for difficult. Although Parkinson's per se does not cause muscle atrophy, the sedentary behaviour, which ensures does.

Prior to prescribing exercise, we need to understand the barriers people face with exercise so that they can be supported to overcome these. Without acknowledging this, adherence to exercise at best will be short term.

Common barriers to exercise[28]

- Do not know where to start?
- Too tired
- Lack of specialist help
- Not enough time
- Don't like gyms
- Fear
- Lack of confidence

Motivators to exercise

- Targeted education
- Feedback on performance
- Specialist professionals
- Support network
- Community Network
- Sustainability of service

6.13: Key Learning Points

Key learning points:

- No one approach to exercise will benefit PwP, a varied approach is required.
- Exercise should be individually tailored to meet PwP symptoms
- Exercise needs to be progressive in nature, with an emphasis on moderate to high intensity with regular changes to content.
- Exercise needs to be frequent
- Exercise programmes should incorporate the following elements:
  - Strengthening exercises
  - Balance exercises
  - Functional based exercises
  - High intensity aerobic exercise
  - Amplitude training
  - Cognitive/thinking aspect

The key areas that need to be worked on are amplitude of movement, the spine, hips, things, and ankles

6.14: Further reading and guidance on exercise

Parkinson's UK Exercise framework

In 2018, Parkinson's UK published an exercise framework which was created by a group of specialist exercise professionals. This framework was designed to provide guidance and recommendations about exercise participation at each stage of Parkinson's. The ethos of the Exercise Framework is about the importance of investing in exercise from diagnosis and embedding exercise as part of your everyday life.

European Physiotherapy Guideline for Parkinson's

European Physiotherapy Guideline for Parkinson's Disease

Developed with nineteen European professional associations

Key points from these guidelines include:

- Exercise prescription should be based upon people with Parkinson's treatment goals, abilities, motivation and preferences, as well as external factors such as the availability of exercise group.
- Minimum of 45 minutes three times a week
- Varied approach to exercise prescription
- Delivery by specialist therapists
- Exercise can be delivered individually or as a group.

7.0: Promoting self-management

Self-management is defined as management of or by oneself; the taking of responsibility for one's own behaviour and well-being.
Therefore, for self-management to be successful therefore
patients need to be informed, and have self-confidence or efficacy

7.1: What self-management means for people with Parkinson’s

- Taking responsibility for one’s self
- Partnership
- Equality
- Provision of information
- Respect for their view

People with Parkinson’s perceived barriers to self-management

- Lots of information is provided, however, little support was given with the interpretation of this. People are left to make their own choices, which the information per se did not allow them to do.
- Information often depressing and not delivered in a manner which encouraged people to do what they could to limit the impact of the condition.
- Not everyone is at a stage to be ready to self-management, and enabling people to self-manage was seen as an essential.

7.2: Motivational factors for self-management:

- Sound justification for the need to do something such as exercise
- Clear signposting from healthcare professionals, so people with Parkinson’s can be guided to manage their own condition
- Partnership and equity in decision-making was emphasised
- Self-management should be provided both individually and as a group. Preference for individual at the beginning so it is tailored to meet their needs and stage of acceptance of the diagnosis.
- Where appropriate significant others/partners/care partners should be invited to self-management.

People with Parkinson’s perceptions of motivational factors to participate in exercise and be more physically active.

- WHY exercise is important for those with Parkinson’s, including information about the principles and purpose of exercise(s), what exercise should they be doing and why
- When new to the exercise – clear information on the purpose of the exercise, e.g. what is it targeting strength, aerobic fitness, balance etc. etc. what are the key components to get rights
- Develop an understanding as to why exercise have been selected,
- Understand the key components of what the exercise can achieve so that people can relate to this and build this in to everyday activities like walking the dog focussing on arm swing for example
- feedback on exercise form, intensity, quality of performance
- Variation of types of exercises, have understanding of different value they offer.
- Awareness of exercise options available locally.

PDConnect

8.0: Behaviour Change

8.1: Learning Outcomes:

Key Learning outcomes for physiotherapists:

1. To critically discuss behaviour change theory and application to the Parkinson population
2. To critically evaluate different behavioural change strategies
3. To select, plan and justify appropriate behaviour change strategies for PwP

Key Learning outcomes for Fitness Instructors:

1. To provide effective strategies to support the initiation, and maintenance of engagement in exercise for PwP
2. To effectively communicate the value of exercise
3. To provide effective strategies to support the initiation, and maintenance of engagement in exercise for PwP

8.2: Behaviour change applied to PDConnect

The philosophy of PDConnect is to empower PwP to make informed decisions about their own health care with a focus on exercise participation and resuming control of their lives, through the provision of education and an evidence-based toolkit of strategies to enable them to live more active, fulfilled, and meaningful lives. Therefore, behaviour change is seen as central to the success of the PDConnect intervention.

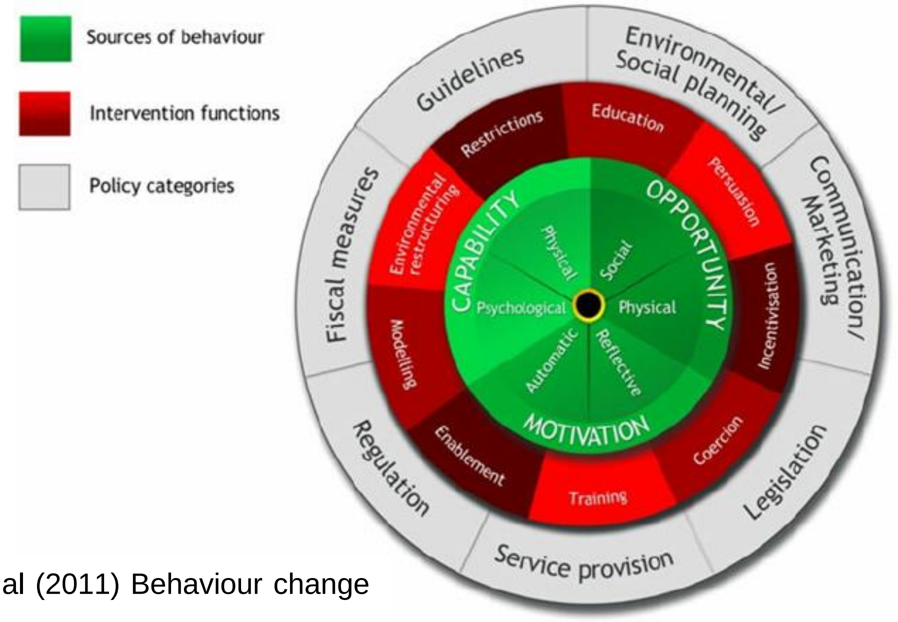
While all of us are recognise the need to be more physically active, it is quite a different thing to actually make that step to adopting a physically active lifestyle. Prior research has shown that PwP benefit from exercise, however, when that intervention ends, they revert back to their prior sedentary lifestyle. This would suggest that while exercise had caused changes at a physical level, they have not occurred at a behavioural level. Parkinson's is a long-term condition, therefore, there is a need to promote changes at a behavioural level, such that people become more physically active in order to positively impact on their condition in the longer term. Therefore, PDConnect aims to provide PwP with a tool kit of behaviour change strategies to promote participation in exercise

Behaviour change techniques (BCTs) "as coordinated sets of activities designed to change specified behaviour patterns"[29], or more practically interventions that enable and equip people to successfully manage themselves[30]. Delivering programmes that combine exercise and BCTs, have the potential to promote long-term exercise adherence but more importantly they provide PwP with strategies to take control of their own health, and promote self-management, and self-efficacy. Lorito et al (2019) provides a nice summary of different models of behaviour change on pages 105-108 of their article. Although an older article and applied to Diabetes Funnell and Anderson (2004) highlight the importance of developing self-efficacy in patient groups.

8.3: Aim of BCT in physiotherapy sessions: to develop self-efficacy, and to prepare participants to be comfortable and confident with exercise on an individual level prior to moving into the group exercise components of the intervention.

8.4: Aim within group based exercise: to develop confidence with independent exercise in the community so that they can continue exercising outwith the class setting.

8.5 Behaviour Change Models: Several different behaviour change models exist, however this study has adopted the Behaviour Change Wheel model designed by Michie et al (2011)[29]. This model was selected as it is frequently used within healthcare, in particular within physical activity interventions and has an internationally recognised evidence base. Central to the Behaviour Change Wheel is the COM-B model, “capability, opportunity, motivation, and behaviour ”. The premise of this model is that the promotion of sustained behaviour change will require change in one or more of these factors. The COM-B model aligns with the ethos of study which aims to promote participation and alter behaviour to embed exercise in to their everyday lives.



Michie et al (2011) Behaviour change wheel and COM-B model

PDConnect

8.0: Behaviour Change

Michie and Colleagues also developed a taxonomy (classification system) for behaviour change techniques. The taxonomy is broken down into 16 interventions (for example, goal, planning, self-belief), within which suggested BCT that can be selected. Owing to diversity within the Parkinson's population, some BCT's may resonate with some more than others, and currently there is a lack of clarity of which BCT work best for those with Parkinson's. This study has selected the following from the BCT taxonomy.

Please click on the behaviour change taxonomy hyperlink above and read through the taxonomy. Please make any

8.6: PDConnect Behaviour change interventions.

	Behaviour change Intervention	**What will be delivered in the PDConnect**
1	Goals and Planning	All participants will have a **health contract** which they will be asked to sign, agreeing to undertake exercise and HEPs. **Joint goal setting** will be undertaking at the start of the programme and will be refreshed at each phase of the programme to meet participant's needs.
2	Feedback and monitoring	Feedback either visual, verbal, auditory or sensorisomatic, will be provided when participants are conducting their treatment interventions and exercises. This will be undertaken at all stages of the intervention
3	Social support	Care partners will be invited to attend and participate in all elements of the intervention including exercise prescription
4	Shaping knowledge	1:1 education will be provided by physiotherapists, exploring the value of exercise, the purpose and aim of exercise and how this relates to their symptoms. This will be delivered in parallel with feedback to correct technique or provide reward as appropriate. Group based discussions will be conducted as part of the group-based exercise phase of this intervention. education will be delivered by: staff delivering the intervention, via the PDConnect manual, and signposting to external resources.

8.6: PDConnect Behaviour change interventions.

	Behaviour change Intervention	What will be delivered in the PDConnect
5	Natural Consequences	Delivered in parallel with shaping knowledge, information provided about health consequences and the immediate, short and long term benefits of exercise for their Parkinson's and wider health. Education pertaining to the normal effects of exercise for example, delayed onset of muscle stiffness, will be explored as well as information pertaining to the dosage of exercise in particular the potential value of moderate to high intensity exercise has on Parkinson's. This will be reinforced by using the band and REHABGuru.
6	Comparisons of behaviour	REHABGuru provides both images and short videos of exercises, providing participant an observer-able sample of the exercise to be performed in their own time. Within the physiotherapy sessions, the physiotherapists will also demonstrate the exercise, providing key information in relation to; starting position, end position, feedback upon accuracy, dosage, purpose, and proposed benefit. To aid adherence and optimum technique when exercising independently at home, where possible the carers will also be shown the exercises and provided the same information.

PDConnect

8.0: Behaviour Change

	Behaviour change Intervention	What will be delivered in the PDConnect
7	Associations	Mi band, completion of the activity diary, and adherence with HEP will be used as prompts and cues by those delivering the intervention.
8	Repetition and substitutions	Advice such as do not sit for longer than 30 minutes at a time, discussing with participants to substitute sitting time with more physically active tasks will form part of the behaviour change aspect of the study. This substitution and habit forming of being more physically active can be documented within the diary, and will be monitored with the Mi Band output
9	Comparisons of outcome	In parallel with discussing health consequences, participants will be asked to discuss their thoughts on the pros and cons of changing their behaviour to one, which embraces a more active lifestyle. In discussing the pros, knowledge can be shaped by providing credible sources of information supporting the benefits of exercise for PwP which are available for participants within the PDConnect manual.
10	Reward and threat	Providing social reward, or incentifying reward through setting goals such achieving daily step count targets will be delivered within the intervention. The setting of person centred goals.

8.0: Behaviour Change

	Behaviour change Intervention	What will be delivered in the PDConnect
11	Regulation	Providing participants with strategies to reduce anxiety associated with participants reported triggers. This may encompass stress management techniques to practical strategies such as the use of auditory cueing to reduce cognitive burden during dual task activities.
12	Antecedents	Suggested changes will be informed by the reported barriers to exercise articulated by the participant. Physical changes may involving creating a space to promote safe exercise within the home, or advising how exercise can be adapted to use objects commonly found within the home for example. Socially changes could be advised in relation to walking outdoors, signposting to local groups, making suggestions as to how the participant and carer could exercise together.
13	Identity	Aim to support the reframing and valuing of self-identity. Building confidence through motivational coaching, feedback, education, all of which are BCTs in their own right, to enable to participants to feel confident in themselves and within the group environment. Supporting the development of a strong social network.

14	Scheduled consequences	Not included in the PDConnect intervention
15	Self-belief	Self-belief will be instilled by providing verbal feedback on physical activity tasks or exercises undertaken, but also when reviewing and re-establishing goals such that past successes can be celebrated
16	Covert learning	Not included in the PDConnect intervention

Please write any notes or questions that you have on behaviour change here.

9.0: Developing effective participant’s relationships

9.1: Learning Outcomes:

Key Learning outcomes for physiotherapists:

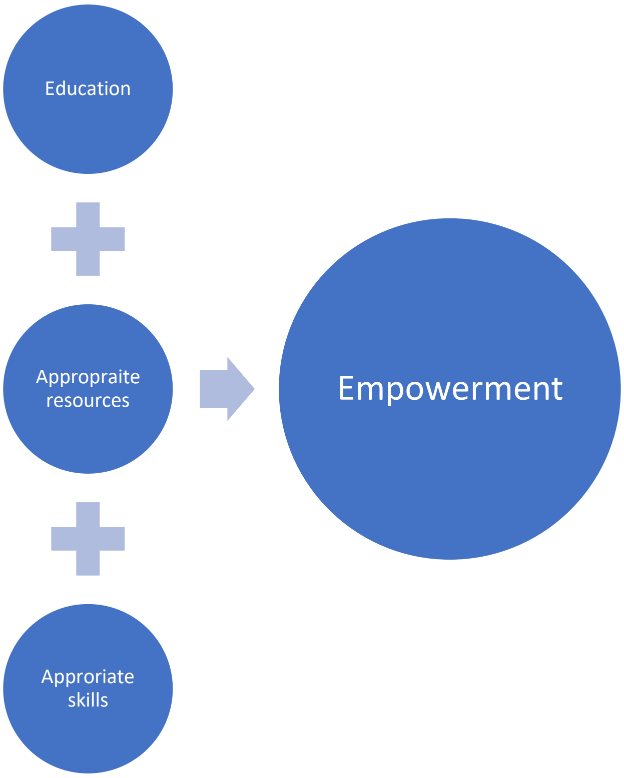
1 To critically discuss empowerment theory and the application to the management of PwP.
2 To apply motivational interviewing within management of PwP.
3 To critically discuss collaborative practice and reflect on delivery within practice.

Key Learning outcomes for Fitness Instructors

1 To discuss empowerment theory and develop an awareness of application to PwP
2 To apply theory of motivational interviewing amongst those with Parkinson’s
3 To reflect on interactions with those with Parkinson’s

9.0: Developing effective participant’s relationships

Rappaport (1987) defined empowerment as a process whereby “people gain mastery over their affairs”, which when applied within the health context Funnel et al (1991) described empowerment as “helping patients discover and develop inherent capacity to be responsible for one’s own life”. However, this vision of empowerment can only be delivered when people have the sufficient knowledge, skills, and resources to make rational decisions and inform their behaviour.



Empowered people can make informed decisions, exert control, access resources to execute their decisions, and then reflect on effectiveness. Therefore, central to the success PDConnect is the aim to empower PwP to make informed decisions about their own health care with a focus on exercise participation and resuming control of their lives, through the provision of education and an evidence-based toolkit of strategies to enable them to live more active, fulfilled, and meaningful lives. Participant empowerment while being the vision of PDConnect it is also fundamentally the desired outcome.

9.2 Theory

Overview of empowerment theory

Empowerment theory chapter, Zimmerman 2012

In your own words, define the following terms:

- Patient empowerment
- Self-efficacy

Why do you think patient empowerment is important in healthcare?

9.3: Motivational Interviewing

Read the following chapter on motivational interviewing, making notes of your learning as required.

Introduction of Motivational interview ppt and voice over

BMJ Motivational interviewing role play video.

Reflect on one of your own patients, which you have seen recently, and think about how you have applied the OARS approach. What challenges did you face, and how did you overcome these. How

9.0: Developing effective participant's relationships

Before we move onto the next section, let's just pause to consolidate the learning from this section. Please read through the following statements below and tick as applies. If you tick no to any of these, read back through the study materials, and if you have any further questions, please email Julie- j.c.jones@rgu.ac.uk

		YES	NO
1.	To be able to define the term empowerment, and demonstrate awareness of empowerment models		
2.	To define the term empowerment from a patient's perspective		
3.	To define self-efficacy, and the value this brings to patient management		
4.	To discuss the relationship between self-management, self-efficacy and empowerment theory		
5.	To be able discuss how delivering an empowerment approach to care differs from traditional modes		
6.	To be able to deliver an empower approach to patients care		
7.	To define and apply the key principals of motivational interviewing		
8.	Critically reflect on the application of motivational interviewing in practice		

10.0: PDConnect intervention

10.1: Learning Outcomes:

Key Learning outcomes for physiotherapists and Fitness Instructors

1. To articulate the aims, values and ethos of the PDConnect Programme, and apply these to practice
2. To apply the PDConnect model to PwP

This study aims to explore the feasibility and acceptability of PDConnect. The intervention acknowledges the collaborative ethos between providers and PwP, which combines specialist physiotherapy and, community delivered group exercise, with a strong emphasis on supporting behaviour change to promote long-term effective self-management. The ultimate aim is to investigate the long-term effectiveness of PDConnect by way of a randomised controlled trial (RCT) and the impact PDConnect has on physical activity participation.

The PDConnect programme has evolved from:

- Consultation with Parkinson's Community
- Focus groups with the exercise community
- Clinical experience
- Research

10.0: PDConnect Intervention

Drawing from all these sources, clear themes emerged which became the driver for the development of the PDConnect Programme. The drivers to design this programme were as follows:

- Current service provision only allows short term exercise interventions
- Services are often delivered by Physiotherapists who do not have any expertise in management of PwP
- Once exercise programmes stop, adherence to exercise declines
- Current provision is not sustainable
- Exercise in isolation cannot change behaviour
- PwP wish exercise guidance from experts who understand their needs.

Conclusions:

Exercise programmes informed by research that is delivered by specialist practitioners, which are tailored to individual needs is required. Exercise programmes need to be delivered in parallel with self-management and behaviour change strategies to promote long-term exercise engagement.

Key Themes of PDconnect are:

Exercise

Behaviour change

Education

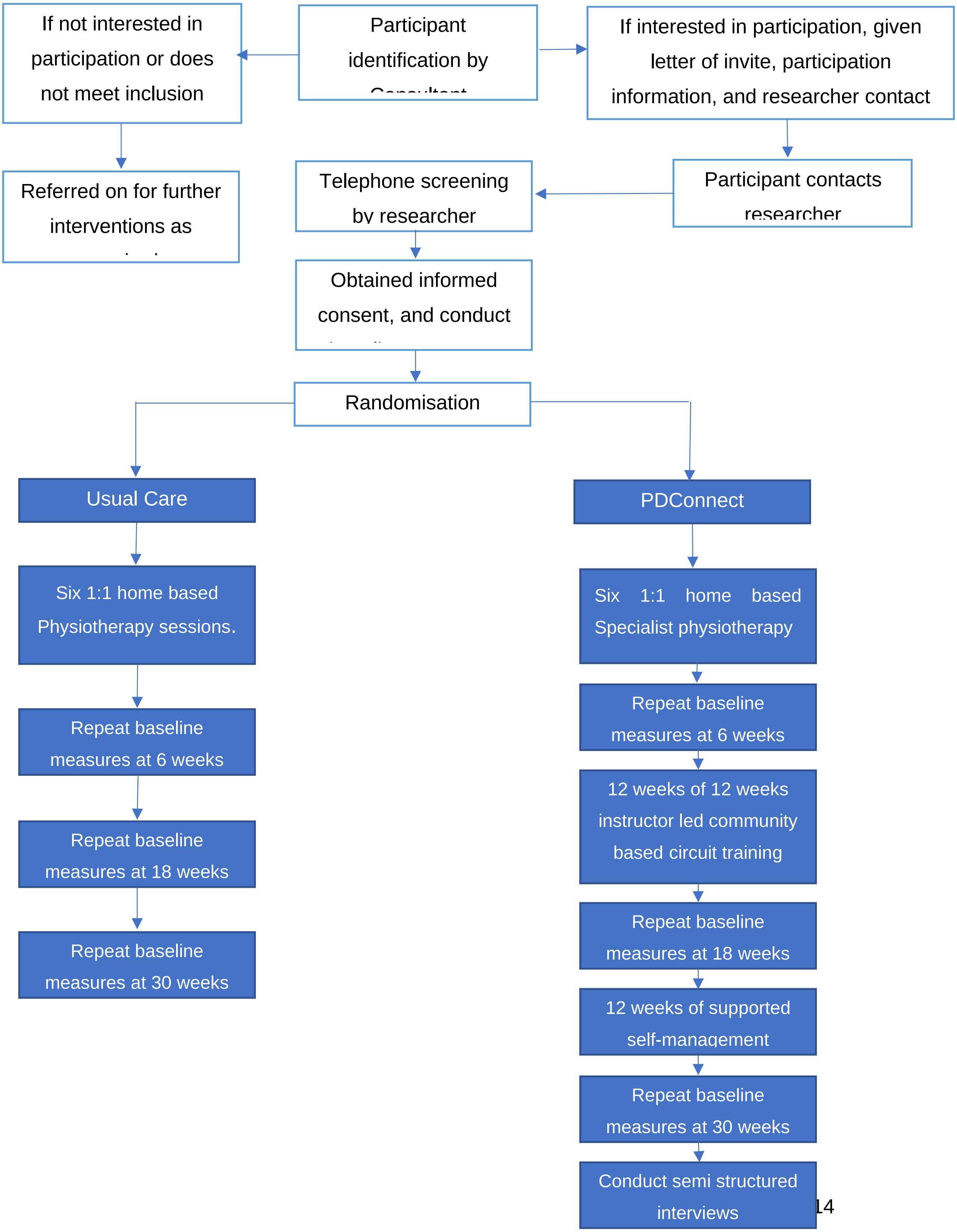
Developing social networks

Empowerment

Developing self-efficacy

PDConnect

10.2: Basic Study Flowchart



10.0: PDConnect in more detail

10.3: Specialist Physiotherapy Phase:

Six session of 1:1 Specialist Physiotherapy

12 weeks of circuit group-based exercise delivered in the RGU Sport

12 weeks of independently managed exercise

This will include:

- Six sessions delivered at home by a Parkinson’s specialist Physiotherapist.
- Assessment, which will involve discussions about your expectations, your perceived needs, and goals, as well as a physical assessment.
- Setting of short- and long-term exercise goals
- Opportunity to ask any questions which you may have about your condition.
- Each session will last an hour and will include a minimum of 35 minutes of exercise, including warm up and cool down.
- Sessions will include the development of strategies to promote exercise engagement.
- Provision an individualised home exercise programme.
- Development of a weekly exercise activity planner.
- You will be asked to wear a physical activity tracker (Mi Band) and keep an activity diary
- Repeating of baseline measures

10.4: Group Based Exercise Phase:

Six session of 1:1 Specialist Physiotherapy

12 weeks of circuit group-based exercise delivered in the RGU Sport

12 weeks of independently managed exercise

This will include:

- 12 sessions of group based circuit exercise delivered at RGU SPORT by a Parkinson’s Trained Fitness Instructor.
- One hour of exercise including a warm up and cool down. Ina addition there will be 30 minutes of group discussion.
- Rotating around 10 different exercise stations. Each station has four levels of difficulty to allow exercise to be tailored to individual need.
- Spending 4 minutes at each station.
- Exercises are selected from current research and will target key areas of Parkinson’s.
- Regular review of your exercise goals and home exercise programmes to ensure these remain challenging and appropriate to meet your needs.
- Opportunity within discussion sessions will be given to address any questions
- Development of strategies to develop and maintain exercise habits
- Wearing a physical activity tracker (Mi Band) and keeping an activity diary
- Repeating of baseline measures

10.0: PDConnect in more detail

10.5: Self-management Phase

Six sessions of 1:1 Specialist Physiotherapy

12 weeks of circuit group-based exercise delivered in the RGU Sport

12 weeks of independently managed exercise

This will include:

- Exercising independently
- Following your home exercise programme.
- The Fitness Instructors will call you once a month to check on your progress with maintaining being active
- Wearing your physical activity tracker and completing your activity diary.
- Repeating of baseline measures
- Invitation to participate in semi structured interviews

10.6: Your role in PDConnect

On the practical workshop, we will discuss this is greater detail and there will be opportunity to ask questions. The key expectation of your role are detailed below.

Physiotherapy:

Having undergone this training and completed the practical study day, you will be responsible for delivering the six session of physiotherapy, outline above.

Aims of the sessions:

In these sessions, there should be focus upon establishing strong foundations in exercise, providing participants with all the information, and tools they need to start embedding exercise into their everyday life. Latterly, it is building self-confidence to be able to actively participate in group-based exercise. Therefore, while exercise prescription is a major component of each session, this should be delivered in parallel with behaviour change techniques, delivered in a pro-active and motivational manner. This will include provision of a HEP, use of the activity diary, gaol setting and the provision of education.

There is no restriction on the range of exercises you prescribe for your patient, these need to be based on your own professional judgement as per normal practice so that they meet individual patient need. However, they do need to incorporate the key exercise types:

- Strength
- Balance
- Aerobic – working towards high intensity
- Amplitude
- Functional
- Cognitive element

All HEP will be issued through REHABGuru, which is similar to Physiotools, but has improved graphics, and accessibility.

10.7: Your role in PDConnect

Fitness Instructors:

Your role in this study will be the delivery of the 12-week circuit based exercise classes. In addition to this as detailed in prior sections is to build upon and develop the foundations of exercise covered by the physiotherapist and promoting confidence with independent exercise, preparing participants for the self-management stage of the intervention.

Integral to this role will be progressing exercises within the circuit classes and adapting their HEP as they required. You will also facilitate the weekly post exercise discussions forums. The first of these three of these sessions will be as follows:

- Barriers to exercise and sharing of tips to overcome barriers
- Benefits of exercise and sharing of feedback from participants thoughts of how exercise has impacted upon them
- Strategies to overcome apathy and fatigue

The remaining nine sessions will be governed by the participants, who will be asked to place topic suggestions within a suggestion box. This idea arose from a consultation event where PwP felt that an suggestion box, maybe useful if participants lacked self-confidence to raise this openly. This also allows you to review the topic area in advance and prepare as appropriate. In the event that no suggestions are made, based on prior experience of running groups, the following topics could be used:

- Sleep and Parkinson's –why is this a problem, and things you can do to help this
- Diet and Parkinson's – cover key guidance from Parkinson's UK to diet
- Medication, participants experiences and discuss mode of action, and role of medication.
- Keeping motivated – handy
- Hints and tips to keep exercising

10.8: PDConnect Practical Workshop

Draft Agenda – below is a draft agenda, as it is subject to amendments based on your feedback and will accommodate any issues which you would like to go through in further detail which have arisen from the training.

Date: TBC **Time:** 0930-1630.

Venue: RGU, School of Health Sciences, Ishbel Gordon Building, room TBC

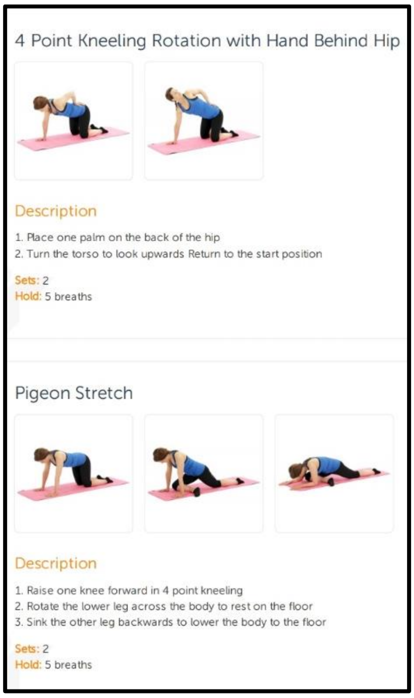
Time	Plan
0930-0945	Welcome and introductions
0945-1015	PDConnect intervention
1015-1115	Exercise – practical delivery
1115-1130	Break
1130-1230	Exercise – practical delivery
12.30-1300	Lunch
1300-1330	Mi Bands
1330-1400	REHABGuru
1400-1500	Exercise practical delivery
1500-1515	Break
1515-1615	Behaviour change Techniques
1615-1630	Questions.

11.0: REHABGuru®

REHABGuru is similar to PhysioTools, which many of you will be familiar with. REHABGuru was selected for the purposes of this study as it has improved graphics, videos of exercises, and option for exercises to be emailed, printed or for participants to access this through an app. All participants participating in PDConnect will be provided with a HEP, prescribed through REHABGuru, which will be updated as they progress through the programme.

11.1: Example of print version of Home Exercise Programme

Below is an example of what participants sent via Microsoft Teams



4 Point Kneeling Rotation with Hand Behind Hip

Description

1. Place one palm on the back of the hip
2. Turn the torso to look upwards Return to the start position

Sets: 2
Hold: 5 breaths

Pigeon Stretch

Description

1. Raise one knee forward in 4 point kneeling
2. Rotate the lower leg across the body to rest on the floor
3. Sink the other leg backwards to lower the body to the floor

Sets: 2
Hold: 5 breaths

Forward Lunge with Side Bend

Description

1. Take a knee with the other foot stretched far in front
2. Push the hips forward and raise the arms above the head
3. Bend to the same side as the front leg reaching the hands high & across

Sets: 2
Hold: 5 breaths

Overhead Forward Lunge with Side Bend

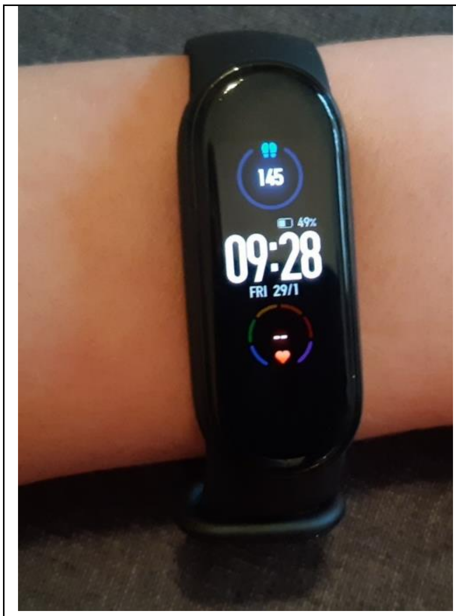
Description

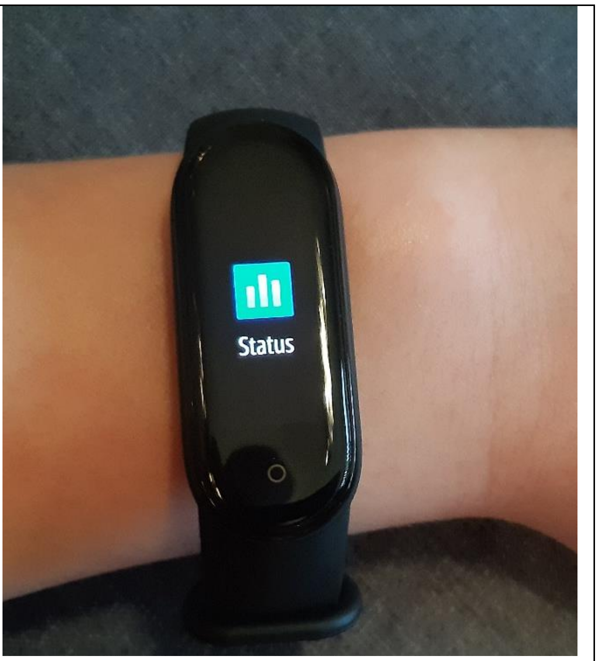
1. Step forward with Aarms overhead
2. Turn the rear foot inwards and push the hips forward
3. Reach the arms high & over to the side of the front leg

Sets: 2
Hold: 5 breaths

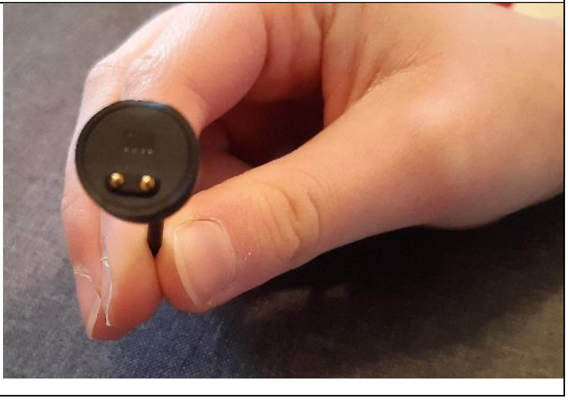
12.0: Mi Fit Bands –Activity Tracker

As part of the study every participant will receive a Mi band, which is a wrist worn activity tracker to be worn for the duration of the study. Each participant will be set up prior to the study and will be shown how to use the device. The following pages are a copy of the guide which has been given to all participants to familiarise yourself with the device. The device will be covered further in the practical workshop

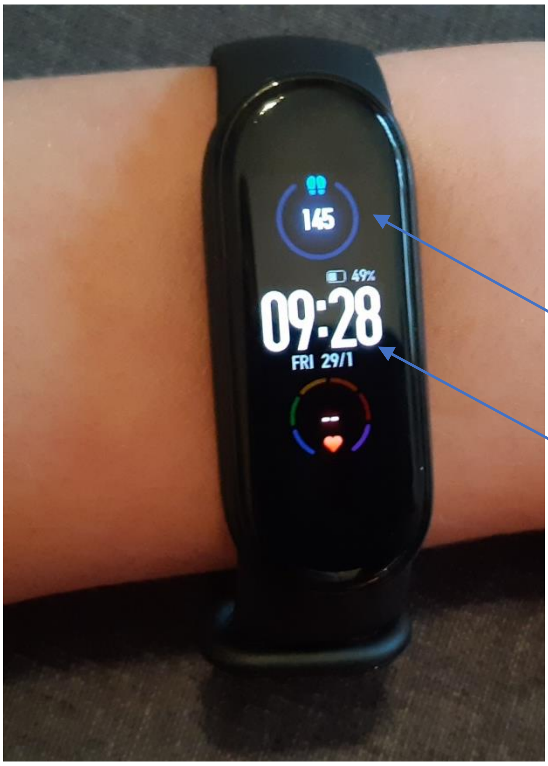




Mi band Charging components



Wearing the Mi Band



When wearing the Mi band, to conserve power the screen will automatically switch off. However, it will still be recording information. To see the time on the watch tap the

Cumulative daily step count

Date, time, battery level

Any activity that you undertake will be counted. At midnight, the device resets itself and it will return to 0. You will be able to view prior days step count through the Mi Fit phone

By touching the bottom of the screen and sliding your finger up the face of the watch, you can see other features on the watch. Tapping the status icon as shown in the picture will tell you your total

Fastening your Mi Band

Charging your Mi Band:

You can check your battery level by touching the bottom of the watch face and the battery life is illustrated on the watch face. When the battery is low, please charge it. The battery normally lasts 5 days without charging.

To charge: Take the watch off. Connect the charger head to the back of the watch, aligning it with the two emtal spots on the back of the watch. It is magnet so it will click on. Then plug the USB post into a plug or charging unit. To check when complete- all bars should be full.

Battery charging points

Attach the charging cable to the back of the watch as shown

Attach the sensor and cable to a USB plug or point, and switch on to charge. Disconnect when battery is 100% full.

Showering and bathing:

The Mi band is water resistant but not waterproof. Therefore, splashes of water from handwashing will be ok, but you are advised NOT to wear your Mi band in the shower, bath, or if you go swimming. Please also not wear the device when in a sauna or steam room.

Cleaning your Mi Band:

Remove the sensor from the band, and wash the band in warm soapy water, and dry off with a tea towel. The sensor itself should not be submerged in water, if this requires cleaned, please do so with a damp cloth and dry afterwards.

12.0 YOUR MI ACTIVITY TRACKER

When to wear your Mi Band:

This study is primary interested in your physical activity levels so you are only required to wear the tracker when you get up in the morning, until you go to bed in the evening. We wish to collect this data for the 30 weeks, which the study lasts for. Please take it off when bathing, and should you go swimming.

The Mi band will start collecting data as soon as you put the device on. There is no need to press any buttons. The Mi band has a built-in energy saving feature, so unless you tap the bottom of the screen located on the screen it will be blank. It is still working even with screen blank. If you wish to see the information, being collected tap the button, and for more in detail information slide your finger up and tap on the other features to see the information.
Further information about your activity can be found on the Mi app on your phone, which we will explore on the next few pages.

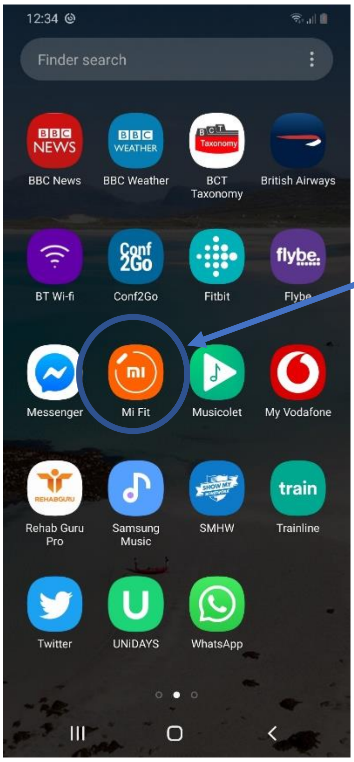
Just tap the icon, and it will take you to your information.

The Mi Band Phone App

When setting your phone and band up, Julie will download an app to your phone called Mi Fit app. The icon is opposite. By tapping this icon you will be able to see all you physical activity data.

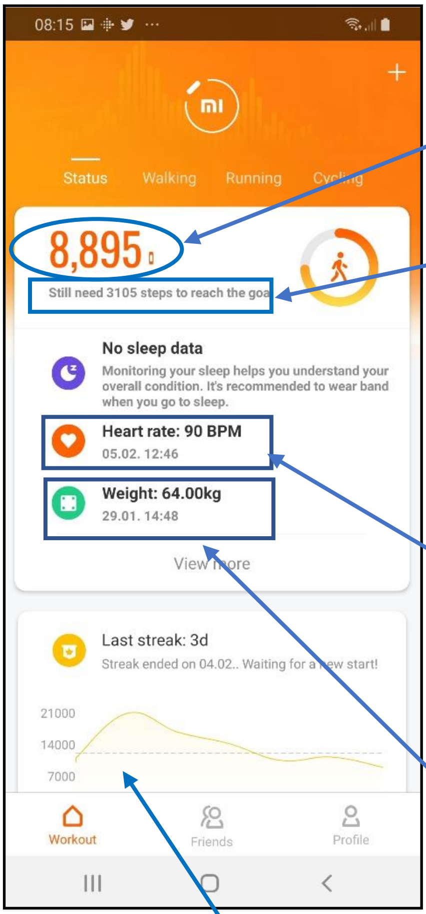
Getting started:

So start by opening up your phone, to your normal home page. All apps are normally listed alphabetically, so may need to swipe the screen depending on how many apps you have.



When you open your phone on the home page, you will see the Mi Fit app listed amongst your other apps that you have on your phone.

Tapping the Mi Fit App will take you to a page like this, which will then refresh and open the page detailed below.



Still need 3105 steps to reach the goa

No sleep data

Monitoring your sleep helps you understand your overall condition. It's recommended to wear band when you go to sleep.

Heart rate: 90 BPM
05.02. 12:46

Weight: 64.00kg
29.01. 14:48

View more

Last streak: 3d

Streak ended on 04.02.. Waiting for a new start!

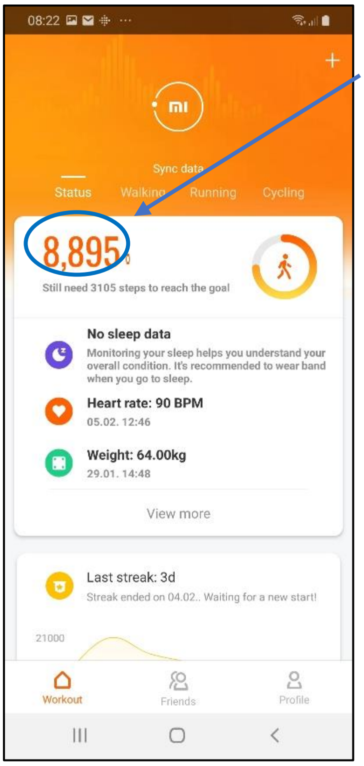
This illustrates the number of steps completed on this day at this time.

This states how many more steps that need to be undertaken to achieve your daily step goal, which in this example is set as 12, 000. When this goal has been achieved the orange circle surrounding the stick man will be entirely orange.

This provides information about heart rate in beats per minute (Bpm). In this example it was recorded on the 5th of february (05.02), at 12.46.

This illustrates graphically the total daily step count over the last 3 days.

Weight on the 29th of January was 64kg


08:22

Sync data

Status Walking Running Cycling

8,895

Still need 3105 steps to reach the goal

No sleep data

Monitoring your sleep helps you understand your overall condition. It's recommended to wear band when you go to sleep.

Heart rate: 90 BPM

05.02. 12:46

Weight: 64.00kg

29.01. 14:48

View more

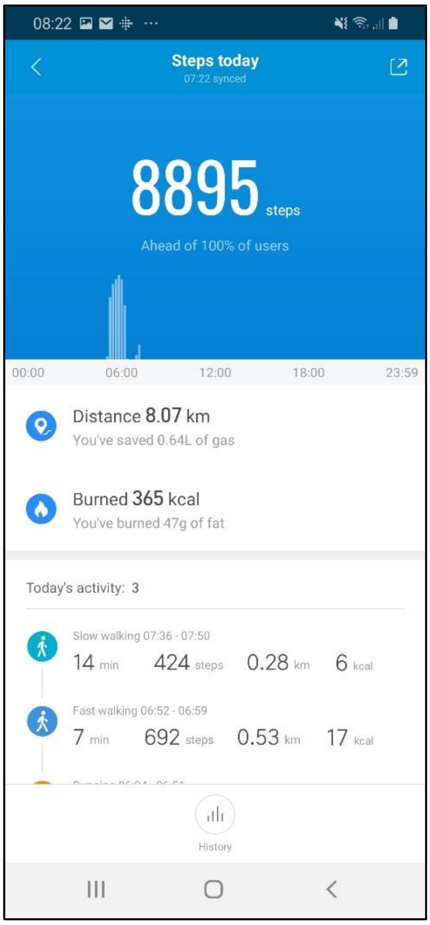
Last streak: 3d

Streak ended on 04.02.. Waiting for a new start!

21000

Workout Friends Profile

Taping your current daily step count here, takes you to this display


08:22

Steps today

07:22 synced

8895 steps

Ahead of 100% of users

00:00 06:00 12:00 18:00 23:59

Distance 8.07 km

You've saved 0.64L of gas

Burned 365 kcal

You've burned 47g of fat

Today's activity: 3

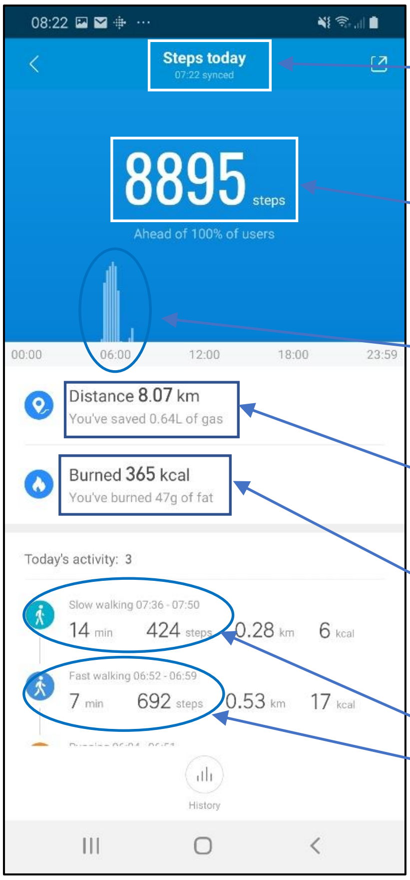
Slow walking 07:36 - 07:50

14 min 424 steps 0.28 km 6 kcal

Fast walking 06:52 - 06:59

7 min 692 steps 0.53 km 17 kcal

History


08:22

Steps today

07:22 synced

8895 steps

Ahead of 100% of users

00:00 06:00 12:00 18:00 23:59

Distance 8.07 km

You've saved 0.64L of gas

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You've burned 47g of fat

Today's activity: 3

Slow walking 07:36 - 07:50

14 min 424 steps 0.28 km 6 kcal

Fast walking 06:52 - 06:59

7 min 692 steps 0.53 km 17 kcal

History

Time, which Mi band data synchronised with the Mi Fit app 7.22,

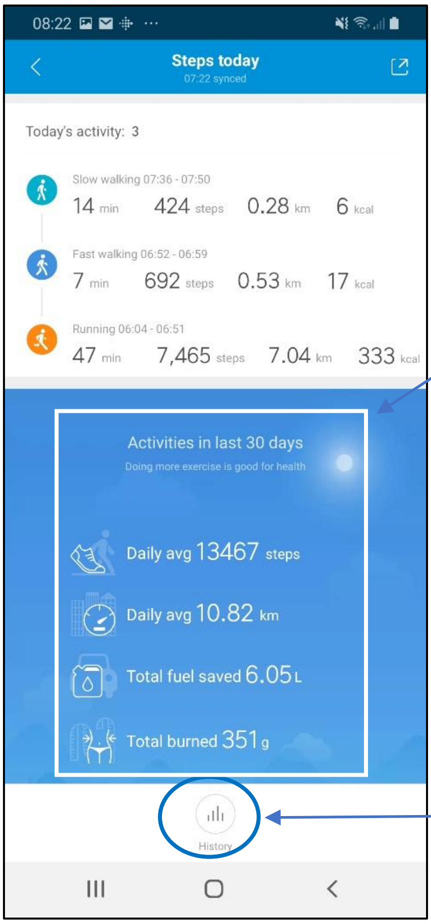
Number of steps taken on this point of time.

Timeline of stepping activity. In this activity, all activity occurred between 6 and 7am

Distance travelled in this example – 8.07km

Amount of energy spent by stepping activity on this day

The Mi band, categories stepping into slow, fast walking, light



Steps today
07:22 synced

Today's activity: 3

Slow walking 07:36 - 07:50
14 min 424 steps 0.28 km 6 kcal

Fast walking 06:52 - 06:59
7 min 692 steps 0.53 km 17 kcal

Running 06:04 - 06:51
47 min 7,465 steps 7.04 km 333 kcal

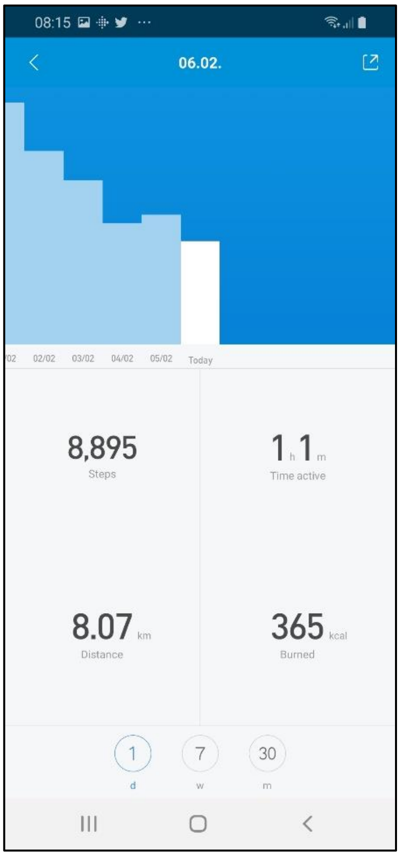
Activities in last 30 days
Doing more exercise is good for health

Daily avg 13467 steps
Daily avg 10.82 km
Total fuel saved 6.05 L
Total burned 351 g

By scrolling down this page, you will be able to see cataloguing of other activities you have done on this day, but also the app summaries conducted over the last 30 days

Tapping this history icon takes you to your activity history and illustrates this in a bar graph format as is shown below.

This display illustrated your total step count on the prior days. In this example, you can see the last 6 days total steps



8,895 Steps
1 h 1 m Time active
8.07 km Distance
365 kcal Burned

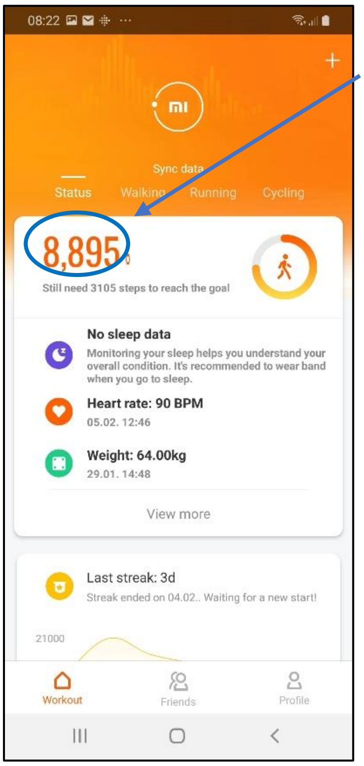
Recording your physical activity information

So we can review your physical activity, you will need to share the information collected on your tracker. It is advisable that you write down each day your total activity within your activity diary. It would be best to do this last thing at night or first thing in the morning where you record the prior day's activity. The activity diary is discussed in section 10.0.

The information we wish you to record is:

- Total step count for that day
- Total distance travelled
- Time spent slow walking
- Time spent fast walking

This information can be found by:



8,895

Still need 3105 steps to reach the goal

No sleep data

Monitoring your sleep helps you understand your overall condition. It's recommended to wear band when you go to sleep.

Heart rate: 90 BPM
05.02. 12:46

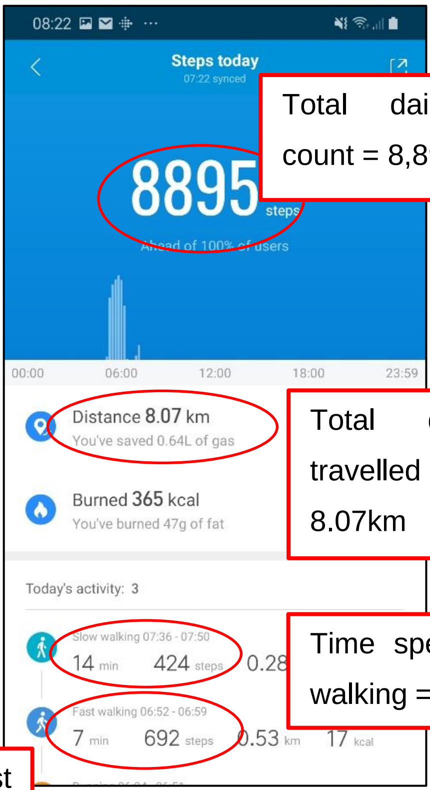
Weight: 64.00kg
29.01. 14:48

View more

Last streak: 3d

Streak ended on 04.02.. Waiting for a new start!

Taping your current daily step count here, takes you



8895 steps

Ahead of 100% of users

Distance 8.07 km
You've saved 0.64L of gas

Burned 365 kcal
You've burned 47g of fat

Today's activity: 3

Slow walking 07:36 - 07:50
14 min 424 steps 0.28

Fast walking 06:52 - 06:59
7 min 692 steps 0.53 km 17 kcal

Total daily step count = 8,895

Total distance travelled = 8.07km

Time spent slow walking = 14 mins

Time spent fast walking = 7mins

13.0: References

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8.22 APPENDIX 22: FITNESS INSTRUCTOR DOCUMENTATION

PDConnect

Study Name: Exercise for people with Parkinson’s -the PDConnect study.

Study Number:_______________

Participant ID:________________

Fitness Instructor Documentation Booklet

This study is funded by:

PARKINSON'S UK
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.

CHIEF
SCIENTIST
OFFICE

PDConnect

Fitness Instructor Documentation

This document is for use by Fitness Instructors for during the 12-week group based exercise and the self-management phase of the PDConnect programme

The purpose of this document is to:

- Document any participants reported changes/issues which occur during the 12-week group-based exercise phase
- To document progression with group-based exercise, goals, and HEP during the 12 week group based exercise phase
- To document video or audio calls with participants during the self-management phase of the programme.

If additional space to add notes is required, blank note pages have been added into this booklet. Please can you ensure that all entries are dated and signed.

Completed examples are provided for guidance.

PDConnect

Fitness Instructor Documentation -Group based exercise (EXAMPLE)

Week 1:	**YES**	**NO**
Did the participant report any issues from prior week? If yes please state below Been to see Consultant on 07/09/20. No changes to medication planned until next review	✓	
Has the participant experienced any changes in medication since last visit, if yes please state below		✓
Does the participant report any issues with their HEP? If yes please state below The yellow theraband provided by the Physiotherapist, broken during the week. New piece provided and exercise technique using the band checked.	✓	

Exercise programme record.

Exercise Number	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
Level	1	1	3	2	2	1	1	2	2	2

Notes:

No significant changes since last week. In good spirits and worked hard for the duration of the session. Guidance need for maintaining technique of squat and lunge based exercise as stability is poor. Review next week

Signed: Julie Jones Date: 10th Sept 2020

PDConnect

Fitness Instructor Documentation

Week 1:	**YES**	**NO**
Did the participant report any issues from prior week? If yes please state below		
Has the participant experienced any changes in medication since last visit, if yes please state below		
Does the participant report any issues with their HEP? If yes please state below		

Exercise programme record.

Exercise Number	1	2	3	4	5	6	7	8	9	10
Level										

Notes:

Signed:

Date:

Week Nine Goal Review

Have all the goals from last session been achieved YES/NO

Comments:

	Agreed Goals for next three weeks
1	
2	
3	
4	
5	

Signed: Date:

PDConnect

Fitness Instructor Documentation

Please when completed can you return this Julie Jones.

If you have any questions at any time, please contact Julie.

☎ 01224 263282 ✉ j.c.jones@rgu.ac.uk

8.23 APPENDIX 23: PHYSIOTHERAPIST TO FITNESS INSTRUCTOR HANDOVER SHEET

PDConnect

PDConnect Handover Document

Handover document to be completed by the physiotherapists and provided to the Fitness instructor for each participant.

Participants name: •
Summary of main problem areas: •
Current patient goals:
Other relevant information.

Participants name: •
Summary of main problem areas: •
Current patient goals:
Other relevant information.

Participants name: •
Summary of main problem areas: •
Current patient goals:
Other relevant information.

8.24 Appendix 24: Fitness equipment Information

PDConnect Equipment

Dear all,

I hope this package finds you well. Enclosed within this package is some exercise equipment for use within your home exercise programme and use within the group-based exercise. **You will be directed when to use this equipment by either Michelle or Lyndsay.** You will all know Michelle at this point, but Lyndsay van der Starre is the fitness instructor who will be delivering the group exercise element of the PDConnect Programme. Lyndsay will be in touch with you shortly via email, to introduce herself, and to provide you with the Microsoft Teams link to join the group exercise class.

Inside this package you should have the following items:

- A soft ball
- Yellow, red, and green pieces of resistance band (theraband)
- Four spot mats
- A scarf
- 2 wall markers and blu tac

Enjoy.

Many thanks

Julie.

8.25 Appendix 25: Physiotherapy session Plans

PDConnect

Physiotherapy session plans

- The session plans are designed as a guide of what needs to be included within every session to ensure that there is standardisation in approach within and between sessions for those receiving PDConnect.

- The main aim of PDConnect is to empower PwP to become more physically active. The key elements to each session are exercise, education, and BCTs with the aim by the end of the programme that will be able to self-manage their own exercise routine**.**

- The selection of exercise should be a joint decision between you and the participants and should be individualised to their needs. During initial session this may require a steer from yourselves, while later sessions this should be more of a mutual discussion to ensure exercise prescribed align with the persons preferences. Exercise programmes should include the following elements, strength, aerobic, balance, flexibility, and functional based exercises, with the latter session also including dual task training.

- Please use these session plans to a guide what needs to be included within each session. As discussed within the training, inclusion of education, and BCTs should be embedded within the session, rather than as an add on at the end of the session.

- Participants should be encouraged to work through the PDConnect manual over the 6 weeks of physiotherapy sessions.

- In addition, participants need to complete their activity diaries and complete the weekly activity planners**.**

Session One

By the end of this sessions participants should have:

- a HEP, in paper or email format, which needs to be conducted on 5 days in the following week
- a completed activity planner for the next week
- an understanding of the benefits of exercise has for their Parkinson's and wider health and well-being
- an understanding of what they need to record in their activity diary, and when.
- a daily step count target
- 4 mutually agreed goals, 3 to be addressed in the next 6 weeks and one long term goal.
- your contact details and an appointment for their session next week

Discuss within the session:

- What they perceive are the main barriers and motivators to exercise and explore potential solutions to these
- What they perceive as the benefits of exercise are for their Parkinson's and wide health
- Environmental alterations and potential solutions to promote PA during their normal week, eg walking to get the paper not taking the car.
- Make suggestions where PA could substitute sedentary activity
- What their what his/her exercise preferences are

The purpose of these discussions is to gain an insight into their perceptions, but also provide opportunity for you to provide education, and guidance to shape their views, emphasising the value of exercise for their Parkinson's and beyond. These discussions can be done in isolation, or combined with exercise prescription

Exercise prescription:

Within the one hour session participants should be exercising for a minimum of 35 minutes

Exercises should be selected based on individual needs and preferences and should encompass a combination of:

- Strength exercises with particular focus hip, knees, ankle and shoulder
- Flexibility exercise with emphasis upon the trunk, shoulder, and ankle
- Balance exercises should be progressive working towards dynamic and functional balance.
- Aerobic exercises, working towards working at RPE13
- Functional and amplitude based exercises

To promote development of fitness levels, alternating aerobic exercise with other forms of exercise maybe beneficial to promote working at a more stable RPE

Build in teaching points within the exercise prescription:

These can be noted down within the participant's manual as required.

- Provide instruction and demonstrate how to do the exercise- ie skills training
- Provide real time feedback on their technique and any refinements which are required
- Discuss the intended benefits of the exercise
- Ensure that the participant understands the value this exercise has for them
- Provide insight into what they exercise should feel like
- Information on DOM's
- Provide any health and safety information that is relevant

PDConnect

Session Two

By the end of this sessions participants should have:

- a review/update of HEP, in paper or email format, which needs to be conducted on 5 days in the following week
- a review and update of their activity planner for the next week
- an understanding of the consequences of inactivity, and the impact of discontinuing exercise
- a review of the purpose of the activity planner and diary.
- a review of their daily step count target
- 4 mutually agreed goals, 3 to be addressed in the next 5 weeks and one long term goal. These can be reviewed from prior week and amended as appropriate/required
- an appointment for their session next week

Discuss within the session:

- Review the pros and cons of exercise
- Reflect on how they found their HEP last week, explore any barriers and problem solve solutions as required
- Discuss adherence to activity planner, explore any barriers and problem solve solution as required
- Signpost participants to exercise videos within the manual to support motivation
- Make suggestions where PA could substitute sedentary activity

The purpose of these discussions is continue to promote the benefits of exercise, and acknowledge the progress from last week. This session can allow for deeper exploration of the benefits of exercise to promote shaping participants views on the principles of exercise prescription (FITT). Introduce concept of "daily dose of exercise"

Exercise prescription:

Within the one hour session participants should be exercising for a minimum of 35 minutes

Exercises should be selected based on individual needs and preferences and should encompass a combination of:

- Strength exercises with particular focus hip, knees, ankle and shoulder
- Flexibility exercise with emphasis upon the trunk, shoulder, and ankle
- Balance exercises should be progressive working towards dynamic and functional balance.
- Aerobic exercises, working towards working at RPE13
- Functional and amplitude based exercises

To promote development of fitness levels, alternating aerobic exercise with other forms of exercise maybe beneficial to promote working at a more stable RPE

Exercise Progression Criteria:

Exercises should be progressed as appropriate for each individual, by altering either increasing the intensity, duration, frequency, or amount of activity or exercise

Build in teaching points within the exercise prescription:

These can be noted down within the participant's manual as required.

- Provide instruction and demonstrate how to do the exercise- ie skills training
- Provide real time feedback on their technique and any refinements which are required
- Reinforce the intended benefits of the exercise and the value this exercise has for them
- Provide insight into what they exercise should feel like
- Provide any health and safety information as relevant

Session Three

By the end of this sessions participants should:

- Have reviewed and discussed the activity diary and activity planner from the prior week
- Have an updated HEP, either changing the prescription and or new exercises added to reflect progress. Participants should be actively involved in exercise selection
- A completed activity planner for the next week.
- Be aware that next week they need to bring in a activity planner for week 4 which they have populated for discussion
- Discuss, review, and amend as appropriate agreed goals, 3 to be addressed in the next 3 weeks and one long-term goal.
- Have an understanding of the range of physical activities which they can participate in.

Discuss within the session:

- re-evaluation of goals, their perception of progress and, what challenges they perceive.
- Reflect on how they found their HEP last week, explore any barriers and problem solve solutions as required.
- Discuss adherence to activity planner, explore any barriers and problem solve solution as required.
- Introduce environmental cues and pacing prompts to promote challenge within exercise out with the sessions.

This is the halfway point therefore, the next two sessions focus is upon developing confidence in exercise, and reflecting upon progress that has been made. Emphasis needs to be promoting levels of PA (ie increasing number of distance of daily walks), re-evaluation of goals. In particular feedback on improvement and emphasis on reward for achievements made is crucial.

Exercise prescription:

Within the one hour session participants should be exercising for a minimum of 35 minutes

Exercises should be selected based on individual needs and preferences and should encompass a combination of:

- Strength exercises with particular focus hip, knees, ankle and shoulder
- Flexibility exercise with emphasis upon the trunk, shoulder, and ankle
- Balance exercises should be progressive working towards dynamic and functional balance.
- Aerobic exercises, working towards working at RPE13
- Functional and amplitude based exercises,
- Introduce dual tasking, and increased task complexity as able
- Increase as appropriate daily walking

To promote development of fitness levels, alternating aerobic exercise with other forms of exercise maybe beneficial to promote working at a more stable RPE

Exercise Progression Criteria:

Exercises should be progressed as appropriate for each individual, by altering either increasing the intensity, duration, frequency, or amount of activity or exercise

Build in teaching points within the exercise prescription:

These can be noted down within the participant's manual as required.

- Provide instruction and demonstrate how to do new exercises- ie skills training
- Provide real time feedback on their technique and any refinements which are required
- Reinforce the intended benefits of the exercise and the value this exercise has for them
- Provide any health and safety information as relevant

PDConnect

Session Four

The focus from here in is on developing **confidence with exercise.** Within that there needs to be an emphasis on promoting exercise at a higher intensity, **aiming to work at RPE13** for as much of the session as possible. Exercise complexity needs to be enhanced to include exercises, which have a **physical and cognitive component.**

By the end of this session, all participants should:

- Have reviewed thier HEP, and progressed as appropriate
- Review daily step goals and progressed as appropriate
- Discuss participant completed weekly activity planner
- Review activity diary and discuss progress
- Have received information on locally available social networks for PwP

Key discussion points:

- Familiar with the basic exercise principles (FITT) and how this applied to them and their exercise programme
- Need and value of regular exercise routine
- Revisit how PA could substitute sedentary activity’s
- Need for quality of movement, and need to increase physical and cognitive loading
- Discus impact how current exercise programme has influenced friends and family
- Introduce concept of group based exercise, exploring perceptions and offer potential solutions.
- Discuss different forms of exercise choices
- Discuss progress and reward achievements

Exercise prescription:

Within the one-hour session participants should be exercising for a minimum of 35 minutes.

Exercises should be jointly selected based on individual needs and preferences. But be challenging.

Exercise should involve several muscle groups, with incorporation exercises which combine strength, balance, intensity, and functionality.

- Integrated approach
- Consider speed, power, directional changes, multiple planes of movement, goal orientated exercise, sustain amplitude of movement
- Motivate to work between RPE10-13 for whole session.
- Functional and amplitude-based exercises,
- Dual tasking, and increased task complexity as able
- Increase as appropriate daily walking
- Introduce Pilates, Tai chi, PWR, PDwarrior style exercises

To promote development of fitness levels, alternating aerobic exercise with other forms of exercise maybe beneficial to promote working at a more stable RPE

Build in teaching points within the exercise prescription:

These can be noted down within the participant's manual as required.

- Provide instruction and demonstrate how to do new exercises- ie skills training
- Provide real time feedback on their technique and any refinements which are required
- Reinforce the intended benefits of the exercise and the value this exercise has for them
- Provide any health and safety information as relevant

PDConnect

Session Five

The focus from here in is on **sustaining confidence with exercise.** Within exercise prescription, the inclusion of increased diversity of challenging exercises in terms of physical and cognitive load. These remaining two weeks need to **foster a sense of self-confidence**, to prepare the participants to exercise within the group sessions which follow.

By the end of this session:

- Review goals and review performance
- Review activity planner and activity diary from prior week
- Review daily step cunt goals and performance
- Modify HEP and session-based exercise programme as required
- Review perception of progress since week one

Key discussion points:

- Why exercise programmes need modified
- Explore any issues which participants are not clear on or whether they have questions arising from the manual
- Explore perceived issues, challenges of group-based exercise, and discuss strategies to address these
- Discussion of exercise buddy to attend class with them
- Compare outcome from last week to this week
- Add in further environmental promote to maintain levels of motivation
- Signpost to the manual to continue to develop understanding
- Explore how perceived abilities, perceptions and capabilities have changed over time
- Congratulate on progress to date

Exercise prescription:

Within the one hour session participants should be exercising for a minimum of 35 minutes.

Exercises should be jointly selected based on individual needs and preferences. But be challenging.

Exercise should involve several muscle groups, with incorporation exercises which combine strength, balance, intensity and functionality.

- Integrated approach
- Consider speed, power, directional changes, multiple planes of movement, goal orientated exercise, sustain amplitude of movement
- Motivate to work between RPE10-13 for whole session.
- Functional and amplitude-based exercises,
- Dual tasking, and increased task complexity as able
- Increase as appropriate daily walking
- Introduce Pilates, Tai chi, PWR, PDwarrior style exercises

To promote development of fitness levels, alternating aerobic exercise with other forms of exercise maybe beneficial to promote working at a more stable RPE

Build in teaching points within the exercise prescription:

These can be noted down within the participant's manual as required.

- Provide instruction and demonstrate how to do new exercises- ie skills training
- Provide real time feedback on their technique and any refinements which are required
- Reinforce the intended benefits of the exercise and the value this exercise has for them
- Provide any health and safety information as relevant

Session Six

The final week. The emphasis here is to celebrate the successes, which have been made over the last 6 weeks. Address any concerns which may still persist in relation to the group based intervention. To update HEP, and to reset, and document goals for the next 12 weeks. Finally inform participants on what happens next.

By the end of this session, participants should:

- Have renewed short- and long-term goals (up to 12 weeks)
- Have renewed daily step count goals
- Have an updated HEP
- Be independent in planning their weekly activity planner, and maintaining their activity diary.
- Completed reading of study manual and activities.

Key discussion points:

- Reflect on session one, with an emphasis on how their abilities, perceptions and capabilities have changed in that time
- Explore how perceived abilities, perceptions and capabilities have changed over time
- Discuss strategies to support socialisation and confidence within social environment.
- Revisit readiness to exercise scale, and contrast with session one
- Congratulate on progress to date
- Encourage participants to reward self as a result of changed behaviour
- Provide information about locally available social support networks for PwP

Exercise prescription:

Within the one-hour session participants should be exercising for a minimum of 35 minutes.

Exercises should be jointly selected based on individual needs and preferences. But be challenging.

Exercise should involve several muscle groups, with incorporation exercises which combine strength, balance, intensity, and functionality.

- Integrated approach
- Consider speed, power, directional changes, multiple planes of movement, goal orientated exercise, sustain amplitude of movement
- Motivate to work between RPE10-13 for whole session.
- Functional and amplitude based exercises,
- Dual tasking, and increased task complexity as able
- Increase as appropriate daily walking
- Introduce Pilates, Tai chi, PWR, PDwarrior style exercises

To promote development of fitness levels, alternating aerobic exercise with other forms of exercise maybe beneficial to promote working at a more stable RPE

Build in teaching points within the exercise prescription:

These can be noted down within the participant's manual as required.

- Provide instruction and demonstrate how to do new exercises- ie skills training
- Provide real time feedback on their technique and any refinements which are required
- Reinforce the intended benefits of the exercise and the value this exercise has for them
- Provide any health and safety information as relevant

PDConnect

Thank you

Thank you very much for your time during the course of this study, it is very much appreciated. Should you experience any problems during the course of the study or wish to feedback on the experience please feel free to contact Julie Jones,

Julie Jones ☎ 01224 263282 ✉ j.c.jones@rgu.ac.uk

PDConnect

Group Based Exercise Session Plans

- The session plans are designed as a guide of what needs to be included within each session to ensure that there is standardisation in approach within and between sessions for those receiving PDConnect.
- The main aim of PDConnect is to empower PwP to become more physically active. The key elements to each session are exercise, education, and BCTs with the aim by the end of the programme that will be able to self-manage their own exercise routine
- Every week the circuit will consist of 10 stations. Every participant will spend 4 minutes at each station. Within each station there are four levels of difficulty, so to allow everyone to work within their own ability.
- Each session lasts 90 minutes. 60 minutes of exercise followed by 30 minutes of discussion forum. With the exception of week one where discussion forum is held first to allow for introductions
- Please use these session plans to a guide what needs to be included within each session. Feedback and teaching points on exercise technique should be embedded within exercise delivery, and delivered in real time
- Participants will be required to continue with their HEP 5 times a week, and progressing their outdoor walking
- From week 9, emphasis need to be placed on preparing to self-manage their own exercise engagement and sharing of community based exercise opportunities so that established exercise habits are maintained following this 12 week programme.
- In addition participants need to continue to wear their Mii Bands, complete their activity diaries and complete the weekly activity planners.

8.26 APPENDIX 26: FITNESS INSTRUCTOR SESSION PLANS

PDConnect

Session One

In week one only the discussion forum is delivered prior to the exercise to allow for group introductions.

Discussion forum:

- ❖ The purpose of this discussion forum is to introduce participants and fitness instructor to the rest of the group
- ❖ Each person to introduce themselves, including time since diagnosis, and share what their exercise goals are, and what it is they enjoy about exercise
- ❖ Cover basic health and safety information about attending the class
- ❖ Remind participants about individuality
- ❖ Create an informal exercise environment
- ❖ Encourage people to get themselves a drink to bring along to the discussions
- ❖ Promote culture of asking questions and clarification
- ❖ Provide overview of how the discussion forums will be run – informal discussion to develop social support network and opportunity for shared learning
- ❖ The first 6 session have planned topics, but the remaining six will be guided by what the group wish to discuss

By the end of this session one participants should have:

- ❖ been reminded to complete their weekly activity diary, activity planner, and record daily step count
- ❖ been reminded to continue to undertake their HEP 5 times a week.
- ❖ prompted to be walking outdoors at least 4 times a week
- ❖ your contact details and completed one full circuit class

Participants should be exercising for a minimum of one hour including warm up and cool down

During the circuit:

- Feedback on performance and technique is vital for effectiveness as well as to avoid injury.
- As required demonstrate the technique, so participants can model appropriately
- Remind participants of the required effort level, they should be aiming to work at RPE 13, somewhat hard
- Provide motivation to maintain level of effort and performance
- Discuss and ensure that the participants understand the intended benefits and values of each exercise has for them
- Monitor performance to inform whether participants need progressing
- Ensure participants remain hydrated throughout
- Provide insight into what they exercise should feel like
- Information on DOM’s
- Provide any health and safety information that is relevant

PDConnect

Session Two

Start with exercise circuit this week followed by group based discussion forum

By the end of this session one, participants should have:

- Be reminded to complete their weekly activity diary, activity planner and record daily step count
- Be reminded to continue to undertake their HEP 5 times a week
- Prompted to walk outdoors at least 4 times a week
- Completed one full circuit
- You contact details

Participants should be exercising for a minimum of one hour including warm up and cool down

During the circuit:

- Feedback on performance and technique is vital for effectiveness as well as to avoid injury.
- As required demonstrate the technique, so participants can model appropriately
- Remind participants of the required effort level, they should be aiming to work at RPE 13, somewhat hard
- Provide motivation to maintain level of effort and performance
- Discuss and ensure that the participants understand the intended benefits and values of each exercise has for them
- Monitor performance to inform whether participants need progressing
- Ensure participants remain hydrated throughout
- Provide insight into what they exercise should feel like
- Information on DOM’s and health and safety information

Week Two Discussion forum topic guide:

Purpose: is to share experience of experience of exercise, and the impact that it has. Below are some suggestions of some prompts to get people started

- what sort of exercise have people tried
- what are the groups perceived benefits of exercise
- how have participants built up their PA and exercise levels
- what strategies have they found useful to help them keep exercise
- sharing of any top tips
- sharing of exercise goals and why they have selected them
- discuss solutions to promote greater physical activity engagement
- promote concept of exercise buddy and social network to support exercise and physical activity involvement
- provide discussion on how to alter physical environment to promote greater activity, ie walking to shops instead of using the car
- promote discussion of strategies to reduce the impact of non-motor symptoms on their lives
- Share information about locally available social support networks and exercise opportunities for PwP

Finish by:

- Congratulate participants on achievements to date
- Encourage participants to reward self as a result of changed behaviour

PDConnect

Session Three

Set up and run circuit as previous week. **NO change** to how circuit is delivered from week two. Please refer back to the teaching points from week two to guide delivery. **However review/update of Goals and HEP is required**

By the end of this session three, participants should have:

- Be reminded to complete their weekly activity diary, activity planner and record daily step count
- Be reminded to continue to undertake their HEP 5 times a week
- Prompted to walk outdoors at least 4 times a week
- Completed one full circuit
- Your contact details
- **Reviewed and updated GOALs and HEP**

Week Three Discussion forum topic guide:

Purpose: To discuss within the group the value of strength training, and why this is especially important for PwP, and how to participate in strength training safely. The following are some pointer to guide discussions. Where possible these sessions should be participatory.

- What is strength training?
- Why is strength training important, including application to the ageing process
- What are the key muscles to focus on strength training on in Parkinson’s and why
- Discuss the difference with power and how this needs to be trained, and highlight key stations from the circuit where this is addressed.
- How many times that strength exercise should be done each week
- Cover the key considerations for undertaking strength training ie body positioning, biomechanics, reps, sets, EOR holds
- Top tips for how you can do strengthening exercises safely at home.

- Get the group to think how they could build strength training into everyday tasks eg sit to stand
- Introduce environmental cues eg when adverts come on TV to promote sit to stand practice
- Does the group have any questions in relation to strength training or any concerns?
- What types of strength training are or have participants engaged in? has anybody been to the gym before?
- Cover any relevant health and safety information/education pertinent to strength training.

Finish by:

- Opening the floor to any further questions
- Ask the group what their take home messages are from today
- Recap learning intentions

Session Four

Set up and run circuit as previous week. **NO change** to how circuit is delivered from week two. Now that participants are familiar with the exercise, this week you can focus more of quality and refinement of the exercises. Emphasise within the exercises as appropriate:

- Large amplitude movements.
- Whole body movements
- Speed
- Rotation
- Changes in direction
- Intensity of exercise

Below is reminder of key teaching points

Build in teaching points within the exercise prescription:

These can be noted down within the participant's manual as required.

- Provide instruction and demonstrate how to do new exercises- ie skills training
- Provide real time feedback/education on their technique and any refinements which are required
- Reinforce the intended benefits of the exercise and the value this exercise has for them and their Parkinson's
- Provide any health and safety information as relevant

Week four discussion forum topic guide:

Purpose: To discuss within the group the value of flexibility training, and why this is especially important for PwP, and how to participate in flexibility training safely. The following are some pointer to guide discussions. Where possible these sessions should be participatory.

- What is flexibility training? Why is flexibility training important, including application to the ageing process
- What are the key areas to focus on flexibility training on in Parkinson's and why

- Discuss the EOR hold, and the normal sensation that you would expect with a stretch
- The importance of daily stretching as well as before and after exercise
- Importance of flexibility of flexibility for function tasks such as walking eg arm swing, axial rotation, stride
- Top tips on key stretches, TA, Trunk ext, shoulders, Csp, Hip flexors, knee extensors. Run through seated and standing options as appropriate
- Introduce environmental cues eg mirror when brushing teeth
- Does the group have any questions in relation to flexibility training or any concerns?
- What types of flexibility training are or have participants engaged in? pilates, yoga, dance?
- Cover any relevant health and safety information/education pertinent to flexibility training.

Finish by:

- Ask the group what their take home messages are from today
- **Remind the group from week by the end of week 6, they need to make suggestions as to what the discussion forum should be about.**

Session Five

Set up and run circuit as previous week. **NO change** to how circuit is delivered from week two. Now that participants are familiar with the exercise, this week you can focus more of quality and refinement of the exercises. Emphasise within the exercises as appropriate:

- Large amplitude movements.
- Whole body movements
- Speed
- Rotation
- Changes in direction
- Intensity of exercise

Below is reminder of key teaching points

Build in teaching points within the exercise prescription:

These can be noted down within the participant's manual as required.

- Provide instruction and demonstrate how to do new exercises- ie skills training
- Provide real time feedback/education on their technique and any refinements which are required
- Reinforce the intended benefits of the exercise and the value this exercise has for them and their Parkinson's
- Provide any health and safety information as relevant

Week five discussion forum topic guide:

Purpose: To discuss within the group the value of aerobic training, and why this is especially important for PwP, and how to participate in aerobic training safely. The following are some pointer to guide discussions. These sessions should be participatory.

- Check in on how group are finding it so far.

- What are their favourite exercise stations?
- Which are their least favourite stations?
- What is aerobic training and why is it important for PwP
- What are the key considerations when training aerobically. Exercise snacking, duration, and frequency and intensity, RPE
- Discuss the normal sensation that you would expect aerobic exercise
- Top tips on increasing aerobic capacity when walking out doors, eg increasing rate and pace for short durations, use environmental cues
- Does the group have any questions in relation to aerobic training or any concerns?
- What types of aerobic training are or have participants engaged in? dance, boxing, walking, biking, running
- Cover any relevant health and safety information/education pertinent to aerobic training

Finish by:

- Ask the group what their take home messages are from today
- **Remind the group from week by the end of week 6, they need to make suggestions as to what the discussion forum should be about.**
- **Congratulate on progress to date.**

Session Six

Half way week. The emphasis here is to celebrate the successes, which have been made over the last 6 weeks. Address any concerns which may still persist in relation to exercise and their Parkinson's. To update HEP, and to reset, and document goals for the next 6 weeks. Finally inform participants on what happens next.

By the end of this session, participants should:

- Have renewed short and long term goals (up to 12 weeks)
- Have renewed daily step count goals
- Have an updated HEP
- Be independent in planning their weekly activity planner, and maintaining their activity diary.
- Completed reading of study manual and activities.
- Thinking about topics for the next 5 discussion forums

Set up and run circuit as previous week. **NO change** to how circuit is delivered from week two. Now that participants are familiar with the exercise, this week you can focus more of quality and refinement of the exercises. Emphasise within the exercises as appropriate:

- Large amplitude movements.
- Whole body movements
- Speed
- Rotation
- Changes in direction
- Intensity of exercise

Let participants know that **some changes to the stations will be made next week**, to keep them motivated in the circuit. Up to half the exercises will change, so you can reassure them that they will not all be new.

Week six discussion forum topic guide:

Purpose: These sessions should be participatory. The focus of this session is to reflect on the progress made to date, and what impact exercise and physical activity is having on them.

This session is about bringing the group together, and developing a social support network. So emphasis on shared experience and learning.

- Congratulate on progress to date
- Encourage participants to reward self as a result of changed behaviour
- Reflect on session one, with an emphasis on how their abilities, perceptions and capabilities have changed over time
- Explore perceived issues, challenges of group based exercise, and discuss strategies to address these
- Discuss strategies to support socialisation and confidence within social environment.
- Revisit readiness to exercise scale, and contrast with session one
- Provide information about locally available social support networks for PwP
- Add in further environmental cue to promote to maintain levels of motivation
- Why exercise programmes need modified balance between learning and motivation, and challenge
- Explore any issues which participants are not clear on or whether they have questions arising from the manual
- What would the group like to discuss in the next 6 weeks, what would be useful or of value to them?

Session Seven

By the end of this session, participants should:

- ❖ Be able to perform the new exercises within the circuit
- ❖ To be aware of the purpose, and key considerations of these new exercises
- ❖ Be independent in planning their weekly activity planner, and maintaining their activity diary.
- ❖ Completed reading of study manual and activities.
- ❖ Thinking about topics for the next 4 discussion forums
- ❖ Be thinking about seeking and trying alternative exercise opportunities within local community, eg swimming, yoga, pilates, walking groups, aerobics, boxing.

There is five different stations this week, just to keep the circuit fresh. See document for details. All participants will need an introduction to these exercise stations, including purpose, technique and key teaching points. With all exercises, emphasise:

- ❖ Large amplitude movements.
- ❖ Whole body movements
- ❖ Speed
- ❖ Rotation
- ❖ Changes in direction
- ❖ Intensity of exercise
- ❖ Challenge yourself
- ❖ Think effort – RPE 13
- ❖ Encourage participants to focus on how they are moving and encourage big, consistent moves

Week seven discussion forum topic guide:

Purpose: These sessions should be participatory.

This session is about bringing the group together, and developing a social support network. So emphasis on shared experience and learning. Always finishing positively, reminding participants to:

- **Keep up with their HEP 5 times a week**
- **Continue walking outdoors 4-5 times a week**
- **Complete their weekly activity planners**
- **Complete their activity diary**
- **Continue waring their Mii Bands**

This weeks topic should be selected by the group, and should have arisen as a suggestion from the group.

In the event of no suggestions being made below are some suggestions which could be covered

- **Balance training** – you could adapt the discussion session plan from week 5, but substitute balance
- **Motivation** – strategies to keep you motivated to exercise. share thoughts and experiences from the group and yourself
- **Different types of exercise**: what different types of exercise is there out there. Discussion of exercise appropriateness
- **Exercising as your Parkinson's progresses**: how you may need to modify the rate and pace. See exercise framework

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Session Eight

By the end of this session, participants should:

- Be able to perform the new exercises within the circuit
- To aware of the purpose, and key considerations of these new exercises
- Be independent in planning their weekly activity planner, and maintaining their activity diary.
- Completed reading of study manual and activities.
- Thinking about topics for the next 3 discussion forums
- Be thinking about seeking and trying alternative exercise opportunities within local community, eg swimming, yoga, pilates, walking groups, aerobics, boxing.

Participants should be familiar with the new stations, however may still require guidance, including purpose, technique and key teaching points. With all exercises, emphasise:

- Large amplitude movements.
- Whole body movements
- Speed
- Rotation
- Changes in direction
- Intensity of exercise
- Challenge yourself
- Think effort – RPE 13
- Encourage participants to focus on how they are moving and encourage big, consistent moves

Discussion forum:

As week 7. See guidance on page 15

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Session Nine

Three-quarters of the way through. The emphasis here is to celebrate the successes, which have been made over the last 9 weeks of group exercise. Address any concerns which may still persist in relation to exercise and their Parkinson's. To update HEP, and to reset, and document goals for the next 3 weeks.

Within the group discussion promote the group to consider how they will continue your exercise after this 12 week session ceases.

By the end of this session, participants should:

- Have had their HEP reviewed and updated as required
- Have reviewed their goals for the next 3 weeks
- Be able to perform the new exercises within the circuit
- To aware of the purpose, and key considerations of these new exercises
- Be independent in planning their weekly activity planner, and maintaining their activity diary.
- Completed reading of study manual and activities.
- Thinking about topics for the next 2 discussion forums
- Be thinking about seeking and trying alternative exercise opportunities within local community, eg swimming, yoga, pilates, walking groups, aerobics, boxing.

Participants should be familiar with the new stations, however may still require guidance, including purpose, technique and key teaching points. With all exercises, emphasise:

- Large amplitude movements.
- Whole body movements
- Speed
- Rotation
- Changes in direction

- Intensity of exercise
- Challenge yourself
- Think effort – RPE 13
- Encourage participants to focus on how they are moving and encourage big, consistent moves

Discussion forum:

As week 7. See guidance on page 15

- Within the group discussion, promote the group to consider how they will continue your exercise after this 12 week session ceases.
- What strategies have they considered?
- Will they still remain in contact as a group?   How could this be facilitated
- What other exercise/PA have they considered they may start/try?

Session Ten

By the end of this session, participants should:

- Be able to perform the ALL exercises within the circuit
- To aware of the purpose, and key considerations of these new exercises
- Be independent in planning their weekly activity planner, and maintaining their activity diary.
- Completed reading of study manual and activities.
- Thinking about topics for the next 3 discussion forums
- Be thinking about seeking and trying alternative exercise opportunities within local community, eg swimming, yoga, pilates, walking groups, aerobics, boxing.

Participants should be familiar with the new stations, however may still require guidance, including purpose, technique and key teaching points. With all exercises, emphasise:

- Large amplitude movements.
- Whole body movements
- Speed
- Rotation
- Changes in direction
- Intensity of exercise
- Challenge yourself
- Think effort – RPE 13
- Encourage participants to focus on how they are moving and encourage big, consistent moves

Discussion forum:

As week 7. See guidance on page 15

- Within the group discussion, promote the group to consider how they will continue your exercise after this 12 week session ceases.
- What strategies have they considered?

- Will they still remain in contact as a group? How could this be facilitated
- What other exercise/PA have they considered they may start/try?

Session Eleven

By the end of this session, participants should:

- Be able to perform the ALL exercises within the circuit
- To aware of the purpose, and key considerations of these new exercises
- Be independent in planning their weekly activity planner, and maintaining their activity diary.
- Completed reading of study manual and activities.
- Thinking about topics for the next 3 discussion forums
- Be thinking about seeking and trying alternative exercise opportunities within local community, eg swimming, yoga, pilates, walking groups, aerobics, boxing.

Participants should be familiar with the new stations. With all exercises, emphasise:

- Large amplitude movements.
- Whole body movements
- Speed
- Rotation
- Changes in direction
- Intensity of exercise
- Challenge yourself
- Think effort – RPE 13
- Encourage participants to focus on how they are moving and encourage big, consistent moves

Discussion forum:

As week 7. See guidance on page 15

- Within the group discussion, promote the group to consider how they will continue your exercise after this 12 week session ceases.
- What strategies have they considered?
- Will they still remain in contact as a group?   How could this be facilitated
- What other exercise/PA have they considered they may start/try?

REMIND PARTICIPANTS THAT NEXT WEEK IS THE LAST GROUP BASED SESSION.

Session Twelve

They have made it!! You have made it!!!

By the end of this session, participants should:

- Be able to perform the ALL exercises within the circuit
- Be independent in planning their weekly activity planner, and maintaining their activity diary.
- Completed reading of study manual and activities.
- Have their goals refreshed for the next 12 weeks
- Have their HEP refreshed for the next 4 weeks
- Be clear on what happens next.
- What the expectations are and means of communication are for the next 12 weeks
- Have an appointment date for the first communication session

❖ Be independent with their undertaking their weekly planners and diaries ❖ Be reminded of the need to continue wearing their Mii Bands ❖ Have a clear plan of how they will remain active.	

Participants should be familiar with the new stations. With all exercises, emphasise:

- ❖ Large amplitude whole body movements.
- ❖ Speed
- ❖ Rotation and directional changes
- ❖ Intensity of exercise, Think effort – RPE 13
- ❖ Challenge yourself
- ❖ Encourage participants to focus on how they are moving and encourage big, consistent moves

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Thank you

Thank you very much for your time during the course of this study, it is very much appreciated. Should you experience any problems during the course of the study or wish to feedback on the experience please feel free to contact Julie Jones,

Julie Jones ☎ 01224 263282 ✉ j.c.jones@rgu.ac.uk

8.27 APPENDIX 27: PDCONNECT MEASUREMENT MANUAL

PDConnect

PDConnect Measurement Manual

Study Name: Exercise for people with Parkinson’s -the PDConnect study.

Study Number:_280159_________

Participant Number:_________________

Date:_________________________

Please complete all of the following measures. These measures need to be completed at baseline, and repeated at 6, 18, and 30 weeks, using a new pack on each occasion. **When you have completed this document in full, please return to Julie Jones, using the stamped addressed envelope provided.**

This study is funded by:

PARKINSON'S UK
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.

CHIEF
SCIENTIST
OFFICE

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Measurement Information.

Measurement Information.

Thank you again for being part of this study. As previous enclosed is booklet of self-administered measurement tools which we would like you to complete. The purpose of these measurements is to gain insight into how Parkinson's effects and impacts your daily life.

This booklet contains all the measurements we would like you to complete. If you would prefer to complete these in an electronic format, please email and Julie will arrange for you to have access to an electronic version of the forms j.c.jones@rgu.ac.uk

There are 11 different self-administered measures for you to complete. You can complete them all at once, or you can complete some, and return to the form later in the day. Completion of these measures should take no longer than 1 hour. Some overlap, exists between the measures however, this is unavoidable. If we were to remove certain questions from the measures, it would affect their structure and reliability. As this is a feasibility study, a large number of measures are include, as the researchers will be evaluating which measures to use in a future study.

Data collected will be shared with the research team, and will be stored in line with GDPR guidelines. Data will be anonymised prior to analysis, so individual participants cannot be identified.

If you have any questions prior to or during completion of this booklet, please contact j.c.jones@rgu.ac.uk

When you have completed the booklet, please return to Julie, using the provided addressed envelope.

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Unified Parkinson’s Disease Rating Scale (UPDRS)

Standardised participant introduction.

This measure is called the Unified Parkinson’s Disease Rating Scale or UPDRS for short. Your consultant may have conducted this test when you were diagnosed or when you last saw them, as it is a standard test used within the clinic to assess Parkinson symptoms.

Instructions: This questionnaire will ask you about your experiences of daily living. **There are 20 questions.** Some of these questions may not apply to you now or ever. If you do not have the problem, simply mark **0 for NO**.

Please read each one carefully and read all answers before selecting the one that best applies to you. We are interested in your average or usual function over the past week. Some participants can do things better at one time of the day than at others. However, only one answer is allowed for each question, so please mark the answer that best describes what you can do most of the time.

You may have other medical conditions besides Parkinson’s. Do not worry about separating Parkinson’s disease from other conditions. Just answer the question with your best response. Use only 0, 1, 2, 3, 4 for answers, nothing else. Do not leave any blanks.

Non-Motor Aspects of Experiences of Daily Living	
SLEEP PROBLEMS: Over the past week, have you had trouble going to sleep at night or staying asleep through the night? Consider how rested you felt after waking up in the morning. **0: Normal:** No problems. **1: Slight:** Sleep problems are present but usually do not cause trouble getting a full night of sleep. **2: Mild:** Sleep problems usually cause some difficulties getting a full night of sleep. **3: Moderate:** Sleep problems cause many difficulties getting a full night of sleep, but I still usually sleep for more than half the night. **4: Severe:** I usually do not sleep for most of the night.	**Score** ☐
DAYTIME SLEEPINESS: Over the past week, have you had trouble staying awake during the daytime? **0: Normal:** No daytime sleepiness. **1: Slight:** Daytime sleepiness occurs, but I can resist and I stay awake. **2: Mild:** Sometimes I fall asleep when alone and relaxing. For example, while reading or watching TV. **3: Moderate:** I sometimes fall asleep when I should not. For example, while eating or talking with other people. **4: Severe:** I often fall asleep when I should not. For example, while eating or talking with other people.	**Score** ☐
PAIN AND OTHER SENSATIONS: Over the past week, have you had uncomfortable feelings in your body like pain, aches, tingling, or cramps? **0: Normal**: No uncomfortable feelings. **1: Slight:** I have these feelings. However, I can do things and be with other people without difficulty. **2: Mild:** These feelings cause some problems when I do things or am with other people. **3: Moderate:** These feelings cause many problems, but they do not stop me from doing things or being with other people. **4: Severe:** These feelings stop me from doing things or being with other people.	**Score** ☐

URINARY PROBLEMS: Over the past week, have you had trouble with urine control? For example, an urgent need to urinate, a need to urinate too often, or urine accidents. **0: Normal:** No urine control problems. **1: Slight:** I need to urinate often or urgently. However, these problems do not cause difficulties with my daily activities. **2: Mild:** Urine problems cause some difficulties with my daily activities. However, I do not have urine accidents. **3: Moderate:** Urine problems cause many difficulties with my daily activities, including urine accidents. **4: Severe:** I cannot control my urine and use a protective garment	**Score** ☐
CONSTIPATION PROBLEMS: Over the past week, have you had constipation troubles that cause you difficulty moving your bowels? **0: Normal:** No constipation. **1: Slight:** I have been constipated. I use extra effort to move my bowels. However, this problem does not disturb my activities or my being comfortable. **2: Mild:** Constipation causes me to have some troubles doing things or being comfortable. **3: Moderate:** Constipation causes me to have a lot of trouble doing things or being comfortable. However, it does not stop me from doing anything. **4: Severe:** I usually need physical help from someone else to empty my bowels.	**Score** ☐
LIGHT HEADEDNESS ON STANDING: Over the past week, have you felt faint, dizzy, or foggy when you stand up after sitting or lying down? **0: Normal:** No dizzy or foggy feelings. **1: Slight:** Dizzy or foggy feelings occur. However, they do not cause me troubles doing things. **2: Mild:** Dizzy or foggy feelings cause me to hold on to something, but I do not need to sit or lie back down. **3: Moderate:** Dizzy or foggy feelings cause me to sit or lie down to avoid fainting or falling. **4: Severe:** Dizzy or foggy feelings cause me to fall or faint	**Score** ☐

FATIGUE: Over the past week, have you usually felt fatigued? This feeling is not part of being sleepy or sad. **0: Normal:** No fatigue. **1: Slight:** Fatigue occurs. However, it does not cause me troubles doing things or being with people. **2: Mild:** Fatigue causes me some troubles doing things or being with people. **3: Moderate:** Fatigue causes me many troubles doing things or being with people. However, it does not stop me from doing anything. **4: Severe:** Fatigue stops me from doing things or being with people	**Score** ☐
Motor Aspects of Experiences of Daily Living	
SPEECH: Over the past week, have you had problems with your speech? **0: Normal:** Not at all (no problems). **1: Slight**: My speech is soft, slurred or uneven, but it does not cause others to ask me to repeat myself. **2: Mild:** My speech causes people to ask me to occasionally repeat myself, but not every day. **3: Moderate:** My speech is unclear enough that others ask me to repeat myself every day even though most of my speech is understood. **4: Severe:** Most or all of my speech cannot be understood.	**Score** ☐
SALIVA AND DROOLING: Over the past week, have you usually had too much saliva during when you are awake or when you sleep? **0: Normal:** Not at all (no problems). **1: Slight:** I have too much saliva, but do not drool. **2: Mild:** I have some drooling during sleep, but none when I am awake. **3: Moderate:** I have some drooling when I am awake, but I usually do not need tissues or a handkerchief. **4: Severe:** I have so much drooling that I regularly need to use tissues or a handkerchief to protect my clothes	**Score** ☐
CHEWING AND SWALLOWING: Over the past week, have you usually had problems swallowing pills or eating meals? Do you need your pills cut or crushed or your meals to be made soft, chopped, or blended to avoid choking?	**Score**

0: Normal: No problems. **1: Slight:** I am aware of slowness in my chewing or increased effort at swallowing, but I do not choke or need to have my food specially prepared. **2: Mild:** I need to have my pills cut or my food specially prepared because of chewing or swallowing problems, but I have not choked over the past week. **3: Moderate:** I choked at least once in the past week. **4: Severe:** Because of chewing and swallowing problems, I need a feeding tube	☐
EATING TASKS: Over the past week, have you usually had troubles handling your food and using eating utensils? For example, do you have trouble handling finger foods or using forks, knives, spoons, chopsticks? **0: Normal**: Not at all (no problems). **1: Slight:** I am slow, but I do not need any help handling my food and have not had food spills while eating. **2: Mild:** I am slow with my eating and have occasional food spills. I may need help with a few tasks such as cutting meat. **3: Moderate**: I need help with many eating tasks but can manage some alone. **4: Severe:** I need help for most or all eating task	**Score** ☐
DRESSING: Over the past week, have you usually had problems dressing? For example, are you slow or do you need help with buttoning, using zippers, putting on or taking off your clothes or jewellery? **0: Normal:** Not at all (no problems). **1: Slight:** I am slow, but I do not need help. **2: Mild:** I am slow and need help for a few dressing tasks (buttons, bracelets). **3: Moderate:** I need help for many dressing tasks. **4: Severe:** I need help for most or all dressing tasks.	**Score** ☐
HYGIENE: Over the past week, have you usually been slow or do you need help with washing, bathing, shaving, brushing teeth, combing your hair, or with other personal hygiene? **0: Normal:** Not at all (no problems). **1: Slight:** I am slow, but I do not need any help. **2: Mild:** I need someone else to help me with some hygiene tasks.	**Score** ☐

3: Moderate: I need help for many hygiene tasks. **4: Severe**: I need help for most or all of my hygiene tasks	
HANDWRITING: Over the past week, have people usually had trouble reading your handwriting? **0: Normal:** Not at all (no problems). **1: Slight:** My writing is slow, clumsy or uneven, but all words are clear. **2: Mild:** Some words are unclear and difficult to read. **3: Moderate:** Many words are unclear and difficult to read. **4: Severe:** Most or all words cannot be read.	**Score** ☐
DOING HOBBIES AND OTHER ACTIVITIES: Over the past week, have you usually had trouble doing your hobbies or other things that you like to do? **0: Normal:** Not at all (no problems). **1: Slight:** I am a bit slow but do these activities easily. **2: Mild:** I have some difficulty doing these activities. **3: Moderate:** I have major problems doing these activities, but still do most. **4: Severe:** I am unable to do most or all of these activities.	**Score** ☐
TURNING IN BED: Over the past week, do you usually have trouble turning over in bed? **0: Normal:** Not at all (no problems). **1: Slight**: I have a bit of trouble turning, but I do not need any help. **2: Mild:** I have a lot of trouble turning and need occasional help from someone else. **3: Moderate**: To turn over I often need help from someone else. **4: Severe**: I am unable to turn over without help from someone else	**Score** ☐
TREMOR: Over the past week, have you usually had shaking or tremor? **0: Normal:** Not at all. I have no shaking or tremor. **1: Slight:** Shaking or tremor occurs but does not cause problems with any activities. **2: Mild:** Shaking or tremor causes problems with only a few activities. **3: Moderate:** Shaking or tremor causes problems with many of my daily activities. **4: Severe:** Shaking or tremor causes problems with most or all activities	**Score** ☐

GETTING OUT OF BED, A CAR, OR A DEEP CHAIR: Over the past week, have you usually had trouble getting out of bed, a car seat, or a deep chair? **0: Normal:** Not at all (no problems). **1: Slight**: I am slow or awkward, but I usually can do it on my first try. **2: Mild:** I need more than one try to get up or need occasional help. **3: Moderate**: I sometimes need help to get up, but most times, I can still do it on my own. **4: Severe:** I need help most or all of the time	**Score** ☐
WALKING AND BALANCE: Over the past week, have you usually had problems with balance and walking? **0: Normal:** Not at all (no problems). **1: Slight:** I am slightly slow or may drag a leg. I never use a walking aid. **2: Mild**: I occasionally use a walking aid, but I do not need any help from another person. **3: Moderate:** I usually use a walking aid (cane, walker) to walk safely without falling. However, I do not usually need the support of another person. **4: Severe:** I usually use the support of another person to walk safely without falling.	**Score** ☐
FREEZING: Over the past week, on your usual day when walking, do you suddenly stop or freeze as if your feet are stuck to the floor? **0: Normal:** Not at all (no problems). **1: Slight:** I briefly freeze, but I can easily start walking again. I do not need help from someone else or a walking aid (cane or walker) because of freezing. **2: Mild:** I freeze and have trouble starting to walk again, but I do not need someone's help or a walking aid (cane or walker) because of freezing. **3: Moderate:** When I freeze, I have a lot of trouble starting to walk again and, because of freezing, I sometimes need to use a walking aid or need someone else's help. **4: Severe:** Because of freezing, most or all of the time, I need to use a walking aid or someone's help.	**Score** ☐
We may have asked about problems you do not even have, and may have mentioned problems that you may never develop at all. Not all participants develop all these problems, but because they can occur, it is important to ask all the questions to every participant.	

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Parkinson’s Disease Fatigue Scale (PFS-16)
(Brown et al, 2005)

The Parkinson’s Fatigue Scale is a series of statements about fatigue and the impact that it can have on many aspects of life. How well do the statements describe your own feelings and experiences over the past two weeks? Read each item and decide how much you agree or disagree with it. Then tick the appropriate box. Tick only one box for each item and try not to miss any out.

		Strongly disagree	**Disagree**	**Uncertain**	**Agree**	**Strongly Agree**
1	I have to rest during the day					
2	My life is restricted by fatigue					
3	I get tired more quickly than other people I know					
4	Fatigue is one of my three worst symptoms					
5	I feel completely exhausted					
6	Fatigue makes me reluctant to socialise					
7	It takes me longer to get things done because of fatigue					
		Strongly disagree	**Disagree**	**Uncertain**	**Agree**	**Strongly Agree**
8	I have a feeling of heaviness					

9	If I wasn't so tired I could do more things					
10	Everything I do is an effort					
11	I feel tired for much of the time					
12	I feel totally drained					
13	Fatigue makes it difficult for me to cope with everyday activities					
14	I feel tired even when I haven't done anything					
15	Because of fatigue I do less in my day than I would like					
16	I get so tired I want to lie down wherever I am					

Brown, R., Ditter, A., Findlay, L., Wessley, S. (2005). The Parkinson's fatigue Scale. Parkinsonism and Related Disorders. 11: 49-55

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Parkinson’s Anxiety Scale (Leentjens et al, 2014)

Information for Participants: Many people with Parkinson’s experience anxiety. Please read the questions below, place one tick in the box per question which best applies to you.

1	**Persistent anxiety**					
	In the past four weeks, to what extent did you experience the following symptoms?					
		Not at all or never	Very mild or rarely	Mild or sometimes	Moderate or often	Severe, or (nearly) always
	Feeling anxious or nervous					
	Feeling tense or stressed					
	Being unable to relax					
	Excessive worrying about everyday matters					
	Fear of something bad, or even the worst, happening					

2	**Episodic Anxiety**					
	In the past four weeks, did you experience episodes of the following symptoms					
		Never	Rarely	Sometimes	Often	Nearly always
	Panic or intense fear					
	Shortness of breath					
	Heart palpitations or heart beating fast (not related to physical effort or activity					
	Fear of losing control					

3	**Avoidance Behaviour**					
	In the past four weeks, to what extent did you fear or avoid the following situations?					
		Never	Rarely	Sometimes	Often	Nearly always
	Social situations (where one may be observed, or evaluated by others, such as speaking in public, or talking to unknown people)					
	Public settings (situations from which it may be difficult or embarrassing to escape, such as queues or lines, crowds, bridges, or public transportation					

	Specific objects or situations (such as flying, heights, spiders or other animals, needles, or blood					

Leentjens, A., Dijardin, K., Pontone, G., Starkstein, S., Weintraub, D., and Martinez-Martin, P. (2014). The Parkinson Anxiety Scale (PAS): development and validation of a new anxiety scale. Movement Disorders. 29(8):1035-43. doi: 10.1002/mds.25919

Geriatric Depression Scale (GDS) (Yesavage et al 1983)

Information: This questionnaire is commonly used in clinical practice. It comprises 30 easy to use items, which require a yes/no response. Please place a tick in either the yes or no box.

	Question	**Yes**	**No**
1	Are you basically satisfied with your life?		
2	Have you dropped many of your activities and interests?		
3	Do you feel that your life is empty?		
4	Do you often get bored?		
5	Are you hopeful about the future?		
6	Are you bothered by thoughts you can't get out of your head?		
7	Are you in good spirits most of the time?		
8	Are you afraid that something bad is going to happen to you?		
9	Do you feel happy most of the time?		
10	Do you often feel helpless?		
11	Do you often get restless and fidgety?		
12	Do you prefer to stay at home, rather than going out and doing new things?		
13	Do you frequently worry about the future?		
14	Do you feel you have more problems with memory than most?		
15	Do you think it is wonderful to be alive now?		
16	Do you often feel downhearted and blue?		

17	Do you feel pretty worthless the way you are now?		
18	Do you worry a lot about the past?		
	Question	**Yes**	**No**
19	Do you find life very exciting?		
20	Is it hard for you to get started on new projects?		
21	Do you feel full of energy?		
22	Do you feel that your situation is hopeless?		
23	Do you think that most people are better off than you are?		
24	Do you frequently get upset over little things?		
25	Do you frequently feel like crying?		
26	Do you have trouble concentrating?		
27	Do you enjoy getting up in the morning?		
28	Do you prefer to avoid social gatherings?		
29	Is it easy for you to make decisions?		
30	Is your mind as clear as it used to be?		
	Total		

Yesavage, J., Brink, T., Rose, T., Lum, O., Haung, V., Adley, M., and Leirer, V. (1983). Development and validation of a geriatric depression screening scale: a preliminary report. Journal of Psychiatry Research. 17:37-49.

PDConnect

Activities-Specific Balance Confidence (ABC) Scale

(Haung and Wang (2009))

The ABC tool requires you to rate your balance confidence in a variety of functional tasks.

There are 16 items in this questionnaire. Each item is rated on a 0-100 scale, with 100 representing complete confidence and 0 no confidence.

For each of the following activities, please indicate your level of self-confidence by choosing a corresponding number from the following rating scale:

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

No confidence --Completely confident

"How confident are you that you will not lose your balance or become unsteady when you…

	Questions
1	Walk around the house? _______%
2	Walk up or down stairs? _______%
3	Bend over and pick up a slipper (or item) from the front of a cupboard ______%
4	Reach for a small can off a shelf at eye level? ______%
5	Stand on your tiptoes and reach for something above your head? ______%
6	Stand on a chair and reach for something? ______%
7	Sweep the floor? ______%
8	Walk outside the house to a car parked in the driveway? ______%
9	Get into or out of a car? ______%
10	Walk across a car park to the shops? ______%
11	Walk up or down a ramp? ______%

12	Walk in a crowded shopping area where people rapidly walk past you? _____%
13	Are bumped into by people as you walk through shops? _____%
14	Step onto or off an escalator while you are holding onto a railing? _____%
15	Step onto or off an escalator while holding onto parcels such that you cannot hold onto the railing? _____%
16	Walk outside on icy pavements? _____%

Huang, T., and Wang, W. (2009). Comparison of three established measures of fear of falling in community-dwelling older adults: psychometric testing. International Journal of Nursing Studies. 46(10):1313–1319. Doi: 10.1016/j.ijnurstu.2009.03.010.

PDConnect

Physical Activity Scale for the Elderly (PASE).
(Washburn et al, 1993)

Purpose: This measure was designed to assess ***physical activity***. The PASE score combines information on leisure, household and occupational ***activity***. The PASE assesses the types of activities typically chosen by older adults (walking, recreational activities, exercise, housework, yard (gardening or outdoor) work, and caring for others.

When answering each of the following questions, please only reflect on the last seven days. Please complete this questionnaire by placing a tick at the relevant answer.

	Leisure Time Activity	
1.	**Over the past 7 days, how often did you participate in sitting activities such as reading, watching TV, or doing handcrafts?**	
0	NEVER (go to question 2)	☐
1	SELDOM (1-2 DAYS) (go to question 1.a and 1.b)	☐
2	SOMETIMES (3-4 DAYS) (go to question 1.a and 1.b)	☐
3	OFTEN (5-7 DAYS) (go to question 1.a and 1.b)	☐
1a	**What were these activities? Please write below:**	
1b	**On average, how many hours did you engage in these sitting activities each day?**	
0	Less than 1 hour	☐
1	1 hour but less than 2 hours	☐

2	2 - 4 hours	☐
3	more than 4 hours	☐
2.	**Over the past 7 days, how often did you take a walk outside your home or yard for any reason? For example, for fun or exercise, walking to work, walking the dog, etc.**	
0	NEVER (go to question 3	☐
1	SELDOM (1-2 DAYS) (go to question 2.a)	☐
2	SOMETIMES (3-4 DAYS) (go to question 2.a)	☐
3	OFTEN (5-7 DAYS) (go to question 2.a)	☐
2a.	**On average, how many hours per day did you spend walking?**	
0	Less than 1 hour	☐
1	1 hour but less than 2	☐
2	2 - 4 hours	☐
3	More than 4 hours	☐

3	**Over the past 7 days, how often did you engage in light sport or recreational activities such as bowling, golf with a cart, shuffleboard, fishing from a boat or pier or other similar activities?**	
0	NEVER (go to question 4)	☐
1	SELDOM (1-2 DAYS) (go to question 3.a and 3.b)	☐
2	SOMETIMES (3-4 DAYS) (go to question 3.a and 3.b)	☐
3	OFTEN (5-7 DAYS) (go to question 3.a and 3.b)	☐
3a	**What were these activities? Please write below:**	
3b	**On average, how many hours did you engage in these light sport or recreational activities?**	
0	Less than 1 hour	☐
1	1 hour but less than 2 hours	☐
2	2 - 4 hours	☐
3	more than 4 hours	☐

4	**Over the past 7 days, how often did you engage in moderate sport and recreational activities such as doubles tennis, ballroom dancing, hunting, ice skating, golf without a cart, softball or other similar activities?**	
0	NEVER (go to question 5)	☐
1	SELDOM (1-2 DAYS) (go to question 4.a and 4.b)	☐
2	SOMETIMES (3-4 DAYS) (go to question 4.a and 4.b)	☐
3	OFTEN (5-7 DAYS) (go to question 4.a and 4.b)	☐
4a	**What were these activities? Please write below:**	
4b	**On average, how many hours did you engage in these moderate sport or recreational activities?**	
0	Less than 1 hour	☐
1	1 hour but less than 2 hours	☐
2	2 - 4 hours	☐
3	More than 4 hours	☐
5.	**Over the past 7 days, how often did you engage in strenuous sport and recreational activities such as jogging, swimming, cycling, singles tennis, aerobic dance, skiing (downhill or cross-country) or other similar activities?**	

0	NEVER (go to question 6)	☐
1	SELDOM (1-2 DAYS) (go to question 5.a and 5.b)	☐
2	SOMETIMES (3-4 DAYS) (go to question 5.a and 5.b)	☐
3	OFTEN (5-7 DAYS) (go to question 5.a and 5.b)	☐
5a	**What were these activities? Please write below:**	
5b	**On average, how many hours did you engage in these strenuous sport or recreational activities?**	
0	Less than 1 hour	☐
1	1 hour but less than 2 hours	☐
2	2 - 4 hours	☐
3	More than 4 hours	☐
6	**Over the past 7 days, how often did you do any exercises specifically to increase muscle strength and endurance, such as lifting weights or pushups, etc.?**	
0	NEVER (go to question 7)	☐
1	SELDOM (1-2 DAYS) (go to question 6.a and 6.b)	☐
2	SOMETIMES (3-4 DAYS) (go to question 6.a and 6.b)	☐

3	OFTEN (5-7 DAYS) (go to question 6.a and 6.b)	☐
6a	**What were these activities? Please write below:**	
6b	**On average, how many hours did you engage in these strenuous sport or recreational activities?**	
0	Less than 1 hour	☐
1	1 but less than 2 hours	☐
2	2 - 4 hours	☐
3	More than 4 hours	☐
	Household Activity	
7	**During the past 7 days, have you done any light housework, such as dusting or washing dishes?**	
1	NO	☐
2	YES	☐
8	**During the past 7 days, have you done any heavy housework or chores, such as vacuuming, scrubbing floors, washing windows, or carrying wood**	
1	NO	☐

2	YES	☐
9	**During the past 7 days, did you engage in any of the following activities? Please answer YES or NO for each item.**	
a	Home repairs like painting, wallpapering, electrical work, etc.	YE ☐ NO ☐
b	Lawn work or yard care, including snow or leaf removal, wood chopping, etc.	YE ☐ NO ☐
c	Outdoor gardening	YE ☐ NO ☐
d	Caring for another person, such as children, dependent spouse, or another adult	YE ☐ NO ☐
	Work-related Activity	
10	**During the past 7 days, did you work for pay or as a volunteer?**	
1	YES (go to questions 10.a and 10.b)	
2	NO	
10a	**How many hours per week did you work for pay and or as a volunteer?** **_____ hours**	
10b	**Which of the following categories best describes the amount of physical activity required on your job and or volunteer work?**	
	Mainly sitting with some slight arm movement (Examples: office worker, watchmaker, seated assembly line worker, bus driver, etc.)	☐
	Sitting or standing with some walking (Examples: cashier, general office worker, light tool and machinery worker)	☐
	Walking with some handling of materials generally weighing less than 50 pounds (Examples: mailman, waiter/waitress, construction worker, heavy tool and machinery worker)	☐
	Walking and heavy manual work often requiring handling of materials weighting over 50 pounds (Ex: lumberjack, stone mason, farm or general labourer)	☐

Washburn, R., Smith, K., Jette, A., and Janney, C. (1993). The physical activity scale for the elderly (PASE): Development and evaluation. Journal of Clinical Epidemiology. 46 (2): 153-162. Doi: 10.1016/0895-4356(93)90053-4

PDConnect

Schwab and England Activities of Daily Living Scale
(Schwab, and England 1969)

Participant Information: This questionnaire aims to capture your perceptions of your functional ability to complete common activities of daily living. Please read the statements below and put tick in the box that you think best describes your level of function, based on the last week.

	Activities of daily Living	**Tick**
100%	Completely independent. Able to do all chores without slowness, difficulty or impairment. Essentially normal. Unaware of any difficulty.	
90%	Completely independent. Able to do all chores with some degree of slowness, difficulty and impairment. Might take twice as long. Beginning to be aware of difficulty.	
80%	Completely independent in most chores. Takes twice as long. Conscious of difficulty and slowness.	
70%	Not completely independent. More difficulty with some chores. Three to four times as long in some. Must spend a large part of the day with chores.	
60%	Some dependency. Can do most chores, but exceedingly slowly and with much effort. Errors; some impossible.	
50%	More dependent. Help with half, slower, etc. Difficulty with everything.	
40%	Very dependent. Can assist with all chores, but few alone.	
30%	With effort, now and then does a few chores alone or begins alone. Much help needed.	
20%	Nothing alone. Can be a slight help with some chores. Severe invalid	
10%	Totally dependent, helpless. Complete invalid	

Schwab, R., and England, A. (1969). Projection techniques for evaluating surgery in Parkinson's Disease. Third Symposium on Parkinson's Disease, Royal College of Surgeons in Edinburgh. E. & S. Livingstone Ltd. (1969).

PDConnect

Physical Activity Scale for individuals with Physical disabilities (PASIPD). (Washburn et al, 2002)

Purpose:

Instructions: This questionnaire is about your current level of physical activity and exercise. Please remember there are no right or wrong answers. We simply need to assess your current level of activity.

When answering each of the following questions, please only reflect on the last seven days. Please complete this questionnaire by placing a tick at the relevant answer.

Leisure Time Activity		
1. During the past 7 days, how often did you engage in stationary activities such as reading, watching TV, computer games, or doing handcrafts?		
0	NEVER (go to question 2)	☐
1	SELDOM (1-2 DAYS)	☐
2	SOMETIMES (3-4 DAYS)	☐
3	OFTEN (5-7 DAYS)	☐
1a	**What were these activities, please write below:**	
1b	**On average, how many hours per day did you spend in these stationary activities?**	
1	Less than 1 hour	☐
2	1 hour but less than 2 hours	☐

3	2 - 4 hours	☐
4	More than 4 hours	☐
2.	**During the past 7 days, how often did you walk, wheel, push outside your home other than specifically for exercise. For example, getting to work or class, walking the dog shopping, or other errands?**	
1	NEVER (go to question 3)	☐
2	SELDOM (1-2 DAYS)	☐
3	SOMETIMES (3-4 DAYS)	☐
4	OFTEN (5-7 DAYS)	☐
2a.	**On average, how many hours per day did you spend walking, wheeling or pushing outside your home?**	
1	Less than 1 hour	☐
2	1 hour but less than 2	☐
3	2 - 4 hours	☐
4	More than 4 hours	☐
3	**During the past 7 days, how often did you engage in light sport or recreational activities such as bowling, golf with a cart, hunting or fishing, darts, billiards or pool, therapeutic exercise (physical or occupational therapy, stretching, use of a standing frame) or other similar activities?**	
0	NEVER (go to question 4)	☐
1	SELDOM (1-2 DAYS))	☐

2	SOMETIMES (3-4 DAYS)	☐
3	OFTEN (5-7 DAYS)	☐
3a	**What were these activities? Please write below:**	
3b	**On average, how many hour per day did you spend in these light sport or recreational activities?**	
1	Less than 1 hour	☐
2	1 hour but less than 2 hours	☐
3	2 - 4 hours	☐
4	More than 4 hours	☐

4	During the past 7 days, how often did you engage in moderate sport and recreational activities such as doubles tennis, softball, golf without a cart, ballroom dancing, wheeling or pushing for pleasure or other similar activities?	
1	NEVER (go to question 5)	☐
2	SELDOM (1-2 DAYS)	☐
3	SOMETIMES (3-4 DAYS)	☐
4	OFTEN (5-7 DAYS)	☐
4a	**What were these activities? Please write below:**	
4b	**On average, how many hours per day did you spend in these moderate sport and recreational activities?**	
0	Less than 1 hour	☐
1	1 hour but less than 2 hours	☐
2	2 - 4 hours	☐
3	More than 4 hours	☐
5.	**During the past 7 days, how often did you engage in strenuous sport and recreational activities such as jogging, wheelchair racing (training), off-road pushing, swimming, aerobic dance, arm cranking, cycling (hand or leg), singles tennis, rugby, basketball, walking with crutches and braces, or other similar activities**	
0	NEVER (go to question 6)	☐

1	SELDOM (1-2 DAYS)	☐
2	SOMETIMES (3-4 DAYS)	☐
3	OFTEN (5-7 DAYS)	☐
5a	**What were these activities? Please write below:**	
5b	**On average, how many hours per day did you spend in these strenuous sport or recreational activities**	
0	Less than 1 hour	☐
1	1 hour but less than 2 hours	☐
2	2 - 4 hours	☐
3	More than 4 hours	☐
6	**Over the past 7 days, how often did you do any exercises specifically to increase muscle strength and endurance, such as lifting weights or pushups, etc.?**	
0	NEVER (go to question 7)	☐
1	SELDOM (1-2 DAYS)	☐
2	SOMETIMES (3-4 DAYS)	☐
3	OFTEN (5-7 DAYS)	☐
6a	**What were these activities? Please write below:**	

6b	**On average, how many hours per day did you spend in these exercises to increase muscle strength and endurance**	
0	Less than 1 hour	☐
1	1 but less than 2 hours	☐
2	2 - 4 hours	☐
3	More than 4 hours	☐
	Household Activity	
7	**During the past 7 days, have you done any light housework, such as dusting or washing dishes?**	
1	NEVER (go to question 8)	☐
2	SELDOM (1-2 DAYS)	☐
3	SOMETIMES (3-4 DAYS)	☐
4	OFTEN (5-7 DAYS)	☐
	On average, how many hours per day did you spend doing light housework or chores?	
1	Less than 1 hour	☐

2	1 but less than 2 hours	☐
3	2 - 4 hours	☐
4	more than 4 hours	☐
8	**During the past 7 days, how often have you done any heavy housework or chores such as vacuuming, scrubbing floors, washing windows, or walls, etc?**	
1	NEVER (go to question 9)	☐
2	SELDOM (1-2 DAYS)	☐
3	SOMETIMES (3-4 DAYS)	☐
4	OFTEN (5-7 DAYS)	☐
8b	**On average, how many hours per day did you spend doing heavy housework or chores?**	
1	Less than 1 hour	☐
2	1 but less than 2 hours	☐
3	2 - 4 hours	☐
4	more than 4 hours	☐
9	**During the past 7 days, how often you done home repairs like carpentry, painting, furniture refinishing, electrical work, etc?**	
1	NEVER (go to question 10)	☐
2	SELDOM (1-2 DAYS)	☐
3	SOMETIMES (3-4 DAYS)	☐
4	OFTEN (5-7 DAYS)	☐

9b	**On average, how many hours per day did you spend doing home repairs**	
1	Less than 1 hour	☐
2	1 hour but less than 2 hours	☐
3	2 - 4 hours	☐
4	more than 4 hours	☐
10	**During the past 7 days how often have you done lawn work or yard care including mowing, leaf or snow removal, tree or bush trimming, or wood chopping, etc**	
1	NEVER (go to question 11)	☐
2	SELDOM (1-2 DAYS)	☐
3	SOMETIMES (3-4 DAYS)	☐
4	OFTEN (5-7 DAYS)	☐
10b	**On average, how many hours per day did you spend doing lawn work?**	
1	Less than 1 hour	☐
2	1 hour but less than 2 hours	☐
3	2 - 4 hours	☐
4	more than 4 hours	☐

11	**During the past 7 days, how often have you done outdoor gardening?**	
1	NEVER (go to question 12)	☐
2	SELDOM (1-2 DAYS)	☐
3	SOMETIMES (3-4 DAYS)	☐
4	OFTEN (5-7 DAYS)	☐
11b	**On average, how many hours per day did you spend doing outdoor gardening**	
1	Less than 1 hour	☐
2	1 hour but less than 2 hours	☐
3	2 - 4 hours	☐
4	more than 4 hours	☐
12	**During the past 7 days, how often did you care for another person, such as children, a dependent spouse, or another adult**	
1	NEVER (go to questions 13)	☐
2	SELDOM (1-2 DAYS)	☐
3	SOMETIMES (3-4 DAYS)	☐
4	OFTEN (5-7 DAYS)	☐
12b	**On average, how many hours per day did you spend caring for another person?**	
1	Less than 1 hour	☐
2	1 hour but less than 2 hours	☐

3	2 - 4 hours	☐
4	more than 4 hours	☐
13	During the past 7 days, how often did you work for pay or as a volunteer? (Exclude work that mainly involved sitting with slight arm movement such as light office work, computer work, light assembly line work, driving bus or van, etc.)	
1	NEVER (go to END)	☐
2	SELDOM (1-2 DAYS)	☐
3	SOMETIMES (3-4 DAYS)	☐
4	OFTEN (5-7 DAYS)	☐
13b	**On average, how many hours per day did you spend working for pay or as a volunteer?**	
1	Less than 1hr	☐
2	1 but less than 4hr	☐
3	5 but less than 8hr	☐
4	8hr or more	☐

Washburn, R., Zhu, W., McAuley, E., Frogley, M., and Figoni, S. (2002). The Physical Activity Scale for Individuals With Physical Disabilities: Development and Evaluation. Archives of Physical Medicine and Rehabilitation. 83:193-200. Doi:10.1053/apmr.2002.27467

PDConnect

Parkinson’s Disease Questionnaire
PDQ-39 (Jenkinson et al, 1997)

Participant Information: The PDQ-39 is a question which you complete that contains 39 questions, which focusses on eight areas of daily living which people with Parkinson’s report difficulties. Please read each questions and place a tick in the box, which best reflects your experience.

Due to having Parkinson’s, how often during the last month have you....	Never	Occasionally	Sometimes	Often	Always (or cannot do at all)
1 Had difficulty doing the leisure activities which you would like to do?	☐	☐	☐	☐	☐
2 Had difficulty looking after your home, e.g. DIY, housework, cooking?	☐	☐	☐	☐	☐
3 Had difficulty carrying bags of shopping?	☐	☐	☐	☐	☐
4 Had problems walking half a mile?	☐	☐	☐	☐	☐
5 Had problems walking 100 yards?	☐	☐	☐	☐	☐
6 Had problems getting around the house as easily as you would like?	☐	☐	☐	☐	☐
7 Had difficulty getting around in public?	☐	☐	☐	☐	☐

		Never	Occasionally	Sometimes	Often	Always (or cannot do at all)
8	Needed someone else to accompany you when you went out?	☐	☐	☐	☐	☐
9	Felt frightened or worried about falling over in public?	☐	☐	☐	☐	☐
10	Been confined to the house more than you would like?	☐	☐	☐	☐	☐
11	Had difficulty washing yourself?	☐	☐	☐	☐	☐
12	Had difficulty dressing yourself?	☐	☐	☐	☐	☐
13	Had problems doing up your shoelaces?	☐	☐	☐	☐	☐
14	Had problems writing clearly?	☐	☐	☐	☐	☐
15	Had difficulty cutting up your food?	☐	☐	☐	☐	☐
16	Had difficulty holding a drink without spilling it?	☐	☐	☐	☐	☐
17	Felt depressed?	☐	☐	☐	☐	☐

		Never	Occasionally	Sometimes	Often	Always (or cannot do it at al)
18	Felt isolated and lonely?	☐	☐	☐	☐	☐
19	Felt weepy or tearful?	☐	☐	☐	☐	☐
20	Felt angry or bitter?	☐	☐	☐	☐	☐
21	Felt anxious?	☐	☐	☐	☐	☐
22	Felt worried about your future?	☐	☐	☐	☐	☐
23	Felt you had to conceal your Parkinson's from people?	☐	☐	☐	☐	☐
24	Avoided situations which involve eating or drinking in public?	☐	☐	☐	☐	☐
25	Felt embarrassed in public due to having Parkinson's disease?	☐	☐	☐	☐	☐
26	Felt worried by other people's reaction to you?	☐	☐	☐	☐	☐
27	Had problems with your close personal relationships?	☐	☐	☐	☐	☐

		Never	Occasionally	Sometimes	Often	Always (or cannot do it at all)
28	Lacked support in the ways you need from your spouse or partner?	☐	☐	☐	☐	☐
29	Lacked support in the ways you need from your family or close friends?	☐	☐	☐	☐	☐
30	Unexpectedly fallen asleep during the day?	☐	☐	☐	☐	☐
31	Had problems with your concentration, e.g. when reading or watching TV?	☐	☐	☐	☐	☐
32	Felt your memory was bad?	☐	☐	☐	☐	☐
33	Had distressing dreams or hallucinations?	☐	☐	☐	☐	☐
34	Had difficulty with your speech?	☐	☐	☐	☐	☐
35	Felt unable to communicate with people properly?	☐	☐	☐	☐	☐
36	Felt ignored by people?	☐	☐	☐	☐	☐

		Never	Occasionally	Sometimes	Often	Always (or cannot do it at al)
37	Had painful muscle cramps or spasms?	☐	☐	☐	☐	☐
38	Had aches and pains in your joints or body?	☐	☐	☐	☐	☐
39	Felt unpleasantly hot or cold?	☐	☐	☐	☐	☐

PDConnect

Self-Efficacy for Exercise Scale (Resnick and Jenkins, 2000)

Please put a tick in the box on the scale as appropriate. 1 is not confident, and 10 is very confident. How confident are you right now that you could exercise three times per week for 20 minutes if:

NOT CONFIDENT

VERY CONFIDENT

	1	2	3	4	5	6	7	8	9	10
The weather was bothering you										
You were bored by the program or activity										
You felt pain when exercising										
You had to exercise alone										
You did not enjoy it										
You were too busy with other activities										
You felt tired										
You felt stressed										
You felt depressed										

Resnick, B., and Jenkins, L. (2000). Testing the Reliability and Validity of the Self-Efficacy for Exercise Scale. Nursing Research. 49 (3):154-159.

PDConnect

Nottingham Health Profile (*Hunt et al, 1985)*

This measure provides a brief indication of a patient's perceived emotional, social and physical health problems. If you could please put a tick in either the YES or NO box as applies to you. If you are undecided, answer the YES or NO – whichever is more true at that time.

	Yes	**NO**
I'm tired all the time		
I have pain at night		
Things are getting me down		
I have unbearable pain		
I take pills to help me sleep		
I've forgotten what it's like to enjoy myself		
I'm feeling on edge		
I find it painful to change position		
I feel lonely		
I can walk about only indoors		
I find it hard to bend		
Everything is an effort		
I'm waking up in the early hours of the morning		
I'm unable to walk at all		
I'm finding it hard to make contact with people		
The days seem to drag.		
I have trouble getting up and down stairs and steps.		
I find it hard to reach for things.		
I'm in pain when I walk.		
I lose my temper easily these days.		
I feel there is nobody that I am close to.		
I lie awake for most of the night		

	Yes	**NO**
I feel as if I'm losing control.		
I'm in pain when I'm standing.		

I find it hard to get dressed by myself.		
I soon run out of energy.		
I find it hard to stand for long (e.g., at the kitchen sink, waiting in a line).		
I'm in constant pain		
It takes me a long time to get to sleep.		
I feel I am a burden to people.		
Worry is keeping me awake at night.		
I feel that life is not worth living.		
I sleep badly at night.		
I'm finding it hard to get along with people.		
I need help to walk about outside (e.g., a walking aid or someone to support me).		
I'm in pain when going up or down stairs.		
I wake up feeling depressed.		
I'm in pain when I'm sitting.		

Is your present state of health causing problems with your	**YES**	**NO**
Work? (that is, paid employment)		
Looking after the home? (cleaning & cooking, repairs, odd jobs around the home, etc.)		
Social life? (going out, seeing friends, going to the movies, etc.)		
Home life? (that is, relationships with other people in your home)		
Sex life?		
Interests and hobbies? (sports, arts and crafts, do-it-yourself, etc.)		
Holidays (summer or winter holidays, weekends away, etc.)		

PDConnect

Warwick Edinburgh Mental Well Being Scale (WEMWBS)

Below are some statements about feelings and thoughts.

Please circle the number that best describes your experience of each over the last 2 weeks.

	None of the time	**Rarely**	**Some of the time**	**Often**	**All of time**
I've been feeling optimistic about the future					
I've been feeling useful					
I've been feeling relaxed					
I've been feeling interested in other people					
I've had energy to spare					
I've been dealing with problems well					
I've been thinking clearly					
I've been feeling good about myself					
I've been feeling close to other people					
I've been feeling confident					
I've been able to make up my own mind about thing					
I've been feeling loved					
I've been interested in new things					
I've been feeling cheerful					

Tennant, R., Hiller, L., Fishwick, R., Platt, S., Joseph, S., Weich, S., Parkinson, J., Secker, J., and Stewart-Brown, S. (2007) The Warwick-Edinburgh Mental Well-being Scale (WEMWBS): development and UK validation. Health Quality of Life Outcomes **5,** 63 (2007). Doi: 10.1186/1477-7525-5-63

Thank you very much for completing this pack of questionnaires. Please return this to using the stamped addressed envelope provided. If you have misplaced the envelope, please email Julie j.c.jones@rgu.ac.uk

Many thanks again

8.28 APPENDIX 28: PARTICIPANT TOPIC INTERVIEW GUIDE

PDConnect

Semi- structured Interview Topic Guide (extended version)

My name is Liz Hancock, and I am part of PDConnect research team. This study you have been involved in aimed to explore the feasibility and acceptability of the PDConnect programme. As you will be aware following the email from Julie, we the purpose of this interview is to explore in more depth with you, your experiences of receiving PDConnect. You will have received via email, the participants information sheet, and you will be aware that your participation in this interview is voluntary and that it will be recorded. As it is a long time since you originally gave to consent. Before we start please could you confirm that you:

- You have had an opportunity to ask any question in relation to the interviews
- You are aware that you participation is voluntary
- You consent to the interview being recorded.

Thank you for that. The purpose of undertaking these SSI experience and perception of the PDConnect programme, and to gain thoughts in relation to its delivery. The researcher team will use your feedback to refine the future iterations of the PDConnect, so please feel free to be honest in your responses, your views and thoughts are greatly appreciated. The topic which we would like to explore with you include:

- Recruitment
- Satisfaction the PDConnect Intervention
- Staffing
- Study resources: The Mi band, RehabGuru, Microsoft Teams
- Outcome measures
- Anything else they wish to add

Areas of interest within Semi Structured Interviews	
	Probes/prompts to be used depending on how the answer the opening question:
Study Recruitment, we are interested to hear about your experience of being recruited to be involved in this study	
• How did you find out about the study? • What did you think of the participant information sheet that you were provided with? • This study involved participants being randomised to receive PDConnect or usual care which consisted of 6 session of physiotherapy. How did you feel about be randomized as part of this study?	• PIS -was it too much info/not enough/just right? is there any other information that should have been included? • Would you still have taken part if you had been randomised to receive usual care? And why? Being
Satisfaction with and experiences and perceptions of the PDConnect Intervention	
1:1 Physiotherapy: I would now like to focus on the 6 sessions of 1-1 physiotherapy part of PDConnect, that was delivered by Michelle. • Can you tell me what you thought of this part of the intervention? • The aim of 1:1 Physiotherapy was to develop your confidence with exercise, increase your awareness of the benefits of exercise, promote increased physical activity, and to develop an exercise programme that meets your personal needs. What are your perceptions, do you feel that the 1:1 physiotherapy achieved this or not? If yes, tell me about your experience, if no, how does the intervention need to be changed?	• What were their thoughts on the duration, content and delivery • Which elements of the 1:1 physiotherapy did you find the most and least beneficial • Was there anything you felt was missing from the 1:1 element of the programme, or is there anything you think should be removed • Do you have any further comments that you wish to share about the 1:1 physiotherapy component
Group-based exercise	• What were their thoughts on the duration, content and

I now want to focus on the 12 sessions of group based exercise part of PDConnect, that was delivered by Lyndsay. • Can you tell me what you thought of this part of the intervention? • The aim of group exercise was to develop your confidence with exercise, increase your awareness of the benefits of exercise, help support adopting more physically active lifestyle, develop a support network, and to develop an exercise programme that meets your personal needs. What are your perceptions, do you feel that the group class achieved this or not? If yes, tell me about your experience, if no, how does the intervention need to be changed?	delivery • The group-based session consisted of exercise and education discussions. Which elements of the group based exercise did you find the most and least beneficial • Was there anything you felt was missing from the group exercise element of the programme, or is there anything you think should be removed • Do you have any further comments that you wish to share about the group based exercise
I would now like to focus on the 12 weeks of self-management you had. During this time you had monthly contact with Lyndsay to check up on how you were managing your exercise and physical activity. • Can you tell me what you thought of this part of the intervention? • Overall what impact do you think participating in PDConnect has had on you, and why?	• What were your thoughts on the duration, and contact you received during this time • Was the monthly contact sufficient to keep you motivated to be active?
Staffing: in this section we would like to focus upon the staff who delivered the PDConnect intervention. Michelle delivered the physiotherapy components and Lyndsay the group-based exercise and the self-management components.	
• What were your thoughts of the Physiotherapist delivering the programme?: • What did you think of the fitness Instructor delivering the programme?	• How did you find their communication, knowledge, approachability, understanding of PDConnect, supporting your involvement

The next section, we would like to explore are your perception of the study resources – this included the study manual, joint goal setting, behaviour change techniques or strategies to support you to be physically active, the weekly activity planner and the activity diary.	
• What were your thoughts on the PDConnect manual? • During the PDConnect programme Michelle and Lyndsay will have set with you shared activity goals. How did you find the goal setting? • Did you use the weekly activity planner – if yes explore what they thought of it and if no – explore why not • Did you complete the weekly activity diaries, noting your step count? – if yes explore what they thought of it and if no – explore why not • Would you prefer to complete these diaries online or did you prefer the paper version	• Manual- what did they think about the length, content, and level of detail? • How do you think the manual influenced your understanding of Parkinson's? • How do you think that the manual influenced your understanding of the benefits of exercise • How do you think that the manual influenced physical activity behaviour? • What were your thoughts of using goal setting, was this helpful or not? • Is there anything else you would like to comment on in relation to the study resources
The next aspect we would like to explore with you is your experiences of using the Mi band activity tracker	
• What did you think of the Mi band? • Synchronisation, did you experience any problems? Were the study team able to address these for you adequately • Do you think the Mi band influenced your levels of physical activity? If yes or no why? • Would you consider wearing it long term?	• Consider comfort ease of use, readability, functionality

<table>
<tr><td colspan="3">**Next we are interested to hear what you thought about the RehabGuru Home exercise sheets which you received**</td></tr>
<tr><td colspan="2">• Did you use RehaGuru? These were the printed instruction sheets to guide your home exercise progarmmes
• If no, or not often why not?</td><td>• Did you find the images and instructions clear?
• Were they ease to use and follow?</td></tr>
<tr><td colspan="3">This study was originally designed to be delivered face to face. However, due to Covid it was changed to be delivered online. We are interested in your thoughts of participating in an online exercise programme.</td></tr>
<tr><td></td><td>• How did you find using Microsoft teams??
• Did you experience any difficulties to using Microsoft teams? If so, what were these?
• Did you feel that you were able to engage with the staff delivering the intervention effectively on Microsoft Teams, if not, what could be done differently to improve this.
• If you were to participate in this again, would you prefer online or face to face delivery or a combination of face to face and online, and why?</td><td>• Did you experience any challenges participating in any aspect of the PDConnect Intervention online, ie the 1:1 physio, the group based exs or the self management aspect, if yes what were these, and how do you think these could be addressed?
• In the group element of the intervention, how did you find interacting with another participants? Is there anything that could be done to enhance this experience
• Do you think anything could be changed to improve the online exercise experience?
• Do you perceive any benefits with online delivery?</td></tr>
<tr><td colspan="3">You completed a number of questionnaires and measures at 3 different timepoints as part of this study, so we would like to next ask you about your experience in completing these measures. Some of these measures were completed on microsoft teams with Julie and the others you completed yourself online or in a paper booklet.</td></tr>
<tr><td></td><td>• The study involved a variety of measures.</td><td>• What did you feel about the variety of measures that</td></tr>
</table>

	How did you find completing these questionnaires. • How easy was it for you to complete the questionnaires? Did you find this burdensome? • What outcome seemed the most suitable to you? • This study included a variety of measures that captured Parkinson's symptoms, activities of daily living, physical activity and QoL. What do you think is most important for us to measure/what do you most want to see an improvement in from an intervention like this?	were used within the study, too much, too little? • How easy was it for you to complete the questionnaires? Did you find this burdensome? • What did you think about the frequency with which the measures were taken • What is important to measure prompt - "is it physical activity, walking ability, general wellbeing, QoL, self-confidence, anxiety, fatigue, Parkinson's symptoms or something else"?
Other views and comments that they wish to share		
	Is there anything else that you would like to tell me about your experience of taking part in the PDConnect study?	

[Thank participant for their time and go over the right to withdraw, informed consent, anonymity and confidentiality, and who to contact post-interview if they wish to withdraw – Rachel Moss]

Next steps, I will be sharing these recordings with Julie, and she will undertake the analysis of all these conversations. as Julie has previously mentioned, the analysis of all the data will take a few months and she would hope to be able to share a summary of the findings in late spring.

8.29 APPENDIX 29: STAFF INTERVIEW TOPIC GUIDE

PDConnect

Semi- structured Interview Topic Guide (extended version)

My name is Eva Patterson, and I am part of the School of Health Sciences research team. The PDConnect study that you were involved in aimed to explore the feasibility and acceptability of the PDConnect programme. As you will be aware following the email from Julie, the purpose of this interview is to explore in more depth with you, your experiences of delivering PDConnect. You will have received via email, the participants information sheet, and you will be aware that your participation in this interview is voluntary and that it will be recorded. As it is a long time since you originally gave to consent. Before we start please could you confirm that you:

- You have had an opportunity to ask any question in relation to the interviews
- You are aware that you participation is voluntary
- You consent to the interview being recorded.

Thank you for that. The purpose of undertaking these SSI experience and perception of the PDConnect programme, and to gain thoughts in relation to its delivery. The researcher team will use your feedback to refine the future iterations of the PDConnect, so please feel free to be honest in your responses, your views and thoughts are greatly appreciated. The topic which we would like to explore with you include:

- Views, experiences and perceptions of the training and development package (Michelle and Lyndsay only)
  - Perceptions of the use of the study documentation – assessment sheets, manuals, study information, session plans
  - Perceptions of the use of the study resources – joint goal setting, BCTs, weekly diary and exercise planner, REHABGuru, and Mii Band

- Perceptions and experience of delivering the PDConnect programme online
- Perceptions of the impact of participation has had on themselves and PwP
- Other views and comments that they wish to share

Areas of interest within Semi Structured Interviews	
	Probes/prompts to be used depending on how the answer the opening question:
Training manual: we are interest to hear what your thoughts were on the training manual you received prior to delivering PDConnect	
Views, experiences and perceptions of the training and development package	**Training manual –** • Manual- what did they think about the length, content, and level of detail? • Was the manual easy to use? • How do you think the manual influenced your understanding of Parkinson's? Is there anything more/different you would have preferred or that could improve the training manual? • Was it too much info/not enough/just right? is there any other information that should have been included? • Did it address sufficiently your learning needs in relation to Parkinson's, • Did you feel it gave you sufficient information to deliver the PDConnect intervention? If not, what was missing • Would you suggest any changes to the format, if so what? • How long did it take you to complete the training? **Participants manuals** • what did they think about the length, content, and level of detail?

	• How do you think the manual influenced the participants understanding of Parkinson's and of exercise • Do you think anything else should have been included within the participants manuals
Study documents, and resources: a number of documents were produced to support the delivery of PDConnect. We are interested to gauge your thoughts on using these.	
Perceptions of the use of the study documentation – session plans and documentation, goal planners and activity diaries, REHABGuru and mi bands	**Study documents** • **Session plans and documentation -** What were your thoughts of the weekly session plans? Were they clear enough to guide what should be delivered in each session? Was the level of information too much or too little? Would you have like anything further to support the delivery of the intervention? • What were your thoughts on the delivering of the behaviour change techniques within each session, were they helpful or not? If helpful, in what way did you find them helpful ir not in what way were they not helpful? • What were your thoughts of using goal setting, was it helpful or not? Did you experience any challenges with setting goals or any aspect of participant goal planning? If helpful what in particular did you find helpful about setting participant goals? • What were your thoughts on the activity planners were they helpful or not? If not, what challenges did you experience? If helpful what in particular did you find helpful about the planners? • What were your thoughts of using activity diaries, were they helpful or not? If not why not? If helpful, in what way were they helpful? • What were your thoughts on using REHABGuru, was it helpful? Was it easy to use?

	How does it compare to other online exercise libraries? Did you experience any difficulties, would you make any changes to using REHAB Guru? If helpful, in what way were they helpful? • What were your thoughts on the MiBand, what feedback did you get from participants, were they beneficial, did the participants or you experience any issues.
Satisfaction with and experiences and perceptions of delivering the PDConnect Intervention	
1:1 Physiotherapy (ASK MICHELLE ONLY): I would now like to focus on the 6 sessions of 1-1 physiotherapy part of PDConnect, t • Can you tell me what you thought of this part of the intervention? • The aim of 1:1 Physiotherapy was to develop participants confidence with exercise, increase their awareness of the benefits of exercise, promote increased physical activity, and to develop an exercise programme that meets their personal needs. What are your perceptions, do you feel that the 1:1 physiotherapy achieved this or not? If yes, tell me about your experience, if no, how does the	• Did you experience any challenges delivering the 1:1 Physio element? If so, what are these and do you have any solutions that you can suggest to address this in the future? • What were their thoughts on the duration, content and delivery of the 1:1 physiotherapy? Was it long enough/too short or just right. If too short or too long, explore rationale as to why.? • Which elements of the 1:1 physiotherapy did you find the most and least beneficial for participants and why • What do you think participants valued most and least from the 1:1 physiotherapy sessions? • Was there anything you felt was missing from the 1:1 element of the programme, or is there anything you think should be removed? • Do you think the 1:1 physiotherapy session was helpful or not in preparing prepared participants for the group based exercise which followed? • Do you have any further comments that you wish to share about the 1:1 physiotherapy component?

intervention need to be changed?	
Group-based exercise. (ASK Lyndsay ONLY): I now want to focus on the 12 sessions of group based exercise part of PDConnect, • Can you tell me what you thought of this part of the intervention? • The aim of group exercise was to develop your confidence with exercise, increase your awareness of the benefits of exercise, help support adopting more physically active lifestyle, develop a support network, and to develop an exercise programme that meets your personal needs. What are your perceptions, do you feel that the group class achieved this or not? If yes, tell me about your experience, if no, how does the intervention need to be changed?	• Did you experience any challenges delivering the group based classes? If so, what are these and do you have any solutions that you can suggest? • Is there anything you would change if you were to run this again to how the groups were set up and delivered? • In the group element of the intervention, how did you find interacting with all the participants? Is there anything that could be done to enhance this experience • What were your thoughts on the duration, content and delivery of the group based exercise. Was it long enough/too short or just right. If too short or too long, explore rationale as to why.? Should certain aspects be longer or short or explore with participants in greater or lesser detail? • Which elements of the group exercise did you find the most and least beneficial for participants and why • What do you think participants valued most and least from the group exercise sessions? • Was there anything you felt was missing from the group exercise element of the programme, or is there anything you think should be removed? • Do you think the 1:1 physiotherapy session prepared participants for the group based exercise which followed? • Do you have any further comments that you wish to share about the group-based exercise component? • The group-based session consisted of exercise and education discussions. Which elements of the group-based exercise did you find the most and least beneficial

	• Was there anything you felt was missing from the group exercise element of the programme, or is there anything you think should be removed • Do you have any further comments that you wish to share about the group-based exercise
LYNDSAY ONLY I would now like to focus on the 12 weeks of self-management you had. During this time you had monthly contact with participants to check up on how participants were managing their exercise and physical activity.	• What were your thoughts on the duration, and contacts you provided during this time? • Was the monthly contact sufficient to keep participants motivated to be active? • Can you tell me what you thought of this part of the intervention? • Overall what impact do you think this aspect of PDConnect had participants, and why?
This study was originally designed to be delivered face to face. However, due to Covid it was changed to be delivered online. We are interested in your thoughts of participating in an online exercise programme.	
BOTH MICHELLE AND LYNDSAY • How did you find using Microsoft teams?? • Did you experience any difficulties to using Microsoft teams? If so, what were these? • Did you feel that you were able to engage with the participants receiving the intervention effectively on Microsoft Teams, if not, what could be done differently to improve this.	• Did you experience any challenges with the online delivery if yes what were these, and how do you think these could be addressed? • In the group element of the intervention, how did you find interacting with other participants? Is there anything that could be done to enhance this experience • Do you think anything could be changed to improve the online exercise experience? • Do you perceive any benefits with online delivery?

- If you were to participate in this again, would you prefer online or face to face delivery or a combination of face to face and online, and why?	
Other views and comments that they wish to share	
Is there anything else that you would like to tell me about your experience of taking part in the PDConnect study?	

[Thank participant for their time and go over the right to withdraw, informed consent,
anonymity and confidentiality, and who to contact post-interview if they wish to withdraw – Rachel Moss]

Next steps, I will be sharing these recordings with Julie, and she will undertake the analysis of all these conversations. As Julie has previously mentioned, the analysis of all the data will take a few months and she would hope to be able to share a summary of the findings in late spring.

8.30 APPENDIX 30: SATISFACTION SURVEY

Participant satisfaction survey

Now that the PDConnect programme has finished, we are keen to learn from your experience as a participant. This is an important step in this research study as your views, will help shape how we refine the programme in the future. We will be collecting your views by using this survey which will give us an overview of your experience, and we will be inviting you to take part in a 1-1 interview also, as we would like to explore your views in greater detail.

All information will be collected and stored within the requirements of General Data Protection Regulation Act (GDPR, 2018) and Data Protection Act (1998), and in accordance with RGU policies and procedures relating to the collection, storage and retention of research data.

This survey should take no more than 20 minutes to complete

Participant ID:

The PDConnect manual:

1.What did you think about the PDConnect manual? Very useful, useful, not sure, not useful,

2. On a scale of 1 to 10, with 1, being not useful at all, and 10 being very useful, overall how useful did you find the PDConnect manual?

3. For each of the elements included in the manual, please tick as appropriate, should be removed, no use at all, useful, extremely useful

1. About the PDConnect Programme
2. Understanding Parkinson’s
3. The benefits of exercise
4. Types of exercise
5. Exercise framework and government guidance
6. Getting started with PDConnect
7. Getting going with exercise
8. The activity diary
9. Introducing the mi physical activity tracker
10. Home exercise programmes
11. Local exercise opportunities

4. For each element of the manual, do you think we got the level of information just right, too little or too much. I will list the elements above with a tick box for just right, too little or just right

5. Was there anything else you would have found useful that could be added to the manual? Open

6. The resources in the manual were easy to engage with: (Likert scale: yes, extremely, very, no, not at all)

Physiotherapy Staff:

1. The physiotherapist delivering the programme was knowledgeable about Parkinson’s? (likert scale yes, extremely, very, no, not at all)
2. The Physiotherapist was very approachable: (likert scale yes, extremely, very, no, not at all)
3. The physiotherapist was easy to communicate and engage with (likert scale yes, extremely, very, no, not at all)
4. Overall, how satisfied were you with the 1:1 Physiotherapy you received as part of PDConnect. very satisfied, satisfied, uncertain, not satisfied, and very unsatisfied.
5. Open comments box

Fitness Instructor:

1. The fitness instructor delivering the programme was knowledgeable about Parkinson’s? (likert scale yes, extremely, very, no, not at all)
2. The fitness instructor was very approachable: (likert scale yes, extremely, very, no, not at all)
3. The fitness instructor was easy to communicate and engage with (likert scale yes, extremely, very, no, not at all)
4. Overall, how satisfied were you with the fitness instructor who delivered the group based exercise of PDConnect. very satisfied, satisfied, uncertain, not satisfied, and very unsatisfied.

Open comments box

The delivery of the PDConnect Programme.

The PDConnect programme had 3 components: 1:1 Physiotherapy, Group based exercise and 12 weeks of self management

What do you think about the duration of the whole PDConnect programme, too long, too short, just right? If too short or too long, what duration do you think would be preferable?

The 1:1 Physiotherapy components lasted 6 weeks. What did you think about the duration of this component, too long, too short, just right? If too short or too long, what duration do you think would be preferable?

The group exercise component lasted 12 weeks. What did you think about the duration of this component, too long, too short, just right? If too short or too long, what duration do you think would be preferable?

The self-management component lasted 12 weeks. What did you think about the duration of this component, too long, too short, just right? If too short or too long, what duration do you think would be preferable

Do you they think anything should be changed about how the PDConnect programme is delivered. Y/N. if yes, what do you think should be changed and why?
In particular, do you think any changes should be made to the 1:1 Physiotherapy component. If yes, what do you think should be changed and why?

In particular, do you think any changes should be made to the group based exercise component. If yes, what do you think should be changed and why
In particular, do you think any changes should be made to the self-management component. If yes, what do you think should be changed and why

What did you think about the combination of the 1:1 physiotherapy and the group based exercise components of the class. Valuable, not valuable, or you would have been happy with either on their own. Add open comments box
What did you think about participating in exercise online? I enjoyed it, I would prefer face to face, I would be happy to do either.

Would you recommend the PDConnect programme to other people with Parkinson’s? YES/NO, if no why not, and if yes why

On a scale of 1-10, with 10 being complete satisfied and 1 being not satisfied- How satisfied over all were you with the delivery of the PDConnect Programme overall? VAS 1-10
On a scale of 1-10, with 10 being complete satisfied and 1 being not satisfied- How satisfied over all were you with the delivery of the 1:1 Physiotherapy component of the PDConnect Programme? VAS 1-10
On a scale of 1-10, with 10 being complete satisfied and 1 being not satisfied- How satisfied over all were you with the delivery of the group based exercise component of the PDConnect Programme? VAS 1-10
On a scale of 1-10, with 10 being complete satisfied and 1 being not satisfied- How satisfied over all were you with the delivery of the self-management component of the PDConnect Programme? VAS 1-10

The experience of PDConnect.

Participation in the PDConnect Programme has developed my confidence to participate in exercise (likert scale yes, extremely, very, no, not at all)

Participation in the PDConnect Programme helped me see why particular exercises would benefit my Parkinson's (likert scale yes, extremely, very, no, not at all)

Participation in the PDConnect programme has improved my knowledge and understanding of Parkinson's (likert scale yes, extremely, very, no, not at all)

I participated in setting my own goals during the PDConnect programme (likert scale, yes, some of the time, no, the goals were set for me)

The goals set during the PDConnect Programme kept me motivated (likert scale yes, extremely, very, no, not at all)

Participating in PDConnect has provided with me strategies to help me be more active (likert scale yes, extremely, very, no, not at all)

On a scale of 1-10, with 10 being a noticeable positive impact on your Parkinson's, and 1 being no impact at all, what impact do you think being involved in the PDConnect Programme has had on your Parkinson's?

What impact do you think participating in PDConnect has had on you? Strongly agree, agree, neither agree or disagree, disagree and strongly disagree.

I feel stronger
I feel more flexible
I feel fitter
I have less pain
My walking is better
I feel confident exercising
I feel more self-confident
I have a better understanding of my Parkinson's
I feel able to self-manage my own physical activity
I have less fatigue
I am more motivated to be active
I sleep better

Rehab Guru home exercises.

During the PDConnect programme you will have received a home exercise programme. We used an exercise library called RehabGuru**.**

The RehabGuru exercise sheets were clear and easy to follow. (likert scale yes, extremely, very, no, not at all)

The exercise pictures made it clear how to perform the exercises at home (likert scale yes, extremely, very, no, not at all)
If not what other information would you have liked.

The Mi Band Activity Tracker
The Mi band guide was easy to follow and was useful to set up the mi band and connect the mi band with my device (likert scale yes, extremely, very, no, not at all) if not, what else would you have fund useful
Setting up the mi band was straightforward (likert scale yes, extremely, very, no, not at all) if no or not at all, what issues did you experience
The Mii band was comfortable to wear (likert scale yes, extremely, very, no, not at all)
The Mi band was ease to put on and take off (likert scale yes, extremely, very, no, not at all)
The Mi band was easy to use (likert scale yes, extremely, very, no, not at all)
It was easy to view your daily step count on the mii band (Likert scale yes, extremely, very, no, not at all)
On a scale of 1-10, with 10 being very motivating and 1 being not at all. How motivating did you find the mii band tracker in encouraging you to be more active
Would you consider wearing the mii band long term? Yes, no, if no why not
Did the mi band help you achieve your physical activity goals? Y/N
On a scale of 1-10, with 10 being very satisfied, and 1 being not satisfied at all, overall, ow satisfied were you that the mi band? VAS
Open comments box

Microsoft Teams: PDConnect was delivered online due to the Covid pandemic. To inform future delivery of PDConnect we would like to explore your thoughts on online, face to face delivery, or a combination of the two often referred to as a blended approach.
If you were to participate again, could you rank in order of preference how you would prefer PDConnect to be delivered:
Online/face to face or blended
Did you find Microsoft teams easy to use? Y/N
Did you experience any issues using Microsoft teams Y/N, if so what were they
Would you consider attending online exercise classes in the future? Y/N

8.31 APPENDIX 31: FIDELITY ASSESSMENT

PDConnect

Fidelity Assessment

Intervention Checklist for 1:1 Physiotherapy sessions

Date of assessment	
Date of Session reviewed	
Session Number:	
Session start time	
Session finish time	
Method of observation	
Time spent on exercise (mins)	
Adverse events	If yes, please give brief details

Intervention checklists are below - Please complete the corresponding session plan that is bring observed.

Session One				
Intervention Component checklist	Completed	Not completed	Attempted	Comments
Discussion with participants:				
Main barriers and motivators to exercise and explore potential solutions to these				
Perceived benefits of exercise are for their Parkinson's and wider health				
Strategies to promote PA during their normal week				
Make suggestions where PA could substitute sedentary activity				
Explore exercise preferences				
By the end of the session one, participants should have				
An HEP, which needs to be conducted on 5 days in the following week				
A completed activity planner for the next week				
An understanding of the benefits of exercise has for their Parkinson's and wider health and well-being				
An understanding of the benefits of exercise has for their Parkinson's and wider health and well-being				
A daily step count target				

4 mutually agreed goals, 3 to be addressed in the next 6 weeks and one long term goal.				
Your contact details and an appointment for their session next week				
Exercise prescription:				
Participation in exercise for minimum of 35 minutes				
Exercise prescription should encompass:				
Strength exercises with particular focus hip, knees, ankle and shoulder				
Flexibility exercise with emphasis upon the trunk, shoulder, and ankle				
Progressive Balance exercises working towards dynamic and functional balance.				
Aerobic exercises, working towards working at RPE13				
Functional and amplitude based exercises				
Based on individual preference and need				
Teaching points to be incorporated				
Instruction and demonstration of exercise				
Real time feedback on technique				
Intended benefits of the exercise				
Ensure understanding of value of specific exercise for them				
Provide insight into what the exercise should feel like				

Information on DOM’s				
Health and safety information as relevant				

Session Two				
Intervention Component checklist	Completed	Not completed	Attempted	Comments
Discussion with participants:				
Review the pros and cons of exercise				
Reflect on how they found their HEP last week, explore any barriers and problem solve solutions as required				
Discuss adherence to activity planner, explore any barriers and problem solve solution as required				
Signpost participants to exercise videos within the manual to support motivation				
Suggestions where PA could substitute sedentary activity				
By the end of the session two, participants should have				
A review/update of HEP, in paper or email format, which needs to be conducted on 5 days in the following week				
A review and update of their activity planner for the next week				

An understanding of the consequences of inactivity, and the impact of discontinuing exercise				
A review of the purpose of the activity planner and diary				
A review of their daily step count target				
4 mutually agreed goals, 3 to be addressed in the next 5 weeks and one long term goal. These can be reviewed from prior week and amended as appropriate/required				
An appointment for their session next week				
Exercise prescription:				
Participation in exercise for minimum of 35 minutes				
Exercise prescription should encompass:				
Strength exercises with particular focus hip, knees, ankle and shoulder				
Flexibility exercise with emphasis upon the trunk, shoulder, and ankle				
Progressive Balance exercises working towards dynamic and functional balance.				
Aerobic exercises, working towards working at RPE13				
Functional and amplitude based exercises				
Based on individual preference and need				
Teaching points to be incorporated				
Instruction and demonstration of exercise				

Real time feedback on technique				
Reinforce intended benefits of the exercise				
Ensure understanding of value of specific exercise for them				
Provide insight into what the exercise should feel like				
Information on DOM’s				
Health and safety information as relevant				

Session Three				
Intervention Component checklist	Completed	Not completed	Attempted	Comments
Discussion with participants:				
Re-evaluation of goals, their perception of progress and, what challenges they perceive				
Reflect on how they found their HEP last week, explore any barriers and problem solve solutions as required				
Discuss adherence to activity planner, explore any barriers and problem solve solution as required				
Introduce environmental cues, and pacing prompts to promote challenge within exercise out with the sessions.				
By the end of the session three, participants should have				

Have reviewed and discussed the activity diary and activity planner from the prior week				
Have an updated HEP. Participants should be actively involved in exercise selection				
A completed activity planner for the next week.				
Be aware that next week they need to bring in a activity planner for week 4 which they have populated for discussion				
Discuss, review, and amend as appropriate agreed goals, 3 to be addressed in the next 3 weeks and one long-term goal				
Have an understanding of the range of physical activities which they can participate in.				
Exercise prescription:				
Participation in exercise for minimum of 35 minutes				
Exercise prescription should encompass:				
Strength exercises with particular focus hip, knees, ankle and shoulder				
Flexibility exercise with emphasis upon the trunk, shoulder, and ankle				
Progressive Balance exercises working towards dynamic and functional balance.				

Aerobic exercises, working towards working at RPE13				
Functional and amplitude based exercises				
Based on individual preference and need				
Introduce dual tasking, and increased task complexity as able				
Increase as appropriate daily walking				
Teaching points to be incorporated				
Instruction and demonstration of exercise				
Real time feedback on technique				
Reinforce intended benefits of the exercise				
Ensure understanding of value of specific exercise for them				
Provide insight into what the exercise should feel like				
Health and safety information as relevant				

Session Four				
Intervention Component checklist	Completed	Not completed	Attempted	Comments
Discussion with participants:				
The basic exercise principles (FITT) and application to them and their exercise programme				
Need and value of regular exercise routine				
Revisit how PA could substitute sedentary activity’s				

Need for quality of movement, and need to increase physical and cognitive loading				
Impact how current exercise programme has influenced friends and family				
Introduce concept of group based exercise, exploring perceptions and offer potential solutions.				
Different forms of exercise choices				
Progress and reward achievements				
By the end of the session four, participants should have				
Have reviewed thier HEP, and progressed as appropriate				
Reviewed daily step goals and progressed as appropriate				
Discussed participant completed weekly activity planner				
Reviewed activity diary and discuss progress				
Have received information on locally available social networks for PwP				
Exercise prescription:				
Participation in exercise for minimum of 35 minutes				
Exercise prescription should encompass:				
Integrated approach				

Consider speed, power, directional changes, multiple planes of movement, goal orientated exercise, sustain amplitude of movement				
Motivate to work between RPE10-13 for whole session.				
Functional and amplitude based exercises,				
Dual tasking, and increased task complexity as able				
Increase as appropriate daily walking				
Introduce Pilates, Tai chi, PWR, PDWarrior style exercises				
Teaching points to be incorporated				
Instruction and demonstration of exercise				
Real time feedback on technique				
Reinforce intended benefits of the exercise				
Ensure understanding of value of specific exercise for them				
Provide insight into what the exercise should feel like				
Health and safety information as relevant				

Session Five				
Intervention Component checklist	Completed	Not completed	Attempted	Comments
Discussion with participants:				
Why exercise programmes need modified				

Explore any issues which participants are not clear on or whether they have questions arising from the manual				
Explore perceived issues, challenges of group based exercise, and discuss strategies to address these				
Discussion of exercise buddy to attend class with them				
Compare outcome from last week to this week				
Add in further environmental cue to promote to maintain levels of motivation				
Signpost to the manual to continue to develop understanding				
Explore how perceived abilities, perceptions and capabilities have changed over time				
Congratulate on progress to date				
By the end of the session five, participants should have				
Review goals and review performance				
Review activity planner and activity diary from prior week				
Review daily step count goals and performance				
Modify HEP and session based exercise programme as required				
Review perception of progress since week one				
Exercise prescription:				

Participation in exercise for minimum of 35 minutes				
Exercise prescription should encompass:				
Integrated approach				
Consider speed, power, directional changes, multiple planes of movement, goal orientated exercise, sustain amplitude of movement				
Motivate to work between RPE10-13 for whole session.				
Functional and amplitude based exercises,				
Dual tasking, and increased task complexity as able				
Increase as appropriate daily walking				
Introduce Pilates, Tai chi, PWR, PDWarrior style exercises				
Teaching points to be incorporated				
Instruction and demonstration of exercise				
Real time feedback on technique				
Reinforce intended benefits of the exercise				
Ensure understanding of value of specific exercise for them				
Provide insight into what the exercise should feel like				
Health and safety information as relevant				

Session Six				
Intervention Component checklist	Completed	Not completed	Attempted	Comments
Discussion with participants:				
Reflect on session one, with an emphasis on how their abilities, perceptions and capabilities have changed in that time				
Explore how perceived abilities, perceptions and capabilities have changed over time				
Discuss strategies to support socialisation and confidence within social environment.				
Revisit readiness to exercise scale, and contrast with session one				
Congratulate on progress to date				
Encourage participants to reward self as a result of changed behaviour				
Provide information about locally available social support networks for PwP				
By the end of the session six, participants should have				
Renewed short and long term goals (up to 12 weeks)				
Renewed daily step count goals				
An updated HEP				

Be independent in planning their weekly activity planner, and maintaining their activity diary.				
Completed reading of study manual and activities				
Be aware of which group they are in, and the date and time and joining instructions				
Exercise prescription:				
Participation in exercise for minimum of 35 minutes				
Exercise prescription should encompass:				
Integrated approach				
Consider speed, power, directional changes, multiple planes of movement, goal orientated exercise, sustain amplitude of movement				
Motivate to work between RPE10-13 for whole session.				
Functional and amplitude based exercises,				
Dual tasking, and increased task complexity as able				
Increase as appropriate daily walking				
Introduce Pilates, Tai chi, PWR, PDWarrior style exercises				
Teaching points to be incorporated				
Instruction and demonstration of exercise				
Real time feedback on technique				
Reinforce intended benefits of the exercise				

Ensure understanding of value of specific exercise for them				
Provide insight into what the exercise should feel like				

Complete = component was fully delivered by the Physiotherapist
Not Complete = component was not delivered by the Physiotherapist
Attempted = there was an attempt to deliver this component by the physiotherapist but it was not delivered fully
Not applicable = component was not applicable for example participants had exercised every day for the last week

Fidelity scores will be calculated for each session as the percentage of completed components from the total number of components. Components which were not applicable will be excluded from the overall total.

PDConnect

Fidelity Assessment

Intervention Checklist for group-based exercise sessions

Date of assessment	
Date of Session reviewed	
Session Number:	
Session start time	
Session finish time	
Method of observation	
Time spent on exercise (mins)	
Adverse events	If yes, please give brief details

Intervention checklists are below - Please complete the corresponding session plan that is bring observed.

Session One				
Intervention Component checklist	Completed	Not completed	Attempted	Comments
Discussion with participants:				
Be reminded to complete their weekly activity diary, activity planner and record daily step count				
Be reminded to continue to undertake their HEP 5 times a week				
Prompted to walk outdoors at least 4 times a week				
Focus on quality and refinement of the exercises.				
Check in that participants have completed reading of study manual and activities.				
Facilitated discussion – maximum of 30mins				
By the end of the session one, participants should have had				
Exercise prescription:				
Participation in exercise for minimum of 60 minutes				
Exercise prescription should encompass:				
Strength exercises with particular focus hip, knees, ankle and shoulder				
Flexibility exercise with emphasis upon the trunk, shoulder, and ankle				

Progressive Balance exercises working towards dynamic and functional balance.				
Aerobic exercises, working towards working at RPE13				
Functional and amplitude based exercises				
Based on individual preference and need				
Teaching points to be incorporated				
Instruction and demonstration of exercise				
Real time feedback on technique				
Reinforce intended benefits of the exercise				
Ensure understanding of value of specific exercise for them				
Provide insight into what the exercise should feel like				
Monitor performance to inform whether participants need progressing				
Information on DOM's				
Health and safety information as relevant				
Finish:				
Congratulate participants on achievements to date				
Opening the floor to any further questions				
Ask the group what their take home messages are from today				

Session two				
Intervention Component checklist	Completed	Not completed	Attempted	Comments
Discussion with participants:				
Be reminded to complete their weekly activity diary, activity planner and record daily step count				
Be reminded to continue to undertake their HEP 5 times a week				
Prompted to walk outdoors at least 4 times a week				
Focus on quality and refinement of the exercises.				
Be thinking about seeking and trying alternative exercise opportunities within local community.				
Facilitated discussion – maximum of 30mins				
By the end of the session two, participants should have had				
Exercise prescription:				
Participation in exercise for minimum of 60 minutes				
Exercise prescription should encompass:				
Strength exercises with particular focus hip, knees, ankle and shoulder				
Flexibility exercise with emphasis upon the trunk, shoulder, and ankle				

Progressive Balance exercises working towards dynamic and functional balance.				
Aerobic exercises, working towards working at RPE13				
Functional and amplitude based exercises				
Based on individual preference and need				
Teaching points to be incorporated				
Instruction and demonstration of exercise				
Real time feedback on technique				
Reinforce intended benefits of the exercise				
Ensure understanding of value of specific exercise for them				
Provide insight into what the exercise should feel like				
Monitor performance to inform whether participants need progressing				
Information on DOM's				
Health and safety information as relevant				
Finish:				
Congratulate participants on achievements to date				
Encourage participants to reward self as a result of changed behaviour				
Opening the floor to any further questions				
Ask the group what their take home messages are from today				

Session three				
Intervention Component checklist	Completed	Not completed	Attempted	Comments
Discussion with participants:				
Be reminded to complete their weekly activity diary, activity planner and record daily step count				
Be reminded to continue to undertake their HEP 5 times a week				
Prompted to walk outdoors at least 4 times a week				
Focus on quality and refinement of the exercises.				
Be thinking about seeking and trying alternative exercise opportunities within local community.				
Check in that participants have completed reading of study manual and activities.				
Remind them setting new goals next week				
Facilitated discussion – maximum of 30mins				
By the end of the session three, participants should have had				
Exercise prescription:				
Participation in exercise for minimum of 60 minutes				
Exercise prescription should encompass:				
Strength exercises with particular focus hip, knees, ankle and shoulder				

Flexibility exercise with emphasis upon the trunk, shoulder, and ankle				
Progressive Balance exercises working towards dynamic and functional balance.				
Aerobic exercises, working towards working at RPE13				
Functional and amplitude based exercises				
Based on individual preference and need				
Teaching points to be incorporated				
Instruction and demonstration of exercise				
Real time feedback on technique				
Reinforce intended benefits of the exercise				
Ensure understanding of value of specific exercise for them				
Provide insight into what the exercise should feel like				
Monitor performance to inform whether participants need progressing				
Information on DOM's				
Health and safety information as relevant				
Finish:				
Congratulate participants on achievements to date	x			
Encourage participants to reward self as a result of changed behaviour				
Opening the floor to any further questions				
Ask the group what their take home messages are from today				

Remind the group they need to make suggestions as to what the discussion forum should be about from week 6				

Session Four				
Intervention Component checklist	Completed	Not completed	Attempted	Comments
Discussion with participants:				
Be reminded to complete their weekly activity diary, activity planner and record daily step count				
Be reminded to continue to undertake their HEP 5 times a week				
Prompted to walk outdoors at least 4 times a week				
Focus on quality and refinement of the exercises.				
Be thinking about seeking and trying alternative exercise opportunities within local community.				
Check in that participants have completed reading of study manual and activities.				
Reset goals and step count targets for next 4 weeks				
Facilitated discussion – maximum of 30mins				
By the end of the session four, participants should have had				
Exercise prescription:				

Participation in exercise for minimum of 60 minutes				
Exercise prescription should encompass:				
Strength exercises with particular focus hip, knees, ankle and shoulder				
Flexibility exercise with emphasis upon the trunk, shoulder, and ankle				
Progressive Balance exercises working towards dynamic and functional balance.				
Aerobic exercises, working towards working at RPE13				
Functional and amplitude based exercises				
Based on individual preference and need				
Teaching points to be incorporated				
Instruction and demonstration of exercise				
Real time feedback on technique				
Reinforce intended benefits of the exercise				
Ensure understanding of value of specific exercise for them				
Provide insight into what the exercise should feel like				
Monitor performance to inform whether participants need progressing				
Information on DOM’s				
Health and safety information as relevant				
Finish:				
Congratulate participants on achievements to date				

Encourage participants to reward self as a result of changed behaviour				
Opening the floor to any further questions				
Ask the group what their take home messages are from today				
Remind the group they need to make suggestions as to what the discussion forum should be about.				

Session Five				
Intervention Component checklist	Completed	Not completed	Attempted	Comments
Discussion with participants:				
Be reminded to complete their weekly activity diary, activity planner and record daily step count				
Be reminded to continue to undertake their HEP 5 times a week				
Prompted to walk outdoors at least 4 times a week				
Focus on quality and refinement of the exercises.				
Be thinking about seeking and trying alternative exercise opportunities within local community.				
Check in that participants have completed reading of study manual and activities.				
Facilitated discussion – maximum of 30mins				

By the end of the session five, participants should have had				
Exercise prescription:				
Participation in exercise for minimum of 60 minutes				
Exercise prescription should encompass:				
Strength exercises with particular focus hip, knees, ankle and shoulder				
Flexibility exercise with emphasis upon the trunk, shoulder, and ankle				
Progressive Balance exercises working towards dynamic and functional balance.				
Aerobic exercises, working towards working at RPE13				
Functional and amplitude based exercises				
Based on individual preference and need				
Teaching points to be incorporated				
Instruction and demonstration of exercise				
Real time feedback on technique				
Reinforce intended benefits of the exercise				
Ensure understanding of value of specific exercise for them				
Provide insight into what the exercise should feel like				
Monitor performance to inform whether participants need progressing				
Information on DOM’s				
Health and safety information as relevant				

Finish:				
Congratulate participants on achievements to date	x			
Encourage participants to reward self as a result of changed behaviour				
Opening the floor to any further questions				
Ask the group what their take home messages are from today				
Remind the group they need to make suggestions as to what the discussion forum should be about.				

Session Six				
Intervention Component checklist	Completed	Not completed	Attempted	Comments
Discussion with participants:				
Be reminded to complete their weekly activity diary, activity planner and record daily step count				
Be reminded to continue to undertake their HEP 5 times a week				
Prompted to walk outdoors at least 4 times a week				
Focus on quality and refinement of the exercises.				
Be thinking about seeking and trying alternative exercise opportunities within local community.				

Check in that participants have completed reading of study manual and activities.				
Think about topics for the next 4 discussion forums				
Facilitated discussion – maximum of 30mins				
By the end of the session six participants should have had				
Exercise prescription:				
Participation in exercise for minimum of 60 minutes				
Exercise prescription should encompass:				
Strength exercises with particular focus hip, knees, ankle and shoulder				
Flexibility exercise with emphasis upon the trunk, shoulder, and ankle				
Progressive Balance exercises working towards dynamic and functional balance.				
Aerobic exercises, working towards working at RPE13				
Functional and amplitude based exercises				
Based on individual preference and need				
Teaching points to be incorporated				
Instruction and demonstration of exercise				
Real time feedback on technique				
Reinforce intended benefits of the exercise				
Ensure understanding of value of specific exercise for them				

Provide insight into what the exercise should feel like				
Monitor performance to inform whether participants need progressing				
Information on DOM's				
Health and safety information as relevant				
Finish:				
Congratulate participants on achievements to date	x			
Encourage participants to reward self as a result of changed behaviour				
Opening the floor to any further questions				
Ask the group what their take home messages are from today				
Remind the group they need to make suggestions as to what the discussion forum should be about.				

Session seven				
Intervention Component checklist	Completed	Not completed	Attempted	Comments
Discussion with participants:				
Be reminded to complete their weekly activity diary, activity planner and record daily step count				
Be reminded to continue to undertake their HEP 5 times a week				

Prompted to walk outdoors at least 4 times a week				
Focus on quality and refinement of the exercises.				
Be thinking about seeking and trying alternative exercise opportunities within local community.				
Check in that participants have completed reading of study manual and activities.				
Think about topics for the next 4 discussion forums				
Facilitated discussion – maximum of 30mins				
By the end of the session seven, participants should have had				
Exercise prescription:				
Participation in exercise for minimum of 60 minutes				
Exercise prescription should encompass:				
Strength exercises with particular focus hip, knees, ankle and shoulder				
Flexibility exercise with emphasis upon the trunk, shoulder, and ankle				
Progressive Balance exercises working towards dynamic and functional balance.				
Aerobic exercises, working towards working at RPE13				
Functional and amplitude based exercises				
Based on individual preference and need				
Teaching points to be incorporated				

Instruction and demonstration of exercise				
Real time feedback on technique				
Reinforce intended benefits of the exercise				
Ensure understanding of value of specific exercise for them				
Provide insight into what the exercise should feel like				
Monitor performance to inform whether participants need progressing				
Information on DOM’s				
Health and safety information as relevant				
Remind participants next week you will be reflecting on goals				
Finish:				
Congratulate participants on achievements to date				
Encourage participants to reward self as a result of changed behaviour				
Opening the floor to any further questions				
Ask the group what their take home messages are from today				
Remind the group they need to make suggestions as to what the discussion forum should be about.				

<table>
<tr><th colspan="5">Session eight</th></tr>
<tr><th>Intervention Component checklist</th><th>Completed</th><th>Not completed</th><th>Attempted</th><th>Comments</th></tr>
<tr><td>**Discussion with participants:**</td><td></td><td></td><td></td><td></td></tr>
<tr><td>Be reminded to complete their weekly activity diary, activity planner and record daily step count</td><td></td><td></td><td></td><td></td></tr>
<tr><td>Be reminded to continue to undertake their HEP 5 times a week</td><td></td><td></td><td></td><td></td></tr>
<tr><td>Prompted to walk outdoors at least 4 times a week</td><td></td><td></td><td></td><td></td></tr>
<tr><td>Focus on quality and refinement of the exercises.</td><td></td><td></td><td></td><td></td></tr>
<tr><td>Be thinking about seeking and trying alternative exercise opportunities within local community.</td><td></td><td></td><td></td><td></td></tr>
<tr><td>Check in that participants have completed reading of study manual and activities.</td><td></td><td></td><td></td><td></td></tr>
<tr><td>Think about topics for the next 4 discussion forums</td><td></td><td></td><td></td><td></td></tr>
<tr><td>Revisiting of goals</td><td></td><td></td><td></td><td></td></tr>
<tr><td>**Facilitated discussion** – maximum of 30mins</td><td></td><td></td><td></td><td></td></tr>
<tr><td>**By the end of the session eight, participants should have had**</td><td></td><td></td><td></td><td></td></tr>
<tr><td>**Exercise prescription:**</td><td></td><td></td><td></td><td></td></tr>
<tr><td>Participation in exercise for minimum of 60 minutes</td><td></td><td></td><td></td><td></td></tr>
<tr><td>**Exercise prescription should encompass:**</td><td></td><td></td><td></td><td></td></tr>
</table>

Strength exercises with particular focus hip, knees, ankle and shoulder	X			
Flexibility exercise with emphasis upon the trunk, shoulder, and ankle				
Progressive Balance exercises working towards dynamic and functional balance.				
Aerobic exercises, working towards working at RPE13				
Functional and amplitude based exercises				
Based on individual preference and need				
Teaching points to be incorporated				
Instruction and demonstration of exercise				
Real time feedback on technique				
Reinforce intended benefits of the exercise				
Ensure understanding of value of specific exercise for them				
Provide insight into what the exercise should feel like				
Monitor performance to inform whether participants need progressing				
Information on DOM's				
Health and safety information as relevant				
Finish:				
Congratulate participants on achievements to date				
Encourage participants to reward self as a result of changed behaviour				
Opening the floor to any further questions				

Ask the group what their take home messages are from today				
Remind the group they need to make suggestions as to what the discussion forum should be about.				

Session Nine				
Intervention Component checklist	Completed	Not completed	Attempted	Comments
Discussion with participants:				
Be reminded to complete their weekly activity diary, activity planner and record daily step count				
Be reminded to continue to undertake their HEP 5 times a week				
Prompted to walk outdoors at least 4 times a week				
Focus on quality and refinement of the exercises.				
Be thinking about seeking and trying alternative exercise opportunities within local community.				
Check in that participants have completed reading of study manual and activities.				
update HEP, and to reset, and document goals for the next 3 weeks.				

group discussion promote the group to consider how they will continue your exercise after this 12 week session ceases.				
Think about topics for the next 3 discussion forums				
Facilitated discussion – maximum of 30mins				
By the end of the session nine, participants should have had				
Exercise prescription:				
Participation in exercise for minimum of 60 minutes				
Exercise prescription should encompass:				
Strength exercises with particular focus hip, knees, ankle and shoulder				
Flexibility exercise with emphasis upon the trunk, shoulder, and ankle				
Progressive Balance exercises working towards dynamic and functional balance.				
Aerobic exercises, working towards working at RPE13				
Functional and amplitude based exercises				
Based on individual preference and need				
Teaching points to be incorporated				
Instruction and demonstration of exercise				
Real time feedback on technique				
Reinforce intended benefits of the exercise				

Ensure understanding of value of specific exercise for them				
Provide insight into what the exercise should feel like				
Monitor performance to inform whether participants need progressing				
Information on DOM’s				
Health and safety information as relevant				
Finish:				
Congratulate participants on achievements to date				
Encourage participants to reward self as a result of changed behaviour				
Opening the floor to any further questions				
Ask the group what their take home messages are from today				
Remind the group they need to make suggestions as to what the discussion forum should be about.				

Session ten				
Intervention Component checklist	Completed	Not completed	Attempted	Comments
Discussion with participants:				
Be reminded to complete their weekly activity diary, activity planner and record daily step count				

Be reminded to continue to undertake their HEP 5 times a week				
Prompted to walk outdoors at least 4 times a week				
Focus on quality and refinement of the exercises.				
Be thinking about seeking and trying alternative exercise opportunities within local community.				
Check in that participants have completed reading of study manual and activities.				
Think about topics for the next 4 discussion forums				
Facilitated discussion – maximum of 30mins				
By the end of the session ten, participants should have had				
Exercise prescription:				
Participation in exercise for minimum of 60 minutes				
Exercise prescription should encompass:				
Strength exercises with particular focus hip, knees, ankle and shoulder				
Flexibility exercise with emphasis upon the trunk, shoulder, and ankle				
Progressive Balance exercises working towards dynamic and functional balance.				
Aerobic exercises, working towards working at RPE13				
Functional and amplitude based exercises				

Based on individual preference and need				
Teaching points to be incorporated				
Instruction and demonstration of exercise				
Real time feedback on technique				
Reinforce intended benefits of the exercise				
Ensure understanding of value of specific exercise for them				
Provide insight into what the exercise should feel like				
Monitor performance to inform whether participants need progressing				
Information on DOM's				
Health and safety information as relevant				
Finish:				
Congratulate participants on achievements to date	x			
Encourage participants to reward self as a result of changed behaviour				
Opening the floor to any further questions				
Ask the group what their take home messages are from today				
Remind the group they need to make suggestions as to what the discussion forum should be about.				
Remind group that they have 2 weeks left to go				

Session eleven				
Intervention Component checklist	Completed	Not completed	Attempted	Comments
Discussion with participants:				
Be reminded to complete their weekly activity diary, activity planner and record daily step count				
Be reminded to continue to undertake their HEP 5 times a week				
Prompted to walk outdoors at least 4 times a week				
Focus on quality and refinement of the exercises.				
Be thinking about seeking and trying alternative exercise opportunities within local community.				
Check in that participants have completed reading of study manual and activities.				
group discussion promote the group to consider how they will continue your exercise after this 12 week session ceases.				
Think about topics for the next weeks discussion forum				
Facilitated discussion – maximum of 30mins				
By the end of the session eleven, participants should have had				
Exercise prescription:				

Participation in exercise for minimum of 60 minutes				
Exercise prescription should encompass:				
Strength exercises with particular focus hip, knees, ankle and shoulder				
Flexibility exercise with emphasis upon the trunk, shoulder, and ankle				
Progressive Balance exercises working towards dynamic and functional balance.				
Aerobic exercises, working towards working at RPE13				
Functional and amplitude based exercises				
Based on individual preference and need				
Teaching points to be incorporated				
Instruction and demonstration of exercise				
Real time feedback on technique				
Reinforce intended benefits of the exercise				
Ensure understanding of value of specific exercise for them				
Provide insight into what the exercise should feel like				
Monitor performance to inform whether participants need progressing				
Information on DOM’s				
Health and safety information as relevant				
Finish:				
Congratulate participants on achievements to date				

Encourage participants to reward self as a result of changed behaviour				
Opening the floor to any further questions				
Ask the group what their take home messages are from today				
Remind the group they need to make suggestions as to what the discussion forum should be about.				
Remind group that they have 1 week left to go				

Session twelve				
Intervention Component checklist	Completed	Not completed	Attempted	Comments
Discussion with participants:				
Be reminded to complete their weekly activity diary, activity planner and record daily step count				
Be reminded to continue to undertake their HEP 5 times a week				
Prompted to walk outdoors at least 4 times a week				
Focus on quality and refinement of the exercises.				
Be thinking about seeking and trying alternative exercise opportunities within local community.				
Check in that participants have completed reading of study manual and activities.				

group discussion promote the group to consider how they will continue your exercise after this 12 week session ceases.				
Think about topics for the next weeks discussion forum				
Facilitated discussion – maximum of 30mins				
By the end of the session twelve, participants should have had				
Exercise prescription:				
Participation in exercise for minimum of 60 minutes				
Exercise prescription should encompass:				
Strength exercises with particular focus hip, knees, ankle and shoulder				
Flexibility exercise with emphasis upon the trunk, shoulder, and ankle				
Progressive Balance exercises working towards dynamic and functional balance.				
Aerobic exercises, working towards working at RPE13				
Functional and amplitude based exercises				
Based on individual preference and need				
Teaching points to be incorporated				
Instruction and demonstration of exercise				
Real time feedback on technique				

Reinforce intended benefits of the exercise				
Ensure understanding of value of specific exercise for them				
Provide insight into what the exercise should feel like				
Monitor performance to inform whether participants need progressing				
Information on DOM's				
Health and safety information as relevant				
Finish:				
Congratulate participants on achievements to date				
Encourage participants to reward self as a result of changed behaviour				
Opening the floor to any further questions				
Ask the group what their take home messages are from today				
Remind the group they need to make suggestions as to what the discussion forum should be about.				
Remind group that they have 1 week left to go				

8.32 APPENDIX 32: EXAMPLE OF PARTICIPANT TRANSCRIBED INTERVIEW

Participant 58 transcript

44 mins including consent

Consent	
Interviewer	My name is Liz Hancock and I'm part of the PD Connect research team. Now. This study that you were involved in aim to explore the feasibility and acceptability of the PD Connect program. Now you'll be aware from the email that you got from Julie. The purpose of this interview is really to sort of explore your experience of the PD Connect program. And now you received by email the participant information sheet and you'll be aware that participation is voluntary, but that was a long time ago, so if you don't mind, I'd just like to confirm that you've had the opportunity to ask any questions in relation to the interviews
Participant	yeah yeah yeah.
Interviewer	Good and let you know that your participation is entirely voluntary.
Participant	Absolutely yes.
Interviewer	And that you consent to the interview being recorded.
Participant	Yeah, no problem.
Interviewer	Oh, thank you very much indeed. Now, as I said, the purpose really is to explore a little bit more in depth about your experience and perceptions of the PD program. Now the whole point of it is really so that the research team can. Ultimately, once you've done the analysis, refine the program and any future iterations of it. So please feel free to be as and as honest as you want in your responses, because your views at any views and thoughts are greatly appreciated and I'd like to cover the recruitment process satisfaction with the program.
Participant	OK.

Interviewer	The study resource is the MI Band, the rehab guru sheets teams and the outcome measures and anything else that you might think would be helpful. So if I start with study recruitment I'm quite keen to hear about how you found being recruited onto the study. So how did you find out about it in the first place?
Participant	A neighbour of mine, XX, who stays in X as well. He's a retired GP and he has Parkinson's and we are on the same committee of the local lifeboat. He said to me, I'm doing this Parkinson study from Robert Gordons, and he knows that I've got Parkinson's as well. So he said, would you like to try it? And I said, I guess is all easily do that. So I got in touch with Julie and I suppose the rest is history as they say.
Interviewer	And what did you think of the participant information sheet that you were provided with? Did it tell you enough about this study? Was it too much, or was it just a bit right?

Participant	I think it was the actual stuff that came through that I thought it was fairly comprehensive and some of it, I think going into the causes of Parkinson's and the other some other bits and pieces that I just found a wee bit tough reading it if you like [confusing this with the manual]
Interviewer	Yeah, bit too much detail?
Participant	A wee bit, those of us with Parkinson’s are aware of what it is and what causes it and really, I think the Parkinson's study was just a way of me controlling it in some way, and you know, trying to get better so thats what I found, very comprehensive, but maybe a wee bit too much I thought.
Interviewer	For being randomized to either receive the PD CONNECT or usual care, which was six sessions of physiotherapy, how did you feel about being randomized as part of the study?
Participant	Well, I mean, I've volunteered, so you've got to go with the flow. You know now?
Interviewer	Would you would you have still done it if you had been in the group that received usual care?
Participant	Ah aye I think so. I mean it's obviously ultimately the information that you're going gather than from both sides of their study that is going to benefit people with Parkinson's and the future. I mean, that's part of the study, you know. So, I mean, one day you’re on the swing and the next day you are on the roundabout so you've just to go with the flow
Interviewer	Absolutely.

1:1 Physiotherapy session	
Interviewer	Now the next section is really just to explore the one-to-one physiotherapy sessions. That was the 6 sessions of 1 to one physiotherapy that were delivered by Michelle. What did you think of that? Part of the intervention?
Participant	Absolutely brilliant. I was a wee bit apprehensive at first. But then you know, just it was silly things like one of the exercises were sitting on the floor and crossing your legs. And I mean for me, if that was just a Uh, you know I just couldn't manage it. But Michelle, you know on the one-to-one basis it was just was really good and I really enjoyed it and I really benefited from it. It was fantastic.
Interviewer	So did you feel that, uh, it increase your confidence with exercise? Or did it increase your awareness of the benefits of exercise?
Participant	I think a bit of both actually. Awareness, you know when I was standing, you know, with one foot behind the other and looking from left to right without falling over. Yeah, I mean that was something that I thought goodness me, I mean I never do that. I mean I do stotter a wee bit and that is without drink. And I just, you know, I just found the whole thing it enlightened me a wee bit and it was just…it was good. I really enjoyed it.

Interviewer	which elements of the one-to-one session with Michelle. Did you find most beneficial and maybe least beneficial?
Participant	Least beneficial. I cannot even think of anything that wasn't beneficial. Because we got an introduction, we got some exercises to do with it, and then you know with this beast on the floor and all kind of nonsense and you know… I mean I just found the whole thing you know over the six weeks I just found the progress was incredible.
Interviewer	Good, do you feel that Michelle
Participant	Yes, yes, definitely because you know she was able to watch what I was doing and then she said look and I can't really think of any examples, but there was a couple of exercises that I was maybe struggling to do you, so she said, well just try this which will lead into this ultimately getting to the exercise, she was trying to get me to do. I mean I think it was the one where you lie down on the floor and you put one arm out in front of you and one of the opposite leg behind and we changed it around as I just found that coordination with a wee bitty difficult at times
Interviewer	So, she split it down for you and then.
Participant	Yes, I think that that's the one where she just said, you know, just don't try and rush it, because I just thought right come on, let's get on with it, you know.
Interviewer	OK, is there anything else that you want to say about the one-to-one component?
Participant	No, I mean I just emphasize the fact that it was extremely beneficial. At first, I thought I wonder what I'm going to get here. Uh, by the end of the six weeks I thought this is good, you know, and I felt really good as well.
Interviewer	Good, do you think 6 weeks were enough?
Participant	I think 6 sessions were a good foundation. You know, in realistic terms you couldn't expect to receive that on a weekly basis forever, and then it just comes back to the discipline required by yourself off to actually get off your backside and do it, you know?
Interviewer	And do think that Michelle motivated you to do that, take control of it yourself.
Participant	She's certainly pointed me in the right direction, but I kind of fell off the horse a few times [laughs]

Group based sessions	
Interviewer	It will anyway now the next. The next section is around the group-based exercise sessions and that's the 12 sessions that were delivered by Lyndsay and I just wondered what you felt about that part of the intervention
Participant	That was very very good for me. I mean, I saw people who had never met before, and although I could only see a group, a wee bit of the group at time and I could see people that had more severe Parkinson's than me. And you know, they were really going for it and I enjoyed it. Lyndsay, it was very varied. I think she was very warming as well. You know she just… I mean she obviously does more intense exercises for different groups. But it came to a level with us, and I mean to be honest, I never thought I'd be

	dancing about the hooose with a scarf thing like that…like a Russian gymnast [laughs]. Yeah, I just had to make sure there was none of my palls walking by the window at the time [laughs]. But no, most enjoyable and it just showed me that you know, obviously, I mean, I always tell people I've just got touch, of Parkinson's because I'm not…I mean I've got a tremor in my right hand and that's about it, and maybe walk a wee bit funny. When I see other people who are struggling at, you know…And for Lyndsay to cater for all 12 of the group or however many it was, I thought she did a very good job as well. Because it was all very varied that wasn't overly intense, but it also at the end of the 45 minutes there was a wee bit of a sweat on. If you know what I mean.
Interviewer	Yes, yeah, now the sessions consisted of exercise and some discussions around education. Which elements of the group-based exercise did you find most beneficial and least beneficial?
Participant	I think the general chat with everybody was good because it was good just to hear how everybody was finding it bearing in mind we were all in very stages are locked down as well. So, the chat kind of veered towards that [lockdown] but I think it was just hearing other people's experiences and then you know sharing of bit exercise time with them. I really enjoyed it and it's you know, it's something that I haven't done since this and you know, I missed the fact that there's… because every week we were doing something and all through the summer, you know, I overlooked Findhorn Bay and I you know, would turn my tablet around and show them the bay and we would have a chat about the weather. And yeah it was. It was just positive.
Interviewer	So, did you find you developed a wee bit of a support network? Did you have you contacted any folk out with me?
Participant	Yes, yes. I didn't contact any of them out with the group, but I just enjoyed the fact that the we had this weekly and there's something to look forward to you and you know along with exercising out with the group it was, you know, it was almost how did you own this week then? It was good
Interviewer	So the group acted sort of as a motivator to each other.
Participant	Definitely, definitely.
Interviewer	That's good. And as I say, the whole aim of the group exercise again was to increase your awareness of the benefits of exercise. Help me to adopt a more physically active lifestyle, develop a support network and develop a program that met your personal needs. Do you feel the group sessions did that?
Participant	Yes, yeah. I mean, my own personal story is prior to starting the this study group I took a tumble to myself and I thought to myself, look I am retired and am mopping about

	the house doing nothing and I was getting a wee bit grumpy and I though I've got to get right and I started doing that thing called the keto diet. And then I started walking in line with that and I had read the book by the front bench MP for Labor, he is not an MP anymore…Watson. He lost a heap of weight doing this keto diet. I listen to his book and it motivated me so I start walking and I still walk on average 5 miles a day with the dog and in the process lost four and a half stone, over about 14 months
Interviewer	Wow, that's some achievement.
Participant	And it's just been fairly steady since then and I now if I want to have a cream cake, have a cream cake. Yeah, but I mean I don't eat carbs per say, I just try and stick to the vegetables, meat, fish. Just all the keto stuff, but avoid the heavy carbohydrates
Interviewer	Do you feel better? You feel better for it.
Participant	Oh, unbelievable unbelievable.
Interviewer	And it's made it made it easier for you to be active, do you feel you know it's less, less energy if you like to go for your walk with the dog.
Participant	Absolutely, I mean, there are some days you know I set out for a walk and I listen to a book when I'm out walking and I've got ear buds and I just listen to book and then I just get lost in the book and then I walk and walk and walk and walk and then there's 7 miles of beach between X and X Beach. And I walk, and suddenly I've gone about four miles and then it's 4 miles home again.
Interviewer	So you'll be close to XX
Participant	Yes, yes. I I walked the X That's my turning point to come back.
Interviewer	We used to go there as kids. Yeah, yeah it's nice beach.
Participant	Beautiful, beautiful,

Self-management	
Interviewer	now the next section is to focus on the 12 weeks of self-management that you had and during that point that was after the group sessions you had monthly contact with Lyndsay really just as a check up to see how you are managing your exercises. Again, what did you think of that part of the intervention?
Participant	Ahh well, it was very interesting because with the full intervention you knew that Thursday morning 10:00 o'clock, you were there. Without that it was a case of Oh well, maybe do it Wednesday. Oh no, I have to go somewhere on Wednesday, no worries I will do it on Thursday and then I find it slipping all the time. I mean it's still done most of it, but if there was, Oh no. I'm going for a game of golf instead, that'll do, that will replace it, you know. As I said to Lyndsay, I just missed the discipline of knowing at 11:00 o'clock or whatever time on Thursday, get the get the tablet setup Look out me wee things out that I flick in the air, and get myself going. But I mean, I still do it. I do a lot of the stretching exercise still. But I don't do that, I've kinda put away

	the ball, the stretchy things, all that away. Because I am just saying to myself well if I'm playing golf at least twice a week, and I'm walking five miles most days. Because if I put on my shoes, I've got a Labrador dog. The dog just knows that if I put on a certain pair of shoes that she's going for a walk and that's it.
Interviewer	Did you find the monthly contact with sufficient to keep you motivated to be active?
Participant	Personally, no because I'm fairly active as it with walking. In relation to the exercises that Lyndsay gave us. Yes, you know, it was suddenly I've got Lyndsay on the phone this week, right come on, let's do some exercise.
Interviewer	I need to give her something to do. I need to be able to speak to her about something then yeah, yeah, yeah.
Participant	Yes, exactly

Impact	
Interviewer	Yeah, so overall, what impact do you think participating in PD Connect has had on you?
Participant	Well, I think. First of it showed me that OK walking as-side, with the exercise on a regular basis I felt a lot better and I didn't feel the Parkinson's was getting any worse touch wood. It gave me a regime to try and stick to because over the period of time it showed me the benefits of it. It's you know…and when you read about people with Parkinson's that they've got a desire to sit down and do nothing. You know, every day I've got to say it myself. No, lets get going. I mean, I find myself sometimes, especially in these dark afternoons watching folk buying a hen house in Spain or something like that. You know, I mean I think to myself I got to do something better than that, you know
Interviewer	You are surrounded by such a lovely piece of countryside as well, you know, and you've got the dog. And yeah.
Participant	Yeah, yeah, but I've tried been cycling, I used to do a lot of swimming but I've kind of gone off the swimming just going to the pool. Because of all the polava, because you have to book to get in, I am finding excuses quite easily for that, you know
Interviewer	And cycling, do you still cycle.
Participant	No, I fell off of it four times. Yeah, the track between X and X is a wee bit lumpy and bumpy. I pushed the bike home and put it in the shed and said I am not going out on that bloody thing again.

Staffing	
Interviewer	OK. So the next section is really just want to focus on the staff that we're delivering the intervention that's Michelle the physio component and Lyndsay, the group based exercise. And if we start with Michelle, how did you find her communication, her

	knowledge, her approachability, and our understanding of PD connect supporting your involvement? But I think yeah, unquestionable I think she understood Parkinson's totally. We chatted about what my actual condition what part of Parkinson's have got, if you like. She fully understood and she chatted about a previous exercise and how he used to keep myself fit like when I was younger. Uh, and how she could introduce some of that later you know not totally the same. But no, I think Michelle was very knowledgeable, very helpful, great communicator. And yeah, just very professional as well
Interviewer	And lyndsay
	Absolutely echo the same. And you know, she was always… Lyndsay was always smiling and you know nothing was too much bother you know. And I think it's very difficult….I think for somebody to be motivational to a group of 12 strangers on a dodgy platform like this teams meeting stuff, you know I take my hat off to her and it was very good.

Study resoucres	
Interviewer	Now the next section is to explore your perception of the study resources. That's the study manual. The joint goal setting, the behaviour change techniques, weekly activity planner, and Activity Diary. What were your thoughts of the PD Connect manual that was?
Participant	I think that was the very comprehensive and maybe just a wee bit meaty for me in places
Interviewer	Yeah, like, I mean, you said earlier on that you know you know enough about Parkinson's that it didn't tell you anything else, but what about…do you do you think that the manual influenced your understanding of the benefits of exercise?
Participant	It certainly introduced it because all the various examples of exercise that was within the manual. You know from basic sitting down exercises, to actually getting involved. There was websites you know to go to, there was other things where you could try and find out local Parkinson's groups, whatever. So yeah, I think that was very beneficial.
Interviewer	OK, do you think it influenced your physical activity behaviour at all
Participant	I think so, yeah. It made me think that, well, OK, I'm walking five miles or whatever a day, but there's other things that could be doing on very wet rainy days when your not wanting to go out and walk the dog. And you know you can go through the house and start dancing about…. You know what I mean?
Interviewer	I would like to see a demo of that
Participant	No you do not….[laughs]
Interviewer	So you mentioned in the manual was quite meaty, so in terms of the length and the level of detail, was it too much do you think?

Participant	Yes, in relation to the causes of Parkinson's and what parkinsons is. I think most of us when we get diagnosed go away and Google it and we read for a few days or weeks or whatever and you think right? OK, that's what that is and then you have your consultant who's told you much as such the same. I mean, I felt I didn't really need any more information.
Interviewer	That's that, that's fine now. During the programme, Michelle and Lindsey will have set shared activity goals with you. How did you find the goal setting?
Participant	Yeah, that was. Yeah, I think it was straightforward enough.
Interviewer	Did you use the weekly activity planner?
Participant	I didn’t use so much the planner and I did when it started. But then I just found myself that it was repeating. You know, once I get into routine, I thought right Monday was a walk, Tuesday was exercise plus a bit of a walk. Wednesday was golf plus, and exercise, Thursday was a walk plus the online class, Friday, you know, and when it was just a routine and I thought, well it's not changing and so I didn't record on the planner, but I did record my steps everyday
Interviewer	Did you want to increase it or just maintain your step count or whatever?
Participant	Some days, some days I went completely daft and it was…Yeah, I think about 15 miles some days. And no, it was on fine summer days, but I didn't set myself a challenge. I just said right one every day I've got to do something that was the challenge.
Interviewer	Would you have preferred to complete the Diaries online or did you prefer the paper version?
Participant	I did the paper version obviously, but I suppose the online thing would be ok, I would be happy doing that. I think it was maybe have been more efficient, and I think that would have been fine
Interviewer	OK, so the planner was helpful initially, but then you got yourself into routine but you felt that the recording of the activity was helpful
Participant	Yeah, I mean because it was just you know if you walked 6 miles one day and then 6 miles another day or exercising could refer back to it and you can say well, last week I've done all that. But this week that’s all I have done, so you can up the game a wee bit.

Mi Band	
Interviewer	Next aspect is to look at you the use of your MI band or the activity tracker. What did you think of the MI Band?
Participant	I thought it was brilliant. I've got the I've got more own one here money here, the the strap came off. But in the summer I. I went swimming in X near me and the mi band parted company in the Bay. So it went off into the sunset somewhere. So it's still it's still swimming about. I mean it was perfect. I thought it was a great motivational thing. You could set alarms on it so to remind you to get off your backside so it was good. It was quite interesting as I

	wore my own one and the one provided it was quite interesting because some days you know I would go for my walk. My own would say I'd done 5 miles and the MI band would say I had done maybe 5 1/2 miles so it was. It was quite interesting. And if I played golf the mi band would say that I have gone further than my own device
Interviewer	Did you any issues synchronizing it?
Participant	no
Interviewer	some folk have been commenting that it was quite difficult to read because the writing was so small.
Participant	I found it fine
Interviewer	so in terms of in terms of readability, functionality and comfort, it was OK.
Participant	I found it ok, and I think it was an additional motivator If you had the alarms on it to say, come on, get going.
Interviewer	So and you mentioned you've got your own one now, so would you consider it wearing something similar long term to keep a track?
Participant	Yes I wear this one all the time. It’s a watch and I set alarms on it for it to ensure that I take my Parkinson's medication spaced out through the day, and I've got my walking. I mean, last year I walked in total 1500 miles so I'm hoping to beat that this this year.
	Some achievement, Yep, excellent

Rehab guru	
Interviewer	OK, now the next section is the rehab guru home exercise sheets which are received. They were the printed instruction sheets with the UM images and I just wanted did you use them to guide your exercise programs?
Participant	I just stuck to what Lindsey and Michelle had given us prior to that.

Teams	
Interviewer	No, OK, now the study was originally designed to be face to face, but you know for obvious reasons due to covert it was it was changed to be delivered online. Some keen to so explore your thoughts of participating in an online exercise program. How did you find using teams? Microsoft Teams?
Participant	No, bit of a nightmare. There was some days you couldn't hear people or you couldn’t be heard. There was some days it just threw you out halfway through and I think there was one chap as part of our group he just gave up because teams. I don’t know whether this was just whether it was his own personal computer or whatever. I don't know. I would have thought it was it was only very awkward at times. Yeah, and I think there's maybe better platforms out there.
Interviewer	Did you experience any challenges in participating in any aspect? You know in the one to one physio or the group exercise program or the self management aspect

Participant	No other than the awkward moments when the thing through you out. Yeah, you know it was. It was OK.
Interviewer	How did you find interacting with the other participants? Was there anything that you think could have been done to make that any better?
Participant	No, I don't think so, I mean I think the fact that we were all online and probably scattered all over the northeast of Scotland, I think it was quite an achievement to get a group of 12 strangers come together and have a chat about their illness or whatever, and go forward and have a bit of fun doing exercise for 12 weeks or whatever it was I think it was there was grand, you know.
Interviewer	Did you find that you were able to engage with Michelle and Lyndsay UM effectively?
Participant	yes
Interviewer	Yeah, OK now burning question here, if you were to participate in this again, would you prefer fully online face to face or like a hybrid? A bit of both. A combination of face to face and online
Participant	I think I bit a both would probably most beneficial. But I appreciate that involves, you know traveling and you know. And as I say, we're all scattered all over the NorthEastern Scotland. Depending on the time of year, it would it be convenient for people to set off. And you know, coming to Aberdeen or wherever, and for a day for a couple hours exercise or whatever and then come all the way back. But I think it would be really beneficial maybe at the start, at the beginning to meet as a group together and then do the online stuff. But then meet at the end again, and you know that then have a face-to-face chart at the start and at the end.
Interviewer	A few people have mentioned that and said, you know, some form of icebreaker to start with to get to know the Group a bit more and might have helped you know the same systems that you do when you're in a face to face scenario. What about locally based exercise programs or locally? You know local delivery as opposed to coming to Aberdeen.
Participant	Yeah, absolutely. And I think I would be up for that, definitely

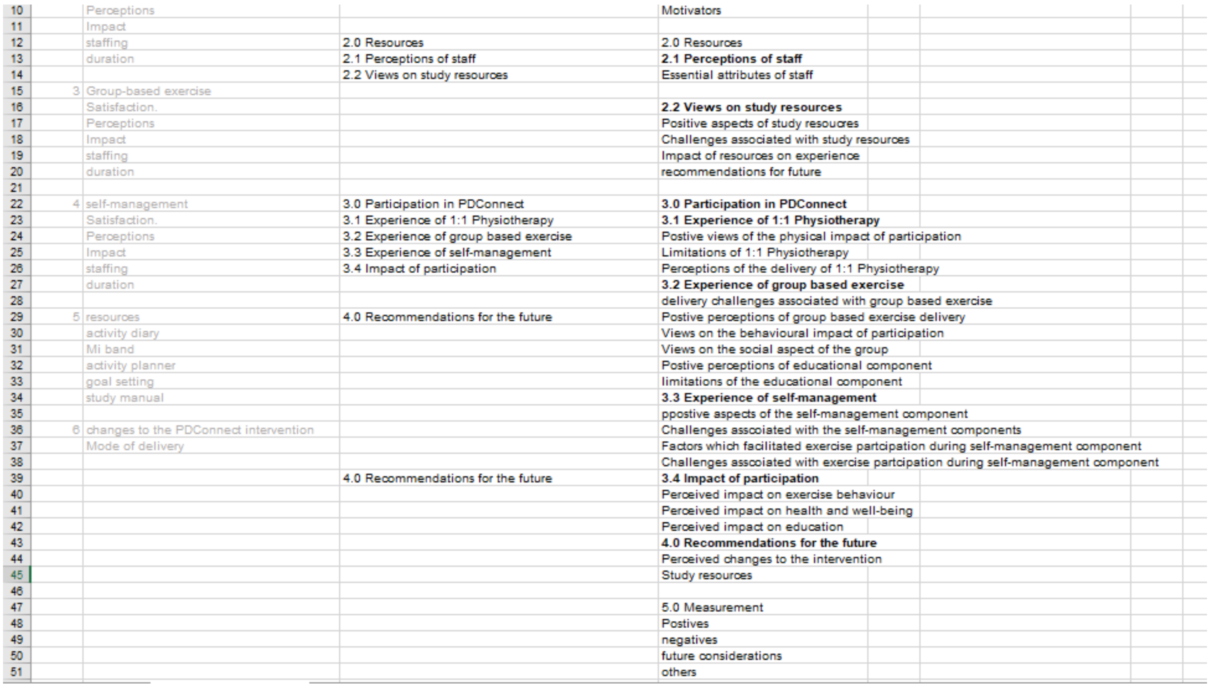
measures	
Interviewer	Good now throughout the study you completed a number of questionnaires. I think there were three time points and so really want to find out what you thought of those. Summary completed on teams with Julie and the others who completed yourself in a booklet. So I just wondered how did you find completing the questionnaires? Did you?
Participant	Well, I did it on my phone. I found it quite difficult scrolling up and doing because you were getting thrown out at questions and then if he did not push the button right it was quickly put you back. So I found it a wee bit frustrating if I'd done it on a PC, it would have probably been a lot easier, but I just done it on the phone.
Interviewer	How did you feel about the variety of measures that were used? Was it too much, too little?

Participant	Well, I don't think it was really for me to comment because I think it's for the experts to analyze that data. I mean, the more data they have, the more the better the picture they have. So you know, as far as I was concerned, bring it on.
Interviewer	What I what outcomes seemed, the more suitable to you? Was it physical activity, walking ability, general well-being quality of life, fatigue, confidence?
Participant	I think I think I mixture of them all up. Yeah, I think certainly the physical stuff was definitely enlightening, because it definitely made me feel a lot better and definitely motivated me and I knew that if I got up and went through there and sat down in the chair. Yeah, and that was doing me no good whatsoever, but have gotten done something and done a wee bit of exercise, and, you know, I would feel better for the rest of the day. And is certainly the true
Interviewer	Yeah, OK, so you know talk to me, but about the variety of measures that capture Parkinson's symptoms. activities of daily living, physical activity, quality of life, what do you think is most important for us to measure?
Participant	I think quality of life.
Interviewer	OK, and what do you most want to see an improvement from an intervention like this?
Participant	I think to maybe enhance your self-discipline every bit to know that although it's a bit of a chav and it's and it always is the hardest thing you know it's the pulling on your training shoes, putting on your training kit, putting on your swimming trunks, to get the bike out the shed or whatever. But to get it.. to try and build in a routine into somebody and for people that is the benefit you'll feel a lot better and it's almost like a drug. Once you get into the routine. And then when you spoil the routine or somebody interferes with the routine, you just go I am not happy with that. You know, I find that you know if I'm walking, if I go walk in first thing in the morning, it's fine, it's me. But then my wife says, oh, we need to go to Inverness, I am bit like I am not sure about that [laughs]. You know, because it breaks, it breaks your routine. You know, and then before you know it, you're through in XX sitting and drinking fancy coffee and eating a score, and that he did not really need, and you know…
Interviewer	But you know it's getting a balance. Because you said before, you know, you watch your diet. You do plenty exercise and the odd the odd, better pleasure you know it's affected that much. But as I said, you've got into your routine of making sure that you do your exercise or not.
Participant	Exactly I think I think you may gather that I have an ever present sense of humour no matter what I'm doing, where are who I'm with. I've got to just throw out these stupid one liners or you know these wee comments, but that's me. Its a constant sense of humour because I just find that if you can't laugh or smile and if you're miserable its hopeless.

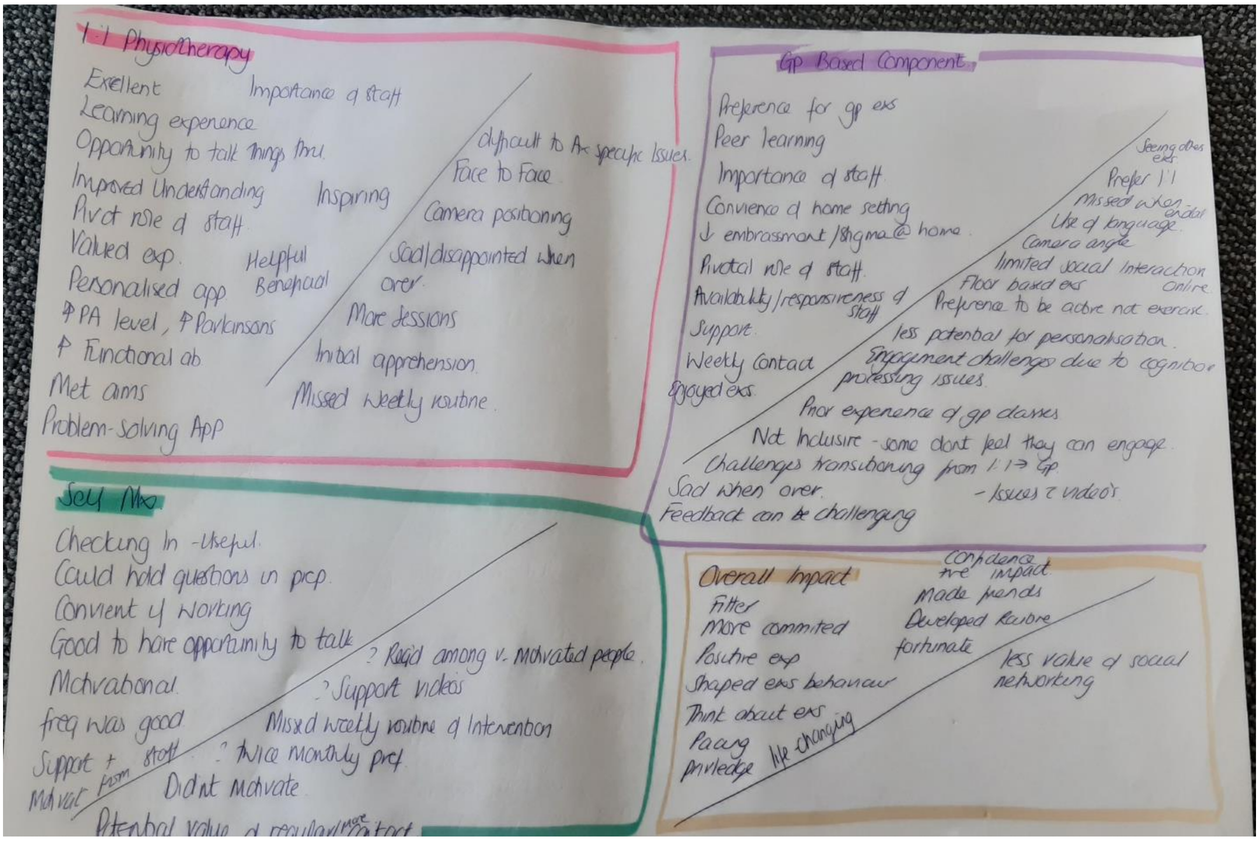
Interviewer	Totally, I totally agree and actually been an absolute pleasure. Speaking to you, is there anything else in X that with you think we've forgotten? Is there anything else you'd like to tell me about it? Anything you'd like to add that I've maybe missed?
Participant	I just think it was really good fun. It was a very interesting to do… enlightening. I think Robert Gordon's or the group have got to be congratulated then. I feel very lucky that I've had the privilege to take part in this because it's showing me that you know, with a bit of discipline and bit of exercise. Parkinson's yes it's a pain in the backside, but it's not going to ruin me. Not yet anyway. I mean if it gets worse it gets worse, but if it does not….But the fact that I can take my dog for a five mile walk I can. I can go through and do various stretches and things like that for half an hour…build up a wee sweat. If that is going to prevent it getting worse and then it's all down to the intervention or taking part in this study. I feel very fortunate.
Interviewer	Good, well that's exactly what it was designed to do is to help you manage it, you know, but listen, I can't thank you enough for giving me up. Giving up your time to speak to me and I just need to remind you that you've got the right to withdraw. Join if you decide on reflection after this interview that you really don't want your information to be used, then please just contact Rachel Moss. Everything about this will be, you know, everything will be anonymized. It'll all be confidential. Nothing will be attributed to yourself, but you do have the right to withdraw.
Participant	No.

8.33 EARLY QUALITATIVE MATRICES

Appendix 33: Early framework analysis matrices and analysis



10		Perceptions		Motivators
11		Impact		
12		staffing	2.0 Resources	2.0 Resources
13		duration	2.1 Perceptions of staff	**2.1 Perceptions of staff**
14			2.2 Views on study resources	Essential attributes of staff
15	3	Group-based exercise		
16		Satisfaction.		**2.2 Views on study resources**
17		Perceptions		Positive aspects of study resouces
18		Impact		Challenges associated with study resources
19		staffing		Impact of resources on experience
20		duration		recommendations for future
21				
22	4	self-management	3.0 Participation in PDConnect	**3.0 Participation in PDConnect**
23		Satisfaction.	3.1 Experience of 1:1 Physiotherapy	**3.1 Experience of 1:1 Physiotherapy**
24		Perceptions	3.2 Experience of group based exercise	Postive views of the physical impact of participation
25		Impact	3.3 Experience of self-management	Limitations of 1:1 Physiotherapy
26		staffing	3.4 Impact of participation	Perceptions of the delivery of 1:1 Physiotherapy
27		duration		**3.2 Experience of group based exercise**
28				delivery challenges associated with group based exercise
29	5	resources	4.0 Recommendations for the future	Postive perceptions of group based exercise delivery
30		activity diary		Views on the behavioural impact of participation
31		Mi band		Views on the social aspect of the group
32		activity planner		Postive perceptions of educational component
33		goal setting		limitations of the educational component
34		study manual		**3.3 Experience of self-management**
35				ppostive aspects of the self-management component
36	6	changes to the PDConnect intervention		Challenges associated with the self-management components
37		Mode of delivery		Factors which facilitated exercise partcipation during self-management component
38				Challenges associated with exercise partcipation during self-management component
39			4.0 Recommendations for the future	**3.4 Impact of participation**
40				Perceived impact on exercise behaviour
41				Perceived impact on health and well-being
42				Perceived impact on education
43				**4.0 Recommendations for the future**
44				Perceived changes to the intervention
45				Study resources
46				
47				5.0 Measurement
48				Postives
49				negatives
50				future considerations
51				others



1:1 Physiotherapy

Exellent
Importance of staff
Learning experience
Opportunity to talk things thru.
Improved Understanding
Inspiring
Pivot role of staff.
Valued exp.
Helpful
Beneficial
Personalised app
↑ PA level, ↑ Parkinsons
↑ Functional ab.
Met aims
Problem-Solving App

difficult to Ax specific Issues.
Face to Face
Camera positioning
Sad/disappointed when over.
More sessions
Initial apprehension.
Missed weekly routine.

Gp Based Component

Preference for gp exs
Peer learning
Importance of staff.
Convience of home setting
↓ embrassment/stigma @ home.
Pivotal role of staff.
Availability/responsiveness of staff
Support.
Weekly Contact
Enjoyed exs.

Seeing others exs.
Prefer 1:1
Missed when ended
Use of language.
Camera angle
limited social Interaction Online
Floor based exs
Preference to be active not exercise.
less potential for personalisation.
Engagement challenges due to cognition processing issues.
Prior experience of gp classes
Not Inclusive - some dont feel they can engage.
Challenges transitioning from 1:1 → Gp.
- Issues c videos
Sad when over.
Feedback can be challenging

Self Mx

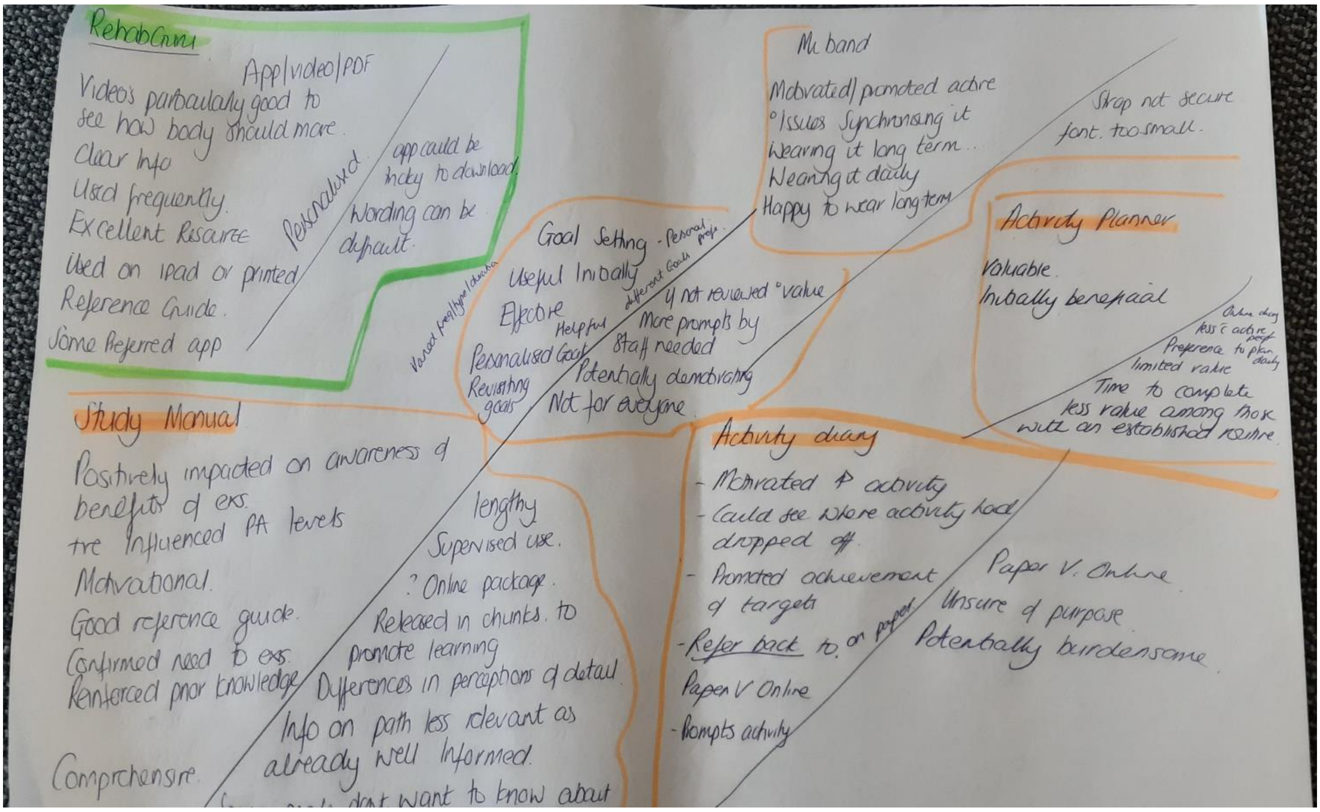
Checking In - Useful.
Could hold questions in prep.
Convient of working
Good to have opportunity to talk
Motivational.
freq was good
Support + Motivat from staff

? Rapid among v. motivated people.
? Support videos
Missed weekly routine of Intervention
? twice monthly pref
Didnt motivate
Potential value of regular/more contact

Overall Impact

Fitter
More commited
Positive exp
Shaped exs behaviour
Think about exs
Pacing
privledge
life changing
Confidence
+ve impact.
Made friends
Developed Routine
fortunate

less value of social networking



RehabCmi

App/video/PDF

Video's particularly good to see how body should move.

Clear Info

Used frequently.

Excellent Resource

Used on iPad or printed

Reference Guide.

Some Preferred app

Personalised.

app could be tricky to download.

Wording can be difficult.

Varied freq/type/duration

Goal Setting - Personal prefs.

Useful Initially

Effective

Helpful

Personalised Goals

Revisiting goals

different Goals

if not reviewed ° value

More prompts by Staff needed

Potentially demotivating

Not for everyone

Mi band

Motivated/promoted active

° Issues Synchronising it

Wearing it long term..

Wearing it daily

Happy to wear long-term

Strap not secure

font. too small.

Activity Planner

Valuable.

Initially beneficial

Online diary less c active peop

Preference to plan daily

limited value

Time to complete

less value among those with an established routine.

Study Manual

Positively impacted on awareness of benefits of exs.

+ve Influenced PA levels

Motivational.

Good reference guide.

Confirmed need to exs.

Reinforced prior knowledge

Comprehensive.

lengthy

Supervised use.

? Online package.

Released in chunks. to promote learning

Differences in perceptions of detail.

Info on path less relevant as already well Informed.

dont want to know about

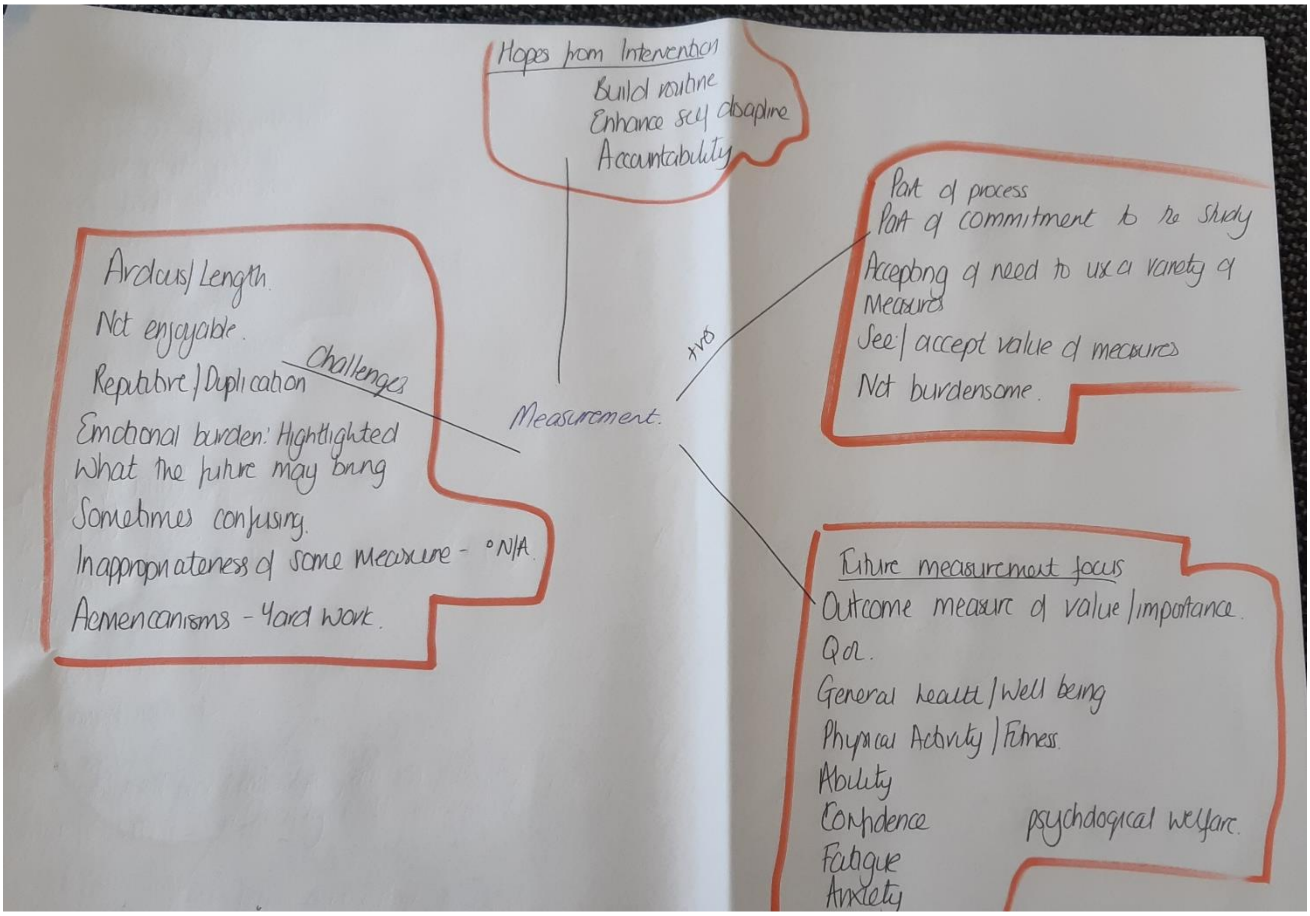
Activity diary

- Motivated ↑ activity
- Could see where activity had dropped off.
- Promoted achievement of targets
- Refer back to. on paper
- Paper V Online
- Prompts activity

Paper V. Online

Unsure of purpose

Potentially burdensome.



Hopes from Intervention

Build routine

Enhance self discipline

Accountability

Challenges

Arduous/Length.

Not enjoyable.

Repetitive/Duplication

Emotional burden: Highlighted What the future may bring

Sometimes confusing.

Inappropriateness of some measure - ° N/A.

Americanisms - Yard work.

Measurement.

+ve

Part of process

Part of commitment to the Study

Accepting of need to use a variety of Measures

See/accept value of measures

Not burdensome.

Future measurement focus

Outcome measure of value/importance.

QoL.

General health/Well being

Physical Activity/Fitness.

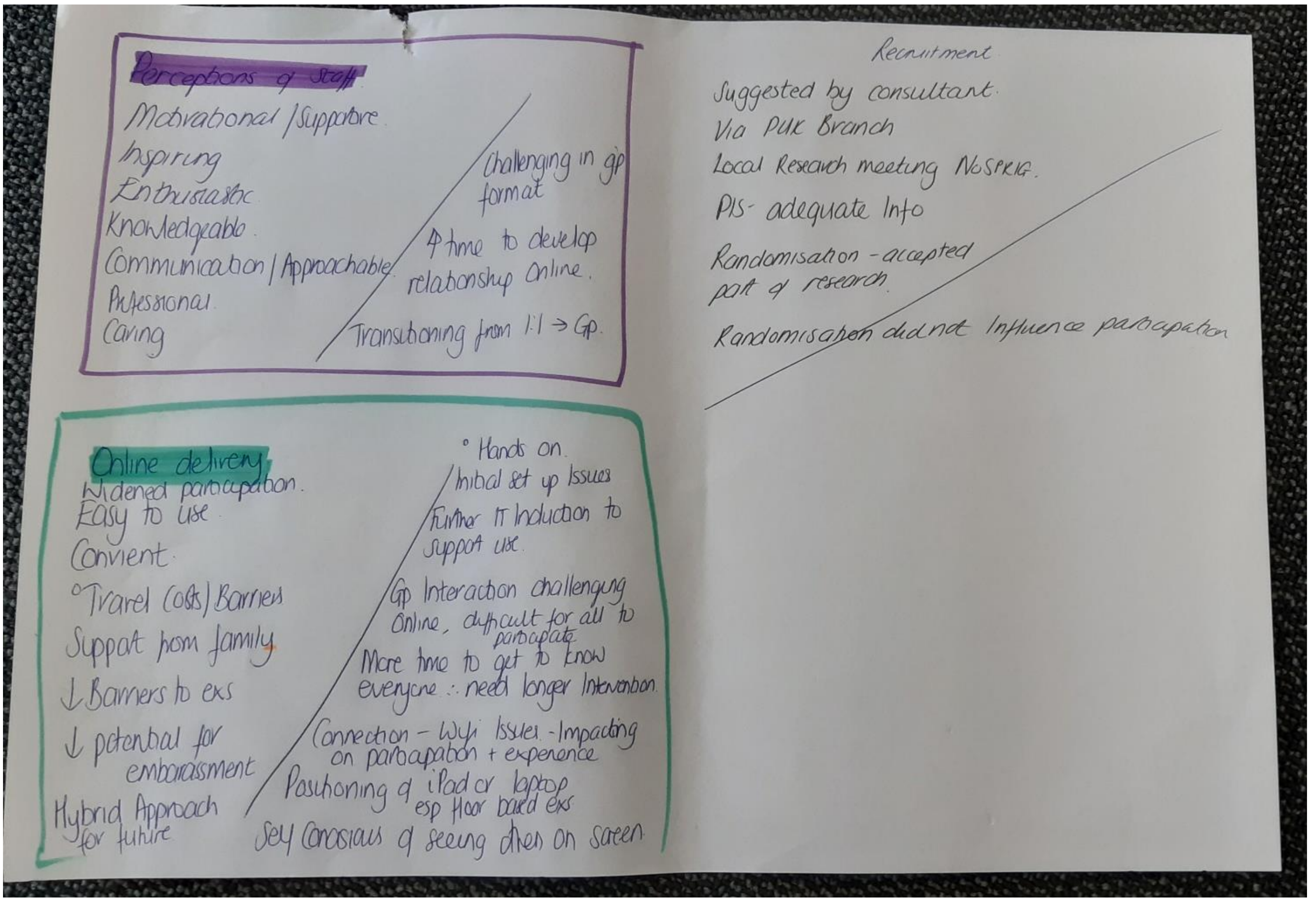
Ability

Confidence

psychological welfare.

Fatigue

Anxiety



Perceptions of staff

Motivational / Supportive.
Inspiring
Enthusiastic
Knowledgeable.
Communication / Approachable.
Professional.
Caring

Challenging in gp format
↑ time to develop relationship Online.
Transitioning from 1:1 → Gp.

Online delivery

Widened participation.
Easy to use.
Convient.
° Travel (costs) Barriers
Support from family
↓ Barriers to exs
↓ potential for embarassment
Hybrid Approach for future

° Hands on.
Initial set up Issues
Further IT Induction to support use.
Gp Interaction challenging Online, difficult for all to participate
More time to get to know everyone ∴ need longer Intervention.
Connection – Wifi Issues – Impacting on participation + experience
Positioning of iPad or laptop esp floor based exs
Self Conscious of seeing others on screen.

Recruitment

Suggested by consultant.
Via PUK Branch
Local Research meeting NoSPRIG.
PIS - adequate Info
Randomisation – accepted part of research.

Randomisation did not Influence participation