

Co-designing the inflammatory arthritis self-management (aiM) intervention.

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2023

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CO-DESIGNING THE INFLAMMATORY ARTHRITIS SELF-MANAGEMENT (aiM) INTERVENTION

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DPT

2023

Co-designing the inflAmmatory arthrItis
self-Management (aiM) Intervention

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ABSTRACT

Background

Self-management is an integral part of care for people living with inflammatory arthritis. The benefits of self-management interventions for people living with long-term conditions are well established. To date, most of the inflammatory arthritis self-management interventions have only targeted rheumatoid arthritis. Therefore, there is a need for a self-management intervention that reaches beyond just people living with rheumatoid arthritis. The overarching aim of this project was to co-design a self-management intervention for people across the inflammatory arthritis spectrum that is based on co-designer (i.e., people living with IA and healthcare professional) needs and preferences as well as the scientific literature.

Methods

This project commenced with a mixed-method systematic review exploring the effectiveness and acceptability of existing inflammatory arthritis self-management interventions. Then, a two phase, sequential multi-methods approach was employed. The first phase undertook five asynchronous co-design workshops, which was guided by the Intervention Mapping Framework (Bartholomew et al. 2016). The second phase then explored participants' experience in participating in co-design research, including the barriers and facilitators to co-design.

Findings

The mixed-method systematic review demonstrated that inflammatory arthritis self-management interventions produced a clinically meaningful reduction in fatigue and pain in people living with inflammatory arthritis. There was also some data to suggest that inflammatory arthritis self-management interventions have a beneficial effect on self-efficacy; knowledge; communication; health-related quality of life; and engagement with self-management behaviours. Additionally, the review found that inflammatory arthritis self-management interventions are generally acceptable to people living with inflammatory arthritis and healthcare professionals. Workshop findings provided important insight into the health problems and self-management needs of people living with inflammatory arthritis. The workshops also helped to identify the key content and features of the developed self-management intervention (i.e., the

inflAmmatory arthrItis self-Management (aiM) intervention). Participants reported having an overall positive experience participating in the workshops, which provided them with an opportunity to meet others living with IA. The use of asynchronous workshops was attributed to the participants' high attendance rate and the study's low attrition, despite IT-issues that were reported as a barrier to the participants' ability to fully participate in the workshops.

Conclusions

This project developed a novel self-management intervention, which aims to improve the health status of people living with inflammatory arthritis through increased engagement with self-management strategies. The aiM intervention is based on the needs and preferences of the co-designers and is grounded in theory and evidence. The findings have also provided new knowledge regarding the health problems related to people living with inflammatory arthritis; their self-management needs; and mechanisms that facilitate and inhibit co-design processes in an asynchronous remote context. Moving forward, it is recommended that the aiM intervention be tested for its feasibility and acceptability.

Keywords: Inflammatory arthritis, Self-management, Self-management intervention, Intervention development, Co-design, and Intervention Mapping

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EXTERNAL OUTPUTS

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ABBREVIATIONS/ACRONYMS

aiM: inflAMmatory arthrItis self-Management intervention

AILP: Active and Independent Living Programme

ADL: Activities of Daily Living AS: Ankylosing Spondylitis

ASQoL: Ankylosing Spondylitis Quality of Life

ASA-A: Appraisal of Self-Care Agency Scale

AIMS-2: Arthritis Impact Measurement Scales 2

ASES: Arthritis Self-Efficacy Scale

ASAS: Assessment of Spondyloarthritis International Society

axSpA: Axial Spondyloarthropathies

BASFI: Bath Ankylosing Spondylitis Functional Index

BAS-G: Bath Ankylosing Spondylitis Patient Global Score
Biologics: Biologic Disease Modifying Anti-Rheumatic Drugs

BMI: Body Mass Index

BRAF-MDQ: Bristol Rheumatoid Arthritis Fatigue Multidimensional Questionnaire

BRAF-NRS: Bristol Rheumatoid Arthritis Fatigue Numerical Rating Scales

EThOS: British Library for E-Theses Online Service

CVD: Cardiovascular Disease

CDC: Center for Disease Control and Prevention

CIS: Checklist of Individual Strength

CBT: Cognitive Behavioural Therapy

CrIs: Credible Intervals

DASH: Disabilities of the Arm, Shoulder, and Hand Questionnaire

DAS: Disease Activity Score

DMARD: Disease Modifying Anti-Rheumatic Drugs

EULAR: European Alliance of Associations for Rheumatology

EULAR: European Alliance of Associations for Rheumatology

Euro QoL: European Quality of Life

GDPR: General Data Protection Regulations

FFbH: Hannover Functional Ability Questionnaire

ALLIANCE: Health and Social Care Alliance Scotland

HAQ: Health Assessment Questionnaire

HRQoL: Health-Related Quality of Life

HCP: Healthcare Professionals

HDI: Human Development Index

HLA-B27: Human Leukocyte Antigen B27

IRGL: Impact of Rheumatic Diseases on General Health and Lifestyle

IA: Inflammatory Arthritis

IBD: Inflammatory Bowel Disease

IASP: International Association for the Study of Pain

ISRCTN: International Standard Randomised Controlled Trials Number

IM: Intervention Mapping

JBQ-QARI: Joanna Briggs Institute Qualitative Assessment and Review Instrument

JBQ: Joanna Briggs Institute

D-JPBA-S: Joint Protection Behaviour Assessment

JP-SES: Joint Protection Self-Efficacy Scale

MAQ: Medication Adherence Questionnaire

MCID: Minimal Clinically Important Differences

MMAT: Mixed Methods Appraisal Tool

MMSR: Mixed Methods Systematic Review

mHAQ: Modified HAQ

MDT: Multidisciplinary Team

NICE: National Institute for Health and Care Excellence

NIHR: National Institute for Health Research

NRAS: National Rheumatoid Arthritis Society

nr-axSpA: Non-Radiographic Axial Spondyloarthritis

NSAID: Nonsteroidal Anti-Inflammatory Drugs

OT: Occupational Therapists

PIS: Participant Information Sheet

PAM: Patient Activation Measure

PGI: Patient Generated Index

PKQ: Patient Knowledge Questionnaire

PLwIA: People Living with Inflammatory Arthritis

pSpA: Peripheral Spondyloarthropathies

PRISMA: Preferred Reporting Items for Systematic Reviews and Meta- Analyses

PsA: Psoriatic Arthritis

QoL: Quality of Life

RCT: Randomised Controlled Trials

RA: Rheumatoid Arthritis

RAID: Rheumatoid Arthritis Impact of Disease

RAQoL: Rheumatoid Arthritis Quality of Life

RASE: Rheumatoid Arthritis Self-Efficacy Scale

RASQ: Rheumatoid Arthritis Symptom Questionnaire

RGU: Robert Gordon University

SDM: Shared Decision-Making

SE: Self-Efficacy

SMAS: Self-Management Ability Scale

SMILE-RA: Self-Management Individualised Learning Environment for Rheumatoid Arthritis

SMI: Self-Management Intervention

SF: Short Form Survey

SpA: Spondyloarthropathies

TIDieR: Template for Intervention Description and Replication

T2T: Treat-To-Target

uSpA: Undifferentiated Spondyloarthritis

UK: United Kingdom

VAS: Visual Analog Scale

WHO: World Health Organisation

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1 INTRODUCTION

1.1 INTRODUCTION TO THE CHAPTER

The purpose of this project is to develop recommendations for a self-management intervention (SMI) for people living with inflammatory arthritis (PLwIA). This initial chapter begins by introducing and providing background information on inflammatory arthritis (IA). An overview of the clinical management with a focus on self-management is then provided. Next, the policy context for self-management support and the value of co-production in the development of self-management services is presented. The chapter concludes with delineating the research questions, aims, and objectives.

1.2 INFLAMMATORY ARTHRITIS

IA is a group of systemic diseases that are characterised by inflammation in the body's joints and other organ systems. IA has a self-perpetuating nature and is propagated through maladaptive activity of the immune system and inflammatory pathway (Scott, Galloway and Scott 2015). The pathogenesis of IA is not completely understood; however, these diseases are thought to arise from a complex interplay of genetic, environmental, and lifestyle factors (Scott, Galloway and Scott 2015; Deane and Holers 2021; McInnes et al. 2022). There are several types of IA conditions, however the focus of this research is on rheumatoid arthritis (RA) and spondyloarthropathies (SpA) as these are prevalent IA conditions that frequently share common health problems. The following sub-sections provide an overview of RA and SpA in relation to their epidemiology and subgroups.

1.2.1 Rheumatoid Arthritis

RA is an erosive autoimmune condition in which the immune system attacks the joints of the body (Aletaha and Smolen 2018). The hallmark feature of RA is synovitis (inflammation of the synovium) in at least 1 joint (Scott, Galloway and Scott 2015). RA commonly presents with symmetrical inflammation in the peripheral joints, particularly the wrists; proximal interphalangeal and metacarpophalangeal joints of the hand; and the metatarsophalangeal joints of

the feet. However, it can also affect the elbow, shoulder, hip, knee, and ankle (Aletaha and Smolen 2018). Synovitis restricts joint movement and contributes to pain, disability, and early morning stiffness (Hochberg et al. 2018); these symptoms will be discussed in greater detail in section 1.3 below. If left untreated, synovitis can eventually lead to degradation of the synovium; surrounding connective and musculoskeletal tissue; and bone in these joints (Figure 1.1) (Versus Arthritis 2022c).

RA is the most common form of IA (Versus Arthritis 2022c). It is estimated that RA affects approximately 37,000 adults living in Scotland, which is equivalent to 0.6% of the Scottish population (Versus Arthritis 2022c). A recent systematic review estimated the global prevalence of RA to be 0.46%, with the highest prevalence in North America (0.70%) followed by Europe at (0.54%) (Almutairi et al. 2021). RA affects twice as many women as men (Angum et al. 2020) developing at any age (Versus Arthritis 2022c), but mostly between the ages of 30 and 60 (Angum et al. 2020).

People living with RA are divided into two clinical subgroups: seropositive and seronegative. These groups are characterised by the presence or absence of the rheumatoid factor antibody and the anti-cyclic citrullinated peptide (Butler 2020). These autoantibodies, associated with seropositive RA, have been shown to induce inflammation by directing the immune system towards healthy body tissue rather than foreign substances (Deane and Holers 2021) resulting in a more severe disease course for those living with seropositive RA when compared to people living with seronegative RA (Balbir-Gurman et al. 2016; Bugatti et al. 2018; Van Hoovels et al. 2022). Findings from a recent cross-sectional study of 114 people living with RA suggest that seronegative RA is associated with less joint damage; a later disease onset; and require fewer disease-modifying antirheumatic drugs (DMARD) (Carbonell-Bobadilla et al. 2022). Currently, the prevalence of seropositive and seronegative RA is unknown; however, cohort studies conducted in the United Kingdom (UK) and internationally have estimated a higher incidence of seropositive RA than seronegative RA (Coffey et al. 2019; Myasoedova et al. 2019; Soussi et al. 2021).

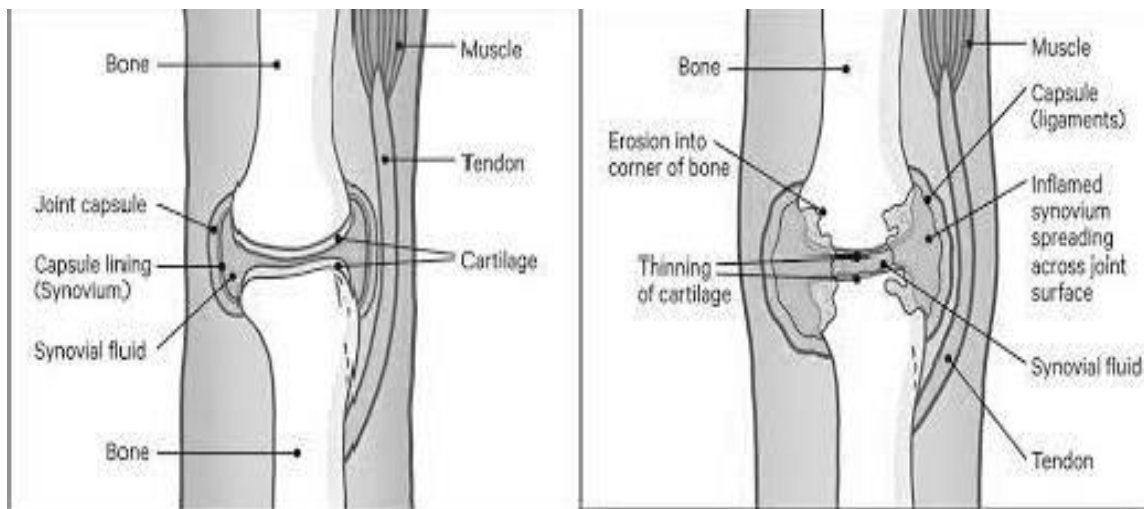


Figure 1.1 A Healthy Synovial Joint (Left) and Joint with RA (Right)
(Source: Versus Arthritis 2022c)

1.2.2 Spondyloarthropathies

SpA is a term describing a group of seronegative disorders that have similar genetic and clinical features (Scott, Galloway and Scott 2015). Figure 1.2 illustrates the conditions included within the spondyloarthropathy family. They all have a strong association with the human leukocyte antigen B27 (HLA-B27) gene (Scott, Galloway and Scott 2015). A systematic review and meta-regression analysis found that the global prevalence of SpA ranged from 0.2% in South-East Asia to 1.6% in Northern Arctic communities (Stolwijk et al. 2016). Again, higher prevalence rates were reported in North America (1.35%) and Europe (0.54%) (Stolwijk et al. 2016).

SpA conditions are characterised by inflammation in the spine, sacroiliac (SI) joints, peripheral joints, and the entheses (the site where tendon, ligament, fascia, or capsule attach to bone) (Poddubnyy 2020). Depending on the areas of the body most affected, SpA conditions are classified as either axial or peripheral (Sieper and Poddubnyy 2016). Axial spondyloarthritis (axSpA) includes people who have already developed radiographic structural damage to the sacroiliac joints (i.e., ankylosing spondylitis (AS)), and those with clinical symptoms of SpA but have not yet developed structural damage visible on radiographs (i.e., non-radiographic axial spondyloarthritis (nr-axSpA)) (National Axial

Spondyloarthritis Society 2018). Peripheral spondyloarthritis (pSpA) includes conditions that present with arthritis predominantly affecting the peripheral joints; enthesitis (inflammation of the enthesis); and/or dactylitis (swelling of the finger) (Poddubnyy 2020). Most SpA conditions will fall clearly under the axSpA or pSpA subgroups; however, some SpA conditions (e.g., enteropathic arthritis) can present in the axial and peripheral skeleton (Barkhodari et al. 2022).

Undifferentiated spondyloarthritis (uSpA) is another form of SpA that does not neatly fall into axSpA or pSpA. People living with uSpA present with signs and symptoms similar to SpA, however they do not fulfil the diagnostic criteria for any other SpA condition (Gemcioglu and Erten 2021). A systematic review and meta-analysis found that 40% of uSpA cases evolve into AS within 10 years of their diagnosis (Xia et al. 2017). There is limited data available on the prevalence of uSpA, however one systematic review has suggested that uSpA makes up about 40% of all SpA cases (Stolwijk et al. 2016).

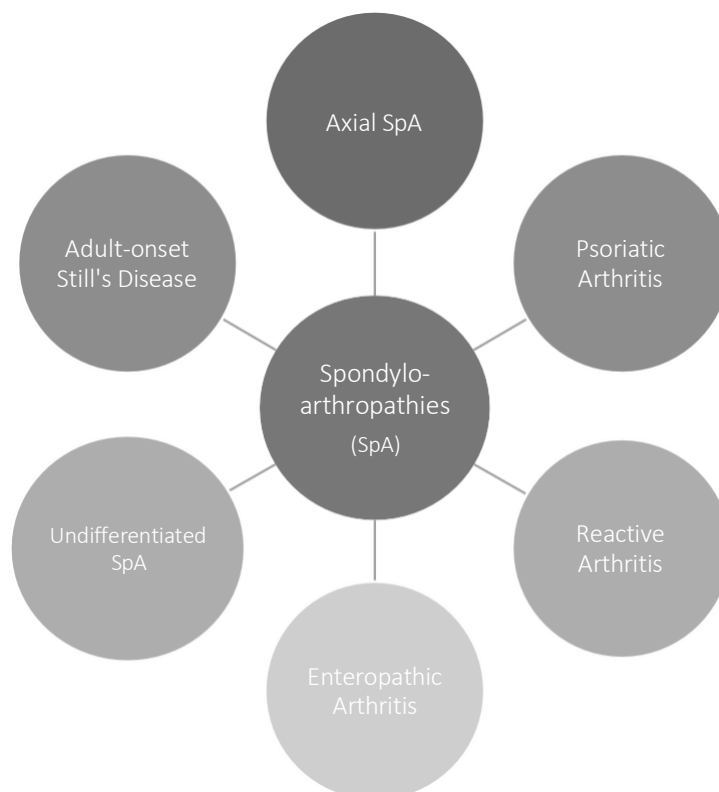


Figure 1.2 Classification of Spondyloarthropathies (Source: Gill and Rosenbaum 2021)

1.2.2.1 Axial spondyloarthropathy

Estimates suggest that the prevalence of axSpA in the UK is approximately 220,000 people (National Axial Spondyloarthritis Society 2021). The global prevalence of axSpA is unknown (Stolwijk et al. 2016). Epidemiologic studies suggest that the prevalence of AS is two to three times more common in men than in women, whereas nr-axSpA affects men and women equally (Wright, Kaine and Deodhar 2020; National Axial Spondyloarthritis Society 2021). This suggests that men are more likely to have structural damage (Wright, Kaine and Deodhar 2020). It typically develops in adolescence and early adulthood with a mean age of onset of 24 years (National Axial Spondyloarthritis Society 2021).

It is characterised by inflammation in the SI joints; intervertebral joints; facet joints; and the connective and musculoskeletal tissue surrounding these joints (Wright, Kaine and Deodhar 2020). Analogous to RA, prolonged inflammation can result in pain and disability (refer to section 1.3 for more detail) (Robinson et al. 2021). If left untreated, the inflammation can erode the bone at the entheses and cause new bone growth (i.e., osteophytes) to develop (Robinson et al. 2021; Schwartzman and Ruderman 2022). Over time, the osteophytes can cause the vertebrae to fuse together into a single unit. This phenomenon is often referred to as a 'bamboo spine' (Schwartzman and Ruderman 2022).

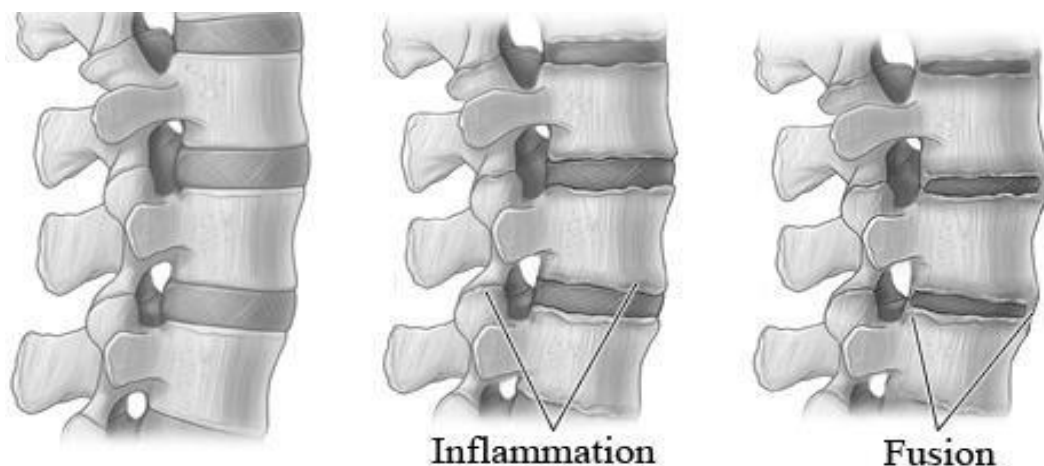


Figure 1.3 Healthy Vertebra and Facet Joints (Left) Compared Against Early axSpA (Middle) and Advanced axSpA (Right) (Modified from source: Waprani 2019)

1.2.2.2 *Peripheral spondyloarthropathies*

pSpA refers to a group of conditions that have a similar clinical presentation and genetic background. There are several forms of pSpA, including psoriatic arthritis (PsA), reactive arthritis, enteropathic arthritis, and adult-onset still's disease (Molto and Sieper 2018). These conditions have similar clinical presentations; they most commonly present with synovitis in the large peripheral joints of the lower limbs; enthesitis at the Achilles tendon, plantar insertion, and patellar tendon; and dactylitis (Molto and Sieper 2018; Carron, De Craemer and Van den Bosch 2020). The remainder of this section provides a brief introduction to each of these conditions and outlines their epidemiological characteristics.

PsA is an inflammatory arthropathy that is associated with psoriasis of the skin (Versus Arthritis 2021). PsA is the most common form of pSpA (Ogdie et al. 2013; Versus Arthritis 2021) and has been estimated to affect 0.19% of Europe's population (Stolwijk et al. 2016). However, the incidence of PsA in people living with psoriasis is approximately 24% (Alinaghi et al. 2019). Women and men are affected equally, and the condition usually develops between the ages of 25 and 50 (Passia et al. 2022; Versus Arthritis 2022a).

Reactive arthritis is an inflammatory arthropathy that occurs following an infection of the gastrointestinal and genitourinary tract (Cheeti, Chakraborty and Ramphul 2022). A systematic review estimated the prevalence of reactive arthritis in Europe ranged from 0.03% in Greece to 0.21% in Lithuania (Stolwijk et al. 2016). However, it is recognised that this data may not be entirely accurate as there is a lack of agreed-upon diagnostic criteria for reactive arthritis which can make it difficult to obtain epidemiologic data (Stolwijk et al. 2016; Misra and Gupta 2017). Reactive arthritis occurs in men more than women and most commonly develops between 20 and 40 years of age (National Institute of Arthritis and Musculoskeletal and Skin Diseases 2017).

Enteropathic arthritis is associated with inflammatory bowel disease (IBD), which is a spectrum of autoimmune disorders affecting the gastrointestinal tract. The two types of IBD associated with SpA are ulcerative colitis (Type 1) and

Crohn's disease (Type 2) (Peluso et al. 2013). Findings from a systematic review suggests that pSpA develops in approximately 17 to 62% of IBD cases (Stolwijk et al. 2016) but is more frequently reported in those living with Crohn's disease (Peluso et al. 2013; Picchianti-Diamanti et al. 2019). Women and men are affected equally and usually develops between the ages of 25 and 45 (Peluso et al. 2013).

Adult-onset Still's disease is a rare form of IA (Bhargava and Panginikkod 2022). There is limited data available on the crude prevalence and incidence of Still's disease (Feist, Mitrovic and Fautrel 2018), but the incidence in Europe is estimated to be 0.1 to 0.4 per 100,000 (Bhargava and Panginikkod 2022). Women are affected more than men. It typically develops between the ages of 15-25 and 36-46 (Feist, Mitrovic and Fautrel 2018; Bhargava and Panginikkod 2022).

This section commenced with a brief introduction to IA, RA, and SpA. Although these conditions have differences in their demographic features and patterns of disease, they share many of the same health problems (Scott, Galloway and Scott 2015; Mease et al. 2022). The following section provides an overview of their shared health problems and presents their common comorbidities.

1.3 CLINICAL FEATURES

1.3.1 Pain

Joint pain is a universal symptom of IA (Geenan et al. 2018). The International Association for the Study of Pain (2020 p.1976) define pain as: "an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage." There are four main classifications of pain: inflammatory, mechanical, chronic persistent, and combination (Lampa 2019; Trouvin and Perrot 2019). Inflammatory pain results from disease activity and inflammation within the joint and the joint's surrounding structures. Inflammation activates the pain receptors located throughout the joint and surrounding tissue and muscle (Salaffi, Giacobazzi and Di Carlo 2018; Lampa 2019). As the IA disease progresses, structural changes can occur within the joint creating mechanical pain (Lampa 2019) which is

associated with structural damage without the presence of inflammation (Trouvin and Perrot 2019). Drug therapy is generally effective in relieving inflammatory and mechanical pain symptoms (Salaffi, Giacobazzi and Di Carlo 2018). However, some people can continue to experience intense and disabling pain (Lee et al. 2011; Lampa 2019). This type of pain is known as chronic persistent pain and is attributed to abnormalities in central pain regulation pathways (Lampa 2019; Trouvin and Perrot 2019). Additionally, PLwIA can experience combination pain, which is a simultaneous or concurrent overlap of two or more of the pain types (Trouvin and Perrot 2019). The prevalence of each type of pain remains to be determined; however, pain is thought to be prevalent in nearly everyone with IA (Geenan et al. 2018; Mogard et al. 2018; Salaffi, Giacobazzi and Di Carlo 2018; Chancay, Guendsechadze and Blanco 2019).

1.3.2 Fatigue

Fatigue is a complex, multi-faceted concept (Saligan et al. 2015). There is currently not a unified definition of fatigue (Billiones et al. 2021; Skau, Sundberg and Kuhn 2021); however, fatigue related to IA has been described as a sustained and profound feeling of weariness that hinders one's ability to perform activities of daily living (ADL) that is different from normal tiredness or malaise as it can occur in the absence of physical or mental activity or illness (Phillips 2015; Primdahl et al. 2019). The crude prevalence of fatigue in PLwIA is unknown, but is thought to range between 44-61% of IA cases (Pilgaard et al. 2019; Ifesemen et al. 2022).

PLwIA have reported that fatigue is their most problematic symptom due to its unpredictable nature and fluctuations in severity (Primdahl et al. 2019; Dures et al. 2019). Interestingly, a cross-sectional survey of 633 people living with RA, PsA, and axSpA found that fatigue severity is similar across the three conditions (Pilgaard et al. 2019). Inflammation is thought to be a primary driver of fatigue in IA (Hewlett et al. 2019), however a recent longitudinal analysis of 729 people living with early RA demonstrated that fatigue severity remained relatively stable for a 3 year period despite drug therapies (Ifesemen et al. 2022). Systematic review evidence has also demonstrated that biologics only have a small to moderate improvement in fatigue (Druce et al. 2016). This suggests that

inflammation alone does not cause fatigue and that there are other drivers (Hewlett et al. 2019). Hewlett et al. (2011) posits that fatigue results from interactions between disease-related processes (e.g., inflammation, drug therapy, and pain); cognitive, emotional and behaviour factors (e.g., health beliefs, depression, and activity levels); and contextual factors (e.g., social support and environment).

1.3.3 Health-related Quality of Life

PLwIA report having a diminished health-related quality of life (HRQoL) compared to the general population (Michelsen et al. 2018; Geijer et al. 2021). Cross-sectional evidence has demonstrated that nearly 60% of people living with RA report an unsatisfactory quality of life (QoL) (Moumita et al. 2020), and 90% of people living with axSpA report that their condition has had a major impact on their QoL.

The terms “HRQoL” and “QoL” are often used interchangeably in the literature; however, it has been argued that these terms have different definitions (Karimi and Brazier 2016). Many definitions exist for QoL (Karimi and Brazier 2016), however the World Health Organisation’s (WHO) QoL definition is the most frequently accepted (Karimi and Brazier 2016). The WHO (2012) define QoL as: “an individual’s perception to their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns” (p.1). This definition suggests that QoL extends beyond a person’s health (Shah 2017). In contrast, HRQoL is defined as “the way health affects QoL” (Karimi and Brazier 2016 p.648). For the purposes of this project, the term “HRQoL” will be used throughout as this project is interested in understanding how IA affects a person’s QoL.

Standard indicators of HRQoL include physical and mental health as well as level of independence (Oude Voshaar et al. 2019). Cohort studies have reported the following factors to influence HRQoL in PLwIA: pain, fatigue, stiffness, functional disability, depression, anxiety, and socio-economic factors (e.g., age, employment, economic status, and lifestyle habits) (Gerhold et al. 2015; Geryk et al. 2015; Law et al. 2018).

1.3.4 Disability

IA is associated with mild to severe physical disability (Myasoedova et al. 2020; Carpenter et al. 2020). A recent large cohort (n=1117) comparing the prevalence of physical disability in people living with RA versus the general population found that physical disability was significantly higher in people living with RA. The prevalence of physical disability was 26% in RA and 11% in the general population (Myasoedova et al. 2020). Currently, there is no data available on the prevalence of physical disability in SpA.

Physical disability is thought to result from disease activity and structural damage (Myasoedova et al. 2020). Cohort studies have found predictors of physical disability in PLWIA to be age, sex, medications, greater baseline disability, psychosocial distress (such as depression and anxiety), disease activity, and body mass index (BMI) (Kronisch et al. 2016; Myasoedova et al. 2020). A cross-sectional study including people living with RA across 11 European countries also found that early morning stiffness can influence physical disability and HRQoL (da Silva and Buttgereit 2011).

Physical disability and fatigue are frequently reported as barriers to fulfilling work/housework/school responsibilities (Connolly et al. 2015; Chung et al. 2017). Work-related issues include absenteeism, presenteeism, and loss of employment (Nikiphorou and Ramiro et al. 2020; Rogier et al. 2021; Boonen et al. 2021). Of those working at the time of diagnosis, it is estimated that 40% of PLWIA will have to retire early (Versus Arthritis 2022c, 2022d). This places a considerable burden on the individual and wider economy (Xavier et al. 2019; Hsieh et al. 2020). Loss of employment due to disease can have devastating effects on a person's HRQoL (Xavier et al. 2019). From an economic perspective, IA work-related issues are estimated to range between £12,000-£19,000 per person per year in the UK (Cooksey et al. 2015; National Axial Spondyloarthritis Society 2022). Systematic review evidence suggests that IA places a similar economic burden in Canada, the USA, and Japan (Batko, Rolska-Wójcik and Władysiuk 2019; Yi et al. 2020).

1.3.5 Comorbidities

The co-occurrence of additional diseases, or comorbidity, is also frequently seen in PLwIA (Baillet et al. 2016; Zhao et al. 2019). The development of comorbidities is thought to be the outcome of disease activity and/or certain drug therapies (Baillet et al. 2016). Cross-sectional evidence suggests that over 60% of PLwIA have at least one comorbidity (Zhao et al. 2019). Cross-sectional evidence estimates that PLwIA are 1.5- to 2-fold more likely to develop CVD when compared to the general population (Crowson et al. 2018); have a 10% greater risk of developing a malignancy (Simon et al. 2019); 50% more likely to develop an infection (Mehta et al. 2019); 2-fold more likely to develop osteoporosis (Lee et al. 2016); and 2- to 3-fold more likely to develop depression. The European Alliance of Associations for Rheumatology (EULAR) have proposed that PLwIA also have an increased susceptibility for gastrointestinal diseases (Baillet et al. 2016), however its prevalence in occurring in PLwIA versus the general population is unknown.

This section discussed the predominate clinical features and comorbidities of IA conditions. The following section discusses the clinical management of IA.

1.4 CLINICAL MANAGEMENT

There is no cure for IA conditions. Therefore, PLwIA require lifelong treatment and management (Scottish Intercollegiate Guidelines Network 2010, 2011; National Institute for Health and Care Excellence 2017, 2020). In Scotland, IA is routinely assessed and managed by a multidisciplinary team (MDT), consisting of consultant rheumatologists, nurses, physiotherapists, occupational therapists (OT), podiatrists, and psychologists (Scottish Intercollegiate Guidelines Network 2020; Butler 2022). Management of IA can be broadly categorised into pharmacotherapy, non-pharmacological interventions, and self-management (Scottish Intercollegiate Guidelines Network 2010, 2011; National Institute for Health and Care Excellence 2017, 2020).

1.4.1 Pharmacotherapy

Early and aggressive treatment to target disease remission (absence of signs or symptoms) or minimal disease activity underpins IA pharmacotherapy (Scottish

Intercollegiate Guidelines Network 2011; National Institute for Health and Care Excellence 2020). Remission is achieved when the patient has a Disease Activity Score (DAS) of less than 2.6 (Anderson et al. 2012). National and international guidelines have endorsed the treat-to-target (T2T) approach as a key tenet of IA pharmacological treatment (Scottish Intercollegiate Guidelines Network 2011; National Institute for Health and Care Excellence 2017, 2020; Smolen et al. 2019). The T2T approach advocates that target outcomes are tailored to each individual patient and developed through a shared decision-making process. An outcome may be formulated by clinical, laboratory, radiographic, and/or patient-reported outcomes (van Vollenhoven 2019). Systematic review evidence has demonstrated that T2T is an effective approach for achieving disease remission in RA and PsA (Wailoo et al. 2017; Yu et al. 2019; Hock et al. 2021; El Miedany et al. 2022). International guidelines also recommend T2T for axSpA (van der Heijden et al. 2017; Smolen et al. 2018); these guidelines assume that T2T will slow or halt radiographic progression of axSpA despite the lack of experimental evidence for T2T in axSpA (Dougados 2020; Dures et al. 2020). This assumption is based on the evidence for T2T in PsA (Smolen et al. 2018).

Guidelines and quality standards recommend use of disease modifying anti-rheumatic drugs (DMARD), biologic DMARDs (biologics), corticosteroids, and analgesics in PLwIA (Scottish Intercollegiate Guidelines Network 2010, 2011; National Institute for Health and Care Excellence 2017, 2020). Conventional DMARDs, such as methotrexate, leflunomide, and sulfasalazine, are provided as first-line agents (National Institute for Health and Care Excellence 2017, 2020). A high-quality systematic review demonstrated that DMARDs slow or halt disease activity; improve symptoms; and reduce long-term disability compared to a placebo (Hazelwood et al. 2016). If there is a lack of response to first-line therapies, treatment is escalated with biologics (Scottish Intercollegiate Guidelines Network 2010, 2011; National Institute for Health and Care Excellence 2017, 2020). Clinical guideline recommendations do not currently recommend biologics as a first-line therapy as they often have more adverse side effects (e.g., increased risk for common and serious infections) and are not as cost-effective as conventional DMARDs (National Institute for Health and Care Excellence 2017, 2020; Benjamin, Goyal, and Lappin 2022).

Corticosteroids are a class of steroids and are used as short-term treatment (Scottish Intercollegiate Guidelines Network 2010, 2011; National Institute for Health and Care Excellence 2017, 2020). Systematic review evidence of five randomised controlled trials (RCT) has demonstrated that glucocorticoids rapidly lower disease activity when compared to a placebo or no treatment (National Institute for Health and Care Excellence 2018a). Corticosteroids are frequently provided to PLwIA at or shortly after diagnosis as DMARDs can take several weeks or months to relieve symptoms (National Institute for Health and Care Excellence 2018a). Corticosteroids are also administered to aid in managing a flare, which is a sudden exacerbation in symptoms (National Institute for Health and Care Excellence 2017).

Analgesics are sometimes prescribed alongside DMARDs to relieve symptoms of pain and stiffness (National Institute for Health and Care Excellence 2018b). Types of analgesics include, non-steroidal anti-inflammatory drugs (NSAID), paracetamol, and opioids. A systematic review of 48 RCTs exploring the clinical effectiveness of analgesics in RA highlights that NSAIDs can help to provide some pain relief. However, the review highlighted that most of the evidence on the use of NSAIDs in RA is inconsistent and of low or very low quality, and conclusions of their clinical benefit were unable to be drawn (National Institute for Health and Care Excellence 2018b). These findings are corroborated by another meta-analysis of 23 RCTs exploring the effectiveness of NSAIDs in axSpA which demonstrated that NSAIDs are more effective in controlling pain than placebo (National Institute for Health and Care Excellence 2017).

1.4.2 Non-pharmacological Interventions

National and international guidelines have also recommended the use of adjunct non-pharmacological interventions for the management of IA (Nikiphorou et al. 2021; National Institute for Health and Care Excellence 2022). These interventions are typically delivered by the wider MDT and include all non-drug treatments, particularly patient education, psychosocial, lifestyle, and behaviour-change interventions that aim to improve the self-management skills of people living with long-term conditions (Roodenrijs et al. 2021). Systematic review evidence has demonstrated that non-pharmacological interventions have beneficial effects on pain (Geenan et al. 2018), fatigue (Cramp 2019), disability

(Smolen et al. 2017), psychosocial functioning (Santos et al. 2019), and HRQoL (Marques et al. 2021). The effectiveness of specific non-pharmacological interventions on IA health outcomes is explored in greater detail in Chapter 4.

1.4.3 Self-management

Effective management of IA also requires substantial patient involvement. PLwIA are required to manage the daily physical and psychosocial implications of their condition which can require significant behavioural and lifestyle modifications (Nikiphorou et al. 2021). Management is therefore also focused on supporting self-management (Scottish Intercollegiate Guidelines Network 2010, 2011; National Institute for Health and Care Excellence 2017, 2020).

1.4.3.1 The concept of self-management

The definition of self-management is constantly evolving as the evidence base continues to grow. Consequently, this has led to considerable ambiguity regarding the concept of self-management (Van de Velde et al. 2019). This project has adopted the definition from Van de Velde et al. (2019 p.10) who define self-management as:

"(...) the intrinsically controlled ability of an active, responsible, informed, and autonomous individual to live with the medical, role, and emotional consequences of his chronic condition(s) in partnership with his social network and the healthcare providers."

This definition of self-management emphasises that a certain skill set is required by people living with long-term conditions to accurately analyse the factors which affect their health and well-being and to take appropriate action to change these factors. These factors are related to medical, role, and emotional consequences of their diagnosis, each of which require tailored management. Medical management requires them to adhere to medical advice (e.g., taking medication or performing physiotherapy exercises). Role management entails maintaining, changing, or creating new meaningful behaviours or life roles the purpose of managing their condition. Emotional management involves the patient coming to terms and coping with the psychosocial consequences of their condition (Van de Velde et al. 2019). Furthermore, this definition suggests that effective self-management is dependent on the collective strength of a person's

social support network and healthcare team as well as the person's confidence and ability to seek information and support from them.

Self-care and self-management are adjacent concepts that are often used interchangeably. For the purposes of this project, however, the two are not considered to be synonymous. Self-care is a broader concept which encompasses what each person does on an everyday basis for normal human development and function, such as brushing one's teeth or taking a shower. Comparatively, self-management is related to the tasks required of a person to manage or mitigate the effects of their diagnosis (e.g., taking medication) related to a long-term condition (Richard and Shea 2011).

1.4.3.2 Self-management support

PLwIA require training and support from health care professionals (HCPs) to effectively self-manage. HCPs can support PLwIA by implementing SMIs that help them to better understand their diagnosis and prognosis; promote peer support; and alleviate psychological distress by promoting healthy behaviour changes (Taylor et al. 2014; Van de Velde et al. 2019; Quispe et al. 2021). Systematic review evidence suggests that self-management support reduces healthcare utilisation and reduces health disparity in low socioeconomic groups (Panagioti et al. 2014; Hardman, Begg and Spelten 2020). Systematic review evidence has also suggested that IA SMIs can have short-term benefits on disability and HRQoL (Taylor et al. 2014).

1.4.4 The Scottish Context

Self-management has had a consistent focus within Scottish health policy and initiatives over the past decade. In 2008, *Gaun Yersel!* was published as Scotland's first strategy for supporting the self-management of people living with long-term conditions. It proposed a new paradigmatic approach in the health and social care system in which people living with long-term conditions were recognised as having expertise in their diagnosis and established them as leading partners in their clinical management (Scottish Government 2008). At the time, it was recognised that this new approach would require major upheavals in the health and social care systems and intersectoral collaboration

of HCPs, people living with long-term conditions, and third-sector organisations (Millar 2019). In accordance, the Scottish Government implemented the Patients Right Act in 2011 which provides the right for people to receive healthcare that enables them to develop the necessary knowledge, skills, and confidence to make informed decisions; manage their own health effectively; and live more independent lives (Scottish Government 2011). This Act now forms the basis for Scotland's person-centred care model, which underpins the modern healthcare system (Scottish Government 2019).

The Patients Right Act (2011) was further bolstered by the publication of the Health and Social Care Delivery Plan in 2016. The Health and Social Care Delivery Plan set out to provide coordinated care and improve the quality of care through an approach founded on prevention, anticipation, and self-management (Scottish Government 2016). The plan also called for reform of the HCP workforce, which led to the development of the Active and Independent Living Programme (AILP) in 2017. The AILP put an important spotlight on the role of allied HCPs in helping to meet the plan's objectives and who are regarded as having the skills necessary to deliver supported self-management services (Scottish Government 2017).

In cases where new services need to be developed, the AILP specifies that AHPs co-produce interventions alongside health and social care partners and third-sector organisations (Scottish Government 2017). Co-production is an approach to the development of services and policies where key stakeholders are actively involved in every step of the process (O'Cathain et al. 2019). Co-production methods are considered vital to meeting the needs of people living with long-term conditions and have become widely used in the development of health and social care services since the publication of the AILP (Scottish Government 2017). Co-production is discussed in depth in section 3.4.2.

Many of the Scottish self-management services formed today are developed in partnership with Health and Social Care Alliance Scotland (ALLIANCE), who are a partnership with Health and Social Care Alliance Scotland (ALLIANCE), who are a strategic partner of the Scottish Government. The ALLIANCE association administers the Self-Management Fund each year to support self-management

services. This fund grants a total of £2 million to third sector organisations to develop or reform self-management services across Scottish health boards. By 2021, the fund has granted over £20 million to 325 self-management services (Health and Social Care Alliance Scotland 2017, 2022).

At the beginning of this research project, ALLIANCE had only assisted in the development of two IA self-management support services. The first one was Joint Potential, which is a programme consisting of weekend events for young people living with arthritis to meet one another; participate in fun activities; and share experiences with one another (Versus Arthritis 2022b). The second was for an e-learning intervention called Self-Management Individualised Learning Environment for Rheumatoid Arthritis (SMILE-RA). This service was developed by the National Rheumatoid Arthritis Society (NRAS) as a patient education intervention for newly diagnosed people living with RA and their families. The purpose of SMILE-RA was to improve individuals' understanding of RA, its treatments, and teach family members how they can support their loved one (Rivzi 2021). To the authors best knowledge, these were the only self-management services to exist for PLwIA in Scotland at the time of this project. Despite these efforts, there is still a need for an IA self-management service to be developed that is inclusive to those with established disease and people living with RA. Furthermore, developing a SMI that targets multiple IA conditions, rather than disease-specific interventions, is more cost-effective given that it takes a substantial amount of time, money, and resources to develop such interventions (Bartholomew et al. 2016).

This section discussed the clinical management of IA in Scotland with particular emphasis placed on self-management. The usefulness of SMIs within health and social care then discussed. This section then explored how Scottish policies have built momentum in advancing implementation of self-management services for long term conditions but also demonstrating the lack of SMI within combined IA populations. The following section presents this project's research question, aim, and objectives.

1.5 RESEARCH QUESTION, AIM, AND OBJECTIVES

1.5.1 Research Question

This project sought to answer the following research question: *Is it possible to co-design a SMI for PLwIA?*

1.5.2 Aim

The overarching aim of this project was to co-design recommendations for an implementation manual for a SMI for PLwIA that is based on participant and HCP co-designer needs and preferences as well as the scientific and theoretical literature. It is hoped that this project will inform future rheumatology practice and co-production research in this field. Evaluation, further development, and implementation of the SMI is intended to follow on from this research.

1.5.3 Objectives

In fulfilment of the above stated question and aim, the objectives of this project were to:

1. Conduct a systematic review to identify the effectiveness and acceptability of IA SMIs.
2. Co-design a SMI alongside PLwIA and HCPs.
3. Explore participants' experience in participating in co-design research, including the barriers and facilitators to co-design.

2 EFFECTIVENESS AND ACCEPTABILITY OF SELF-MANAGEMENT INTERVENTIONS FOR PEOPLE LIVING WITH INFLAMMATORY ARTHRITIS: A MIXED METHODS SYSTEMATIC REVIEW

2.1 CHAPTER INTRODUCTION

The purpose of this mixed methods systematic review (MMSR) was to synthesise the existing evidence for SMIs for PLwIA. This review aimed to comprehensively explore and synthesise the evidence regarding the effectiveness of IA SMIs and the interventions' acceptability among PLwIA and HCPs. The search strategy and screening process resulted in 48 references (32 quantitative, 14 qualitative, and 2 mixed method) being included. Findings from the review then presented and discussed in relation to the literature. The chapter concludes with a discussion of the strengths and limitations of this review, and recommendations for clinical practice and future research.

2.2 BACKGROUND

As highlighted in Chapter 1, self-management is integral to the management of IA, and SMIs are becoming increasingly implemented in healthcare settings (Hochberg 2018). However, prior to the start of this review, there had been only one attempt to synthesise the evidence regarding IA SMIs. A mixed methods umbrella review undertaken by Taylor et al. (2014) explored the effectiveness of IA SMIs and the self-management support needs of PLwIA. The review included 10 quantitative systematic reviews comprised of 132 RCTs and 2 qualitative reviews comprised of 43 qualitative studies. The quantitative findings suggested that IA SMIs had short-term improvements on disability and psychological status. Qualitative findings from the review reported that PLwIA desired more education on the causes of pain and the disease process, however, PLwIA were reluctant to seek self-management advice from HCPs due to concerns related to 'wasting the professionals' time', 'fear that they might be advised to change their lifestyle', or 'early symptoms might not be taken seriously'. PLwIA reported being reluctant to discuss their problems with friends or family as they feared they would be judged as complaining; would be met with apathy; or their problems would not be taken seriously (Taylor et al. 2014).

The review by Taylor et al. (2014) was the first systematic review to attempt to synthesise the evidence regarding the self-management support of PLwIA. Although the review made an invaluable contribution to the IA SMI evidence base, there were a few limitations to their reported findings. Firstly, nearly all the included studies were on people living with RA except for one quantitative review exploring the effectiveness of SMIs on people living with lupus, despite incorporating people living with PsA and axSpA in the review's inclusion criteria. Thus, there is still a need to explore the effectiveness of IA SMIs in a SpA population.

Secondly, the findings may have limited applicability to modern practice given that the included studies were published between 1997-2012, and there has been rapid expansion of the self-management literature and use of SMIs over the past decade (Hochberg 2018). Therefore, there is a need to synthesise more recent evidence.

Thirdly, the review only explored the effects of the SMI on disability and HRQoL, however findings from a recent high-quality systematic review suggests that the effects of IA SMIs may reach beyond just disability and HRQoL (Hansen et al. 2022). Hansen et al. (2022) mapped 12 outcome domains with 39 subdomains to IA SMIs, with the most frequently applied outcome domains being self-management behaviour, skills, and knowledge (e.g., self-efficacy and coping); symptom status (e.g., pain and fatigue); and physical functioning/disability. Although the authors did not report on the extent that the IA SMIs were effective on these outcomes, their findings suggest that IA SMIs may produce a wide range of benefits and highlight a need to determine the effectiveness of IA SMIs on outcomes other than disability and HRQoL.

Lastly, the qualitative findings from Taylor et al. (2014) review did not provide any guidance on aspects of the intervention considered to be acceptable by PLwIA or HCPs. Sekhon, Cartwright, and Francis (2017) define acceptability as "a multi-faceted construct that reflects the extent to which people delivering or receiving a healthcare intervention consider it to be appropriate, based on anticipated or experiential cognitive and emotional responses to the

intervention” (p.8). SMIs that are not found to be acceptable to PLwIA and HCPs have an increased risk of type II error—concluding the SMI is ineffective (Sekhon et al. 2021). However, there is a gap in the literature relating to aspects of SMIs that are perceived to be acceptable to PLwIA and HCPs. Therefore, a MMSR was undertaken to explore the effectiveness and acceptability of IA SMIs; address these evidence gaps; and inform the design of the SMI developed in this project.

2.3 REVIEW QUESTIONS, AIMS, AND OBJECTIVES

The overarching aim of this MMSR was to conduct an integrated synthesis of the quantitative and qualitative evidence on SMIs for PLwIA. A comprehensive MMSR was conducted in respect to the following questions:

- (1) To what extent are SMIs for PLwIA effective?
- (2) How acceptable do PLwIA, their families, and HCPs perceive IA SMIs to be regarding the interventions ability to support the management of the patient’s condition and fit their lifestyle?

The objectives of the first review question are:

- Determine the relative effectiveness of IA SMIs.
- Explore the characteristics of participants included in the interventions.
- Explore the professional qualifications of the intervention facilitators.
- Explore the interventions characteristics and components.

The objectives of the second research question are:

- Explore the acceptability of the IA SMIs amongst PLwIA, their families, and HCPs.
- Explore the perceptions of those who participated in the intervention.
- Explore HCPs perceptions of the barriers and facilitators of delivering the interventions.

2.4 METHODOLOGY

The methodology for this review was adapted from the Joanna Briggs Institute (JBI) guidelines for a MMSR (Lizarondo et al. 2020). Other MMSR guidelines include those produced by Cochrane ([Cochrane](#)), Frantzen and Feters (2015), Heyvaert et al. (2013), and Pluye and Hong (2014). However, there is not a universally accepted method for MMSRs. The JBI method was chosen for this review as it has the most up-to-date version of guidelines and provides detailed, easy-to-follow chapters to help conduct a MMSR. There is also a JBI centre of excellence located within the School of Health Sciences at Robert Gordon University (RGU) that was accessible to the researcher and provided the opportunity for the researcher to undertake JBIs' Comprehensive Systematic Review Training Programme prior to data analysis. Furthermore, the researcher's supervisor is a JBI methodologist and trainer, who was able to provide insightful guidance throughout the review process.

2.5 METHODS

The review followed JBI's guidance for a convergent segregated MMSR (Lizarondo et al. 2020). There are two JBI MMSR typologies: convergent or sequential. Convergent designs infer that data synthesis occurs simultaneously, whereas sequential infers that data synthesis occurs consecutively (Hong et al. 2017). Within the convergent design, there is the convergent integrated and convergent segregated approach (Lizarondo et al. 2020). A description and suggestions for use for each JBI MMSR typology is provided in Table 2.1. Considering the purpose of this research is to explore separate, but equally as important, aspects of IA SMIs (i.e., effectiveness and acceptability), the JBI typology that maps closest to the research question, aims, and objectives of this review is therefore convergent segregated.

Table 2.1 JBI MMSR Typologies (Modified from source: Hong et al. 2017; Lizarondo et al. 2020)

Review Design	Description	Best for:
Convergent Integrated	Data is transformed to allow quantitative and qualitative data to be combined	• Addressing one review question • Identifying/defining main concepts using a qualitative synthesis method (e.g., thematic synthesis) • Exploring/determining relationships between the concepts • Developing a framework or theory
Convergent Segregated	Quantitative and qualitative data are synthesised separately then integrated together	• Addressing two or more complementary review questions
Sequential	Synthesis of one type of data occurs after or is informed by the synthesis of the other type of data	• Addressing one overall review question with sub-questions • Both syntheses complemented each other

The review was conducted according to an *a priori* protocol (Appendix 2.1) that outlines the review processes such as searching, inclusion and exclusion criteria, screening, data extraction, and analysis. The review protocol was registered on PROSPERO (CRD42021225944). The researcher was responsible for conducting all stages of the review. Two members of the supervisory team assisted in the review at all stages (LA and EH). Their contributions are detailed in the following subsections. Support was sought from the School of Health Sciences Research librarian for advice early in the review process and construction of the search strategies, and the chartered statistician for quantitative analysis. The review is reported in adherence to the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) (2020) statement (Page et al. 2021).

2.5.1 Inclusion Criteria

2.5.1.1 Population

This review considered studies in which male and female adults (aged 18 years or older) with a confirmed IA diagnosis, specifically RA or SpA, were included.

Participants of all ethnic origins, disease durations, and disease severities were considered. Mixed-population studies were included, if participants (1) had a diagnosis of IA; (2) made up $\geq 35\%$ of the participant group; and (3) were ≥ 18 years of age. This review excluded participants who were under the age of 18 or were diagnosed with a non-inflammatory musculoskeletal condition (e.g., osteoarthritis) due to differences in aetiology, pathophysiology, and treatment.

2.5.1.2 Intervention

This review considered any study that included a structured SMI as defined by Jonkman et al. (2016) and Lorig and Holman (2003). Jonkman (2016 p.39) defines SMIs as:

"Interventions that aim to equip patients with skills to actively participate and take responsibility in the management of their chronic condition. This includes knowledge acquisition, and a combination of at least two of the following: (1) stimulation of independent sign and/or symptom monitoring; (2) medication management; (3) enhancing problem-solving and decision-making skills for treatment or disease management; (4) or changing physical activity, dietary, and/or smoking behaviour."

The review included studies matching this definition or incorporated at least two of the following self-management skills outlined by Lorig and Holman (2003): problem-solving, decision-making, utilisation of resources, forming or enhancing patient and healthcare relationships, and taking action. Interventions that were purely exercise-based were excluded.

2.5.1.3 Phenomena of interest

Qualitative studies were included if they explored the perceptions and experiences of the effectiveness and acceptability of the SMI amongst persons living with IA, their families, and/or HCPs delivering the intervention.

2.5.1.4 Comparator

This review included quantitative studies in which the intervention was compared with no treatment or usual care.

2.5.1.5 Context

Interventions that were delivered by HCPs, lay-leaders, or a combination via any mode of delivery (e.g., face-to-face, digital, telephone, etc.) were included. Expert patients, or 'lay leaders', are members of the community living with the same or similar condition that are skilled in self-management and are trained in delivering the intervention (Cordier 2014). Only studies from nations classed as 'very high' (top 62 countries) on the United Nations Development Programme's Human Development Index (HDI) (2019) were included as these countries have comparable healthcare systems to the UK.

2.5.1.6 Outcomes

Quantitative studies that used an outcome measure that can be classified under any of the following domains were included: disease specific, self-efficacy, HRQoL, functional status or disability, psychosocial metrics, knowledge of disease, use of self-management strategies, and acceptability of the intervention.

2.5.1.7 Types of studies

Quantitative studies included RCTs as this design allows for comparison of the intervention's effects against a control group and are therefore considered the best research design for determining an intervention's effectiveness (Saunders, Lewis and Thornhill 2019). Cross-sectional study designs were also included as this design provides useful information for assessing the acceptability of the intervention's characteristics amongst recipients and facilitators.

Qualitative studies of experience and perceptions were included to provide data on the acceptability of the interventions. Qualitative designs such as interview studies, focus group studies, phenomenology, and ethnography were considered. Mixed-method studies were included if the specific data could be extracted. Systematic reviews were not included in this study as very few systematic reviews exploring the effectiveness of IA SMIs were published since Taylor et al. (2014). Moreover, the inclusion criteria for this review was thought to increase the likelihood for identifying SMIs that have targeted people living with SpA.

Only studies published in English were considered for inclusion. This is a non-funded study therefore translation of articles written in a language other than English was not possible.

2.5.2 Search Strategy

The review followed the JBI 3-step search strategy (Lizarondo et al. 2020). A search of the following databases was undertaken: CINHALL, MEDLINE, EMBASE, AMED. Initially, the databases were scanned for index terms that described the articles. A second search was then developed and conducted on the databases using the terms listed in Table 5.1 (Lizarondo et al. 2020). The search for unpublished studies and grey literature included: The Center for Disease Control and Prevention (CDC); British Library for E-Theses Online Service (EThOS); National Institute for Health and Care Excellence (NICE) Evidence; International Standard Randomised Controlled Trials Number (ISRCTN) Registry; National Institute for Health Research (NIHR); the EULAR recommendations references; and Google Scholar. When searching Google Scholar, the researcher scanned the first 15 pages or until there are no new relevant studies after 3 pages. The search terms for grey literature can be found in Table 5.2.

Searches were re-run prior to the final analysis to ensure the review was as up to date as possible. Initially, studies were limited to a start date of January 2000 as it was not until around the turn of the century that the current pharmacological treatment practice for IA, biologic response therapies, was introduced (Upchurch and Kay 2012).

Table 2.2 Database Search Strategy

Database	Search Terms
CINHAL	1. TX inflammatory arthriti* OR MH "Arthritis, Rheumatoid" OR TX rheumatoid arthriti* OR MH "Spondyloarthritis" OR TX spondyloarthriti* OR MH "Arthritis, Psoriatic" OR TX psoriatic arthriti* OR TX ankylosing spondyliti* OR TX spondyloarthropath* 2. MM "Self-Management" OR TX self-management OR MM "Self Care" OR TX self care OR TX self-management program* OR MH "Patient Education+" OR TX patient education OR TX self care education OR MH "Disease Management" OR TX disease management OR TX self-management intervention* 3. 1 AND 2
EMBASE	1. rheumatoid arthrit* OR psoriatic arthrit* OR spondyloarthriti* OR ankylosing spondylit* OR spondyloarthropath* OR inflammatory arthrit* 2. self-management OR self-management program* OR self-management intervention* 3. 1 AND 2
MEDLINE	1. MH "Arthritis, Rheumatoid" OR TX rheumatoid arthrit* OR MH "Arthritis, Psoriatic" OR TX psoriatic arthrit* OR MH "Spondylarthritis" OR TX spondyloarthriti* OR MH "Spondylitis, Ankylosing" OR TX ankylosing spondylit* OR MH "Spondyloarthropathies" OR TX spondyloarthropath* OR TX inflammatory arthrit* 2. MH "Self-Management" OR TX self-management OR TX self-management program* OR MH "Self Care" OR TX self care OR MH "Disease Management" OR TX disease management OR MH "Patient Education as Topic" OR TX patient education as topic OR TX self-management intervention* 3. 1 AND 2
AMED	1. TX rheumatoid arthrit* OR TX psoriatic arthrit* OR TX spondyloarthriti* OR TX ankylosing spondylit* OR TX spondyloarthropath* OR TX inflammatory arthrit* 2. TX self-management OR TX self-management program* OR TX self care OR TX disease management OR TX patient education OR TX self-management intervention* 3. 1 AND 2

Table 2.3 Grey Literature Search Strategy

Source	Search Terms
Center for Disease Control and Prevention	1. Arthritis self-management
British Library for E-Theses Online Service	1. Arthritis AND self-management OR patient education
National Institute for Health and Care Excellence Evidence	1. Arthritis self-management
National Institute for Health Research Journal Library	1. "Self-management"
Google Scholar	1. "self-management" OR "patient education" AND "inflammatory arthritis" 2. "self-management" OR "patient education" AND "rheumatoid arthritis" 3. "self-management" OR "patient education" AND "psoriatic arthritis" 4. "self-management" OR "patient education" AND "ankylosing spondylitis"
International Standard Randomised Controlled Trials Number Registry	1. self-management OR patient education within Condition: Rheumatoid arthritis 2. self-management OR patient education within Condition: Psoriatic arthritis 3. self-management OR patient education within Condition: Ankylosing spondylitis 4. self-management OR patient education within Condition: Spondyloarthritis
European Alliance of Associations for Rheumatology Recommendation References	1. EULAR recommendations for patient education for people with inflammatory arthritis 2. EULAR recommendations for cardiovascular disease risk management in patients with rheumatoid arthritis and other forms of inflammatory joint disorders: 2015/2016 update 3. 2010 update of the ASAS/EULAR recommendations for the management of ankylosing spondylitis 4. 2016 update of the ASAS-EULAR management recommendations for axial spondyloarthritis

	5. 2016 update of the EULAR recommendations for the management of early arthritis 6. EULAR recommendations for the role of the nurse in the management of chronic inflammatory arthritis 7. EULAR recommendations for the health professional's approach to pain management in inflammatory arthritis and osteoarthritis 8. EULAR recommendations for patient education for people with inflammatory arthritis 9. 2021 EULAR recommendations for the implementation for self-management strategies in patients with inflammatory arthritis 10. 2021 EULAR recommendations regarding lifestyle behaviours and work participation to prevent progression of rheumatic and musculoskeletal diseases 11. 2022 EULAR points to consider for remote care in rheumatic and musculoskeletal diseases 12. EULAR points to consider for the management of difficult-to-treat rheumatoid arthritis 13. EULAR Points to consider for designing, analysing, and reporting of studies with work participation as an outcome domain in patients with inflammatory arthritis

2.5.3 Study Selection

All searches were uploaded into RefWorks (ProQuest 2020) and then into Covidence systematic review software ([Veritas Health Innovation 2020](#)) where duplicates were removed. Two reviewers independently screened titles, abstracts, and full texts of relevant studies (AK and LA). Articles that appeared to meet the inclusion criteria were retrieved for their full text. Full-text articles were then independently screened again by the same reviewers against the inclusion criteria. If there were any disagreements between the reviewers at each stage, it was resolved through discussion.

2.5.4 Risk of Bias Assessment

Included studies underwent methodological quality assessment using JBI critical appraisal tools (JBI). One reviewer (AK) appraised all the studies with 10% consistency checks made by a second reviewer (LA). Although the protocol originally stated that two independent reviewers would appraise all the studies, time constraints prevented a second reviewer from being able to appraise all included studies. Another systematic review (Schalken and Rietbergen 2017) has used a similar method, in which a second reviewer selected a random sample from the included study to check for consistency.

Quantitative studies were appraised using the JBI Critical Appraisal Checklist for Randomized Controlled Trials (Tufanaru et al. 2017) and the JBI Critical Appraisal Checklist for Analytical Cross-Sectional Studies (Moola et al. 2017). Qualitative studies were appraised using the standardised critical appraisal tool on JBI SUMARI (The Joanna Briggs Institute et al. 2017), while mixed-method studies were appraised using the Mixed Methods Appraisal Tool (MMAT) v.2018 (Hong et al. 2018). The decision to use the MMAT was a deviation from protocol as it was later decided that the MMAT was better suited to appraise relevant studies rather than using a combination of assessment tools as some critical appraisal questions in the other assessment tools were deemed to be not applicable. Any disagreements that arose between the reviewers were resolved through discussion. All studies, regardless of their appraisal score, underwent data extraction and synthesis. Although the protocol specifies that authors would be contacted to request additional information or missing data relevant to critical appraisal, this was not required for the review.

2.5.5 Data Extraction

The data from included quantitative and qualitative studies was extracted concurrently. Quantitative data was extracted from the included papers using the standardised JBI Meta-Analysis of Statistics Assessment and Review Instrument and uploaded onto a Microsoft Excel spreadsheet. This spreadsheet was piloted between the reviewers prior to extraction. One reviewer extracted data (AK) with 10% consistency checks made by the two other reviewers (LA and EH). The data extracted from the quantitative and mixed-method (quantitative information only) studies included information related to the SMI,

including the country the study was conducted in; study method (i.e., RCT or cross-sectional); target population; sample size; intervention characteristics and content; type of comparison; primary and secondary outcome measures; results; and the authors conclusions. Details of the intervention's characteristics were reported using the Template for Intervention Description and Replication (TIDieR) checklist to determine the extent interventions are reported fully and accurately (Hoffmann et al. 2014).

Qualitative and mixed-method (qualitative information only) data were extracted by two independent reviewers using the standardised JBI Qualitative Assessment and Review Instrument (JBI-QARI) in JBI SUMARI (The Joanna Briggs Institute et al. 2017). Data collected included details of the country the study was conducted, study methodology (e.g., phenomenological, or ethnographic), target population, phenomena of interest, setting, culture, study methods and findings, and the authors conclusions. Reviewers then assigned a level of credibility (unequivocal, credible, or unsupported evidence) to each finding. Any disagreements that arose between reviewers were resolved through discussion. One author (Chang et al. 2014) was contacted with a request for additional HRQoL data (see section 2.7.4); however, the author did not respond.

2.5.6 Data Synthesis and Integration

This review undertook a convergent segregated approach to synthesis and integration as per the JBI methodology for MMSRs (Lizarondo et al. 2020), which entails separate quantitative and qualitative syntheses followed by integration of the individual syntheses into an overall configured analysis (Lizarondo et al. 2020). This process allowed for a greater breadth of understanding into IA SMIs' applicability to clinical practice (Stern et al. 2020). Data that was unable to be pooled in either stage was synthesised narratively (Lizarondo et al. 2020).

2.5.6.1 Quantitative synthesis

The quantitative data was extracted and transformed into pairwise-controlled effect sizes comparing mean differences between SMIs for PLwIA and the comparator group. Absolute value mean differences (post-intervention – pre-intervention) were selected to facilitate clinical interpretations. Standard

distributional assumptions were used to calculate effect size standard errors including assumed pre- to post-intervention correlations of 0.7 (Morris and DeShon 2002). Subgroup analyses were performed for the following outcomes: pain, fatigue, self-efficacy, and HRQoL. Subgroup analyses were performed for all studies using a Visual Analog Scale (VAS) for global pain; VAS for fatigue impact; the Arthritis Self-Efficacy Scale (ASES) subscales self-efficacy (SE) Pain and SE Other Symptoms; and the Short Form (SF) 36-Item Survey HRQoL domains social functioning, role physical, and emotional well-being. Quantitative data that could not be pooled into meta-analyses (due to heterogeneity) were analysed descriptively and presented as a narrative.

Most previous meta-analyses have been conducted within a frequentist framework where parameters such as the pooled effect size are estimated, and uncertainty expressed with 95% confidence intervals (i.e., the values that would not be rejected by $p < 0.05$) (Cox 2006). However, confidence intervals contain no distributional information, such that there is no direct sense by which parameter values in the middle of the interval are more probable than the ends (Cox 2006). In contrast, Bayesian frameworks combine prior beliefs regarding the most plausible values with data to provide values that can be directly interpreted as probabilities within a flexible framework. Results can therefore be interpreted intuitively, and more clinically relevant contexts can be addressed including calculating the probability that the pooled estimate exceeds thresholds such as established minimal clinically important differences (MCID). In the present meta-analysis, the Bayesian framework was implemented through three-level hierarchical models with random effects to account for variation in study mean effect and covariance of multiple outcomes reported in the same study at different time points (Fernández-Castilla et al. 2020).

Weakly informative Student-t prior and half-t priors with 3 degrees of freedom were used for intercept and variance parameters, respectively (Morris and DeShon 2002). Inferences from all analyses were performed on posterior samples generated by Hamiltonian Markov Chain Monte Carlo with Bayesian 95% and 75% credible intervals (CrIs) used for intercept and variance estimates, respectively. Interpretations were initially based on visual inspection of the posterior sample, the median value ($ES_{0.5}$: 0.5-quantile) and CrIs. MCID

value of 3.4 was used to interpret non-controlled mean differences for pain (Wolfe and Michaud 2007) and 2.4 was used for fatigue (Elera-Fitzcarrald et al. 2020). The probability that the pooled effect size exceeded the MCID was calculated and interpreted. Analyses were performed using the R wrapper package brms, which interfaced with Stan to perform sampling. Convergence of parameter estimates was obtained for all models with Gelman-Rubin R-hat values below 1.1 (Gelman 2006).

2.5.6.2 *Qualitative synthesis*

For the qualitative data, data was pooled via a meta-aggregative approach using JBI SUMARI. Meta-aggregation is a pragmatic approach to qualitative data synthesis and focuses on producing actionable results that can be used to inform clinical practice and policy (Hannes and Lockwood 2011). Findings from the included qualitative and mixed-method studies were initially extracted and then aggregated into a set of statements (i.e., categories) of at least two like findings. Categories then were consolidated into a comprehensive set of synthesised findings. Categories and synthesised findings were developed in collaboration with the supervisory team.

2.5.6.3 *Integration of quantitative and qualitative syntheses*

The findings from the individual quantitative and qualitative syntheses were then compared and culminated into an overall synthesis. This process consisted of juxtaposing the individual syntheses to determine if the findings from a single method synthesis complimented, explained, or contradicted the findings from the other synthesis. Additionally, aspects of the qualitative data that were not explored in the quantitative data were identified and vice-versa. The findings from the integration of the individual syntheses were presented as a narrative. Due to the complexities associated with the integration process, JBI MMSR guideline does not recommend assessing the certainty of the evidence (Lizarondo et al. 2022). Therefore, the GRADE and ConQual approach were inappropriate for the review.

These sections provided a rationale for the MMSR; presented the review's research questions, aims, and objectives; and the methods undertaken. The following section presents the findings from the quantitative synthesis.

2.6 RESULTS

2.6.1 Study Inclusion

The initial search identified 11,424 references. After the searches were updated on August 21, 2022, an additional 4,129 references were identified resulting in a total of 15,553 references (Appendix 2.2 and 2.3). Unfortunately, NICE discontinued their search service, and the service was unable to be used to rerun that search. The EULAR alliance also produced an additional five recommendations following the initial search whose references were later screened. Following the removal of duplicates, 14,177 records were title and abstract screened. Of these records, 190 potentially relevant publications were sought for their full-text and were evaluated against the inclusion criteria. After reviewing the 190 publications, it was decided by the review team (AK and LA) to focus on more recent publications from 2010 onwards to ensure relevance to practice and the inclusion of more up to date evidence. A total of 48 studies met the inclusion criteria and were included in this review (Figure 2.2). The top reasons for exclusion were: only the abstracts were provided (n=41), duplicate (n=33), and wrong study design (n=30). One study (Revenas et al. 2016) was excluded retrospectively at critical appraisal due to lack of participant voices within the qualitative data. Although this exclusion was a deviation from protocol, including only qualitative studies with rich data would provide a more detailed understanding of the participants' perceptions and experiences (Ames, Glenton and Lewin 2019). A detailed summary of the excluded studies is presented in Appendix 2.4.

For the purposes of the rest of this chapter, superscript referencing will be used to enhance readability while still maintaining transparency of the review's findings. The decision for this pragmatic presentation of the review findings was made in collaboration with the supervisory team. A reference list for the included studies is presented in Appendix 2.5.

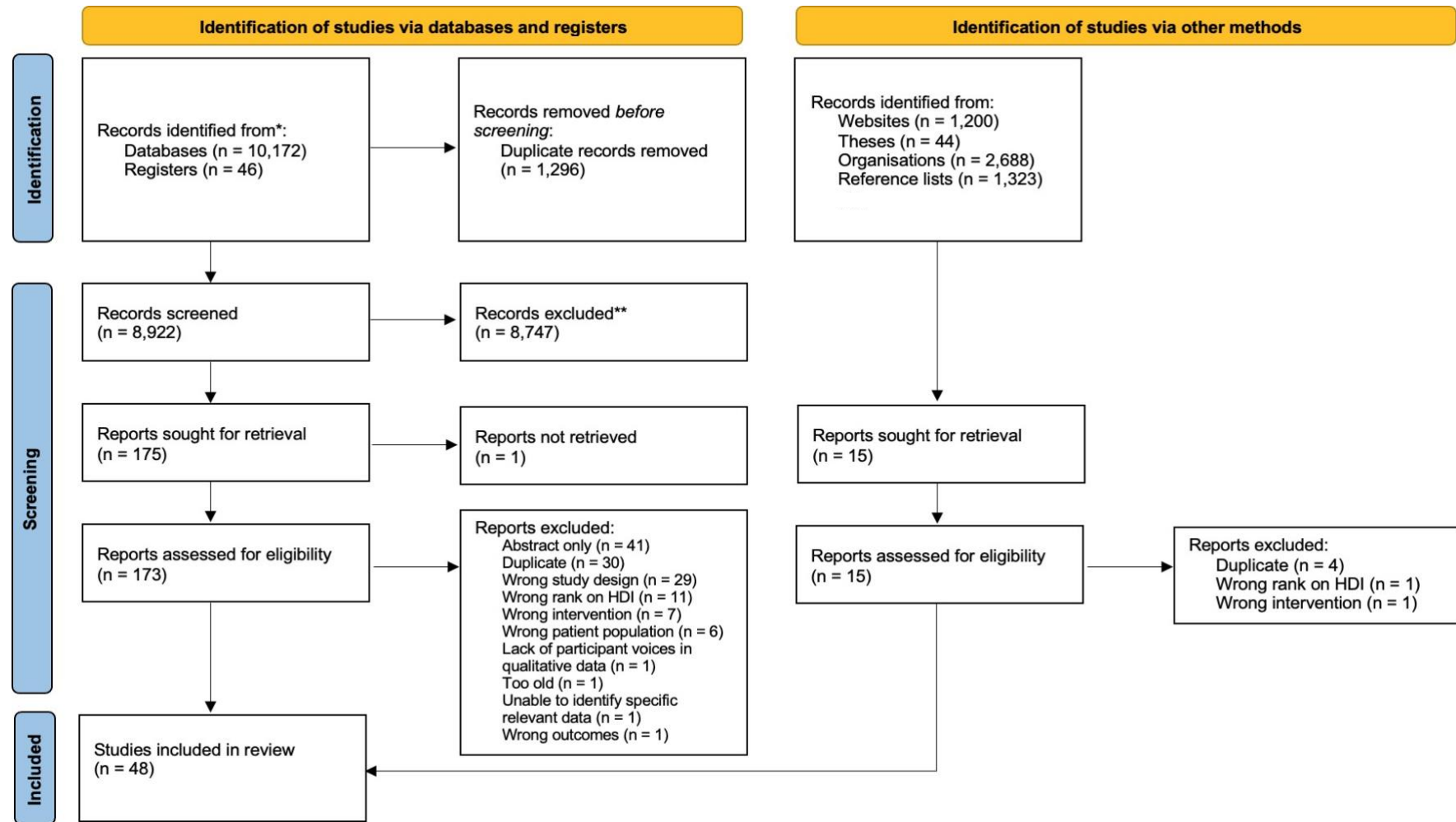


Figure 2.1 PRISMA 2020 Flow Diagram (Source: Page et al. 2021)

2.6.2 Methodology and Methods

There were 33 reports of quantitative studies included in this MMSR. Two of the quantitative studies (Chang et al. 2014; Gilbert et al. 2018), however, were merged into a single study¹¹ as one of these studies reported the methods (Chang et al. 2014) and the other the results (Gilbert et al. 2018). Therefore, a total of 32 quantitative studies^{1-3,5,7,8,10,11,13,15-19,22,23,25,26,28-30,32,33-37,41-44,46,47}, 14 qualitative studies^{4,6,9,12,14,20,21,27,31,38,39,41,45,48}, and 2 mixed-method^{4,24} studies were included in this MMSR. Several of the included quantitative^{17,22,23,29,46,47} and qualitative^{6,14,45,48} studies explored different aspects of the same interventions (Table 2.3). In these studies, the effectiveness and acceptability of these interventions were published separately.

Most of the quantitative publications were RCT trials (n=27), except for one cross-sectional study⁴¹ exploring the acceptability of an IA SMI and three longitudinal studies^{35,18,19} that were follow-up studies from an original RCT. The inclusion of these longitudinal studies was a deviation from protocol, however the data provided was thought to provide important information related to the long- term effects of IA SMIs.

Of the qualitative studies, eight were interviews^{6,7,12,20,31,38,39,48}; three were focus groups^{4,14,45}; and one study²¹ used a combination of interviews and focus groups. The remaining qualitative study²⁷ used a combination of an ethnographic study design, interviews, and focus groups. Regarding data analysis, the majority of qualitative studies^{4,6,9,12,14,24,38,39} used thematic analysis; five^{21,27,31,41,45} used content analysis; and one²⁰ used systemic text condensation.

Lastly, there were two mixed-method studies included in the review^{4,24}. One of these studies²⁴ used a combined study design consisting of an RCT and focus groups, while the other⁴ used a combination of a questionnaire and focus groups.

2.6.3 Quality Appraisal

2.6.3.1 Quantitative studies

Thirty-four studies were evaluated using the JBI Critical Appraisal Checklist for RCTs (Tufanaru et al. 2017; Table 2.4). For the longitudinal studies, the original RCT was referred to for additional information regarding the study design when needed. Due to the nature of the IA SMIs, HCPs were unable to be blinded in any of the studies as HCPs would know they were delivering the SMI. For this reason, scoring of the appraisal tool was amended and the included studies were scored out of 12 rather than 13. The included studies were of moderate to high quality, with 16 studies of moderate quality (i.e., scoring between 5-8 out of 12) and 18 of high quality (i.e., scoring ≥ 9 out of 12). Most of the studies (n=31) were unable to blind the participants during the RCT as most individuals would know whether they have received the SMI. However, two studies^{13,33} were able to achieve participant blinding by omitting information regarding the SMI on the consent form. Another study² was also able to achieve participant blinding by granting access to different sections and features of an online SMI to the intervention group while the control group was not allowed access. Quality appraisal scores were also affected in 18 studies due to not blinding outcome assessors. Many of the studies (n=23) may have also introduced bias by not concealing allocation to the treatment groups.

Table 2.4 Appraisal of Included RCT Studies¹

REFERENCE	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Q13	Score
<i>Aksoy et al. 2017</i>	N	N	Y	N	NA	N	Y	N	N	Y	Y	Y	Y	6
<i>Allam et al. 2015</i>	Y	N	Y	Y	NA	N	Y	Y	Y	Y	Y	Y	Y	10
<i>Arvidsson et al. 2012</i>	N	N	N	N	NA	N	Y	N	N	Y	Y	Y	Y	5
<i>Barsky et al. 2010</i>	Y	N	Y	N	NA	Y	Y	N	Y	Y	Y	Y	Y	9
<i>Beauvais et al. 2022</i>	Y	N	Y	N	NA	Y	Y	Y	Y	Y	Y	Y	Y	10
<i>Berdal et al. 2018</i>	Y	N	Y	Y	NA	Y	Y	Y	Y	Y	Y	Y	Y	11
<i>Breedland et al. 2011</i>	N	Y	Y	N	NA	Y	Y	Y	N	Y	N	Y	Y	8
<i>Chang et al. 2014/Gilbert et al. 2018</i>	Y	N	Y	N	NA	Y	Y	N	N	Y	Y	Y	Y	8
<i>Davis et al. 2015</i>	Y	N	U	N	NA	N	Y	Y	Y	Y	Y	Y	Y	8
<i>Feldthusen et al. 2015</i>	Y	Y	Y	N	NA	Y	Y	Y	Y	Y	Y	Y	Y	12
<i>Ferwerda et al. 2017</i>	N	N	Y	N	NA	N	Y	Y	Y	Y	Y	Y	Y	8
<i>Grønning et al. 2012</i>	Y	N	Y	N	NA	N	Y	Y	Y	Y	Y	Y	Y	9
<i>Grønning et al. 2014</i>	Y	N	Y	N	NA	N	Y	Y	NA	Y	Y	Y	Y	9

¹ Q1-Was true randomization used for assignment of participants to treatment groups?; Q2-Was allocation to treatment groups concealed?; Q3-Were treatment groups similar at the baseline?; Q4-Were participants blind to treatment assignment?; Q5-Were those delivering treatment blind to treatment assignment?; Q6-Were outcomes assessors blind to treatment assignment?; Q7-Were treatment groups treated identically other than the intervention of interest?; Q8-Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analysed?; Q9-Were participants analysed in the groups to which they were randomized?; Q10-Were outcomes measured in the same way for treatment groups?; Q11-Were outcomes measured in a reliable way?; Q12-Was appropriate statistical analysis used?; Q13-Was the trial design appropriate, and any deviations from the standard RCT design (individual randomisation, parallel groups) accounted for in the conduct and analysis of the trial?

REFERENCE	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Q13	Score
<i>Grønning, Lim and Bratås 2019</i>	Y	N	Y	N	NA	N	Y	Y	NA	Y	Y	Y	Y	6
<i>Hammond et al. 2017</i>	Y	Y	Y	N	NA	N	Y	N	Y	Y	Y	Y	Y	10
<i>Hewlett et al. 2011</i>	Y	N	Y	N	NA	Y	Y	Y	Y	Y	Y	Y	Y	5
<i>Hewlett et al. 2019</i>	Y	Y	Y	N	NA	Y	Y	Y	Y	Y	Y	Y	Y	9
<i>Kaya et al. 2016</i>	N	N	Y	N	NA	N	Y	N	N	Y	Y	Y	Y	10
<i>Kjeken et al. 2013</i>	Y	Y	Y	N	NA	Y	Y	N	N	Y	Y	Y	Y	11
<i>Lumley et al. 2014</i>	Y	Y	Y	N	NA	Y	Y	Y	Y	Y	Y	Y	Y	8
<i>Manning et al. 2014</i>	Y	N	N	N	NA	Y	Y	Y	Y	Y	Y	Y	Y	8
<i>McBain et al. 2016</i>	N	N	N	N	NA	N	Y	Y	Y	Y	Y	Y	Y	8
<i>Molto et al. 2020</i>	Y	N	Y	N	NA	N	Y	N	N	Y	Y	N	Y	12
<i>Ndosi et al. 2016</i>	Y	Y	N	Y	NA	N	Y	Y	N	Y	Y	Y	Y	8
<i>Niedermann et al. 2011</i>	Y	Y	Y	N	NA	Y	Y	N	Y	Y	Y	Y	Y	9
<i>Niedermann et al. 2012</i>	Y	Y	N	N	NA	Y	Y	Y	Y	Y	Y	Y	Y	9
<i>Nilssen et al. 2017</i>	Y	N	Y	N	NA	N	Y	Y	Y	Y	Y	Y	Y	6
<i>Pot-Vaucel et al. 2016</i>	Y	N	Y	N	NA	N	Y	Y	N	Y	Y	Y	Y	10
<i>Rodríguez-Lozano et al. 2013</i>	Y	Y	Y	N	NA	N	Y	N	N	Y	Y	Y	Y	5
<i>Sharpe and Schreiber 2012</i>	Y	Y	N	N	NA	Y	Y	N	Y	Y	Y	Y	Y	9
<i>Shigaki et al. 2013</i>	U	N	Y	N	NA	Y	Y	N	N	Y	Y	Y	Y	10
<i>Unk and Brasington 2014</i>	U	N	Y	N	NA	Y	Y	N	N	Y	Y	Y	Y	11
<i>Zangi et al. 2012</i>	Y	N	Y	N	NA	Y	Y	Y	Y	Y	Y	Y	Y	8
<i>Zuidema et al. 2019a</i>	Y	N	N	N	NA	N	Y	N	Y	Y	Y	Y	Y	8

2.6.3.2 *Qualitative studies*

Fourteen of the included studies were measured using JBI-QARI (The Joanna Briggs Institute et al. 2017; Table 2.5). These studies were of moderate to high quality, with six studies of moderate quality (i.e., scoring between 4-7 out of 10) and seven of high quality (i.e., scoring ≥ 8 out of 10). The predominant methodological risk of bias for these studies was not reporting their philosophical perspective. A potential reason for this is that these studies were submitted to applied health research journals, which have a tighter word count restriction in comparison to purely qualitative journals and recognition of philosophical perspectives is less commonly reported. Included studies also underreported on question 6 (i.e., is there a statement locating the researcher culturally or theoretically?) and question 7 (i.e., is the influence of the researcher on the research, and vice-versa, addressed?). A possible explanation for this underreporting is that these dimensions are not often reported or discussed in qualitative descriptive studies.

2.6.3.3 *Mixed method studies*

Four of the included studies were appraised using the MMAT (Hong et al. 2018; Table 2.6). Three studies were of high quality, scoring ≥ 13 out of 17. One study was of moderate quality scoring a 10 out of 17. The predominant reasons for deductions in the critical appraisal score related to poor reporting or not reporting the integration of the qualitative and quantitative findings (question 5.2); the overall interpretations derived from integrating the qualitative and quantitative findings (question 5.3); divergences and inconsistencies between the quantitative and qualitative findings (question 5.4).

Table 2.5 Methodological Quality of Qualitative Studies²

REFERENCE	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10
<i>Bain et al. 2016</i>	N	Y	Y	Y	Y	N	N	Y	Y	Y
<i>Bearne et al. 2017</i>	N	Y	Y	Y	Y	Y	Y	Y	Y	Y
<i>Berry et al. 2022</i>	N	Y	Y	Y	Y	N	N	Y	N	Y
<i>Dures et al. 2012</i>	N	Y	Y	Y	Y	N	N	Y	Y	Y
<i>Grønning, Midttun and Steinsbekk 2016</i>	N	Y	Y	Y	Y	N	Y	Y	Y	Y
<i>Hewlett et al. 2019</i>	N	Y	Y	Y	Y	N	N	Y	Y	Y
<i>Kristiansen and Antoft 2016</i>	N	Y	Y	Y	Y	Y	N	Y	Y	Y
<i>Prior et al. 2015</i>	N	Y	Y	Y	Y	N	N	Y	Y	Y
<i>Prior et al. 2017</i>	N	Y	Y	Y	Y	Y	N	Y	Y	Y
<i>Salmon 2016</i>	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
<i>Zangi et al. 2011</i>	N	Y	Y	Y	Y	Y	N	Y	Y	Y
<i>Zuidema et al. 2019</i>	N	Y	Y	Y	Y	N	N	Y	Y	Y
<i>Total</i>	1	12	12	12	12	5	3	12	11	12

² Q1-Is there congruity between the stated philosophical perspective and the research methodology?; Q2-Is there congruity between the research methodology and the research question or objectives?; Q3-Is there congruity between the research methodology and the methods used to collect data; Q4-Is there congruity between the research methodology and the representation and analysis of data?; Q5-Is there congruity between the research methodology and the interpretation of results; Q6-Is there a statement locating the researcher culturally or theoretically?; Q7-Is the influence of the researcher on the research, and vice-versa, addressed?; Q8-Are participants, and their voices, adequately represented? Q9-Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?; Q10-Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?

Table 2.6 Methodological Quality of Mixed Methods³

Reference	Screening		Qualitative					Quantitative Non-Randomised Studies					Quantitative Descriptive					Mixed Methods				
	S1	S2	1.1	1.2	1.3	1.4	1.5	3.1	3.2	3.3	3.4	3.5	4.1	4.2	4.3	4.4	4.5	5.1	5.2	5.3	5.4	5.5
Bain et al. 2016	Y	Y	Y	Y	Y	Y	Y	NA	NA	NA	NA	NA	Y	Y	Y	Y	Y	Y	N	N	U	Y
Cramp et al. 2020	Y	Y	Y	Y	Y	Y	Y	NA	NA	NA	NA	NA	Y	Y	Y	N	Y	Y	U	N	N	Y
Haglund et al. 2015	Y	Y	Y	Y	Y	N	Y	NA	NA	NA	NA	NA	Y	Y	Y	N	Y	Y	Y	U	U	Y
Mollard and Michaud 2018	Y	Y	Y	Y	Y	Y	Y	Y	Y	U	N	U	NA	NA	NA	NA	NA	N	N	N	N	Y
Total	4	4	4	4	4	3	4	1	1	0	0	0	3	3	3	1	1	3	1	0	0	4

³ S1- Are there clear research questions?; S2- Do the collected data allow to address the research questions?; 1.1- Is the qualitative approach appropriate to answer the research question?; 1.2- Are the qualitative data collection methods adequate to address the research question?; 1.3- Are the findings adequately derived from the data?; 1.4- Is the interpretation of results sufficiently substantiated by data?; 1.5- Is there coherence between qualitative data sources, collection, analysis and interpretation?; 3.1-Are participants representative of the target population?; 3.2-Are measurements appropriate regarding both the outcome and intervention (or exposure)?; 3.3-Are there complete outcome data?; 3.4-Are the confounders accounted for in the design and analysis?; 3.5-During the study period, is the intervention administered (or exposure occurred) as intended?; 4.1-Is the sampling strategy relevant to address the research question?; 4.2-Is the sample representative of the target population?; 4.3-Are the measurements appropriate?; 4.4-Is the risk of nonresponse bias low?; 4.5-Is the statistical analysis appropriate to answer the research question?; 5.1-Is there an adequate rationale for using a mixed methods design to address the research question?; 5.2-Are the different components of the study effectively integrated to answer the research question?; 5.3-Are the outputs of the integration of qualitative and quantitative components adequately interpreted?; 5.4-Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?; 5.5-Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?

2.6.4 Study Characteristics

Characteristics of the included publications are shown in the Tables 2.7-2.8. Publications are separated by study design and organised alphabetically by first author. A narrative summary of the included study characteristics are provided in the following sub-sections.

2.6.4.1 Study origin

Twelve of the included studies were conducted in the UK^{6,9,12,22-24,29,30,33,38,39,41}; nine in Norway^{8,17-20,26,36,45,46}; eight in the USA^{5,11,13,14,28,31,43,44}; four in the Netherlands^{10,16,47,48}; three in France^{7,32,37}; three in Switzerland^{2,34,35}; three in Sweden^{3,15,21}; two in Turkey^{1,25}; one in Australia⁴²; one in Canada⁴; one in Denmark¹; and one in Spain¹.

2.6.4.2 Study population

This review included a total of 5589 PLwIA and HCPs (i.e., 5555 PLwIA and 34 HCPs, respectively). Most of the papers targeted only RA (n=25). Five publications targeted only SpA; of these publications, four studies targeted people living with AS, and one targeted people living with axial SpA. The remaining publications (n=18) included a range of IA conditions. A higher percentage of females were reported in most of the included studies (n=42), except for studies targeting SpA in which a higher percentage of men were reported (n=6). This finding is largely reflective of the gender differences associated with different IA conditions. Interestingly, one study² targeting RA had a higher percent of men. The mean age of participants ranged from 27.1²⁷ to 69.3². Most of the studies included in this review (n=39) did not report on the ethnicity of their included participants; however, a large majority of participants reported White/Caucasian in the studies who had reported on ethnicity. A detailed account of the participant characteristics can be found in Appendix 2.6.

Table 2.7 Characteristics of Included RCT Studies

Author	Participants				Control Group	Intervention	Outcomes*	Assessment Times	Findings
	Population	Gender (% F)	Age ($\mu \pm SD$)	Ethnicity (%)					
Aksoy et al. 2017	AS (n=41)	IG: 25% CG: 19%	IG: 37.9 $\pm$ 9.8 CG: 37.4 $\pm$ 11.1	NR	Usual care	Education focusing on AS, anatomy and physiology, exercises, treatment, lifestyle advice, and social support Duration: 5 days	Disability: BASFI & SF-36 role physical; HRQoL: ASQoL and SF-36 General Health; Pain: SF-36 bodily pain; Fatigue: SF-Vitality	Baseline and 3 months follow-up	All findings were NS at all time points
Allam et al. 2015	RA (n=157)	I: 43% SS: 10% G: 14% SS+G: 46% CG: 18%	I: 55.1 $\pm$ 10.5 SS: 53.2 $\pm$ 13.3 G: 54.5 $\pm$ 12.0 SS+G: 53.5 $\pm$ 9.9 CG: 69.3 $\pm$ 6.4	NR	Access to website	Social support and education covering IA, HCP collaboration, coping methods, patient testimonies, and chat forum Duration: 2 months	Knowledge: PKQ	Baseline, post-intervention, and 2- and 4-months follow-up	All findings were NS at all time points
Arvidsson et al. 2012	IA (n=120)	IG: 71% CG: 73%	IG: 56.4 $\pm$ 7.2 CG: 55.2 $\pm$ 13.2	NR	Usual care	Problem-based and goal-setting intervention in which facilitators taught PLwIA how to search for learning materials. It also included a Q&A session with a physician or physio. Duration: 1 year	Engagement with self-management: ASA-A; HRQoL: SF-36; Pain: VAS; Fatigue: VAS	Baseline, and 1 Week, and 6 months follow-up	All findings were NS at all time points
Barsky et al. 2010	RA (n=168)	CBT: 90% RR: 82% AE: 87%	CBT: 54.3 $\pm$ 13.1 RR: 54.0 $\pm$ 12.3 AE: 51.9 $\pm$ 13.4	White CBT: 85% RR: 75% AE: 77% Black CBT: 9% RR: 14% AE: 16% Other CBT: 6% RR: 11% AE: 7%	AE	Two treatment conditions: CBT and relaxation response skills training Duration: 8-12 weeks + 12 months of telephone booster calls	Pain: RASQ; Disability: AIMS2	Baseline, post-intervention, and 6- and 12-months follow-up	All findings were NS at all time points

Author	Participants				Control Group	Intervention	Outcomes*	Assessment Times	Findings
	Population	Gender (% F)	Age ($\mu \pm SD$)	Ethnicity (%)					
Berdal et al. 2018	RA and SpA (n=389)	IG: 75.8% CG: 65.1%	IG: 58 CG: 57 (SD NR)	NR	Usual care	Usual care + CBT self-management booklet, goal setting, and telephone follow-up support Duration: time spent in rehab (average 5 days) + 5 months post discharge	Self-efficacy: ASES; HRQoL: PGI and SF-36 PCS & MCS; Pain: VAS; Fatigue: VAS	Baseline, discharge, and 6- and 12-months follow-up	Significant improvements in HRQoL (PGI) at discharge (p=0.03)
Breedland et al. 2011	RA (n=34)	IG: 63% CG: 80%	IG: 45 $\pm$ 11.9 CG: 51.8 $\pm$ 9.4	NR	Waiting list	Education covering pain, fatigue, sleeping disorders, limited functional ability, and psychological distress Duration: 8 weeks	Self-efficacy: ASES; HRQoL: AIMS2	Baseline, post-intervention, and 13-weeks follow-up	Both outcomes were NS at all time points
Beauvais et al. 2022	RA, axSpA, and pSpA (n=129)	IG: 64% CG: 63%	IG: 48.6 $\pm$ 12.6 CG: 45.4 $\pm$ 13.0	NR	Usual care	Education on safety skills and self-injection. The intervention contained information related to medications, communication with HCPs, and signs of adverse side effects. Duration: 3 months	Coping: VAS subscale from RAID; Well-being: VAS subscale RAID	Baseline and post-intervention	Significant improvements in coping (p=.0275)
Chang et al. 2014/Gilbert et al. 2018	RA (n=185)	All participants: 84%	All participants: 54.8 $\pm$ 13.7	NR	Physician counselling	Usual care + physical activity counselling and motivational interviewing Duration: 2 years	Disability: HAQ; HRQoL: SF-36	Baseline, 3, 6, 12, 18, and 24 months	Significant improvements seen for overall SF-36 mental component (p=.02)
Davis et al. 2015	RA (n=143)	All participants: 68.5%	All participants: 54.3 $\pm$ 13.8	All participants: 85% Caucasian	Arthritis education	Two treatment conditions: (1) CBT training in cognitive reappraisal, relaxation, and activity pacing and (2) mindfulness training Duration: 8 weeks	Pain: VAS; Fatigue: VAS; Disability: VAS	Baseline and post-intervention	Significant improvements (p<.0001) in pain, disability, and fatigue in all groups

Author	Participants				Control Group	Intervention	Outcomes*	Assessment Times	Findings
	Population	Gender (% F)	Age ($\mu \pm$ SD)	Ethnicity (%)					
Feldthusen et al. 2015	RA (n=70)	IG: 88.9% CG: 88.2%	IG: 54.2 $\pm$ 8.5 CG: 52.7 $\pm$ 10.9	NR	Usual care	Exercise intervention consisting of goal setting, exercise, and lifestyle advice Duration: 12 weeks	Self-efficacy: ASES; Fatigue: VAS and BRAF-MDQ; Pain: VAS; HRQoL: Euro QoL	Baseline, post-intervention, and 6 months	Significant improvements in general fatigue post-intervention (p=.042) for VAS outcome
Ferwerda et al. 2017	RA with elevated levels of distress (n=133)	IG: 61% CG: 66%	IG: 55.5 $\pm$ 10.7 CG: 57.1 $\pm$ 9.4	NR	Usual care	CBT intervention tailored to individual needs and characteristics; modules consisted of pain and functional disability, fatigue, negative mood, and social functioning Duration: 9 to 65 weeks	Pain: IRGL pain scale; Fatigue: fatigue scale of the checklist individual strength; Disability: IRGL self-care and mobility scales; Work productivity: RAND-36 role limitations	Baseline, post-intervention for the IG and 6 months after baseline in the CG, and 3, 6, 9, and 12 months	Significant improvements in overall role limitations due to emotional problems (p<.001)
Grønning et al. 2012	RA, PsA, and UA (n=141)	IG: 68% CG: 70%	IG: 58 $\pm$ 12 CG: 58 $\pm$ 11	NR	Usual care	Education covering the arthritic process, treatment, problem-solving, emotions, goal setting, and lifestyle advice Duration: 8 weeks	Self-efficacy symptoms and pain: VAS; Self-Management Engagement: PAM; Well-being: AIOS; HRQoL: AIMS2; Pain: VAS; Fatigue: VAS	Baseline and 4-months	Significant improvements in self-efficacy symptoms (p=.04); self-management engagement (p=.010); well-being (p=.01); pain (p=.01)
Grønning et al. 2014	RA, PsA, and UA (n=141)	All participants: 69%	All participants: 58 $\pm$ 11	NR	See Grønning 2012	See Grønning 2012	See Grønning 2012	12-month follow-up from original RCT	Significant improvements in well-being (p=.015)
Grønning, Lim and Bratås 2019	RA, PsA, and UA (n=101)	88%	58 (SD NR)	NR	See Grønning 2012	See Grønning 2012	See Grønning 2012	5-year follow up from original RCT	All findings were NS

Author	Participants				Control Group	Intervention	Outcomes*	Assessment Times	Findings
	Population	Gender (% F)	Age ($\mu \pm SD$)	Ethnicity (%)					
Hammond et al. 2017	RA, PsA, and UA (n=55)	IG: 75.9% CG: 76.9%	IG: 47.7 $\pm$ 10.4 CG: 50.5 $\pm$ 6.4	NR	Arthritis education	Job retention intervention consisting of written work information, tailored work advice, and optional work visits Duration: 4 weeks	Self-efficacy: VAS; HRQoL: Euro QoL and SF 12v2; Pain: VAS; Hand/wrist pain: VAS; Disability: HAQ; Fatigue: VAS	Baseline, 6-months and 9-months	All findings were NS at all time points
Hewlett et al. 2011	RA (n=168)	IG: 75.4% CG: 71%	IG: 61.1 $\pm$ 10.5 CG: 58.3 $\pm$ 12.0	NR	Arthritis education	Usual care + CBT focusing on fatigue, energy management, prioritisation, goal setting, sleep, assertiveness, coping with setbacks, problem-solving, self-monitoring of activity, and relaxation Duration: 6 weeks + booster session at week 14	Self-efficacy: RASE; Fatigue Impact: MAF and VAS; Fatigue severity: VAS; Fatigue coping: VAS; Pain: VAS; HRQoL: RA QoL Scale; Disability: HAQ and Personal Impact HAQ	Baseline and 18 weeks	Significant improvements in self-efficacy (p=.042); fatigue severity (p=.003); fatigue coping (p=.0007); HAQ (p=.031)
Hewlett et al. 2019	RA with severe fatigue (n=333)	IG: 80.1% CG: 79.6%	IG: 63.7 CG: 61.8 (SD NR)	White IG: 151; CG: 147 Asian/Asian British IG: 5; CG: 3	Arthritis education	See Hewlett et al. 2011	Self-efficacy: RASE; Fatigue Impact: BRAF-NRS impact & BRAF-MDQ; Fatigue severity: BRAF-NRS severity; Fatigue coping: BRAF-NRS coping; Pain: VAS; HRQoL: AIMS-2 VAS; Disability: MHAQ	Fatigue severity, coping and overall impact: baseline, post-intervention, and weeks 52, 78, 104 Pain, disability, HRQoL, and self-efficacy: week 0, 6, 26, 52, 78 and 104	Significant improvements in self-efficacy at 26 weeks (p<.01); BRAF-NRS impact at post-intervention (p< 0.01), 26 weeks (p= 0.02), 52 weeks (p=0.01), and 104 weeks (p= 0.04); BRAF-NRS coping at 2 years (p=.02)
Kaya et al. 2016	AS (n=80)	IG: 7.5% CG: 5%	IG: 43.1 $\pm$ 9.1 CG: 40.9 $\pm$ 9.3	NR	Arthritis education	Education related to AS, treatment, exercise, and joint protection. Opportunities were provided to share experiences. Duration: 4 weeks	Disability: BASFI; HRQoL: SF-36 and ASQoL	Baseline, post-intervention, and 6 months	All findings were NS at all time points

Author	Participants				Control Group	Intervention	Outcomes*	Assessment Times	Findings
	Population	Gender (% F)	Age (μ ±SD)	Ethnicity (%)					
Kjeken et al. 2013	AS (n=100)	IG: 21.7% CG: 46.9%	IG: 49.4±10.3 CG: 48.6±9.4	NR	Usual care	Exercise and education covering information related to fatigue management, sleep hygiene, energy conservation, assistive devices, and home/work accommodations Duration: length of stay in rehab	Disability: BASFI; Well-being: BAS-G; HRQoL: SF-36	Baseline, 4-, and 12 months	Significant improvements were found for well-being (p=0.02); social functioning (p=0.05); role physical (0.04); role mental (p=0.006) at 1-year
Lumley et al. 2014	RA (n=262)	WED+CST: 80.6% WED+CT: 81.2% CW+CST: 84.1% CW+CT: 78.8%	WED+CST: 56.0±10.4 WED+CT: 55.2±12.3 CW+CST: 54.0±13.7 CW+CT: 55.3±11.9	White WED+CST: 12.5% WED+CT: 16.4% CW+CST: 16.8% CW+CT: 19.1% Black WED+CST: 8.0% WED+CT: 9.1% CW+CST: 6.8% CW+CT: 4.2% Other WED+CST: 0.4% WED+CT: 0.8% CW+CST: 0.4% CW+CT: 1.5%	Control writing and control training groups	Two treatment conditions: (1) CBT training and education on theoretical mechanisms of pain, pain and fatigue management, relaxation techniques, coping skills, communication, and problem-solving and (2) written emotional disclosure Duration: 10 weeks	Pain: AIMS-2 pain subscale; Disability: AIMS-2; HRQoL: AIMS-2	Baseline and 1-, 4-, and 12-months follow-up	All findings were NS at all time points
Manning et al. 2014	RA (n=108)	IG: 84.6% CG: 67.8%	IG: 53±16 CG: 57±15	NR	Usual care	Individualised home exercise programme and group education covering RA, exercise, managing flares, coping with pain, goal setting, and motivation Duration: 12 weeks	Self-efficacy: ASES; Disability: DASH; HRQoL: RAQoL; Pain: VAS; Fatigue: VAS	Baseline, 12 week and 36 weeks	Significant improvements in pain self-efficacy at 12-weeks (p=.021) and 36-weeks (p=.047); symptoms self-efficacy at 12 weeks (p=.039); disability at 12-weeks (p=.022); pain at 12-weeks (p=.013) and 36-weeks (p=.049)

Author	Participants				Control Group	Intervention	Outcomes*	Assessment Times	Findings
	Population	Gender (% F)	Age ($\mu \pm$ SD)	Ethnicity (%)					
McBain et al. 2016	RA and PsA (n=128)	IG: 46.2% CG: 64.6%	IG: 54.8 $\pm$ 11.2 CG: 58.8 $\pm$ 12.2	White IG:88.5%; CG:89.6% Indian IG:3.9%; CG:4.2% Chinese IG:0%; CG:2.1% Black-African IG:0%; CG:2.1% Black-Caribbean IG:2%; CG:0% Other IG: 5.8%; CG: 2.1%	Usual care	Skills training to improve DMARD self-monitoring Duration: one-off training session	Pain: VAS; Fatigue: VAS; Disability: HAQ-II; HRQoL: SF-12v1	Baseline, and after the 3rd and 6th blood tests	All findings were NS at all time points
Molto et al. 2020	axSpA (n=502)	IG: 40% CG: 34%	IG: 47 $\pm$ 12 CG: 47 $\pm$ 12	NR	Comorbidity screening and management programme	Education covering axSpA and treatment followed by a discussion of video with an HCP and prescription of a home exercise programme Duration: one-off consultation	Coping: VAS; Disability: BASFI; HRQoL: ASAS Health Index	Baseline and at one-year visit	All findings were NS
Ndosi et al. 2016	RA (n=132)	IG: 68% CG: 63%	IG: 54 $\pm$ 12.3 CG: 56 $\pm$ 13.3	NR	Usual care	Usual care + tailored education covering one or more of the following: managing pain, movement, feelings, arthritic process, treatments, self-help strategies, and social support Duration: one-off consultation	Self-efficacy: ASES; Knowledge: PKQ-RA; HRQoL: AIMS-2	Baseline, week 16, and week 32	Significant improvements were seen for self-efficacy pain (p=0.008) and other symptoms (p=0.003) at week 32

Author	Participants				Control Group	Intervention	Outcomes*	Assessment Times	Findings
	Population	Gender (% F)	Age ($\mu \pm SD$)	Ethnicity (%)					
Niedermann et al. 2011	RA (n=53)	IG: 85% CG: 82%	IG: 62.1 $\pm$ 12.6 CG: 53.4 $\pm$ 15.7	NR	Arthritis education	Tailored joint protection education with goal setting, self-monitoring, and social support Duration: 3 weeks	Self-Management Engagement: D-JPBA-S; Self-efficacy: ASES and the JP Self-Efficacy Scale; Hand Pain: VAS; HRQoL: EUROHIS-QoL	Baseline, 3 weeks, and 3 months follow-up	Significant improvements in self-management (p=.008); self-efficacy (p=.015) and joint protection self-efficacy (p=.047) at 3 months
Niedermann et al. 2012	See Niedermann 2011	See Niedermann 2011	See Niedermann 2011	See Niedermann 2011	See Niedermann 2011	See Niedermann 2011	See Niedermann 2011	6 and 12 months	Significant improvements in self-management at 6 months (p=.02) and 12 months (p=.04)
Nilssen et al. 2017	RA, PsA, AS, Polyarthritis, JIA (n=64)	IG: 66% CG: 59%	IG: 27.1 $\pm$ 5.3 CG: 28 $\pm$ 4.6	NR	Usual care	Exercise intervention and patient education covering physical activity, coping, sleep, and lifestyle advice Duration: 2.5 weeks	Coping: EC-17; Disability: FFbH; HRQoL: EQ-5D-5L; Pain: VAS; Fatigue: VAS	Baseline, and at 3, 6 and 12 months after intervention	All findings were NS
Pot-Vaucel et al. 2016	RA (n=54)	NR	IG: 58.2 $\pm$ 10.7 CG: 62.4 $\pm$ 9.8	NR	Arthritis education	Tailored education covering one or more of the following: RA, treatment, mobility, workers' rights, diet, and self-image Duration: 6 months	Fatigue: VAS; HRQoL: VAS	Baseline and 6 months	All findings were NS

Author	Participants				Control Group	Intervention	Outcomes*	Assessment Times	Findings
	Population	Gender (% F)	Age (μ ±SD)	Ethnicity (%)					
Rodríguez-Lozano et al. 2013	AS (n=756)	IG: 29% CG: 27%	IG: 45±12 CG: 46±11	NR	Usual care	Education covering information related to AS, treatment, lifestyle advice, assistive devices, sexuality, pregnancy, exercise, psychological support. Peer support group also included. Duration: One-off session	Knowledge: researcher developed Likert-scale (0-4) about knowledge of the disease, lifestyle, ergonomics, and exercise; Disability: BASFI; Pain & Nocturnal Pain: VAS; HRQoL: ASQoL	Baseline and week 24	Significant differences in knowledge of disease (p=0.0041); knowledge of lifestyle and ergonomics (p=0.003); knowledge of exercise (p=0.001); disability (p= 0.002); Pain Total: (p=0.020); QoL: (p=.009)
Sharpe and Schreiber 2012	RA (n=104)	All participants: 78%	CT: 55.2±13.3 BT: 57.9±12.9 CBT: 57.7±15.4 CG: 54.2± 11.0	NR	Waiting list	CBT + education covering relaxation training, attention diversion, goal setting, pacing, problem-solving, cognitive restructuring, communication, and flares Duration: 8 weeks	Disability: HAQ	Baseline, post-Intervention, and 6 months	All findings were NS at all time points
Shigaki et al. 2013	RA (n=108)	IG: 93% CG: 92%	IG: 50.3±11.6 CG: 49.3±12.3	White IG: 93% CG: 96%	Waiting list	Education covering rationale for the intervention, stress, coping, goals, pain, emotional responses, managing change, self-esteem, relationships, and community participation. Peer support and weekly contact with HCP also included. Duration: 10 weeks	Self-efficacy: ASES; HRQoL: AIMS-2	Baseline, post-intervention, and 9 months	Significant improvements in self-efficacy post-intervention (p=.00001) and at 9 months (p=.00001); and QoL post-intervention (p=.003) and at 9 months (p=.004)
Unk and Brasington 2014	RA (n=108)	IG: 85.2% CG: 74.1%	IG: 50.1±12.9 CG: 50.5±11.3	Black IG: 29.6% CG:31.5% White IG: 70.4% CG:68.5%	Arthritis education	Educational intervention covering RA, treatments, healthy self-care, and signposting Duration: one-off session	Self-management Engagement: MAQ; Coping: BIPQ; Disability: HAQ	Baseline, and 1-month post-intervention	All findings were NS

Author	Participants				Control Group	Intervention	Outcomes*	Assessment Times	Findings
	Population	Gender (% F)	Age ($\mu \pm SD$)	Ethnicity (%)					
Zangi et al. 2012	RA, AS, PsA, and other IA (not specified) (n=73)	87.5%	N/A	NR	Usual care and a mindfulness CD	Mindfulness-based intervention to encourage experiential learning. Activities included guided imagery, music, drawing, and poetry. Duration: 15 weeks	Self-efficacy: ASES; Pain: VAS; Fatigue: VAS; HRQoL: VAS	Baseline, post-intervention, and after 12 months	Overall significant improvements were seen in self-efficacy pain ($p=.001$); self-efficacy symptoms ($p<.001$); and fatigue ($p=.002$)
Zuidema et al. 2019a	RA (n=157)	IG: 65.0% CG: 66.0%	IG: 61.0 $\pm$ 11.3 CG: 62.9 $\pm$ 10.2	N/A	Usual care	Usual care + education covering balancing activity and rest, setting boundaries, communicating needs, social support, medication, communicating with HCPs, assistive devices, exercise, and coping. Duration: 12 months	Self-management Engagement: PAM-13 and SMAS-S; Self-efficacy: RASE; Pain: VAS; Fatigue: VAS; Disability: HAQ	Baseline, 6- and 12 months	All findings were NS at all time points

Key: AE= arthritis education; AS= ankylosing spondylitis; axSpA=axial spondyloarthritis; BT= behavioural therapy; CBT= cognitive behavioural therapy group; CG= control group; CST= behavioural coping skills training; CT= arthritis education control training (Lumley); CT= cognitive therapy (Sharpe and Schreiber); CW= control writing; DMARDs= disease-modifying antirheumatic drugs; G= gaming group; I= information group; IA= inflammatory arthritis; IG= intervention group; N/A= not applicable; NR= not reported; NSAIDs= non-steroidal anti-inflammatory drugs; OT= occupational therapist; pSpA=peripheral spondyloarthritis; RA= rheumatoid arthritis; RR= relaxation response training group; SD= standard deviation; SpA= spondyloarthritis; SS+G= social support and gaming group; SS= social support group; UA= unspecified polyarthritis; WED= written emotional disclosure

*Abbreviations for outcome measures are listed on page vi-ix

Table 2.8 Characteristics of Included Qualitative Studies

Author	Participants				Methods	Phenomena of interest	Setting	Findings
	Population	Gender (% F)	Age ($\mu \pm$ SD)	Ethnicity (%)				
Bain et al. 2016	IA (n=25)	83.3%	N/A	NR	Focus groups And thematic analysis	Explore the experiences of PLWIA participating in an educational SMI	Outpatient clinic	Participants perceived the SMI to be acceptable and an overall positive experience. Particularly, participants found the SMI to be emotionally supportive and they enjoyed meeting other people living with the same or similar condition.
Bearne et al. 2017	RA (n=12)	83%	57.8 $\pm$ 16.6	Black Caribbean 25% White 59% Pakistani 8% Black African 8%	Semi-structured interviews and thematic analysis	Explore participants' experience of self-management	Hospital	Participants reported improved confidence in managing their RA independently and felt that the SMI could be easily integrated into their lives.
Berry et al. 2022	IA (n=22); Rheumatology HCPs (n=11)	78%	N/A	White 86.4% Prefer not to say 4.5% Missing 9.1%	Semi-structured interviews and inductive thematic analysis	Explore the acceptability and potential refinements of a CBT SMI	Unspecified NHS sites	Participants found the SMI was effective in changing their behaviour and they reported increased acceptance, sense of control, and confidence. However, HCPs reported some implementation concerns.
Cramp et al. 2020	RA (n=12); Band 6 primary care MSK physios (n=3)	RA 75% Physios NR	RA 57.6 $\pm$ 14.5 Physios NR	RA NR Physios NR	Semi-structured interviews and inductive thematic analysis	Explore physiotherapists' views of delivering an exercise and educational SMI and training and participants' experiences of the SMI	Not Reported	The SMI was found to be acceptable to both parties. The group format of the SMI was attributed to the reported enhanced motivation, coping skills, and engagement with self-management strategies in participants.
Dures et al. 2012	RA and have severe fatigue (n=38)	78.9%	60.9 $\pm$ 9.4	NR	Focus group and a hybrid (deductive and inductive) thematic analysis	Explore participants perceptions on a CBT intervention targeting RA fatigue	Hospital	Participants reported that the SMI improved their ability to manage their fatigue. They highlighted that CBT elements were key to making behaviour changes and responsible for psychosocial outcomes. Metaphors and visual aids were facilitators to behaviour change.

Author	Participants				Methods	Phenomena of interest	Setting	Findings
	Population	Gender (% F)	Age ($\mu \pm$ SD)	Ethnicity (%)				
Grønning, Midttun, And Steinsbekk 2016	RA, PsA, and US (n=26)	88%	58 (SD NR)	NR	Semi-structured interviews and systematic text condensation	Explore participants ability to cope with their condition after completing the intervention	Rheumatology clinic	Participants reported increased confidence in their ability to cope with their diagnosis post-intervention, which was attributed to sharing their experiences with others.
Haglund et al. 2017	SpA (n=11); 6 participated in two focus groups and 5 in individual interviews	36%	N/A	NR	Two focus groups, five individual interviews, and content analysis approach	Explore PLwIA' experiences and needs in patient education	Research centre	Participants reported that patient education was an important aspect to the treatment and management of SpA. Participants preferred patient education to be delivered in a one-to-one format.
Hewlett et al. 2019	HCP; <i>Interviews</i> (n=15; 9 nurses and five OTs); <i>Focus Group</i> (n=8; 3 nurses and 5 OTs)	NR	NR	NR	Individual interviews, focus group, and inductive thematic analysis	Explore the facilitators experience of CBT intervention training, delivery, and the future implementation considerations	Hospital (interviews and focus group)	Facilitators considered the SMI to be a valuable resource for PLwIA. It took time and effort for the facilitators to become confident in delivering the intervention as it differed from their usual approach to care. However, they reported that the training taught them new clinical skills.
Kristiansen and Antoft 2016	RA (n=28)	NR	NR	NR	Ethnographic study, 6 semi structured interviews, and two focus groups; qualitative content analysis	Explore participation in an educational SMI to support people living with RA	Two community healthcare centres	Findings indicate that timing of participation is an important factor affecting whether the SMI succeeds. HCPs were reported to empower participants by giving them access to professional knowledge and guidance. Social support was reported as a facilitator to engagement with the SMI.
Mollard and Michaud 2018	RA (n=12); Intervention participants who did not complete the study	NR	NR	NR	Interview (unspecified) and content analysis	Explore barriers to using the mobile app in adults with RA.	Telephone	Participants reported that IT-issues decreased their engagement with the SMI mobile app.
Prior et al. 2015	OT (n=6); Band 6 (n=6), Band 7 (n=2), Band 8 (n=1)	NR	NR	NR	Semi-structured interviews; thematic analysis	Explore OTs experiences of delivering the intervention, and potential barriers and facilitators to delivery	Outpatients	HCPs reported concerns regarding the feasibility of implementing the SMI within the NHS.

Author	Participants				Methods	Phenomena of interest	Setting	Findings
	Population	Gender (% F)	Age ($\mu \pm SD$)	Ethnicity (%)				
Prior et al. 2017	IA (n=32)	71.9%	49.4 $\pm$ 8.5	NR	Semi-structured interviews; thematic analysis	Explore PLwIA views on work rehabilitation programme and to identify the impact of it on their life and work status	Telephone, participant's homes, or private rooms at the host hospital (patient's preference)	Participants reported the SMI helped them to cope better at work and become more confident in self-managing their condition. Additionally, participants had a more positive outlook about being employed in the future.
Salmon 2019	RA (n=9)	88.9%	58.3 $\pm$ 11.0	NR	Questionnaire with free text answers; content analysis	Explore acceptability of a physical activity and educational intervention for managing fatigue	Online	The SMI was found to be acceptable to the participants, particularly in relation to its format, content, and support materials. Participants also provided suggested improvements to the SMI, including ongoing support and follow-up to the intervention.
Zangi et al. 2011	IA (n=69)	87.5%	53.0 $\pm$ 9.4	NR	Focus group; content analysis	Explore participant experiences participating in a mindfulness-based SMI	Rheumatology clinics	Following the SMI, participants reported being able to better recognise their emotions and becoming more aware of their needs. Participants felt that social support was an important determinant to their success.
Zuidema et al. 2019b	RA (n=21)	NU: 50.0% LU: 100% HU: 57.1% HUP: 50.0%	N/A	NR	Semi-structured interviews; inductive content analysis	Explore barriers to participant in web-based SMI	Telephone	Participants that did not receive benefit from the SMI reported they were not motivated to use the SMI; did not have clear expectations or different expectations of the intervention; and/or did not support their needs.

Key: CBT= cognitive behavioural therapy; CG= control group; HCP= healthcare professional; HU=high-user; HUP=high-user plus; IA= inflammatory arthritis; IG= intervention group; LU= low-user; MSK= musculoskeletal; N/A= not applicable; NHS= national health service; NR= not reported; NU=non-user; OT= occupational therapy; PLwIA= people living with inflammatory arthritis; PsA= psoriatic arthritis; RA= rheumatoid arthritis; SMI= self-management intervention; SpA= spondyloarthritis

2.6.4.3 Intervention characteristics

The characteristics of the IA SMIs were mapped to the TIDieR checklist (Hoffman et al. 2014). Figure 2.2 illustrates the quality of data reporting of the included studies and a more detailed table of the intervention characteristics from the included studies can be seen in Appendix 2.7. Overall, the quality of intervention reporting across studies ranged from poor to high. The reporting of the intervention characteristics from the included studies was low for the following TIDieR Checklist Items: why (rationale, theory, or goal; 26.3%), modifications (modifications to the intervention during the study; 5.3%), fidelity planned (if intervention adherence or fidelity was assessed; 23.7%), and fidelity actual (if the intervention was delivered as planned; 23.7%). The TIDieR guidance was published in 2014 and studies published before then may not be reported as robustly.

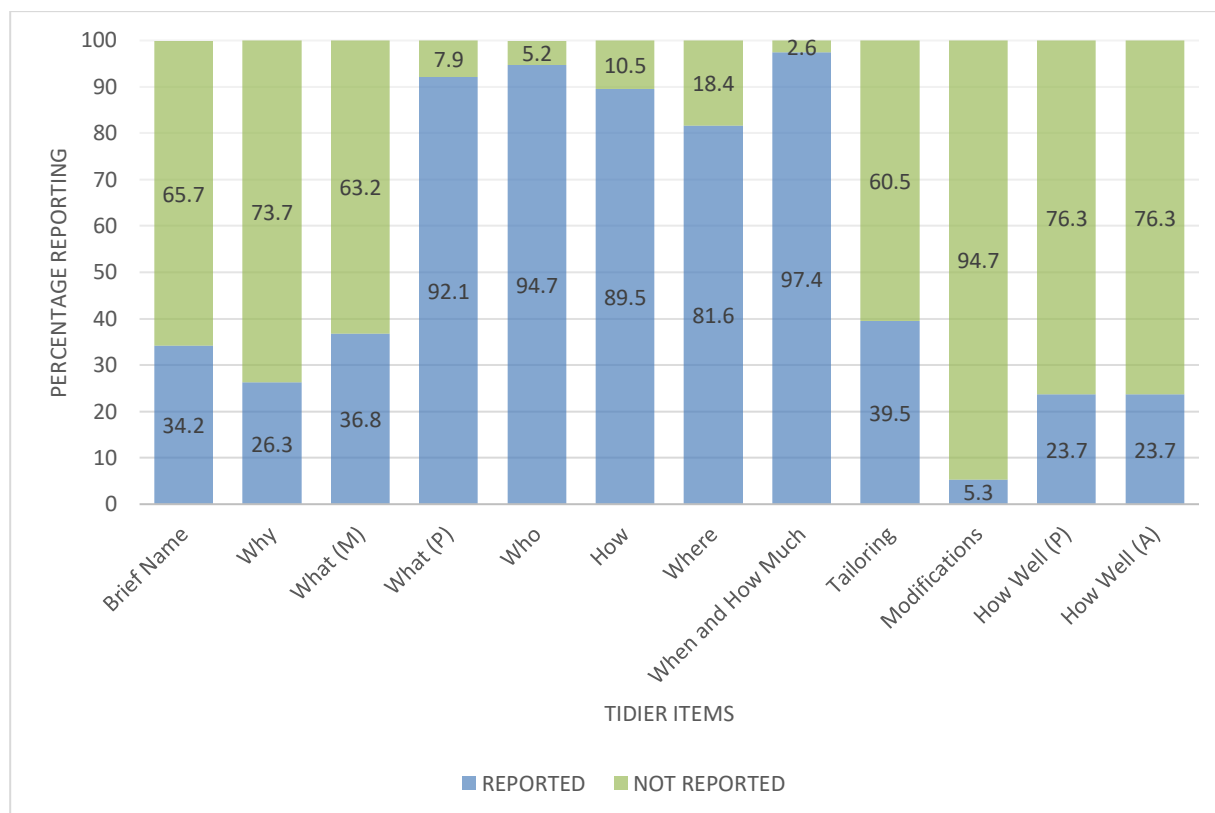


Figure 2.2 Reporting of Intervention Characteristics

2.6.4.4 Comparator

For the quantitative studies, the control group in many (n=17) of the included studies^{1,3,7,8,15-19,26,29,33,36,40,44,47} was usual care. One study had a comparator as usual care and a mindfulness CD⁴⁵. Nine studies^{2,5,13,22-25,34,35,37} used arthritis education as the comparator; three studies^{10,42,43} used a waiting listing; one¹¹ used physician counselling; and one³² used multi-morbidity screening and management programme. One study²⁸ had two comparator groups: control writing and control training.

2.7 SYNTHESIS OF QUANTITATIVE FINDINGS

2.7.1 Pain

Twenty-two studies^{1,2,5,8,13,15,16,17-19,22-24,28-30,34-36,40,46,47} investigated the effect of the SMI on pain. Pain was measured using five outcome measures across the included studies: SF-36 bodily pain, visual analogue scale (VAS), Rheumatoid Arthritis Symptom Questionnaire (RASQ), Impact of Rheumatic Diseases on General Health and Lifestyle (IRGL), and the Arthritis Impact Measurement Scales 2 (AIMS-2).

The meta-analysis included 12 studies^{8,15,17,18,22-24,29,36,40,45,47} with 2,455 participants. Studies using VAS to measure global pain were pooled for inclusion in the meta-analysis. Prior to the analysis, 10-cm VAS scores were transformed to 100-cm VAS scores. The meta-analysis generated a pooled effect size estimate of $ES_{0.5} = -3.5$ [95%CrI: -5.8 to -1.3] and the between study variance was $\tau_{0.5} = 2.6$ [75%CrI: 1.1 to 4.3]. The probability that the pooled effect size was below zero and the MCID favouring the intervention was $p=0.997$ and $p=0.559$, respectively. Taken together, these findings indicated PLwIA who were exposed to the SMI had reduced pain in a time frame of one day⁴⁰ to one year⁴⁷. The pooled mean difference surpassed the MCID of 3.4 points (Wolfe and Michaud 2007), indicating that SMIs have a clinically meaningful impact on pain reduction in PLwIA.

Only one study¹³, not included in the meta-analysis, with 143 participants found a statistically significant reduction in pain in 8 weeks. This study found that mindful awareness and acceptance has a greater effect on pain reductions when compared to CBT or information only. However, CBT demonstrated significant improvements in participants ability to cope with pain¹³. This study was unable to be included in the meta-analysis as the authors reported F statistic rather than p-values. A conversion formula was considered as a potential solution to allow the study to be included in the meta-analysis, however the use of a conversion formula can make it difficult to infer clinical significance (Ioannidis, Patsopoulos and Rothstein 2008). For this reason, the researcher decided to report findings from the study¹³ narratively.

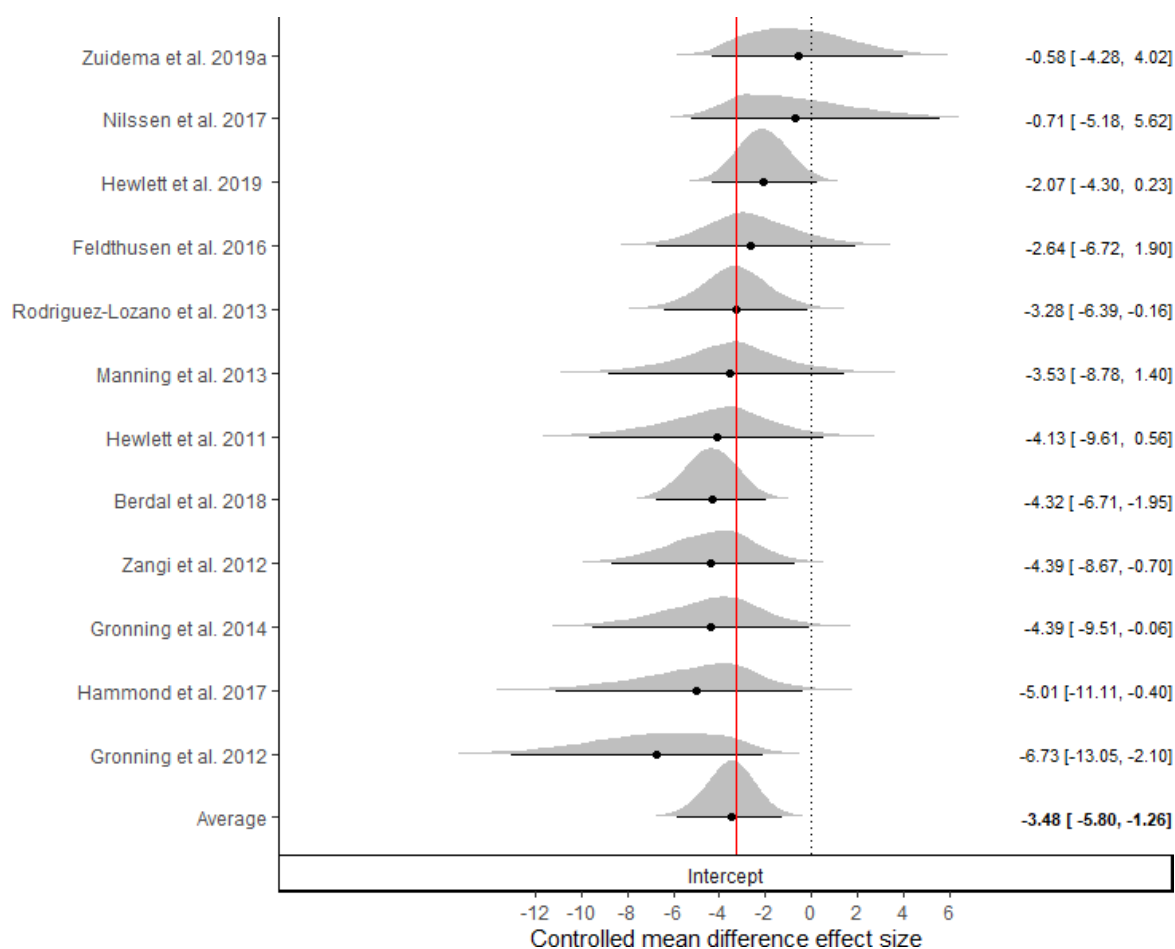


Figure 2.3 Forest Plot Comparison: IA SMI Versus Comparator, Outcome Pain

2.7.2 Fatigue

Eighteen studies^{1,3,8,13,15,16,17-19,22-24,29,30,36,37,46,47} explored the effect of the SMI on fatigue. Fatigue was measured using four different outcomes across the included studies: SF-36 vitality subscale, VAS, the Bristol Rheumatoid Arthritis Fatigue Multidimensional Questionnaire (BRAFMQ), Bristol Rheumatoid Arthritis Fatigue Numerical Rating Scales (BRAFNRS), and the Checklist of Individual Strength (CIS). Studies using VAS to measure fatigue severity were included in the meta-analysis. Prior to the analysis, 10-cm VAS scores were transformed to 100-cm VAS scores. The analysis included 11 studies^{8,15,17,18,22,23,29,36,37,46,47} with 1,420 participants. The meta-analysis generated a pooled effect size estimate of $ES_{0.5} = -4.7$ [95%CrI: -8.3 to -1.2] and between study variance $\tau_{0.5} = 4.7$ [75%CrI: 2.7 to 7.2]. The probability that the pooled effect size was below zero was $p = 0.993$. Taken together, these findings demonstrate that SMIs lead to a clinically meaningful decrease in fatigue severity in a time frame of approximately 5 days⁸ to 1 year^{17,47} with low heterogeneity (Elera-Fitzcarrald et al. 2020). The probability that the MCID favouring intervention was $p = 0.906$, respectively (Figure 2.4). This finding indicates that SMIs decrease the impact of fatigue when compared to those in the control groups in a time frame of approximately 5 days⁸ to 1 year^{17,47} and represents a clinically meaningful difference.

One study²³, not included in the meta-analysis, including 168 participants found significant improvements in fatigue coping ($p = .0007$) and severity ($p = .003$) at 18 weeks. This study led to revisions in the SMI and a second, scaled-up RCT trial²⁴ ($n = 333$) of this study was later conducted, which showed significant findings in fatigue impact using the BRAFNRS at 14 weeks ($p < .01$), at 26 weeks ($p = .02$), 52 weeks ($p = .01$), and 104 weeks ($p = .04$). Additionally, improvements in fatigue coping were found at 2 years follow-up ($p = .02$). These studies were not included in the meta-analysis due to heterogeneity of outcome measures.

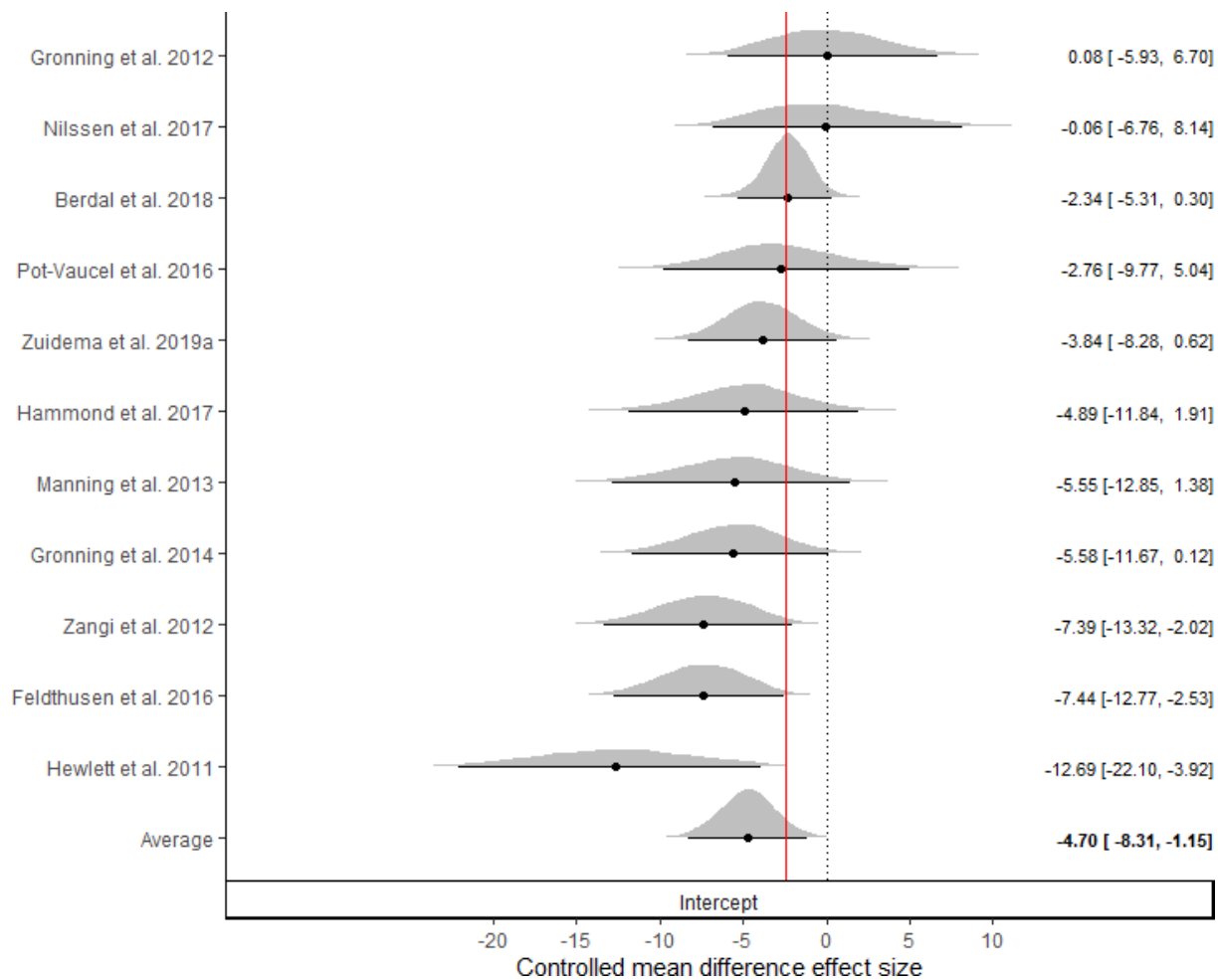


Figure 2.4 Forest Plot Comparison: IA SMI Versus Comparator, Outcome Fatigue

2.7.3 Self-efficacy

Sixteen studies^{8,10,15,17-19,22-24,29,33-35,43,46,47} reported on SE. SE was measured using the ASES, VAS, the Rheumatoid Arthritis Self-Efficacy Scale (RASE), the Joint Protection Self-Efficacy Scale (JP-SES), and the RA Task-Specific SE Scale. Studies using the ASES subscales of SE Pain and SE Other Symptoms were included in the meta-analysis. The analysis included 6 studies^{8,15,17,29,33,46} with 913 participants and generated a pooled effect size estimate of $ES_{0.5}=3.8$ [95%CrI: 0.6 to 7.0] with a between study variance of $\tau_{0.5}=3.3$ [75%CrI: 2.1 to 5.2]. The probability that the pooled effect size exceeded zero and favoured intervention was $p=0.987$ (Figure 2.5). The pooled data suggest that SMIs improve SE in a time frame of approximately 5 days⁸ to 1 year⁴⁶. An MCID has yet to be established for SE in an IA population and therefore it is not possible to determine whether these results are clinically meaningful.

Three other studies^{17,23,24} not included in the meta-analysis also demonstrated significant improvements in SE. Two studies^{23,24} also demonstrated significant improvements in SE using the RASE outcome measure, which measures the confidence of PLwIA to perform emotional and practical coping behaviours (Hewlett et al. 2001). One of these studies²³ included 168 participants and demonstrated improvements in task-specific SE at 18 weeks ($p=.042$), while the other study included 333 participants and found similar improvements at 26 weeks ($p=.02$)²⁴. One study¹⁷ with 141 participants found improvements in the confidence of PLwIA on their ability to manage their symptoms (i.e., SE symptoms) at 4 months ($p=.04$) using the VAS outcome measure. These studies were unable to be included in the MMSR due to heterogeneity of outcome measures.

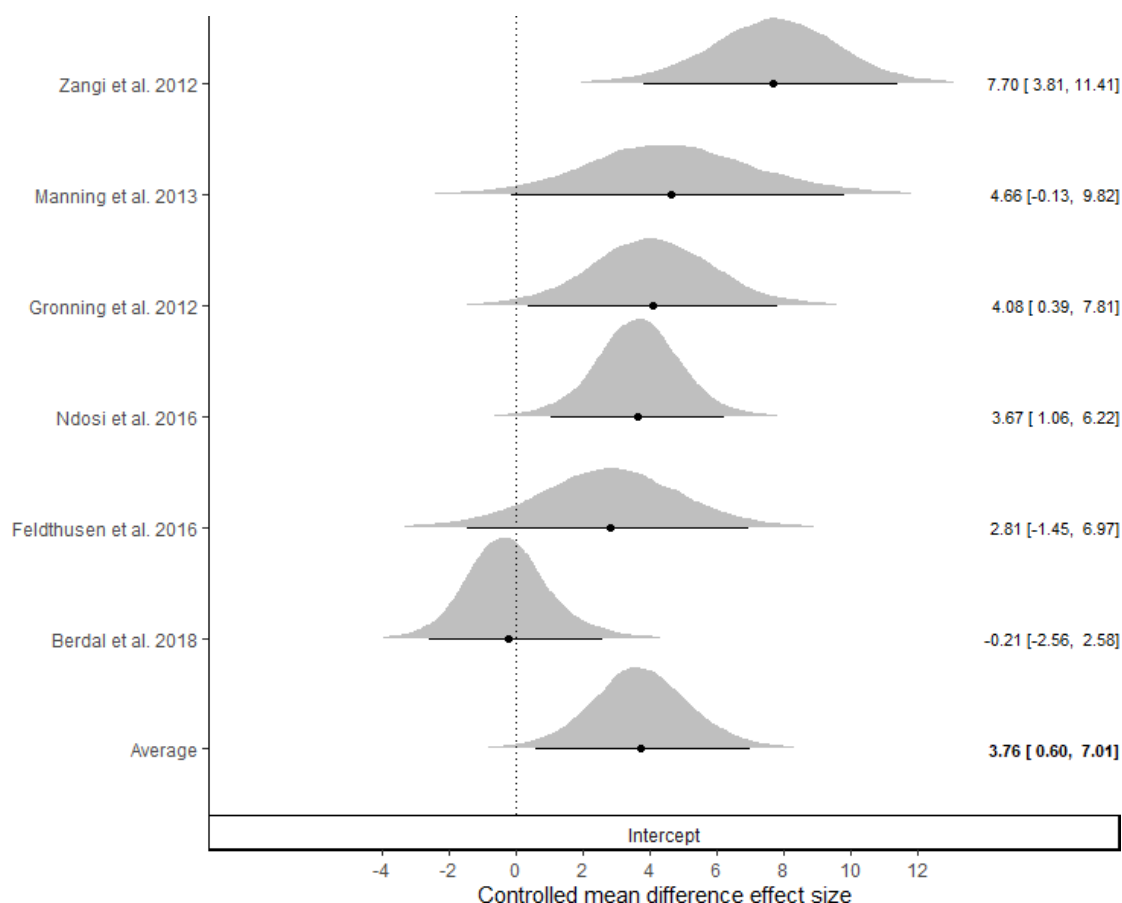


Figure 2.5 Forest Plot Comparison: IA SMI Versus Comparator, Outcome Self-Efficacy

2.7.4 Health-related Quality of Life

Twenty-six of the included studies^{1,3,8,10,11,15,17-19,22-26,28,30,32-37,40,43,45} investigated the association between the effectiveness of the SMIs and HRQoL. A wide range of HRQoL outcome measures were used across the included studies. These included the Ankylosing Spondylitis Quality of Life (ASQoL), Assessment of Spondyloarthritis International Society (ASAS), Patient Generated Index (PGI), AIMS-2, European Quality of Life (Euro QoL), Rheumatoid Arthritis Quality of Life (RAQoL), Rheumatoid Arthritis Impact of Disease (RAID), VAS, QoL Scale, and the SF-36, -12v1, -12v2. The meta-analysis included studies using the SF-36 subscales social functioning, role physical, and emotional well-being. Social

functioning is measured as the extent the physical and emotional consequences of IA interferes on the ability of PLwIA to develop, maintain, and nurture relationships with others in the past four weeks. Role physical is measured as the extent the physical health of PLwIA interferes with their ability to engage in work and ADLs in the past four weeks. Emotional well-being assesses the amount of time spent anxious, depressed, peaceful, happy, and calm over the past 4 weeks (Ware and Sherbourne 1992; RAND Corporation 2022).

Four studies^{1,3,25,26} with 341 participants were analysed to determine the overall effectiveness of IA SMI on HRQoL. The analysis generated a pooled effect size estimate of $ES_{0.5}=0.4$ [95%CrI: -73 to 8.5] and between study variance $\tau_{0.5}=5.9$ [75%CrI: 1.9 to 11.7]. The probability that the pooled effect size exceeded zero and favoured intervention was $p=0.530$ (Appendix 2.8). Findings from the analysis suggest that SMIs do not improve overall HRQoL.

Subgroup analyses were also performed on each subscale. Each analysis also included four studies^{1,3,25,26} with 341 participants. An analysis on social functioning generated a pooled effect size estimate of $ES_{0.5}=4.4$ [95%CrI: -4.2 to 13.4] and between study variance $\tau_{0.5}=9.5$ [75%CrI: 5.4 to 15.1]. The probability that the pooled effect size exceeded zero and favoured the intervention was $p=0.852$ (Appendix 2.8). Findings from the subgroup analysis suggest that SMIs do not improve the HRQoL social functioning domain.

The role physical analysis generated a pooled effect size estimate of $ES_{0.5}=4.4$ [95%CrI: -4.2 to 13.4] and between study variance $\tau_{0.5}=9.5$ [75%CrI: 5.4 to 15.1]. The probability that the pooled effect size exceeded zero and favoured intervention was $p=0.852$ (Appendix 2.8). Findings from the subgroup analysis suggest that SMIs do not improve the HRQoL role physical domain.

The emotional well-being analysis generated a pooled effect size estimate of $ES_{0.5}=2.0$ [95%CrI: -4.2 to 8.3] and between study variance $\tau_{0.5}=5.1$ [75%CrI: 2.3 to 8.9]. The probability that the pooled effect size exceeded zero and

favoured intervention was $p=0.765$ (Appendix 2.8). Findings from the subgroup analysis suggest that SMIs do not improve the HRQoL emotional well-being domain.

However, four studies^{8,11,40,43} not included in the meta-analysis found significant improvements in HRQoL measures. One of these studies¹¹ with 185 participants found overall significant improvements ($p=0.02$) in 2 years using the SF-36. However, this study reported overall mental component scores. Authors were contacted by the researcher (AK) to request non-aggregated scores for the SF-36 subscales; however, the study authors did not respond, and the data was unable to be pooled in the meta-analysis. One study⁴³ with 108 participants living with IA also found improved HRQoL using the AIMS-2 at 10 weeks ($p=0.003$) and 9 months ($p=0.004$). Another study⁴⁰ with 756 people living with AS demonstrated HRQoL improvements at 24 weeks ($p=0.009$) using the ASQoL. While one study with 389 PLwIA found improvements in HRQoL using the PGI following discharge (approx. 5 days) from the SMI ($p=0.03$). Additionally, one study¹⁶ with 133 participants found significant improvements ($p<.001$) at 65 weeks in role limitations at work due to emotional problems at work using the SF-36 measure.

Three other studies^{7,17,18} also demonstrated improvements in emotional well-being. One study⁷ with 129 participants found significant improvement ($p=.0275$) at 3 months in coping using the VAS subscale from RAID. Another study¹⁷ with 141 participants demonstrated improvements in emotional well-being at 4 months ($p=.01$), which were sustained at the 12-month follow-up¹⁸. Taking all this together may indicate slightly better improvements in emotional well-being in the SMI group than the observed pooled effects.

2.7.5 Disability

Eighteen studies^{1,11,13,16,22-26,28,29,30,32,36,40,42,44,47} examined the SMI effects on disability. Several outcomes were used to measure disability, including the Bath Ankylosing Spondylitis Functional Index (BASFI), SF-36, AIMS-2, Health Assessment Questionnaire (HAQ), Modified Health Assessment Questionnaire

(mHAQ), IRGL, Hannover Functional Ability Questionnaire (FFbH), Bath Ankylosing Spondylitis Patient Global Score (BAS-G), and Disabilities of the Arm, Shoulder, and Hand Questionnaire (DASH). Five studies^{13,23,26,29,40} demonstrated beneficial effects on disability. One study¹³ demonstrated improvements in disability at 8 weeks using the BASFI ($p<.0001$). Other studies have demonstrated similar results at 12 weeks ($p=0.013$) and at 18 weeks ($p=0.031$) using DASH²⁹; at 24 weeks ($p=0.002$) using BASFI⁴⁰; and at 1 year ($p=0.02$) using the BAS-G²⁶ (Kjeken et al. 2013).

2.7.6 Knowledge

Three of the included studies^{2,33,40} explored the benefits of the SMIs on improving participants' disease-related knowledge and self-management behaviours. Knowledge was measured using Likert scales and the Patient Knowledge Questionnaire (PKQ). Only one of these studies⁴⁰ with 756 participants demonstrated beneficial effects at 24 weeks on disease-related knowledge ($p=0.0041$); knowledge of lifestyle and ergonomics ($p=0.003$); and knowledge of exercise ($p=0.001$).

2.7.7 Engagement with Self-management Behaviours

Eight studies^{3,17-19,34,35,44,47} explored SMIs effects on participant's engagement with self-management behaviours. Five different outcome measures were used including the Patient Activation Measure (PAM), Joint Protection Behaviour Assessment (D-JPBA-S), Self-Management Ability Scale (SMAS), Medication Adherence Questionnaire (MAQ), and the Appraisal of Self-Care Agency Scale (ASA-A). Three of these studies^{17,34,35} showed improvements in participant's engagement. One study³⁴ with 53 participants yielded positive effects ($p=0.008$) on engagement with joint protection techniques at 3 months using the D-JPBA-S. These benefits were sustained at 12 months³⁵. One other study¹⁷ with 141 participants demonstrated similar improvements ($p=0.01$) at 4 months using PAM; however, these benefits were not sustained at 12-months¹⁸.

2.8 SYNTHESIS OF QUALITATIVE FINDINGS

Fifteen of the included studies^{4,6,9,12,14,20,21,24,27,31,38,39,41,45,48} explored the experiences of PLwIA and HCPs. This review was unable to identify any papers exploring the family members perceptions of the acceptability of the SMIs. A total of 118 findings and their illustrations were extracted. Of these findings, 88 were unequivocal (U) and 30 were credible (C) (Table 2.9-2.10). These findings were organised into 14 categories, which were further deduced into 2 synthesised findings.

2.8.1 Synthesised Finding 1: IA SMIs are reported to have a wide range of benefits for PLwIA and HCPs with low burden on both groups. These outcomes should be considered by groups and individuals when developing future SMIs.

This synthesised finding was developed from eight categories and 51 findings (Table 2.9). It describes the benefits experienced by PLwIA and HCPs following exposure to the SMI and represents the following categories: perceptions of PLwIA and HCPs regarding IA SMIs; PLwIA had improved understanding and ability to manage their fatigue; the health problems of PLwIA were validated by the SMI and HCPs; PLwIA had increased their engagement with self-management strategies; PLwIA had increased self-efficacy; PLwIA were more aware of their emotions and had better emotional regulation; PLwIA were better able to communicate about their needs and diagnosis with others; the SMI led to a range of other benefits for PLwIA; and benefits to HCPs.

Table 2.9 Synthesised Finding 1: IA SMIs are reported to have a wide range of benefits for PLwIA and HCPs with low burden on both groups. These outcomes should be considered by groups and individuals when developing future SMIs.

Categories	Findings	Illustrations
1.1: PLwIA had improved the understanding and ability to manage their fatigue	Exploration of fatigue in the context of their own lives (C)	"Well you can read all the things on the um internet, whatever, or read pamphlets about what the illness entails, but you don't know where you fit into it, you don't know how it's going to affect you." -E11, PLwIA (Dures et al. 2011 p.496)
	Increased engagement with self-management behaviours (U)	"It started me... paying a bit more attention to things like sleep and diet and lifestyle, but actually specifically thinking about how those could affect the fatigue... I'm sure the sessions helped with that." -C344, PLwIA (Berry et al. 2022 p.8)
	Greater acceptance of RA and fatigue (C)	"...fatigue is very much part and parcel of this condition and what the course has done is put perspective on that and also an acceptance." -H08, PLwIA (Dures et al. 2011 p.499)
	Reduction in fear of becoming fatigued (U)	"I think I was very scared of the fatigue bit before because I don't think I really understood it, I'm not so scared of it [fatigue] now." -D15, PLwIA (Dures et al. 2011 p.499)
	Increased their sense of control (U)	"It just feels like I've got more control over fatigue... it's given me permission and a licence to give myself that care, which I don't think I was allowing myself before." -D468, PLwIA (Berry et al. 2022 p.8)
	Increased confidence to manage fatigue (U)	"Some days... take you into nothing but red activity and today is heading in that direction. I will be ill if I allow that to happen, therefore it's in my control. I can either do something about it and not feel so bad tomorrow, or ignore it and not be able to get up tomorrow." -B229, PLwIA (Berry et al. 2022 p.9)
	Improved coping skills (U)	"You might not be able to control the fatigue, you know that's going to be there, it's the feature of this condition but you can control how you manage it." -M02, PLwIA (Dures et al. 2011 p.499)
	Sessions helped them to accept their fatigue (U)	"It's not the be all and the end all now. I accept it is part of the condition, I accept that it might be there more prominent some days than others, or some weeks than others. And there's no point worrying about it." -A103, PLwIA (Berry et al. 2022 p.7)
	Change in lifestyle would not affect their symptoms of fatigue (U)	"I think my condition is governing my fatigue and I don't think there's anything that... I think it is what it is and I think for me the big thing is being more aware of it." -D461, PLwIA (Berry et al. 2022 p.8)
1.2: The health problems of PLwIA were validated by the SMI and HCPs	Feeling of being realized as more than the disease (U)	"For me personally, it is important not just to be an ill person. I mean the fact that I am a whole person even though I have a chronic disease. Yes, they [the topics in the VTP] reminded me of it. I got it confirmed that I really am a whole person in spite of being an ill person. I realize this, but it really makes a difference to work on it. I am not only a disease, I am so much more." -IA group 5, PLwIA (Zangi et al. 2011 p.421)
	Beneficial to have their fatigue validated (U)	"Just that the fatigue is acknowledged... having a medical professional sit in front of you and say 'this is a thing... we understand it's a thing, we can't explain why it's a thing and we can't give you a tablet to fix it, but we understand it is a thing'." -D466, PLwIA (Berry et al. 2022 p.6)
	The program validated the experience of having inflammatory illness, provided empathy, and was a positive experience overall (C)	"Lots of information. It pertains to what you're going through. You know what you thought was just out there and then oh, that's what they're describing; it's happening to me so now I have a reason for it." -Speaker 2, PLwIA (Bain et al. 2016 p.2324)

Categories	Findings	Illustrations
1.2 Cont.	Recognizing oneself as both ill and healthy (U)	"I have never liked my weak side, like needing rest and care and such, I have never really liked this. Now I just have to accept it. And in fact I really like this side of myself, it is more human, I think it has completely different facets." -FM group 2, PLwIA (Zangi et al. 2011 p.421)
	Benefits of the therapeutic relationship developed with occupational therapists (C)	"The therapist actually listened to me, you know, asked me about my experience of having the RA rather than telling me what I should expect! This put me at ease, I found just talking to her about my problems and her acknowledgement of these made me feel better about it." -6003, PLwIA (Prior et al. 2017 p.44)
1.3: PLwIA had increased their engagement with self-management strategies	Attitude of commitment to change (C)	"The thing is you have to think of what you're doing and why you're doing it; you've been doing things out of habit for 40 years. You think it's not something very useful, I just do it because I've always done it. You question a few things and you get to do them differently, but I honestly think that maybe you didn't think that way until somebody brought it up at the course. So you think, I could do that way and there's a beneficial way of doing it. So, I'm saving myself a lot of energy and doing it much better now." -Speaker 4, PLwIA (Bain et al. 2016 p.2324)
	Patients appreciated the range of topics covered (U)	"It reinforced really what I should do, and what I needed to think about, and that was helpful... I mean I knew about trying to get proper sleep and relaxation. Trying to pace oneself, those kinds of things." -C343, PLwIA (Berry et al. 2022 p.6)
	Understanding and knowledge of medicines had changed (U)	"Before, I just took pills (...) Now, I pay more attention to them (...). I'm more conscious and watchful and I have more respect for them [the medicines]." -Male living with RA from IG, PLwIA (Grønning, Midttun and Steinsbekk 2016 p.5)
	Identify how they were driving their behaviours (U)	"The one that um helped me most was the one about pacing yourself throughout the day because I personally was on my own little personal guilt trip about feeling tired all the time, not finishing things properly and it wasn't until I came here and they started talking about pacing and really going into it, that I realized that that's just what I wasn't doing." -H08, PLwIA (Dures et al. 2011 p.497)
	Intervention group participants valued the practical advice received (U)	"Yes, the advice I got was really helpful, because it made you realise what things did help you for the better and, you know, how to look after yourself a bit more. I learned to listen and appreciate what my body is telling me, you know, things like I take regular breaks to reserve my energy now to keep going and have a better sleep hygiene." -4002, PLwIA (Prior et al. 2017 p.42)
	New ways of thinking (U)	"We were challenged in a very gentle, professional way, we were challenged. But actually it did make me think about what I was doing and take responsibility actually." -D15, PLwIA (Dures et al. 2011 p.497)
	Intervention group participants had applied the strategies learned from the work rehabilitation programme (U)	"I have been more aware of trying to really take breaks and listen to my body in terms of not try and always do things, and go at a good pace so that I'm not going to irritate my condition in any way. So now I know I can't go at a speed as I did before and expect to do it all over again the next day. I know I must slow down and listen to my body. This way I get more done, even though it may take me a little longer to do things." -4006, PLwIA (Prior et al. 2017 p.42)
	Determined to continue with these actions and behaviours (C)	"I have become more conscious about reducing stress. We talked about such things in the course, and I think I manage this well. I kind of woke up." -Male living with IA from IG, PLwIA (Grønning, Midttun and Steinsbekk 2016 p.5)
	One man had up-taken relaxing techniques he had learned many years ago (C)	"This [the technique] is something I have done more consciously lately. We discussed such techniques in the meetings and I got reminded about stuff I used to know, but somehow had forgotten." -Male living with RA from IG, PLwIA (Grønning, Midttun and Steinsbekk 2016 p.5)

Categories	Findings	Illustrations
1.3 Cont.	Patients set their own behaviour change goals (U)	"We're all totally different people with different lifestyles and so you try to reach those goals within your own lifestyle and I knew where mine um differed and I knew where mine needed to go." -M09, PLwIA (Dures et al. 2011 p.497)
	Learning to be more analytical (U)	"Learning from my own experiences and just analysing that in a very different way... so it sort of gave me a bit of a distance actually, and a bit of a capacity to be um slightly, well slightly more analytical about it." -M02, PLwIA (Dures et al. 2011 p.498)
	Clearer understanding of the symptom, enhanced problem-solving skills, and a new way of responding to inevitable challenges (U)	"I do things in a much more calculated way, that doesn't mean to say I have a sterile life, you know without any surprises. But things are done in a much more measured fashion instead of like a bull in a China shop." -K08, PLwIA (Dures et al. 2011 p.499)
1.4: PLwIA had increased self-efficacy	EXTRA gave some participants new skills, understanding and confidence which lead to a sense of empowerment (C)	"It builds up your confidence, if you know you are doing the right things for your body, you know what I mean? and then if you see progress, you feel your confidence build up." -Bella, PLwIA (Bearne et al. 2017 p.432)
	Factors affecting motivation- reflective (C)	"Given confidence to do more [sic]." -Anonymous, PLwIA (Salmon 2016 p.264)
	Confidence made them feel empowered (C)	"It was like some missing pieces fell into place (...) I don't care about what others say anymore. We agreed at the course that we, who are sick, are the only ones who really know how we feel." -Female living with PsA from IG, PLwIA (Grønning, Midttun and Steinsbekk p.4)
1.5: PLwIA were more aware of their emotions and had better emotional regulation	Becoming aware that feelings of anger and frustration had been like heavy burdens (U)	"I have started to understand that anger can be very positive and that I need it in any case, because then you get rid of tension, and in a way you may get rid of a big heavy backpack, like we were talking about, and as I said, now I only have a small nylon knapsack. Anger has kinda developed into something that lets you set limits, and you are even allowed to say no." -IA group 3, PLwIA (Zangi et al. 2011 p.422)
	Reduction in unhelpful feelings of guilt (U)	"I don't feel guilty because I don't call myself lazy anymore." -M09, PLwIA (Dures et al. 2011 p.499)
	Recognizing own emotions (U)	"It has been very important to acknowledge my sorrow over no longer being healthy. It is a fundamental feeling, as we are of course in the middle of life and everyone else is healthy and they expect that we are too, and there we are feeling desperate at having lost something that is so valuable." -FM group 2, PLwIA (Zangi et al. 2011 p.421)
	Important to recognize emotions that they previously had labelled as negative (U)	"They [the topics in the VTP] touched on something that I don't think I wanted to admit to myself. I mean something that, consciously or unconsciously, I was leaving alone, as I think I used to regard myself as a positive person, someone who tried to look on the bright side of everything, and when my body started to tell me something else, I noticed that I was on a shorter fuse, that my anger and irritation were far nearer than I thought." -FM group 2, PLwIA (Zangi et al. 2011 p.422)
1.6: PLwIA were better able to communicate about their needs and diagnosis with others	Reluctant about talking about limitations (U)	"I don't like to talk about being ill. I have pain, and that is life. You don't need to talk to anyone about it." -Female living with RA from CG, PLwIA (Grønning, Midttun and Steinsbekk p.4)
	Setting boundaries (U)	"After using the program, I started to communicate about my illness to others. I explained them what RA is and requested that they do not ask too much." -Low user, PLwIA (Zuidema et al. 2019b p.1174)
	Acknowledged their individual capacity (U)	"If someone asks: Can you lend me a hand? I just say that I cannot because I do not have a body for it (...) It is quite simple!" -Male living with RA from IG, PLwIA (Grønning, Midttun and Steinsbekk p.3)

Categories	Findings	Illustrations
1.6 Cont.	Permission to say "no" and set one's own limits (U)	"Help! I had said "no" to someone. I don't usually do this. So, it was very peculiar to think about after I had done it... I usually only say 'yes'..., but now I have been better at thinking of myself... Those round me respect me when I say 'no'... absolutely, they have always said that I should think more of myself. In fact, I really said 'no' before, but with a really bad conscience and stomach-ache, but now I say "no" with a far better conscience." -IA group 7, PLwIA (Zangi et al. 2011 p.422)
	Felt guilty if they had to turn others down and rather avoided such situations or pushed themselves harder (C)	"It is a bit difficult to handle that you are not able to do the things you used to do." - Female living with RA from CG, PLwIA (Grønning, Midttun and Steinsbekk p.4)
	Better communication (U)	"I think my friends and family, I would try and keep going and keep up with them instead of telling them about my illness and how I might feel, but now I do... And that's how I am with my family a lot, that has brought us quite a lot closer together." -A03, PLwIA (Dures et al. 2011 p.499)
1.7: The SMI led to a range of other benefits for PLwIA	Sessions led to planning for future lifestyle changes (C)	"It's very easy to get into a rut and just do each day as it comes, and don't even think about going forward or anything else... Having things to aim for... I have already booked a few things and doing things in the future." -D465, PLwIA (Berry et al. 2022 p.8)
	Reengagement in previously abandoned activities (U)	"And I have gone back to sewing, I do a lot of machine embroidery, patchwork, and so on." -F07, PLwIA (Dures et al. 2011 p.499)
	Increased social participation (U)	"I do more, going and meeting new people as well and that's really good." -H03, PLwIA (Dures et al. 2011 p.499)
1.8: Benefits to HCPs	More confident talking about fatigue (C)	"I liked the communication one [session] and I've used some of those concepts a lot in clinic because I feel that it's quite useful even in, a few sentences in the clinic we have got somebody who has got fatigue and they're isolating themselves, you can talk to them about communicating with friends and family." -INT12, HCP (Hewlett et al. 2019 p.58)
	Working with the whole person (U)	"I feel I'm a better practitioner, I feel I'm more compassionate and empathetic. I think I look at them much more holistically as opposed to 'Right what dog can I throw at them now?'" -INT3, HCP (Hewlett et al. 2019 p.57)
	A different way of working (U)	"I wasn't used to that kind of role, the cognitive-behavioural role rather than, just, as a nurse you just want to help them and say 'Yes, I'll do that for you' so it was changing my kind of way of thinking." -INT3, HCP (Hewlett et al. 2019 p.52)
	Integrating the intervention approach and materials into routine practice (U)	"I have already taken advice from the manual and repeated it to PLwIAs in clinic. Snippets of useful information is a quick and easy way of helping PLwIAs when I am more pressed for time in a 'normal' clinic setting." -DTTM1, HCP (Berry et al. 2022 p.10)
	Increased confidence in ability to do a work assessment (U)	"I've altered the way that I probably discuss with patients the work having been on the course because I look at things differently and therefore I ask more delving questions and I would go into things more deeply than I have done before and looking at things like, particularly, equipment and talking about trolleys and computer equipment and things perhaps more deeply than I would have done before. So it's made me be aware much more of what I can do." -OT04, HCP (Prior et al. 2015 p.471)
	Knowing how to draw things out, sit back and listen (U)	"I think as nurses you tend to often want to give the answer all the time and give advice and it's very nurse-y to do that, but it's learning when to listen and stand back and try and get the patients to find the answers more rather than you delivering the answers to them and the solutions all the time." -INT6, HCP (Hewlett et al. 2019 p.57)

Categories	Findings	Illustrations
1.8 Cont.	Those with less experience of providing fatigue support reported gaining confidence (U)	<i>"As I've been doing the sessions, the more confident I've got, part of it is knowing the people, but also knowing the material as well. I've really enjoyed it, because you can see how much a patient is getting out of it." -CTTM1, HCP (Berry et al. 2022 p.9)</i>
	Lack of previous experience in using structured assessments (U)	<i>"I was feeling the need to do everything and tick all the boxes, whereas previously on the trial, one that I'd done with the mentor over the phone, I hadn't and I wouldn't normally do that, and it was just interesting that it's just becoming familiar with using a lengthy standardized assessment I think." -OT02, HCP (Prior et al. 2015 p.470)</i>
	New skills reinforced her role within the team (U)	<i>"As I got more clients to work with, it became easier to do. Some of the things it was all very new to me... I'd never, kind of, done adaptive work around keyboards and what have you, but the manual [Work Rehabilitation Resource Manual] was really helpful for that and, again, there was always a person at the end of a telephone, so, you know, I've worked away with some experience of those areas now. It has led to changes in practice, it's still on-going at work, we still get referrals for people with work issues, so it's definitely highlighted my role or reinforced my role within the team and it's quite nice." -OT03, HCP (Prior et al. 2015 p.471)</i>

2.8.1.1 Category 1.1: PLwIA had improved their understanding and ability to manage their fatigue

This category was developed from illustrations representing PLwIAs' improved understanding, acceptance, and ability to manage their fatigue following the SMI. It represents nine findings (7 unequivocal and 2 credible) from two studies^{9,14}. Four unequivocal findings discuss that the IA SMI helped PLwIA to better understand their fatigue and the factors that can influence the severity of their fatigue.

"I think I was very scared of the fatigue bit before because I don't think I really understood it, I'm not so scared of it [fatigue] now." -D15, PLwIA (Dures et al. 2011 p.499)

"It started me... paying a bit more attention to things like sleep and diet and lifestyle, but actually specifically thinking about how those could affect the fatigue... I'm sure the sessions helped with that." -C344, PLwIA (Berry et al. 2022 p.8)

The remaining four unequivocal findings highlight that this improved understanding helped PLwIA accept their fatigue and perceive they were in control for how they manage their fatigue.

"It's not the be all and the end all now. I accept it is part of the condition, I accept that it might be there more prominent some days than others, or some weeks than others. And there's no point worrying about it." -A103, PLwIA (Berry et al. 2022 p.7)

"It just feels like I've got more control over fatigue... it's given me permission and a licence to give myself that care, which I don't think I was allowing myself before." -D468, PLwIA (Berry et al. 2022 p.8)

2.8.1.2 Category 1.2: The health problems of PLwIA were validated by the SMI and HCPs

This category was developed from five findings (3 unequivocal and 2 credible) from four studies^{4,9,39,45}. PLwIA had their health problems and the associated challenges validated by the SMI and HCPs.

"The therapist actually listened to me, you know, asked me about my experience of having the RA rather than telling me what I should expect! This put me at ease, I found just talking to her about my problems and her acknowledgement of these made me feel better about it." -6003, PLwIA (Prior et al. 2017 p.44)

This had helped PLwIA to realise themselves as more than their disease.

"For me personally, it is important not just to be an ill person. I mean the fact that I am a whole person even though I have a chronic disease. Yes, they [the topics in the VTP] reminded me of it. I got it confirmed that I really am a whole person in spite of being an ill person. I realize this, but it really makes a difference to work on it. I am not only a disease, I am so much more." -IA group 5, PLwIA (Zangi et al. 2011 p.421)

2.8.1.3 Category 1.3: PLwIA had increased their engagement with self-management strategies

This category was developed from illustrations representing the increased engagement with self-management strategies by PLwIA following their participation in a SMI. It represents twelve findings (9 unequivocal and 3 credible) from six studies^{4,9,14,20,39,45}. Three findings (2 unequivocal and 1 credible) describe that PLwIA were more aware of their behaviours following the SMI, which led them to take more responsibility over the management of their disease and increased their engagement with self-management strategies.

"The thing is you have to think of what you're doing and why you're doing it; you've been doing things out of habit for 40 years. You think it's not something very useful, I just do it because I've always done it. You question a few things and you get to do them differently, but I honestly think that maybe you didn't think that way until somebody brought it up at the course. So you think, I could do that way and there's a beneficial way of doing it. So, I'm saving myself a lot of energy and doing it much better now." -Speaker 4, PLwIA (Bain et al. 2016 p.2324)

Specifically, six findings (4 unequivocal and 2 credible) describe that PLwIA increased their use of self-management strategies that helped to preserve their energy, such as pacing, taking regular breaks, relaxation techniques, and strategies that improve their quality of sleep.

"Yes, the advice I got was really helpful, because it made you realise what things did help you for the better and, you know, how to look after yourself a bit more. I learned to listen and appreciate what my body is telling me, you know, things like I take regular breaks to reserve my energy now to keep going and have a better sleep hygiene." -4002, PLwIA (Prior et al. 2017 p.42)

"It reinforced really what I should do, and what I needed to think about, and that was helpful... I mean I knew about trying to get proper sleep and relaxation. Trying to pace oneself, those kinds of things." -C343, PLwIA (Berry et al. 2022 p.6)

Two unequivocal findings describe that PLwIA had enhanced problem-solving skills, which helped them to be more analytical in how they approach the management of their diagnosis.

"I do things in a much more calculated way, that doesn't mean to say I have a sterile life, you know without any surprises. But things are done in a much more measured fashion instead of like a bull in a China shop." -K08, PLwIA (Dures et al. 2011 p.499)

Two other findings also describe that PLwIA were more mindful of how they took their medication, and they were managing their stress better.

"Before, I just took pills (...) Now, I pay more attention to them (...). I'm more conscious and watchful and I have more respect for them [the medicines]." -Male living with RA from IG, PLwIA (Grønning, Midttun and Steinsbekk 2016 p.5)

"I have become more conscious about reducing stress. We talked about such things in the course, and I think I manage this well. I kind of woke up." -Male living with IA from IG, PLwIA (Grønning, Midttun and Steinsbekk 2016 p.5)

2.8.1.4 Category 1.4: PLwIA had increased self-efficacy

This category was developed from three credible findings from three studies^{6,20,41} describing that PLwIA report increased self-efficacy following their participation in a SMI.

"It was like some missing pieces fell into place (...) I don't care about what others say anymore. We agreed at the course that we, who are sick, are the only ones who really know how we feel." -Female living with PsA from IG, PLwIA (Grønning, Midttun and Steinsbekk p.4)

"It builds up your confidence, if you know you are doing the right things for your body, you know what I mean? and then if you see progress, you feel your confidence build up." -Bella, PLwIA (Bearne et al. 2017 p.432)

2.8.1.5 Category 1.5: PLwIA were more aware of their emotions and had better emotional regulation

This category was developed from four unequivocal findings from two studies^{14,45} describing that PLwIA became more aware of their emotions and were better able to identify them.

"They [the topics in the VTP] touched on something that I don't think I wanted to admit to myself. I mean something that, consciously or unconsciously, I was leaving alone, as I think I used to regard myself as a positive person, someone who tried to look on the bright side of everything, and when my body started to tell me something else, I noticed that I was on a shorter fuse, that my anger and irritation were far nearer than I thought." - FM group 2, PLwIA (Zangi et al. 2011 p.422)

This awareness was attributed to better emotional regulation in two PLwIA.

"I don't feel guilty because I don't call myself lazy anymore." -M09, PLwIA (Dures et al. 2011 p.499)

"I have started to understand that anger can be very positive and that I need it in any case, because then you get rid of tension, and in a way you may get rid of a big heavy backpack, like we were talking about, and as I said, now I only have a small nylon knapsack. Anger has kinda developed into something that lets you set limits, and you are even allowed to say no." -IA group 3, PLwIA (Zangi et al. 2011 p.422)

2.8.1.6 Category 1.6: PLwIA were better able to communicate about their needs and diagnosis with others

This category was developed from six findings (5 unequivocal and 1 credible) from four studies^{14,20,45,48}. Five of these findings representing the improved ability of

PLwIA to communicate about their needs and diagnosis with others following the SMI.

"After using the program, I started to communicate about my illness to others. I explained them what RA is and requested that they do not ask too much." -Low user, PLwIA (Zuidema et al. 2019b p.1174)

"If someone asks: Can you lend me a hand? I just say that I cannot because I do not have a body for it (...) It is quite simple!" -Male living with RA from IG, PLwIA (Grønning, Midttun and Steinsbekk p.3)

This contrasts with PLwIA who did not take part in the SMI that express reluctance to disclose about their health status with others.

"I don't like to talk about being ill. I have pain, and that is life. You don't need to talk to anyone about it." -Female living with RA from CG, PLwIA (Grønning, Midttun and Steinsbekk p.4)

2.8.1.7 Category 1.7: The SMI led to a range of benefits for PLwIA

This category was developed from two unequivocal and one credible finding from two studies^{9,14} representing the other benefits that PLwIA had reported following their participation in an SMI. Other benefits reported included planning for future lifestyle changes; reengagement with hobbies; and engaged more socially.

"I do more, going and meeting new people as well and that's really good" - H03, PLwIA (Dures et al. 2011 p.499)

"It's very easy to get into a rut and just do each day as it comes, and don't even think about going forward or anything else... Having things to aim for... I have already booked a few things and doing things in the future." -D465, PLwIA (Berry et al. 2022 p.8)

2.8.1.8 Category 1.8: Benefits to HCPs

This category represents nine findings (8 unequivocal and 1 credible) from three studies^{9,23,38} describing the SMIs' benefits for HCPs. One unequivocal finding describes that HCPs delivering the SMI became a more compassionate and empathetic practitioner.

"I feel I'm a better practitioner, I feel I'm more compassionate and empathetic. I think I look at them much more holistically as opposed to 'Right what dog can I throw at them now?'" -INT3, HCP (Hewlett et al. 2019 p.57)

Five findings (4 unequivocal and 1 credible) highlight that HCPs had taken information they had delivered during the SMI and implemented it into their daily practice. Specifically, the findings describe that HCPs changed how they communicated with PLwIA, particularly while answering questions or while discussing certain topics (e.g., how to communicate with their friends and family).

"I have already taken advice from the manual and repeated it to PLwIAs in clinic. Snippets of useful information is a quick and easy way of helping PLwIAs when I am more pressed for time in a 'normal' clinic setting." - DTTM1, HCP (Berry et al. 2022 p.10)

"I liked the communication one [session] and I've used some of those concepts a lot in clinic because I feel that it's quite useful even in, a few sentences in the clinic we have got somebody who has got fatigue and they're isolating themselves, you can talk to them about communicating with friends and family." -INT12, HCP (Hewlett et al. 2019 p.58)

However, the remaining three findings describe that it takes practice to become familiar with SMIs' content and to develop confidence in delivering the SMI.

"As I've been doing the sessions, the more confident I've got, part of it is knowing the people, but also knowing the material as well. I've really enjoyed it, because you can see how much a patient is getting out of it." -CTTM1, HCP (Berry et al. 2022 p.9)

2.8.2 Synthesised Finding 2: IA SMIs are generally acceptable to PLwIA and HCPs delivering the intervention. SMI characteristics that influence acceptability from the perspectives of PLwIA and HCPs should be carefully considered by groups or individuals developing future IA SMIs.

This synthesised finding was developed from six categories and 67 findings (Table 2.10). It describes the acceptability of SMIs from the perspectives of PLwIA and HCPs as well as the intervention characteristics that influence the SMIs' acceptability. This synthesised finding represents the following categories: perceptions of PLwIA and HCPs regarding the delivery of an IA SMI in a group

format; perceptions and preferences of PLwIA regarding education; perceptions of PLwIA regarding the SMIs' structure, setting and activities; perceptions of PLwIA regarding the SMI facilitator; and perceptions of PLwIA and HCPs regarding intervention users who are best suited to participate in the SMI.

2.8.2.1 Category 2.1: Perceptions of PLwIA and HCPs

This category was developed from illustrations representing PLwIA and HCPs perceptions of the IA SMIs. It represents seven findings (6 unequivocal and 1 credible) from five studies^{12,13,23,41,48}. Four findings (3 unequivocal and 1 credible) expressed that PLwIA and HCPs perceived the SMI to be very beneficial to PLwIA and their families.

"I can think of, well, quite a few patients said it's been life-changing." - INT10, HCP (Hewlett et al. 2019 p.59)

"...it's made a massive difference to me, to my whole family, the whole family so it's positive." -JG01, PLwIA (Dures et al. 2011 p.499)

Two unequivocal findings also describe that PLwIA were willing to put in the effort required to overcome the burden associated with attending the SMI, such as driving long distances and paying for petrol or parking.

"I had to jump, like 3 barriers, to get here because my husband had to switch his shift to be able to take my 6-year-old to school because I usually do it. Because, I had to be here earlier before. So, yeah, I had to do a lot to be able to come here." -Speaker 3, PLwIA (Bain et al. 2016 p.2325)

"I had to keep putting money in my car to get here from travelling all the time and obviously paying for parking." -Speaker 2, PLwIA (Bain et al. 2016 p.2325)

The remaining unequivocal finding highlights that HCPs expressed that their colleagues would be interested in delivering the SMIs in the future.

"...people would be engaged and interested to do it..." -Ph3, HCP (Cramp et al. 2020 p.496)

Table 2.10 Synthesised Finding 2: IA SMIs are generally acceptable to PLwIA and HCPs delivering the intervention. SMI characteristics that influence acceptability from the perspectives of PLwIA and HCPs should be carefully considered by groups or individuals developing future IA SMIs

Categories	Findings	Illustrations
2.1: Perceptions of PLwIA and HCPs regarding IA SMIs	Wonderful seeing how patients can benefit (U)	"I can think of, well, quite a few patients said it's been life-changing." -INT10, HCP (Hewlett et al. 2019 p.59)
	Suitable physiotherapists likely to be interested in delivering the intervention in future (U)	"...people would be engaged and interested to do it..." -Ph3, HCP (Cramp et al. 2020 p.496)
	Wide-ranging changes were experienced not only by patients but also by those close to them (U)	"...it's made a massive difference to me, to my whole family, the whole family so it's positive." -JG01, PLwIA (Dures et al. 2011 p.499)
	Support needs for self-management (C)	"I think when someone gets rheumatism, I would recommend this as this program could be a guidance." -High user, PLwIA (Zuidema et al. 2019b p.1173)
	Sessions (U)	"...not threatening- not over intense but helped me to focus on what I need to do to help myself." -Anonymous, PLwIA (Salmon 2016 p.266)
	Overcoming caregiving responsibilities (U)	"I had to jump, like 3 barriers, to get here because my husband had to switch his shift to be able to take my 6-year-old to school because I usually do it. Because, I had to be here earlier before. So, yeah, I had to do a lot to be able to come here." -Speaker 3, PLwIA (Bain et al. 2016 p.2325)
	Cost of attending the program was identified as the cost of accommodation, gas, and parking (U)	"I had to keep putting money in my car to get here from travelling all the time and obviously paying for parking." -Speaker 2, PLwIA (Bain et al. 2016 p.2325)
2.2: Perceptions of PLwIA and HCPs regarding the delivery of an IA SMI in a group format	RA might be assumed to be undesirable as it challenges almost every aspect of everyday life (C)	"Anna says that joining the programme made her reflect on many things related to her illness and her social relations... She says that she has come closer to an acceptance, partly as a result of the entire programme but particularly because she has been part of the group. She talks about having a common understanding and things having calmed her down." (Kristiansen and Antoft 2016 p.40)
	Feeling challenged (U)	"...it was the managing the group and actually when to try to stop somebody or try and include somebody else and the actual feeling at one point... you know the group can change and there are dynamics and sometimes it can feel quite... certainly, intimidating sometimes." -INT14, HCP (Hewlett et al. 2019 p.53)
	Vicarious learning (C)	"...whilst their problem may be the same as yours, their way of dealing with it is different." -P8, PLwIA (Cramp et al. 2020 p.493)
	Importance of opportunity to speak in one-to-one session (C)	"...sometimes when you are in a group you cannot tell your personal things..." -P16, PLwIA (Cramp et al. 2020 p.493)
	Group challenges (C)	"...there's always the one who will monopolize..." -P8, PLwIA (Cramp et al. 2020 p.493)
	Benefit of one-to-one session (C)	"...people don't tell things in the group necessarily that they would say individually..." -Ph3, HCP (Cramp et al. 2020 p.495)
	Active participants provided inspiration and acted as role models (U)	"...everyone else found it quite inspiring having him in the group and probably that had a bit more of an impact than some of the things I was facilitating..." -Ph2, HCP (Cramp et al. 2020 p.495)

Categories	Findings	Illustrations
2.2 Cont.	Alternative methods of communication (U)	<i>"It might have been useful to, like [have] a, I don't know, a follow-up, or an email or, I don't know, maybe that's why I wanted it to be a larger group, to make a connection with someone so that you can remind each other, "how are you getting on with the exercises?" so somebody else is doing them, it motivates me." -Catherine, PLwIA (Bearne et al. 2017 p.435)</i>
	Provided an opportunity for group members to compare their disease and exercise performance (U)	<i>"The main impression was just, wow, it affects so many different people, different ages, um, yeah I wasn't the youngest um, so... it was quite reassuring." -Janice, PLwIA (Bearne et al. 2017 p.434)</i>
	Attending EXTRA eased her feeling of isolation (U)	<i>"When you come to something like the classes... you realize that other people have got those problems." -Ellie, PLwIA (Bearne et al. 2017 p.434)</i>
	Being new to the RAFT programme together (U)	<i>"...you definitely have that camaraderie and that you can continue to bounce things off each other a little bit or whatever, I personally like that environment, and I like to learn in that way." -INT12, HCP (Hewlett et al. 2019 p.54)</i>
	Participants spoke positively about the support and learning gained from other group members (U)	<i>"I was happy, when we come together. It's good to share your problem, because we all got the same problem. I know one things works with you but they are not for me, but is still good to know what they doing." -Bella, PLwIA (Bearne et al. 2017 p.434)</i>
	Observing more disabled participants caused her to worry (U)	<i>"...if you see people... in very bad condition... you start to worry." -Bella, PLwIA (Bearne et al. 2017 p.434)</i>
	Factors affecting opportunity- social (U)	<i>"Liked meeting fellow RA sufferers and any tips they had with handling RA." -Anonymous, PLwIA (Salmon 2016 p.264)</i>
	Group format (C)	<i>"Again the forming of the group was imp [sic]. RA can make one feel isolate. V [sic] reassuring to hear people talk of how RA has affected them." -Anonymous, PLwIA (Salmon 2016 p.265)</i>
	Not the only ones dealing with the condition (U)	<i>"I think the biggest part of this illness is to be feeling alone with your pain unless you met a group... You don't isolate yourself and try to recover from it by yourself by thinking 'I'm the only one dealing with it,' which makes a world of benefit." -Speaker 1, PLwIA (Bain et al. 2016 p.2324)</i>
	Participants identified as a group living with a common condition and having common challenges (U)	<i>"...after a while, Joanne, one of the recently diagnosed women, asks whether the others knew about the problem with low toilets. She looks around in the group and says, "I'm in a torment when I have to get up again". At first, the group is very silent, but after a while, the women begin nutting their heads, and the younger lay expert says, "yes, I know that, too". The older lay expert comments that she could use the disabled toilet, as it has a higher toilet seat, so does she? Joanne looks at the older lay expert and says, "well, that's a problem when you don't feel handicapped enough to use it". The older lay expert smiles and says, "well, I do, then". Lisa, who has lived with RA for many years, smiles and laughs and then says, "well, there are people who won't admit that they are disabled". Joanne smiles back. Again, all the women start laughing loudly and launch into a very informal and humorous conversation on the topic of toilets...After a while, Joanne quietly says, "oh yes, I see." (Kristiansen and Antoft 2016 p.37)</i>
	[Participants] all experienced the onset and progression of RA to be unpredictable and de-regularised (U)	<i>"I talked to the others, and they told me that it fluctuates, it can get better, but it can also get worse. They said that you can feel good for a long time, but then, all of a sudden, it might change for the worse, and you can't tell why... I asked whether it could get worse again and some of the "older" (experienced) ones said that it probably would sooner or later or other side effects or complications might occur... Yes." -Anonymous, PLwIA (Kristiansen and Antoft 2016 p.40)</i>

Categories	Findings	Illustrations
2.2 Cont.	Experience of community had made them safe enough to approach and express their own feelings (U)	"What has been most important for me has been meeting other people with the same condition, or at any rate with a chronic condition that affects their daily life, and then being allowed to talk about all the negative feelings that I have had, all my defeats, my anger, disappointments, and vulnerability, which have been difficult to cope with outside this group." -IA group 2, PLwIA (Zangi et al. 2011 p.422)
	Working as a group (U)	"The opportunity to meet as a group is important because you don't feel that it's only you and you are in isolation." -E07, PLwIA (Dures et al. 2011 p.498)
	Stories from other patients in the patient education program were helpful (U)	"I think it was very positive with the course because you met others in the same situation. Then you kind of handle the disease differently, to put it that way." -Female living with PsA from IG (Grønning, Midttun and Steinsbekk 2016 p.3)
	Training for skills to manage group discussions (U)	"...people went off on massive tangents which is why it took a little longer, that's probably something I need to reflect and work on in the future..." -Ph3, HCP (Cramp et al. 2020 p.495)
2.3: Perceptions and preferences of PLwIA regarding education	Group members provided emotional support (U)	"You know it's just extremely useful being able to bounce things off other people and just see how they're managing it." -M02, PLwIA (Dures et al. 2011 p.498)
	Need for medication knowledge and understanding - Never took his prescribed medications (U)	"I need more information about my medicines before I dare taking them. I need to know more about how they work, how they will affect my body and such like." -Male living with PsA from CG (Grønning, Midttun and Steinsbekk 2016 p.5)
	Informed decision-making and problem-solving with the interprofessional team (U)	"If I know my choices, my options, what's going on, what to do and what not to do. I can make decisions for myself about how to manage this. If I don't have that information, I don't know what to do." -Speaker 2, PLwIA (Bain et al. 2016 p.2324)
	Need for more (scientific) in-depth information (U)	"That issue (about developments in medication) was in the media, that's one example, but I really have a need for this information about this issue. What is new about it and what could I do with it?" -High user plus, PLwIA (Zuidema et al. 2019b p.1173)
	Education to be presented in various formats (U)	"I prefer to receive the education orally. Written education could also work, but it would be better to discuss and to talk." -Anonymous, PLwIA (Haglund et al. 2017 p.6)
	Those who had read the booklet could not identify specific information that helped (C)	"I know I probably have read it because I do remember the pack, whether I've retained that information is another matter really. I think I'm probably one of them people who would have to see somebody face-to-face to retain the information." -6003, PLwIA (Prior et al. 2017 p.44)
2.4: Perceptions of PLwIA regarding the SMIs' structure, setting, and activities	Identifying local opportunities for PA (U)	"The people running it ought to find out first what group activities are available in the areas that people come from so that they could advise them." -P7, PLwIA (Cramp et al. 2020 p.492)
	Venue outside a healthcare setting (U)	"If its [EXTRA] outside a hospital it would kinda get you into the mind set of thinking, 'oh well, this isn't about, you know, hospital and drugs, this is about life and getting on with your life'." -Kay, PLwIA (Bearne et al. 2017 p.435)
	Timing of the sessions (U)	"Working participants suggested that weekly sessions 'at the beginning of the day or at the end of the day would have been easier'." -Catherine, PLwIA (Bearne et al. 2017 p.435)
	Preferred more weekly sessions (C)	"I guess six classes would have been good." -Kay, PLwIA (Bearne et al. 2017 p. 435)
	Programme organisation (U)	"A good structure to have 1 hr of learning and then 1 hr of physical exercise [sic]." -Anonymous, PLwIA (Salmon 2016 p.265)
	Engaging with CBT and learning new skills could be difficult (U)	"...he would be asking us questions... and my brain was totally blank because then I kept thinking, 'Try and understand what he's talking about' you know? But it does fall into place." -C11, PLwIA (Dures et al. 2011 p.498)

Categories	Findings	Illustrations
2.4 Cont.	Using visual illustrations to communicate complex issues (U)	"You don't make any real connections, but when you see it... that was a very good visual clue, and I didn't think that was going to be useful, but actually I found probably the most useful. It's such a visual representation of what you are doing, or where you are slacking or crashing or whatever it may be." -D465, PLwIA (Berry et al. 2022 p.7)
	Using visual illustration to visualise the impact of lifestyle patterns on their fatigue (U)	"That was the biggest wake up call for me... looking at the activity diary. Until you look at it - you could see that I didn't have any pattern or any sort of resemblance to any normality at all. Everything was just chaos." -B221, PLwIA (Berry et al. 2022 p.7)
	Patients were willing to try the tools and strategies (C)	"Obviously the activity diaries... I think they look at it, not realising the actual impact it has, once they've done it... they don't realise until they do it." -CTTM1, HCP (Berry et al. 2022 p.10)
	Keeping a PA log (U)	"...by doing the daily logs it allowed me to actually pace myself..." -P17, PLwIA (Cramp et al. 2020 p.493)
	Some materials were not as useful (U)	"There are better relaxation tapes; there are better guided visualisation tapes." -M02, PLwIA (Dures et al. 2011 p.498)
	Patients found the guided discovery process an effective method for working out their self-management strategies (C)	"What I liked about the course, they didn't tell us, they made us work it out ourselves." -F06, PLwIA (Dures et al. 2011 p.496)
	Personalised goals helped participants independently adapt EXTRA to their needs (U)	"...your goal... you write that in, and you work towards that... and it's a reminder, it's there, so you can turn back to the page and look at it... and, yeah, keep going." -Leila, PLwIA (Bearne et al. 2017 p.433)
	Diary created a sense of obligation (U)	"...I had to do it [the exercises] because I had to write it in that book [exercise diary]." -Fiona, PLwIA (Bearne et al. 2017 p.433)
	'Ask don't tell' approach helpful (C)	"Talking through my specific challenges with a bit of space, and a specialist to give me fresh ideas and not judge me... that one to one support and the time to talk about it, has been very, very welcome... very, very, helpful." -D468, PLwIA (Berry et al. 2022 p.6)
	New ways of thinking about their fatigue (U)	"They gave you like, you got ideas, you got ideas from it without being pushed into anything or feeling uneasy about it." -C10, PLwIA (Dures et al. 2011 p.496)
2.5: Perceptions of PLwIA regarding the SMI facilitator	Physiotherapists as the facilitator (U)	"...the advice from the physiotherapist was perfectly adequate..." -P7, PLwIA (Cramp et al. 2020 p.493)
	The individualised nature of the support was received positively (C)	"...you need to have trust in someone with knowledge of the condition and knowledge about physical exercise to be confident enough to say 'well this is hurting a bit but it's OK for me to do it.'" -P3, PLwIA (Cramp et al. 2020 p.494)
	The physiotherapist as a supportive facilitator and a knowledge professional (C)	"If you handed me a booklet and said 'go away and do it. I'd still want to be kind of talked through about what this was doing and why it was important... rather than just 'here's a booklet'." -Kay, PLwIA (Bearne et al. 2017 p.434)
	Continuing relationship with the physiotherapist was important (U)	"The first session, you get to know each other basically, but then the next session, if you have a different physiotherapist, you have to start from the beginning. I prefer to have the same physiotherapist. I know they see lots of people and it's impossible for them to remember everything about you, I understand that. But it was every week so it's easy [for the physiotherapist] to remember." -Bella, PLwIA (Bearne et al. 2017 p.435)
	Unlikely to receive appropriate professional support if they exercised outside a healthcare facility (U)	"A physical instructor [at a gym] would have to know what he's doing, know about the muscles and joints and how they work, like a physio really, to be able to manage a class with people who have rheumatoid arthritis, to be able to instruct them to do their exercises. For me, I would prefer a physio because she's in the hospital... she's qualified for the job." -Leila, PLwIA (Bearne et al. 2017 p.435)

Categories	Findings	Illustrations
2.5 Cont.	Course leaders (C)	"The support of the people running the group was wonderful." -Anonymous, PLwIA (Salmon 2016 p.265)
	How and by whom the PLwIA education was communicated (U)	"Advice and information should come from people who work with it, people who know what they're talking about." -Anonymous, PLwIA (Haglund et al. 2017 p.6)
	Emotionally uplifting in multiple ways (C)	"The feeling I get is they try very hard to be a good mix of realism and that knowledge, but still giving us opportunities to make choices and think about it and there doesn't seem to be a heck of a lot of pressure." -Speaker 1, PLwIA (Bain et al. 2016 p.2324)
	Factors affecting motivation-automatic (U)	"Making one see that it is not a downward spiral and that things can be done to stabilize or reverse the emotional and some physical issues." -Anonymous, PLwIA (Salmon 2016 p.264)
	Therapist's role in getting them to engage with fatigue-related issues was recognized as vital (U)	"We couldn't have got through it on our own just talking about it on our own..." -F05, PLwIA (Dures et al. 2011 p.498)
	Physiotherapist encouraging, reassuring and motivating (U)	"One therapist '...had a lot of energy, he was quite, you know, tryin' to kinda motivate us and tryin' to help us understand things." -Janice, PLwIA (Bearne et al. 2017 p.434)
	Discussions sometimes challenged participant's perceptions and assumptions (C)	"My main concern was that, if I was exercising whilst I was in pain, was I actually causing damage to the muscles and joints? The physiotherapist kind of said that, 'even if you feel pain, you should still carry on exercising'." -Catherine, PLwIA (Bearne et al. 2017 p.433)
2.6: Perceptions of PLwIA and HCPs regarding intervention users who are best suited to participate in the SMI	Timing of intervention in the care pathway (U)	"I wish it had been available at the beginning because some of the problems, some of the reason why I'm detached from the rest of the world is because in the early days I just and let it all fade away..." -P3, PLwIA (Cramp et al. 2020 p.493)
	Offered sooner after diagnosis (U)	"I wonder if it could be done sooner, especially the education aspects..." -Ph1, HCP (Cramp et al. 2020 p.495)
	Participating as a last resort (U)	"I think it's whether people are at the end of their tether who decide to commit to a course like this." -Speaker 1, PLwIA (Bain et al. 2016 p.2324)
	Some patients require a higher intensity approach and level of support (U)	"Most of the ones who contributed to the study are proactive, and want to change, and they are willing to make changes. And then you have got other patients... who think that we can fix them by giving them a tablet, and we can't. And they put up obstacles about everything you say... but I understand it's hard..." -BTM1, HCP (Berry et al. 2022 p.10)

2.8.2.2 Category 2.2: Perceptions of PLwIA and HCPs regarding the delivery of an IA SMI in a group format

This category was developed from 22 findings (16 unequivocal and 5 credible) from nine studies^{4,6,12,14,20,24,27,41,45}, representing the perceptions of PLwIA and HCPs relating to the delivery of an IA SMI in a group format. Of the findings, 16 (13 unequivocal and 3 credible) describe that PLwIA perceive the group format to be beneficial as it presents an opportunity for them to meet others living with the same or similar condition; learn from others on how to manage their condition; and reduces isolation.

"I was happy, when we come together. It's good to share your problem, because we all got the same problem. I know one things works with you but they are not for me, but is still good to know what they doing." -Bella, PLwIA (Bearne et al. 2017 p.434)

"I think the biggest part of this illness is to be feeling alone with your pain unless you met a group... You don't isolate yourself and try to recover from it by yourself by thinking 'I'm the only one dealing with it,' which makes a world of benefit." -Speaker 1, PLwIA (Bain et al. 2016 p.2324)

"What has been most important for me has been meeting other people with the same condition, or at any rate with a chronic condition that affects their daily life, and then being allowed to talk about all the negative feelings that I have had, all my defeats, my anger, disappointments, and vulnerability, which have been difficult to cope with outside this group." -IA group 2, PLwIA (Zangi et al. 2011 p.422)

However, one finding described that the group format can cause some PLwIA to potentially worry after witnessing more disabled PLwIA.

"...if you see people... in very bad condition... you start to worry." -Bella, PLwIA (Bearne et al. 2017 p.434)

Two credible findings from the perspectives of PLwIA and HCPs had also highlighted that a group format may prevent some PLwIA from disclosing personal information.

"...people don't tell things in the group necessarily that they would say individually..." -Ph3, HCP (Cramp et al. 2020 p.495)

The remaining two findings describe that HCPs found it difficult at times to manage group dynamics.

"...it was the managing the group and actually when to try to stop somebody or try and include somebody else and the actual feeling at one point... you know the group can change and there are dynamics and sometimes it can feel quite... certainly, intimidating sometimes." -INT14, HCP (Hewlett et al. 2019 p.53)

2.8.2.3 Category 2.3: Perceptions and preferences of PLwIA regarding the importance of education to make informed decisions

This category was developed from six findings (5 unequivocal and 1 credible) from five studies^{4,20,21,39,48} and represents the perceptions of PLwIA regarding the importance of education to make informed decisions and decrease ambiguity surrounding medication and diet.

"I need more information about my medicines before I dare taking them. I need to know more about how they work, how they will affect my body and such like." -Male living with PsA from CG (Grønning, Midttun and Steinsbekk 2016 p.5)

"If I know my choices, my options, what's going on, what to do and what not to do. I can make decisions for myself about how to manage this. If I don't have that information, I don't know what to do." -Speaker 2, PLwIA (Bain et al. 2016 p.2324)

Two findings (1 unequivocal and 1 credible) highlight that PLwIA prefer this education to be delivered verbally and face-to-face.

"I prefer to receive the education orally. Written education could also work, but it would be better to discuss and to talk." -Anonymous, PLwIA (Haglund et al. 2017 p.6)

2.8.2.4 Category 2.4: Perceptions and preferences of PLwIA regarding the SMIs' structure, activities, and setting

This category was developed from illustrations representing the perceptions and preferences of PLwIA regarding the SMIs' structure, activities, and setting. It was

developed from 16 findings (12 unequivocal and 4 credible) from five studies^{6,9,12,14,41}. Three findings (2 unequivocal and 1 credible) describe the preferences of PLwIA on the duration and timing of the SMIs.

"I guess six classes would have been good." -Kay, PLwIA (Bearne et al. 2017 p. 435)

"Working participants suggested that weekly sessions 'at the beginning of the day or at the end of the day would have been easier'." -Catherine, PLwIA (Bearne et al. 2017 p.435)

"A good structure to have 1 hr of learning and then 1 hr of physical exercise [sic]." -Anonymous, PLwIA (Salmon 2016 p.265)

One finding described that PLwIA preferred the SMI to take place outside of the hospital.

"If its [EXTRA] outside a hospital it would kinda get you into the mind set of thinking, 'oh well, this isn't about, you know, hospital and drugs, this is about life and getting on with your life'." -Kay, PLwIA (Bearne et al. 2017 p.435)

The remaining findings relate to the perceptions and preferences of PLwIA regarding the intervention activities. Cognitive behavioural therapy (CBT) was perceived by PLwIA as an acceptable approach for determining self-management strategies to implement into their daily lives.

"They gave you like, you got ideas, you got ideas from it without being pushed into anything or feeling uneasy about it." -C10, PLwIA (Dures et al. 2011 p.496)

"What I liked about the course, they didn't tell us, they made us work it out ourselves." -F06, PLwIA (Dures et al. 2011 p.496)

However, one unequivocal finding highlights that it may take PLwIA a few sessions before this approach is helpful.

"...he would be asking us questions... and my brain was totally blank because then I kept thinking, 'Try and understand what he's talking about' you know? But it does fall into place." -C11, PLwIA (Dures et al. 2011 p.498)

Six findings (5 unequivocal and 1 credible) also describe that activity diaries provided a useful visual representation of fatigue; helped PLwIA pace themselves throughout the day; and created a sense of obligation to the SMI.

"You don't make any real connections, but when you see it... that was a very good visual clue, and I didn't think that was going to be useful, but actually I found probably the most useful. It's such a visual representation of what you are doing, or where you are slacking or crashing or whatever it may be." - D465, PLwIA (Berry et al. 2022 p.7)

"...by doing the daily logs it allowed me to actually pace myself..." -P17, PLwIA (Cramp et al. 2020 p.493)

"...I had to do it [the exercises] because I had to write it in that book [exercise diary]." -Fiona, PLwIA (Bearne et al. 2017 p.433)

HCPs also reported the activity diaries to be helpful to PLwIA.

"Obviously the activity diaries... I think they look at it, not realising the actual impact it has, once they've done it... they don't realise until they do it." - CTTM1, HCP (Berry et al. 2022 p.10)

The remaining two unequivocal findings describe that PLwIA would have liked to be signposted to local group activities and online relaxation tapes during the SMI.

"There are better relaxation tapes; there are better guided visualisation tapes." -M02, PLwIA (Dures et al. 2011 p.498)

"The people running it ought to find out first what group activities are available in the areas that people come from so that they could advise them." -P7, PLwIA (Cramp et al. 2020 p.492)

2.8.2.5 Category 2.5: Perceptions of PLwIA regarding the SMI facilitator

This category represents 12 findings (7 unequivocal and 5 credible) from six studies^{4,6,12,14,21,41} describing the perceptions of PLwIA in relation to the SMI facilitator. PLwIA consider HCPs to be the most appropriate choice for an SMI facilitator as they were knowledgeable about IA.

"Advice and information should come from people who work with it, people who know what they're talking about." -Anonymous, PLwIA (Haglund et al. 2017 p.6)

The remaining seven findings (3 unequivocal and 4 credible) describe that PLwIA find physiotherapists to be an acceptable SMI facilitator, particularly for SMIs that have an exercise component.

"...the advice from the physiotherapist was perfectly adequate..." -P7, PLwIA (Cramp et al. 2020 p.493)

"My main concern was that, if I was exercising whilst I was in pain, was I actually causing damage to the muscles and joints? The physiotherapist kind of said that, 'even if you feel pain, you should still carry on exercising'." - Catherine, PLwIA (Bearne et al. 2017 p.433)

2.8.2.6 Category 2.6: Perceptions of PLwIA and HCPs regarding intervention users who are best suited to participate in the SMI

This category was developed from four unequivocal findings from three studies^{4,9,12} describing the perceptions of PLwIA and HCPs regarding the intervention users who are best suited to participate in the SMI. PLwIA and HCPs expressed that the intervention should be offered to people soon after diagnosis.

"I wish it had been available at the beginning because some of the problems, some of the reason why I'm detached from the rest of the world is because in the early days I just let it all fade away..." -P3, PLwIA (Cramp et al. 2020 p.493)

"I wonder if it could be done sooner, especially the education aspects..." - Ph1, HCP (Cramp et al. 2020 p.495)

Contradictory to this finding, some PLwIA expressed that the SMI is best suited for those who are having difficulty managing their diagnosis and have no strength or patience left.

"I think it's whether people are at the end of their tether who decide to commit to a course like this." -Speaker 1, PLwIA (Bain et al. 2016 p.2324)

HCPs also expressed that PLwIA who are proactive and are ready to improve their self-management are the most likely to succeed.

"Most of the ones who contributed to the study are proactive, and want to change, and they are willing to make changes. And then you have got other patients... who think that we can fix them by giving them a tablet, and we can't. And they put up obstacles about everything you say... but I understand it's hard..." -BTTM1, HCP (Berry et al. 2022 p.10)

2.9 INTEGRATION OF QUANTITATIVE AND QUALITATIVE EVIDENCE

In summary, this MMSR demonstrated that IA SMIs produced a clinically meaningful reduction in fatigue and pain in PLwIA. Statistically significant results were demonstrated by the quantitative findings for self-efficacy, which was corroborated by the qualitative data. There was limited quantitative data to suggest that IA SMIs have a beneficial effect on HRQoL, knowledge, and engagement with self-management behaviours. However, the qualitative synthesis largely contradicted these findings. Communication was identified in the qualitative synthesis as another potential outcome of IA SMIs, although this was not explored in the included quantitative studies. Lastly, the qualitative synthesis described that IA SMIs were generally acceptable to PLwIA and HCPs. Acceptable characteristics of the IA SMIs identified by PLwIA included a group format; CBT; activity diaries; education that is given verbally face-to-face; and HCPs as the intervention facilitator. The quantitative and qualitative syntheses are juxtaposed in Table 2.11.

2.9.1 Pain

Quantitative findings for pain demonstrated that IA SMIs reduce pain in PLwIA in up to one year. Improvements in pain were clinically meaningful (i.e., the reductions in pain represent a meaningful change to PLwIA). However, only one study included in the narrative synthesis demonstrated reductions in pain and improvements in pain coping skills. There was no qualitative evidence identified to confirm, contradict, or explain the quantitative findings.

Table 2.11 Juxtaposition of Quantitative and Qualitative Syntheses

Outcome	Quantitative findings	Qualitative findings
Pain	Meta-analysis: (12 studies) - Estimated mean proportions: -3.5 [95%CrI: -5.8 to -1.3], indicating clinically meaningful improvements - Time frame: 1 day to 1 year Narrative synthesis: (1/10 studies demonstrated improvements) - Reduction in pain and improvement in pain coping skills in 8 weeks	Not explored
Fatigue	Meta-analysis: (12 studies) - Estimated mean proportions: -4.7 [95%CrI: -8.3 to -1.2], indicating clinically meaningful improvements - Time frame: 5 days to 1 year Narrative synthesis: (3/3 studies demonstrated improvements) - Improvements in fatigue coping at 18 weeks (p=0.0007) and at 2 years (p=0.02) - Reduced fatigue severity (p=0.003) at 18 weeks - Reduced fatigue impact at 14 weeks (p<0.01), at 26 weeks (p=0.02), 52 weeks (p=0.01), and 104 weeks (p=0.04)	Confirmatory and Explanatory - SMI help PLwIA to better understand their fatigue and the factors that can influence the severity of their fatigue - This improved understanding helped PLwIA accept their fatigue and perceive they were in control for how they manage it. - PLwIA frequently reported using more fatigue self-management strategies, such as pacing, taking regular breaks, relaxation techniques, and better sleep hygiene - Activity diaries provided a visual illustration of fatigue; helped PLwIA to pace themselves throughout the day; and created a sense of obligation
Self-efficacy	Meta-analysis: (6 studies) - Estimated mean proportions: 3.8 [95%CrI: 0.6 to 7.0] - Clinical significance N/A - Time frame: 5 days to 1 year Narrative synthesis: (3/10 studies demonstrated improvements) - Improvements in SE symptoms at 4 months (p=0.04) - Improvements in task-specific SE at 18-weeks (p=0.042) and 26-weeks (p=0.02)	Confirmatory PLwIA reported increased SE following the SMI

HRQoL	<u>HRQoL (n=26 studies)</u> <i>Meta-analysis: (4 studies in each meta-analysis)</i> • Overall HRQoL- Estimated mean proportions: $ES_{0.5}=0.4$ [95%CrI: -73 to 8.5], indicating no difference between IA SMIs and comparators • Social functioning- Estimated mean proportions: $ES_{0.5}=4.4$ [95%CrI: -4.2 to 13.4], indicating no difference between IA SMIs and comparators • Role physical- Estimated mean proportions: $ES_{0.5}=4.4$ [95%CrI: -4.2 to 13.4], indicating no difference between IA SMIs and comparators • Emotional well-being- Estimated mean proportions: $ES_{0.5}=2.0$ [95%CrI: -4.2 to 8.3], indicating no difference between IA SMIs and comparators <i>Narrative synthesis: (7/22 studies demonstrated improvements)</i> • Improved HRQoL at 5 days ($p=0.003$), 24 weeks ($p=0.009$), and 9 months ($p=0.004$) • Overall significant improvements in HRQoL demonstrated during a 2-year period ($p=0.02$) • Significant improvement ($p=0.0275$) in coping at 10 weeks • Improvements in emotional well-being at 4 months ($p=0.01$), sustained at 12-month follow-up • Improvements in role limitations at work secondary to emotional problems ($p<0.001$) at 65 weeks	<i>Contradictory and Explanatory</i> • PLwIA and HCPs describe that the SMI made a 'life-changing' difference to PLwIA and their families • PLwIA engaged with self-management strategies that reduced their stress • PLwIA were more aware and better able to recognise their emotions • PLwIA had better emotional regulation • PLwIA attend more social functions • PLwIA had their health problems and the associated challenges validated by HCPs and the SMIs • Group format reduced feelings of isolation and provided an opportunity for PLwIA to meet others
Disability	<i>Narrative synthesis: (5/18 demonstrated improvements)</i> Improvements in disability at 8 weeks ($p<0.0001$), 12 weeks ($p=0.013$), 18 weeks ($p=0.031$), 24 weeks ($p=0.002$), and at 1 year ($p=0.02$)	<i>Contradictory</i> • PLwIA were better at communicating their physical limitations with others and setting boundaries • PLwIA increased their engagement with self-management strategies

Knowledge	<u>Knowledge (n=3 studies)</u> <i>Narrative synthesis: (1/3 demonstrated improvements)</i> Beneficial effects at 24 weeks on disease-related knowledge (p=0.0041), knowledge of lifestyle and ergonomics (p=0.003), and knowledge of exercise (p=0.001)	<i>Confirmatory and Contradictory</i> • PLwIA had a better understanding of their diagnosis and how to manage their health problems
Engagement with self-management behaviours	<i>Narrative synthesis: (3/8 studies demonstrated improvements)</i> • Positive effects (p=0.008) on patient's engagement with joint protection techniques at 3 months. These benefits were sustained at 12 months. • Similar improvements (p=0.01) seen at 4 months	<i>Confirmatory, Contradictory, and Explanatory</i> • PLwIA were more aware of their behaviour, which led them to take more responsibility over the management of their health problems and increased their engagement with self-management strategies • PLwIA frequently reported using more self-management strategies to reduce fatigue and stress • PLwIA complied better to medical advice regarding their prescriptions • PLwIA had enhanced problem-solving and decision-making skills
Acceptability	<i>Not explored</i>	• SMIs are generally acceptable to PLwIA and HCPs • PLwIA and HCPs perceived the SMI to be very beneficial to PLwIA and their families • HCPs expressed their colleagues would be interested in delivering the SMI in the future • HCPs made alterations to their clinical practice • Acceptable characteristics of the SMI include: group format; CBT; activity diaries; education that is given verbally and face-to-face; HCPs as facilitators • PLwIA were willing to put in the effort required to overcome the burdens associated with attending the SMI
Communication	<i>Not explored</i>	• PLwIA were better able to communicate about their needs and diagnosis with others

Key: PLwIA= people living with inflammatory arthritis; SMI= self-management intervention; CBT= cognitive behavioural therapy; HCP= healthcare professionals

2.9.2 Fatigue

Quantitative findings for fatigue demonstrated that IA SMIs were effective in reducing fatigue severity in PLwIA. Although the meta-analysis indicates that improvements in fatigue are seen up to one year, findings from the narrative synthesis indicates that improvements in fatigue impact are seen at 1.5 years and in fatigue coping at two years. The qualitative findings confirm reduction in fatigue severity and provides a potential explanation for this observation. PLwIA describe an increased understanding and acceptance of their fatigue, which contributed to the perception that they were in control of how they manage it. PLwIA reported an increase uptake with fatigue self-management strategies.

2.9.3 Self-efficacy

Quantitative findings demonstrated statistically significant improvements for SE in a time frame of 5 days to 1 year. It is uncertain whether this result is clinically meaningful as MCID values have yet to be determined. However, three studies in the narrative synthesis demonstrated improvements in SE, specifically SE symptoms and task-specific SE. Qualitative evidence supports the meta-analysis results in that PLwIA describe increased SE following exposure to the SMI.

2.9.4 Health-related Quality of Life

The meta-analyses demonstrated no difference between IA SMIs and the comparators for HRQoL or for the following subscales: social functioning, role physical, or emotional well-being. The narrative findings are largely in-line with the meta-analysis results. However, seven of the 22 studies included in the narrative synthesis indicated improvements in HRQoL, coping, emotional-welling, and role limitations at work secondary to emotional problems.

The qualitative findings are somewhat contradictory to the quantitative findings. PLwIA and HCPs describe that the SMI made a 'life-changing' difference to PLwIA and their families. Although there was no qualitative evidence on the extent IA SMIs influence role physical, qualitative evidence does suggest that the SMI influenced the social functioning and emotional well-being of PLwIA. PLwIA attended more social functions following exposure to the SMI. Additionally,

those participating in an SMI delivered in a group format expressed reduced feelings of isolation as the group format provided an opportunity to meet others in a similar position. PLwIA also described that they were more aware of their emotions; better able to recognise their emotions; were better able to regulate their emotions; and felt their health problems were validated by the SMIs and HCPs. All of which would contribute to an improved emotional well-being.

2.9.5 Disability

PLwIA demonstrated improvements in disability in 28% of the studies (five out of 18), despite qualitative evidence describing that PLwIA increased their use of self-management strategies and were better able to communicate their physical limitations and set boundaries with others.

2.9.6 Knowledge

Only one of three studies included in the narrative synthesis demonstrated that IA SMIs' improved disease-related knowledge; knowledge of lifestyle and ergonomics; and knowledge of exercise. Qualitative evidence confirms that PLwIA had a better understanding of their diagnosis and how to manage their health problems. However, the qualitative evidence would lead to the expectation that more quantitative studies would report improvements in knowledge.

2.9.7 Engagement with Self-Management Behaviours

Quantitative evidence indicates that PLwIA had increased uptake of self-management behaviours, specifically joint protection techniques. Qualitative evidence confirms the quantitative evidence. A possible explanation for this is that PLwIA describe becoming more aware of their behaviour which led them to take more responsibility over the management of their health problems. However, there was not any qualitative evidence to support the increased engagement with joint protection techniques, rather the evidence indicates an increased uptake of fatigue and stress self-management strategies; better adherence to medical advice regarding their prescription medications; and enhanced problem-solving and decision-making skills.

2.9.8 Acceptability

Acceptability was not explored in the included quantitative studies; however, synthesised findings from 16 studies indicates that IA SMIs were generally acceptable to PLwIA and HCPs. Qualitative evidence also describes the characteristics of the SMI that are acceptable to PLwIA, which included a group format; CBT approach; activity diaries; education that is given verbally and face-to-face; and HCPs as facilitators. PLwIA were willing to put in the effort required to overcome the burden associated with attending the SMI, such as driving long distances and paying for parking or petrol.

2.9.9 Communication

This outcome was not explored in the included quantitative studies, however qualitative evidence describes the PLwIA were better able to communicate their needs and diagnosis with others following exposure to the SMI.

2.10 DISCUSSION

This review analysed and synthesised the quantitative and qualitative evidence on the effectiveness and acceptability of IA SMIs. Results from the meta-analysis suggest IA SMIs are effective and have a clinically significant reduction on fatigue severity in PLwIA, which was corroborated by the qualitative data. The qualitative data offers a potential explanation for this, suggesting that reduced fatigue severity can contribute to the increased uptake and engagement with fatigue self-management strategies by PLwIA. The activity diaries used during the SMIs may also contribute to this observation as PLwIA reported that the diaries provided a visual illustration of their fatigue which helped PLwIA to pace themselves throughout the day.

This finding is in-line with a similar high-quality, quantitative systematic review (Marques et al. 2021). In the review by Marques et al. 2021, IA SMIs were categorised based on the primary behaviour change techniques used. The categorised SMIs were then assessed on the extent they were effective in improving the outcomes using GRADE. Findings from Marques et al. (2021) demonstrated the following IA SMIs to influence fatigue: CBT; response training; multicomponent or single exercise/physical activity; specific interactive disease

education; goal setting; problem-solving; psychosocial; educational. Having used the GRADE approach, educational interventions were of very low certainty; with specific interactive disease education, problem-solving, and goal setting low certainty; CBT, psychosocial, and response training were moderate; and multicomponent or single exercise/physical activity was high. It is unclear, however, how the authors define each of these interventions as they are poorly described in their report, which makes it difficult to interpret and compare their findings to the ones in this MMSR. Nevertheless, it can be concluded that IA SMIs produced a clinically significant reduction on fatigue severity in PLwIA. The following factors are considered to contribute this outcome: uptake of fatigue. Results from the meta-analysis in this MMSR also suggest that IA SMIs are effective and have a clinically significant reduction on pain in PLwIA. However, only one of the ten studies in the narrative analysis demonstrated statistically significant improvements in pain (Cramp et al. 2020). There was no qualitative evidence identified to confirm, contradict, or explain these results or the discrepancy that exists between the results. The findings from the meta-analysis are in line with review by Marques et al. (2021) who reported several types of SMIs influence pain including: CBT (low certainty); response training (moderate certainty); specific interactive disease education (low certainty); goal setting (low certainty); problem solving (low certainty); multicomponent or single exercise/physical activity (moderate certainty); psychosocial (moderate certainty); SMIs (i.e., interventions that include swimming sessions, relaxation, exercises, sessions on ADLs, education-discussion sessions, walking, and/or Tai Chi; low certainty); and educational (moderate certainty). Taken together, it is reasonable to conclude that IA SMIs do have a clinically meaningful effect on pain reduction in PLwIA. A potential explanation for the observed discrepancy is that the other pain outcome measures were not sensitive to change or appropriate for PLwIA. Another potential explanation is that there was significant heterogeneity between the SMI characteristics of the included studies. It is also plausible that the studies who did not observe a significant effect on pain did not contain intervention characteristics effective at reducing pain or did not appropriately carry out the pain reducing intervention methods. Attempts were made by the research to compare intervention characteristics of the studies who found a significant effect on pain and those who did not; however, poor reporting of intervention characteristics made it difficult to compare and

conclusions were unable to be drawn.

Statistically significant improvements were also observed in the meta-analysis for SE. This finding is in line with Marques et al. (2021) who found the following to be effective in improving SE: CBT (moderate certainty); response training (moderate certainty); specific interactive disease education (moderate certainty); goal setting (low certainty); problem solving (low certainty); psychosocial (moderate certainty); and educational (moderate certainty). An MCID has yet to be established for SE, therefore it is difficult to conclude whether this finding is clinically significant. Qualitative data highlighted that PLWIA had higher SE following exposure to the SMI, which may indicate some clinical significance (Bearne et al. 2017; Grønning, Midttun, and Steinsbekk 2016). Determining clinical significance of SE is important as SE underpins effective self-management (Lorig and Holman 2003) and has also been attributed to the intervention's acceptability (Sekhon, Cartwright and Francis 2017). Findings from this MMSR and others (Marques et al. 2021) do indicate the SMIs can improve the SE in PLWIA, however conclusions were unable to be drawn regarding whether the SMIs are able to improve the SE of PLWIA to the extent that it improves their ability to effectively self-manage within their daily lives. Thus, more research is needed.

No effect was detected in the meta-analysis of HRQoL nor in the subgroup analyses of the HRQoL domains social functioning, role physical, and emotional well-being. However, the qualitative synthesis does suggest that the SMI influenced the social functioning and emotional well-being of PLWIA. The qualitative findings are in-line with other scientific literature. Marques et al. (2021) demonstrated the following interventions to be effective in improving HRQoL: CBT (low certainty); response training (moderate certainty); specific interactive disease education (low certainty); goal setting (low certainty); and problem-solving (low certainty). However, their results should be interpreted with caution as the authors grouped QoL, health status, and social support into one outcome domain, and the findings reported represent the entire outcome domain. The umbrella review by Taylor et al. (2014) (described in section 2.2) also reported beneficial improvements in QoL, however their review was only able to identify studies that measured emotional well-being. Taking all of this

into consideration, it would have been expected that the analyses would have demonstrated an effect, albeit small, on HRQoL. However, there is not enough data available to determine clinical significance.

The observed large between-study variance could potentially explain why the analyses demonstrated no effect. However, the relatively small number of studies included in each analysis makes the between-study variance less precise and therefore more difficult to interpret (Connor et al. 2020). Heterogeneity related to sample size, participant characteristics and the SMI characteristics could have all contributed to the observed between-study variance. Time-constraints prevented the researcher from exploring reasons for heterogeneity, however meta-regression techniques may be the best approach for exploring this in future studies. Improved reporting of intervention characteristics would also make future meta-regression analyses more robust.

Findings from this MMSR also demonstrated some improvements in knowledge, disability, communication, and engagement with self-management strategies. However, these outcomes were seldomly explored in the quantitative and qualitative literature. More research is needed before conclusions can be drawn regarding the clinical significance of these outcomes.

To the authors best knowledge, this is the first review to explore the acceptability of IA SMIs. The qualitative synthesis indicated that PLwIA and HCPs perceive SMIs to be acceptable, with some highlighting that the SMI was "life-changing" to PLwIA and their families. A wide range of benefits were reported by PLwIA following their participation in the SMI. Furthermore, PLwIA expressed that they were willing to put in the effort required to overcome the burden of attending the SMI, such as driving long distances to attend and paying for petrol and parking. HCPs also reported benefits following their role as the intervention facilitator. HCPs reported being more "empathetic and compassionate" practitioners; better communicators; and reported making a wide range of alterations to their daily clinical practice. Acceptable characteristics of the IA SMIs identified by PLwIA included a group format; CBT; activity diaries; education that is given orally and face-to-face; and HCPs as the intervention facilitator. However, there was some qualitative data to suggest

that IA SMIs are not appropriate to all PLwIA, and PLwIA recruited into the SMI should be carefully selected. There was not enough data to make recommendations for how long to wait following diagnosis before enrolling in the IA SMIs. There is also not enough evidence comparing the intervention characteristics to determine and make recommendations for the specific characteristics that should be implemented within the SMI.

2.11 STRENGTHS AND LIMITATIONS

A strength of this MMSR is its methodological rigour. This review was conducted in accordance with the JBI MMSR guidelines (Lizarondo et al. 2020), which allowed for a rigorous and systematic approach to study selection, appraising, synthesising, and integrating the quantitative and qualitative literature. When compared to similar systematic reviews, this MMSR has a broader patient population; included more study designs; and was the first to explore the acceptability of IA SMIs among PLwIA and HCPs. These strengths are attributed to the use of the JBI approach.

The JBI approach also helped to inform a robust and inclusive search which identified many potential studies, of which 48 were included. The large number of included studies provided the opportunity to perform several meta-analyses to try to gain greater insight into the extent that IA SMIs are effective at improving the following outcomes: pain, fatigue, self-efficacy, and HRQoL and corresponding domains. Despite the large volume of data, the individual quantitative and qualitative syntheses could have been strengthened by the inclusion of more studies. It is possible that the language restrictions delineated in the inclusion criteria (i.e., only studies in English were included) may have limited the quantity of studies included in this review. It is recognised that the researcher could have used a translator or used a translation software, however a pragmatic decision was made along with supervisory team to set language restrictions to complete the review in a timely and cost-effective manner.

2.12 RECOMMENDATIONS FOR FUTURE RESEARCH

This MMSR has identified several recommendations for future research:

- Develop a new SMI for PLwIA
- Determine if IA SMIs demonstrate a clinically significant effect on the following outcomes: self-efficacy, HRQoL, knowledge, engagement with self-management behaviours, and communication.
- Establish a core outcome set for IA SMIs.
- Compare intervention characteristics to determine which are the most effective at improving IA outcomes.
- Examine whether different IA diagnoses or participant characteristics influence the effectiveness of the outcomes.
- Explore the short-term and long-term effects of the outcomes reviewed in this MMSR.
- Explore the experiences and perceptions of PLwIA and HCPs regarding the extent the IA SMIs are effective at reducing pain; improving HRQoL and corresponding domains; reducing disability; improving knowledge; and improving communication.
- Determine the cost-effectiveness and resource use of IA SMIs which should be informed by a health economic analysis.
- Determine the characteristics of PLwIA who are most appropriate to enrol in a SMI.
- Explore measures of feasibility (e.g., adherence and barriers to engagement) in those taking part in and delivering IA SMIs

2.13 RECOMMENDATIONS FOR CLINICAL PRACTICE

This MMSR has identified recommendations for clinical practice:

- SMIs are an effective and acceptable tool to support the self-management of PLwIA.
- SMIs should be considered as an intervention for PLwIA.
- Characteristics of SMIs should include group formats; CBT approach; activity diaries; education that is given verbally and face-to-face; and include HCPs as facilitators.

2.14 CHAPTER SUMMARY

This review systematically evaluated 48 studies to explore the effectiveness and acceptability of IA SMIs. This review demonstrated that IA SMIs produced a clinically meaningful reduction in fatigue and pain in PLwIA. There was also some data to suggest that IA SMIs have a beneficial effect on self-efficacy, HRQoL, knowledge, engagement with self-management behaviours, and communication. However, inferences regarding the clinical significance of these outcomes were unable to be drawn. The IA SMIs were found to be generally acceptable to PLwIA and HCPs. Acceptable characteristics of the IA SMIs identified by PLwIA included a group format; CBT; activity diaries; education that is given orally and face-to-face; and HCPs as the intervention facilitator.

3 METHODOLOGY AND METHODS

3.1 CHAPTER INTRODUCTION

A sequential multi-method was undertaken to meet two of the three core project objectives. The first phase of the project co-designed a SMI in collaboration with PLwIA and HCPs (project objective 2), while the second phase explored the participants' experience in participating in co-design research (project objective 3). The chapter commences with a presentation of key philosophical paradigms and methodologies. Then, the research methods adopted for each phase is detailed. The chapter concludes with a discussion of the ethical considerations of the study.

3.2 PHILOSOPHICAL PARADIGMS

3.2.1 Overview of Paradigms

A philosophical paradigm underpins every study design. A philosophical paradigm is defined as "the philosophical assumptions or the basic set of beliefs that guide the actions and define the way the researcher thinks about and makes sense of the complexities of the world" (Kaushik and Walsh 2019 p.1). There are four common assumptions within every paradigm: ontology—beliefs about the nature of reality; epistemology—assumptions about how we understand the world and how we gain knowledge; axiology—the degree to which beliefs and values impact the research; and methodology—shared understanding of the best means for gaining knowledge about the world (Hesse-Biber and Johnson 2015; Creswell and Plano Clark 2018; Kaushik and Walsh 2019). Although several paradigms exist, the salient paradigms considered for the researcher are post-positivism, constructivism, transformative, critical realism, and pragmatism (Mertens 2012; Linsley, Howard and Owen 2015; Creswell and Plano Clark 2018). A summary of each of these paradigms' philosophical assumptions can be found in Table 3.1.

Table 3.1 Summary of Philosophical Paradigms (Source: Mertens 2012; Linsley, Howard and Owen 2015; Creswell and Plano Clark 2018)

Assumption	Post-positivism	Constructivism	Transformative	Critical Realism	Pragmatism
ONTOLOGY	Single reality; reality is fixed	Multiple realities; reality is relative	Multiple realities; reality is relative	Layered reality; 'external' reality is fixed but it is not always observed by the individual	Single and multiple realities; the researcher chooses a position depending on the research question
EPISTEMOLOGY	Knowledge is objective and generalizable; data is collected on valid and reliable instruments	Knowledge is subjective and interpretive; data constitutes participants' understanding and interpretation of a phenomenon	Knowledge is based on social structures of power and privilege; data is collected on participants' understanding and interpretation of a phenomenon within the context of power and privilege	Knowledge is historically situated, and social facts are agreed upon by people; data is collected on the causal mechanisms and structures of an observed phenomenon	Knowledge is practically obtained; data is collected by the most appropriate method to answer the research question
AXIOLOGY	Value-free; the researcher bias controlled and minimised	Value-laden; the researcher discusses their personal biases	Value-laden; the researcher discusses personal biases and cultural competency	Value-laden and values-driven; the researcher discusses their personal biases and conduct of research is underpinned by emancipatory values	Value-free and value-laden; the researcher's stance is made on a practical basis
METHODOLOGY	Quantitative approaches	Qualitative approaches	Mixed methods and multi- methods	Mixed methods and multi-methods	Single method, mixed methods, and multi-methods

3.2.1.1 *Post-positivism*

From an ontological position, post-positivism argues that there is only one true social reality, and a person's understanding and interpretations of a phenomena do not influence this reality. This view of reality leads a post-positivist to discover the truth about this universal social reality from empirical observation and measurement (Creswell and Plano Clark 2018). Axiologically, post-positivists seek to be objective and remain detached from their own values and beliefs throughout the research process (Hesse-Biber and Johnson 2015). Thus, their findings remain uninfluenced by human bias. Post-positivists use quantitative methodological approaches (Hesse-Biber and Johnson 2015; Creswell and Plano Clark 2018).

3.2.1.2 *Constructivism*

Ontologically, constructivism assumes that there are multiple realities. Reality is constructed through peoples' perceptions and shaped through social interactions. This means that constructivists must consider context in significant detail; they take into consideration factors that impact how different realities might be experienced and interpreted. These factors include but are not limited to historical, geographical, and socio-cultural influences (Creswell and Plano Clark 2018). Constructivists' axiological position is that they cannot completely detach themselves from their findings, thus researchers are required to constantly reflect on and question their own values and incorporate these within their research (Saunders, Lewis and Thornhill 2019). Constructivists use qualitative methodological approaches (Creswell and Plano Clark 2018; Saunders, Lewis and Thornhill 2019).

3.2.1.3 *Transformative*

From a transformative perspective, the purpose of research is to address political, social, and economic injustices to improve society for marginalised groups. The transformative ontological position rejects the idea that a person's beliefs are shaped by their own experiences, however it still recognises that there are multiple realities (Creswell and Plano Clark 2018). These realities, and therefore how knowledge is gained, are based on a person's social power and their privilege (Mertens 2012). The transformative axiological position focuses

on social justice and conducting research that can create changes in social systems (Teddlie and Tashakkori 2009; Mertens 2012). Transformative researchers typically apply either mixed methods or multi-methods approaches (Creswell and Plano Clark 2018).

3.2.1.4 *Critical realism*

Critical realists assume that reality is layered; there is the 'empirical' world, the 'actual' world, and the 'real' world (Saunders, Lewis and Thornhill 2019). The 'empirical' world is comprised of phenomena that are observed by a person. The 'actual' world is comprised of all the phenomena that are happening at any given moment, whether they are observed or not. The 'real' world is comprised of the unobservable causes and mechanisms of a phenomenon (Saunders, Lewis and Thornhill 2019). Critical realists believe that the 'real' world cannot be directly measured. Instead, researchers use empirical data to reason the underlying causes and mechanisms of an event (Bhaskar 1987; Saunders, Lewis and Thornhill 2019). From an epistemological perspective, critical realism assumes that knowledge is historically situated, and social facts are collectively agreed on by people (Saunders, Lewis and Thornhill 2019). Critical realism has a similar axiology to constructivism in that a researcher's personal experiences and perceptions introduce bias to the research. However, critical realism has emancipatory values, meaning that the research is focused on issues of equality within society (Wilson and McCormack 2006; Creswell and Plano Clark 2018). Critical realists primarily apply mixed methods approaches (Creswell and Plano Clark 2018).

3.2.1.5 *Pragmatism*

As a paradigm, pragmatism recognises that there are many ways of interpreting the world and approaches to undertaking research. There are no confined boundaries of ontology or epistemology in pragmatism as no single worldview is believed to give the entire picture (Creswell and Plano Clark 2018). Pragmatists start with a problem and the undertaken research aims to contribute practical solutions to inform future practice (Saunders, Lewis and Thornhill 2019). Pragmatists take a pluralistic approach to selecting research methods. Pragmatists can deploy a single method, mixed methods, or multi-methods

approaches (Kaushik and Walsh 2019; Saunders, Lewis and Thornhill 2019). However, pragmatism is not an 'anything goes' paradigm. Pragmatists must use their discretion in determining the most appropriate research methods to answer the research questions by being self-conscious about how they undertake the research study. They aim to maintain subjectivity in their own reflections on research procedures and objectivity in data collection and analysis (Hesse-Biber and Johnson 2015; Shannon-Baker 2016).

3.2.2 Rationale for the Chosen Paradigm

The purpose of project is to determine whether it is possible to co-design a SMI for PLwIA. Although co-design is inherently qualitative, it is recommended that complex healthcare interventions, such as a SMI, are developed using a flexible approach that allows for the combining of quantitative and qualitative data (O'Cathain et al. 2019; Sidani and Braden 2021). For this reason, O'Cathain et al. (2019) have recommended taking a pragmatic self-selected approach to intervention development, drawing on one or more published approaches. In accordance, pragmatism was the chosen philosophical paradigm for this project as the abandonment of meta-physical concepts in pragmatism offers the researcher the flexibility to implement methods required to best answer the research question and underpin the research in co-production values (Creswell and Plano Clark 2018). Key principles of co-production are discussed further in section 3.4.1.2.

This section reflected on five salient philosophical paradigms and provided a rationale for the chosen paradigm of this project, pragmatism. The following section explores the following methodological approaches to research within a pragmatist philosophy: quantitative, qualitative, mixed methods, and multi-methods.

3.3 METHODOLOGY

3.3.1 Quantitative

A quantitative approach is appropriate when examining relationships between variables (Creswell and Plano Clark 2018). Quantitative data are expressed as

numerical values and analysed using statistical techniques (Bowling 2014). There are four main types of quantitative approaches: experimental, quasi-experimental, correlational, and descriptive (Creswell and Plano Clark 2018). In experimental research, the researcher assesses if a meaningful relationship exists between two variables by manipulating the independent variable. Experimental designs include RCTs that randomised participants to 2 or more groups. Quasi-experimental studies also manipulate the independent variable but do not randomise participants to treatment conditions (Miller, Smith and Pugach 2020). Correlational studies measure the relationship between two variables and use statistical methods to assess their relationship (Creswell and Plano Clark 2018). Lastly, descriptive research seeks to understand characteristics of individuals, events, or conditions using observational or survey data (Siedlecki 2020).

3.3.2 Qualitative

Qualitative approaches are used for exploring and understanding the meaning of social phenomena and human behaviour (Mohsen, Bui and Bui 2022).

Qualitative research presents findings using non-numerical data, such as quotes and images (Saunders, Lewis and Thornhill 2019). There are three types of qualitative methodological approaches: grounded theory, ethnography, and phenomenology (Gutman 2014; Teherani et al. 2015). Grounded theory as an approach aims to develop theories that explain social actions by exploring the perception and experiences of others. Ethnography involves understanding the shared patterns of behaviours, beliefs, and values of a group by observing them in their community over a prolonged period. Phenomenological research seeks to understand the lived experiences of people and the meaning they attach to a particular phenomenon (Gutman 2014).

3.3.3 Mixed Methods

As highlighted in Chapter 2, mixed methods research integrates quantitative and qualitative approaches. Methods are often combined in a complementary or extension design in which the experience gained through one approach is complemented and enriched by the experience of another (Hesse-Biber and Johnson 2015). Quantitative and qualitative techniques can be combined in a variety of ways, namely convergent, explanatory sequential, and exploratory

sequential. In convergent mixed methods, the researcher collects the quantitative and qualitative data separately but at the same time. The quantitative and qualitative data is then analysed and integrated together to provide a richer and more comprehensive understanding to the research problem. In explanatory sequential, the researcher first conducts quantitative research and then builds on the results using qualitative methods. In this case, the qualitative data is used to better explain the quantitative findings. In exploratory sequential, qualitative research undertaken first and followed by quantitative research. The qualitative data is used to select, develop, or design outcome measures, interventions, or the like that is then tested quantitatively (Creswell and Plano Clark 2018).

3.3.4 Multi-methods

A multi-method approach differs from mixed methods in that multi-methods employs two or more different quantitative or qualitative methods within a single research study. Unlike mixed method research, a multi-methods approach does not require combining qualitative and quantitative methods. Instead, multi- methods allow for a variety of possible methodological combinations (Morse 2003). There are two typologies of multi-method approaches: simultaneous and sequential. Simultaneous designs imply that the chosen research methods occur at the same time, whereas sequential refers to the phases of the study occur in a temporal order (Morse 2003). Table 3.3 outlines the possible multi-method designs as defined by Morse (2003).

3.3.5 Rationale for the Chosen Methodological Approach

As highlighted in section 1.5.3, two objectives of this project are: (1) co-design a SMI in collaboration with PLwIA and HCPs and (2) subsequently explore participants' experience in participating in co-design research. To meet these objectives, a sequential multi-methods approach is needed. The multi-method approach that maps to the objectives of this research is one qualitatively driven study is followed by a second qualitative study (QUAL $\square$ qual). This study design allows both co-designer groups' (i.e., PLwIA and HCPs) needs and preferences to be explored and compared against the scientific literature in Phase I, and allows for their experiences participating in co-design research to be explored in-depth in Phase II.

Table 3.2 Multi-Method Typologies (Modified from source: Morse 2003)

Design Type	Combinations
Simultaneous	QUAL + qual, indicates a qualitatively driven, qualitative simultaneous design
	QUAN + quan, indicates a quantitatively driven, quantitative simultaneous design
	QUAL + quan, indicates a qualitatively driven, qualitative and quantitative simultaneous design
	QUAN + qual, indicates a quantitatively driven, quantitative and qualitative simultaneous design
Sequential	QUAL → qual, indicates a qualitatively driven study, followed by a second qualitative study
	QUAN → quan, indicates a quantitatively driven study, followed by a second quantitative study
	QUAL → quan, indicates a qualitatively driven study, followed by a second quantitative study
	QUAN → qual, indicates a quantitatively driven study, followed by a second qualitative study

This section discussed the possible methodological approaches to this research and presented a rationale for the choice of a sequential multi-methods approach. The following sections will discuss the impact of the COVID-19 pandemic on the project and the research methods adopted for each phase.

3.4 IMPACT OF THE COVID-19 PANDEMIC ON THE PROJECT

The COVID-19 pandemic caused several rapid and unintended changes to the original study design. At the start of the pandemic, UK ethics committees placed a hold on all non-COVID related studies which delayed the ethical approval process by 9 months. Several aspects of the original study design were also modified to adhere to the NHS Research Ethics Committee (NHS REC) and NHS Research and Development (NHS R&D) COVID-19 specific standards. The

original project was proposed as a three-phase study; the first phase would aim to co-design a SMI in collaboration with PLwIA and HCPs followed by a qualitative exploration of the participant co-designers' experience participating in Phase I, then the third phase would explore the feasibility and acceptability of the developed SMI. However, the third phase was not undertaken as this study already had a short timeline and there was a significant delay in receiving ethical approval. Furthermore, the development of the SMI was intended to take place in face-to-face workshops, but measures to control the spread of the virus also limited the face-to-face contact with vulnerable participants and the general public. Thus, the originally planned face-to-face workshops were conducted remotely. Lastly, the HCPs were no longer able to attend the workshops as pandemic caused a massive upheaval within the rheumatology service. Instead, HCPs participated via email and MS Team meetings with the researcher. Despite the barriers introduced by the COVID-19, the researcher along with the help of the supervisory team were able to navigate and overcome these unintended challenges. Additionally, these challenges presented opportunities for incorporating novel methods that proved to be time-efficient and cost-effective; these methods are discussed further in the following sections.

3.5 PHASE I: INTERVENTION DEVELOPMENT

In this phase, the SMI was developed using a combination of two well-recognised approaches in healthcare: co-production and the IM framework (Croot et al. 2019). The following subsections will discuss each of these approaches in-depth, including their strengths, weaknesses, and the rationale for their use. A detailed explanation of how the approaches were integrated together will be discussed later in this chapter (refer to section 3.4.3 Study Design).

3.5.1 Co-production

3.5.1.1 Definition

Co-production has been increasingly used as an approach to intervention development as it actively involves key stakeholders to identify and address the needs of the intervention's recipients (Croot et al. 2019; O'Cathain et al. 2019).

Co-production is an approach in which citizens and organisations work collaboratively in equal and reciprocal partnership (National Institute for Health and Care Research INVOLVE 2018; Social Care Institute for Excellence 2022). It is based on the notion that people have the right to be involved in decisions and actions that affect them. This project adopted the Governance International (2020 p.1) definition of co-production who define co-production as:

"User and community co-production of public services and outcomes is about public service organisations and citizens making better use of each other's assets, resources and contributions to achieve better outcomes or improve efficiency."

In the field of health and social care, co-production is the partnership of PLwIA and HCPs to improve or develop services (Osborne and Strokosch 2013). Healthcare services are traditionally designed by people who have little or no direct experience in using the service(s) they create (Scottish Government 2008). Thus, decisions about the service development are made for people and not with them (Scottish Co- production Network 2021). Service co-production, however, challenges this approach by directly involving the service users (Farr et al. 2018). The rationale for working with stakeholders/service users to develop interventions is that it increases the likelihood that the intervention will be acceptable, feasible, practical, and contextually appropriate (O'Cathain et al. 2019). The use of co- production approaches is echoed within new UK health and social care policies calling for a shift away from patient consultation to more integrated ways of incorporating PLwIA and the public in research. Developers of services are encouraged to provide PLwIA with opportunities that enable them to have more choice over the services they receive (Scottish Government 2008).

3.5.1.2 Key principles

The NIHR INVOLVE (2018) and Social Care Institute for Excellence (SCIE) (2022) have outlined four key principles of co-production: equality, diversity, accessibility, and reciprocity. Equality is the idea that each contributing group has equal status and value. Co-production research, therefore, is about conducting research 'with' people rather than 'for' them (Scottish Co-production Network 2021). For equality to be achieved, there needs to be a shift in the balances of power between HCPs, researchers, and patient relationships.

Patients/service users should be recognised as having an important role to play in their health, and HCPs take on a position of enabling and facilitating health rather than providing a health service. Thereby, turning people into co-producers of their own health and well-being (Osborne and Strokosch 2013).

The second key principle is diversity. The concept of diversity means accepting, respecting, and valuing differences and commonalities in individuals. This includes race, ethnicity, culture, beliefs, gender, sexuality, age, and social status (National Institute for Health and Care Research INVOLVE 2018; Social Care Institute for Excellence 2022). Diversity recognises that some groups will consider it more difficult than others to express their views, needs, and perspective. Inclusive and diverse co-production partnerships aim to take into consideration and meet the needs of all groups as well as foster respectful environments (National Institute for Health and Care Research INVOLVE 2018).

The third principle of accessibility relates to the notion that the co-production process must be accessible to all those taking part. Accessibility recognises that everyone needs to be provided with the same opportunity to take part in the co-production and decision-making processes if everyone is going to take part equally. Those involved should be provided with an opportunity to take part in a manner that suits them best. It also means that information is accessible to the co-producers in a timely manner; is provided in appropriate formats; and is free of jargon (National Institute for Health and Care Research INVOLVE 2018; Social Care Institute for Excellence 2022).

Lastly, the fourth key principle is reciprocity. Reciprocity is the equal exchange of assets, such as time, skills, resources, and knowledge. It requires each of the co-producers' roles to be clearly delineated. This serves to ensure that the needs of all co-producers are met, and the views and perspectives of all involved parties are taken into consideration (Shand 2018). Moreover, the notion of reciprocity also entails that all co-producers receive credit for their contributions (Burgess and Durrant 2019).

3.5.1.3 Co-production modes

Co-production has the potential to create partnerships and facilitate change at many levels. Loeffler et al. (2021) recognise four co-production modes: co-commissioning, co-design, co-delivery, and co-evaluation (Loeffler et al. 2021). Each mode represents its own approach to co-production and can be used in different contexts. The first mode of co-production is co-commissioning. Co-commissioning is when the public sector or organisations work with people who use services to prioritise, plan, and resource outcomes. It includes co-planning of policy and strategies, co-prioritisation of outcomes and budgets, and co-financing of projects (Social Care Institute for Excellence 2020). The second mode is co-design of services. Co-design uses a collaborative design process that can be used to develop a new service or improve the quality of an existing service to improve the consumers experience (Moore and Evans 2021). The third mode is co-delivery, in which lay actors collaboratively deliver services. The fourth and final mode is co-evaluation, which utilises joint processes to monitor and evaluate outputs and the quality-of-service delivery (Whitehead 2020). For each of these modes, several approaches can be undertaken and can vary greatly in their intensity of input from stakeholders (Moore and Evans 2021).

The term “co-production” is an all-encompassing term that reflects the co-production principles and modes (Loeffler et al. 2021); however, co-production is sometimes used interchangeably with co-commissioning, co-design, co-delivery, and co-evaluation in the literature. For the purposes of this project and to aid readability, the term “co-production” will be used when discussing the key principles of co-production, and the term “co-design” will be used when discussing the research methods adopted for Phase I. Co-design was considered the most appropriate term as the research aim and objectives (see section 1.5) maps closest to this co-production mode.

3.5.1.4 Co-design

Co-design is a collaborative approach to service design. It aims to produce high quality customer service by working in partnership with stakeholders (Pedersen 2016). Co-design recognises that each group of stakeholders have valuable

assets and personal strengths that can be utilised (Grindell et al. 2022). This is why co-design is often referred to as a strength-based or asset-based approach (Social Care Institute for Excellence 2018). In the field of healthcare, co-design acknowledges PLwIA and HCPs as 'experts by experience' (Saunders and Stappers 2014), and utilises their knowledge to improve the safety, quality, and person-centredness of healthcare services (Fylan et al. 2021). The rationale for involving PLwIA and HCPs during the development of the SMI is that they help to understand the health problems the SMI intends to modify and identify the aspects of the problem that can be changed (O'Cathain et al. 2019; Sidani and Braden 2021). Stakeholders also help to streamline the process for intervention development as their input helps to clarify and better understand how the intervention will fit within the local context (Kirk et al. 2020).

Co-design uses a pragmatic approach to share and generate new knowledge between PLwIA and HCPs (Langley et al. 2018; Grindell et al. 2022). It also uses participatory research methods to empower co-designers and facilitate collaboration and partnership (Pedersen 2016; Tritschler et al. 2018). The most common co-design approach in healthcare is Experience-Based Co-Design (EBCD) (Donetto et al. 2015). This approach uses in-depth interviews, observation, and group discussions to capture the experiences of PLwIA and HCPs. These experiences are then summarised in a short film, which is shown back to PLwIA and HCPs who use the film to identify and implement activities to improve the service (Point of Care Foundation 2020; Fylan et al. 2021).

Although EBCD is primarily used for improving the quality of an established service, this approach has been extended to the development of healthcare interventions (Fylan et al. 2021). Studies using EBCD methods to develop interventions have been criticised for underreporting or poorly describing their intervention theory (Smith et al. 2022). The intervention theory describes how an intervention leads to its intended outcomes within a particular context (O'Cathain et al. 2019). Developing a clearly described intervention theory has been recognised by several guidelines as core step in the intervention development process (Bartholomew et al. 2016; Croot et al. 2019; O'Cathain et al. 2019). There is only one paper to-date that has published guidance on developing the intervention theory using EBCD methods (Fylan et al. 2021).

However, this guidance was not published until after ethical approval was received for the current project and therefore could not be considered.

Recognising the importance of developing an intervention theory for the IA SMI, the researcher used the IM framework as a second intervention development guideline. The IM framework was chosen as it guides the process for developing the SMI's intervention theory (Bartholomew et al. 2016). The following section provides an overview of IM as well as its strengths and limitations. Section 3.5.3 discusses how co-design and the IM framework were combined and utilised in Phase I.

3.5.2 Intervention Mapping

The IM framework is an iterative six-step process for designing theory- and evidence-based interventions that aim to change a person's health behaviour(s) (Bartholomew et al. 2016). In the context of this project, the process begins with a needs assessment which explores the health problems related to PLwIA and identifies the problems' causative factors. In the second step, the SMI's goals and objectives are specified. The objectives delineate the behaviours that need to be changed to achieve the SMI's goal(s). Theory- and evidence-based methods are then selected to change the behaviours in the third step. These strategies form the basis for the SMI's activities. An intervention manual that guides the delivery of the intervention is then prepared in step four. In step 5, the adoption and implementation plan for the SMI is developed. This is proceeded by the development of the SMI's evaluation plan in step 6 (Bartholomew et al. 2016). An outline of these steps can be seen in Table 3.3.

The IM framework has been used to develop over 1000 healthcare interventions in a wide range of contexts (e.g., community, workplace, outpatients, inpatient, etc.) (Fernandez et al. 2019). This approach has also been successfully used to design SMIs for multiple long-term conditions, including but not limited to people living with osteoarthritis (Hurley et al. 2015), back pain (Hurley et al. 2015; Svendsen 2022), type II diabetes (Hadjiconstantinou et al. 2020), and epilepsy (Shegog and Begley 2017). To date, the IM framework has only been used to develop one intervention targeting an IA population. Hilberdink et al. (2020)

Table 3.3 Intervention Mapping Framework (Modified from source: Bartholomew et al. 2016)

Step	Tasks
1. Logic Model of the Problem	• Establish a stakeholder group • Conduct a needs assessment to create a logic model of the problem • Describe the context for the intervention, including the target population and setting • State the intervention's goals
2. Intervention Outcomes and Objectives	• State expected behavioural outcomes • Specify performance objectives for behavioural outcomes • Select modifiable determinants for behavioural outcomes • Construct matrices of change objectives • Create a logic model of change
3. Intervention Design	• Generate intervention themes, components, scope, and sequence • Choose theory- and evidence-based change methods • Select and/or design practical applications to deliver change methods
4. Intervention Production	• Refine intervention structure and organisation • Prepare plans for intervention materials • Draft intervention messages, materials, and protocols • Pre-test, refine, and produce materials
5. Intervention Implementation Plan	• Identify potential service users • State outcomes and performance objectives • Construct matrices of change objectives • Design implementation plan
6. Evaluation Plan	• Write effect and process evaluation questions • Develop indicators and measures for assessment • Specify the evaluation design • Complete the evaluation plan

recently used this approach to develop an intervention to increase exercise behaviour in people living with axial SpA. The efficacy of the intervention has not yet been determined.

The decision for the choice of the IM framework over other popular intervention development approaches (e.g., the Medical Research Council (MRC) framework for developing and evaluating interventions (Craig et al. 2008; Skivington et al. 2021) or the Behaviour Change Wheel (Michie et al. 2011) were two-fold. The utility of the IM framework rests on the triangulation (the collection and integration of multiple data collection methods or sources of data) of data collected at each step. Triangulation is of utmost importance in multi-methods research as it can help to limit the bias that can be introduced from the use of a single data collection method or a lone researcher (Noble and Heale 2019); therefore, enhancing the strength of the research and increases the trustworthiness of the findings (Creswell 2014). The use of triangulation is unique to the IM framework.

Secondly, the end-product of IM is a manual that acts as a protocol for implementing the intervention (Bartholomew et al. 2016). The development of a manual is a useful strategy for promoting fidelity. Fidelity means that the intervention was delivered as intended and is essential to ensuring the expected outcomes (Sidani and Braden 2021). An intervention is delivered with low fidelity if the intervention recipients receive only some of the intended components or at a reduced dose. Low fidelity can cause limited or no improvement in outcomes, thereby diluting the effectiveness of an intervention and resulting in type III error (Sidani 2015; Rixon et al. 2016; Stokes and Allor 2016).

The IM framework is the only approach that provides clear guidance for creating a manual and was therefore considered to be an advantage for use of the IM framework. It is important to highlight, however, that this project did not develop a fit-for-purpose manual. Rather, the end-product of this project is recommendations for an implementation manual. The rationale for this choice is discussed in detail in section 5.4.

One disadvantage of IM, however, is that it requires a considerable amount of time, effort, and resources to properly execute (Croot et al. 2019). While the other approaches are all considered to be less resource extensive and time exhaustive, the advantages of the IM framework appeared to outweigh this disadvantage in this study.

This section described the IM framework and provided a rationale for its use in this project. The following sections will discuss the study design, participant inclusion criteria, sampling methods, and the recruitment strategy for Phase I.

3.5.3 Study Design

This study undertook a novel, pragmatic approach to the development of the SMI for PLwIA. The SMI was developed in five asynchronous, co-design workshops, which were guided by the first four steps of the IM framework. The latter two steps of the IM framework (i.e., steps five and six) were not undertaken as developing an implementation and evaluation plan are out with the scope of this project.

3.5.3.1 Co-design workshops

The SMI was developed in five co-design workshops between September 2021 to December 2021. The rationale for the workshops is that they foster collaboration and active engagement between participants and the researcher (Lain 2017); allow ample time for HCP and participant co-designers to reflect on issues and areas that require further development (Ørngreen and Levinsen 2017); and allow for new idea generation, exploration, and evaluation to occur throughout the design process (Ahmed and Asraf 2018). The overarching aim of the workshops were to bring together co-designers to collaboratively develop a SMI that is based on co-designer needs and preferences as well as the scientific literature. Workshops 1 and 2 aimed to understand the health problems related to PLwIA, while workshops 3-5 aimed to design the SMI (Table 3.4). During the workshops, the researcher led participants through several interactive and creative activities that were designed to get them to work together to generate, explore, and evaluate ideas for the intervention's design (Pavelin, Pundir and Cham 2014). To remain true to the co-production principles outlined in 3.4.2.2,

Table 3.4 Workshop Outline

Chapter	Workshop	IM Steps	Aim	Objectives
4	1 and 2	1	Understand the health problems related to PLwIA	Define the health problems experienced by PLwIA
				Specify barriers to self-management
				Specify behavioural and environmental contributors to the health problems related to IA
				Determine the health problems related to IA that can be remediated by self-management
				Develop a logic model of the factors that influence the self-management of PLwIA
				Explore co-designers' preferences for the SMI
5	3-5	1-4	Design the SMI	Specify the goals and objectives
				Identify the SMI's methods
				Operationalise the methods into activities
				Identify the SMI's mode, dose, and sequence
				Develop the intervention theory
				Develop and refine recommendations for an implementation manual

PLwIA and HCPs were involved in the decision-making processes throughout Phase I. A detailed account of the methods undertaken for workshops 1-2 can be found in Chapter 4, and workshops 3-5 are discussed in more detail in Chapter 5.

Co-designers included PLwIA and HCPs. Participant inclusion criteria and sampling is discussed later in this chapter (refer to sections 3.4.5-3.4.6). Two

members of the researcher's supervisory team (AU and RH), who work in the rheumatology clinic at Aberdeen Royal Infirmary, acted as the HCP co-designers. Only IA participants attended the workshops. The decision for HCPs to not attend the workshops was two-fold. Firstly, the COVID-19 pandemic caused many rheumatology HCPs to be redeployed and the availability of the HCP co-designers was significantly reduced as a result. Secondly, the presence of HCPs at the workshops could have created blurred boundaries with participants regarding HCPs' role in research versus clinical care. For these reasons, the researcher communicated with the HCP co-designers via email and periodic MS Team meetings during Phase I data collection. Where possible, the HCP co-designers consulted with other members of the rheumatology MDT (e.g., nurses, dietician, etc.) regarding their needs and preferences for the developed SMI.

The researcher was responsible for facilitating and organising each of the workshops. The researcher's role as the facilitator was to guide conversation, ensure that the conversation remained focused, and create an ethos of collaboration and partnership in a safe and supportive environment. A semi-structured guide informed from the IM framework was developed before each workshop to support the discussion and planned activities. When available, the researcher's supervisor (LA) acted as a co-facilitator. The co-facilitator's role was to help guide discussion and take notes.

All the workshops were conducted remotely. Due to the impact of COVID-19, the workshops were conducted remotely as (1) face-to-face research was not possible during lock down and the data collection period, and (2) some PLwIA were required to shield due to the biologic therapies they were receiving. Additionally, remote workshops are considered as a less burdensome mode of delivery for participants as it does not require them to travel; is more cost-effective; and provides opportunities for participation for otherwise inaccessible groups, such as those living in rural areas and those with family or work commitments (Shamsuddin, Sheikh and Keers 2021). To prevent the risk of 'zoom fatigue', each workshop lasted between 1.5-2 hours and contained several activities to keep participants engaged (Wiederhold 2020).

Each workshop was conducted asynchronously, which allowed participants to engage and complete the workshops at a time that was convenient to them rather than at a set time and place (Cummings 2015). The rationale for asynchronous workshops was that co-design relies on the contribution of all co-designers, thus methods must allow for participation to be non-burdensome and convenient to all participants (National Institute for Health and Care Research INVOLVE 2018; Social Care Institute for Excellence 2022). Workshops were scheduled one at a time, and the workshops were held with 2 to 3 weeks between them. Participant's availability was requested one week prior to the start of each workshop. Once all participants responded, the researcher set workshop dates and times. Where possible, participants were grouped together.

The remote workshops were conducted over Microsoft Teams. The Microsoft Teams application was used for several reasons. Firstly, it allowed for videoconferencing which enabled face-to-face communication between participants and the researcher that conference calling would not allow for. Secondly, Microsoft Teams is accessible from phones, tablets, and computers. There is also an option for participants to log in online and not have to install anything on their computer. It also allows for collaboration of participants using special functions, such as whiteboarding and the sharing of content and documents, which allowed for a range of workshop activities to occur. Furthermore, Microsoft Teams allows for a private group to be created for co-designers to enable sharing of documents and provide a discussion forum that would allow participants to post questions or communicate with others between workshops. Participants were encouraged throughout data collection to post in the group discussion page. Participants were also informed that they could message the researcher privately on Microsoft Teams if they wanted to share personal information; had any questions; or came up with ideas for the intervention. A how-to guide for creating a Microsoft Teams account and accessing the private group page was emailed to participants prior to the commencement of the study (Appendix 3.1). Lastly, Microsoft Teams has excellent security and is General Data Protection Regulations (GDPR) (2016) compliant. RGU and NHS Scotland have institutional licenses for the use of Microsoft Teams.

3.5.4 Participants

PLwIA meeting the following criteria were included in the study: (1) a confirmed diagnosis of RA or SpA; (2) receiving active treatment for their condition; (3) able to attend all workshops online; (4) have access to the internet; (5) 18 years or older; and (6) able to speak and read English. PLwIA were excluded if: (1) they had an unconfirmed diagnosis; (2) were diagnosed with a non-inflammatory arthritis condition; (3) unable to speak and read English; and/or (4) did not have a computer or laptop fitted with a microphone and video camera. Translation services and technical equipment could not be provided to participants as this was an unfunded study. Therefore, language and hardware restrictions were placed on the inclusion criteria.

3.5.5 Sampling

A non-probability purposive sampling approach was undertaken. Non-probability sampling methods select possible participants based on convenience (i.e., those are close geographically and are willing to participate in the study) (Creswell and Plano Clark 2018). In comparison, probability sampling methods aim to select a large group of participants who are representative of the target population (Creswell and Plano Clark 2018). Non-probability sampling is the most appropriate sampling approach for Phase I because it can be used to identify people that best help the researcher understand the problems and needs of PLwIA, whereas probability sampling is better suited for research that aims to generalise the study's findings to an entire population (Creswell and Plano Clark 2018).

Purposive sampling is a type of non-probability sampling method where participants who have knowledge about or experience with the phenomenon of interest are recruited (Creswell and Plano Clark 2018). For this project, the phenomenon of interest was IA. The rationale for use of purposive sampling was to diversify the participant group to ensure a range of conditions, disease severities, gender, and ages were represented in the study. Participation from diverse backgrounds helps ensure that the developed intervention reflects the needs and experiences from multiple IA groups (Social Care Institute for Excellence 2022); thereby ultimately improving the external validity of the intervention (Sidani and Braden 2021).

It was the aim of this study to create a sensibly sized co-design group of 8-12 participants. This size was thought to be large enough to capture a range of perspectives and promote creative thinking and in-depth discussion. However, this size is small enough for the researcher to manage complex group dynamics as well as facilitate meaningful participation and high-quality discussion amongst participants (Sidani and Braden 2021). The sample was taken from a group that was geographically close to the researcher and who were willing to participate in the study. This approach allowed the research to be undertaken in a short period of time and was cost-effective (Bryman 2016)

3.5.6 Recruitment

Two methods of recruitment were undertaken. Initially, participants were recruited by the researcher's supervisors (AU and RH) who are part of the rheumatology MDT at Aberdeen Royal Infirmary. Participants were recruited at 'Near Me', telephone, or face-to-face clinic appointments. All current PLwIA meeting the inclusion criteria were considered by the rheumatology team. If a potential participant expressed interest, the rheumatology clinicians (AU and RH) asked for their permission to email them the study letter of invitation (Appendix 3.2) and participant information sheet (PIS) (Appendix 3.3) for them to read. The potential participants were also asked if their contact information could be passed on to the student researcher who would contact them to follow-up and answer any questions.

Unfortunately, the COVID-19 pandemic placed significant pressure on the ARI rheumatology MDT and department during Phase I participant recruitment. Participants were no longer able to be recruited via face-to-face appointments as these were reserved for acute, emergency, and new diagnosis cases; many of these cases were not appropriate for recruitment. Additionally, many members of the rheumatology MDT were redeployed to other wards thereby also limiting near me and telephone appointments with potential participants. As a result, no participants were recruited using this recruitment procedure. A second recruitment approach was developed and subsequently submitted to ethics as an amendment (see section 3.7), which was approved and implemented.

The second recruitment procedure had the rheumatology team review their active patients and screen them for eligibility. Identified eligible participants were mailed the study letter of invitation and PIS to their home address. If the participant was interested, they would contact the student researcher to ask questions and opt into the study. This method was successful and recruited enough participants for data collection to commence. Respondents who agreed to participate in the study were asked to provide verbal informed consent as per ethical approval.

3.5.7 Data Collection

Using the workshop outline as a guide (Table 3.4), experiential data was collected from co-designers during the workshops. The specific data that was collected in Workshops 1 and 2 is detailed in Chapter 4; while data collected in Workshops 3-5 is in Chapter 5. Throughout the workshops, the researcher kept a record of events and conversations that had occurred in a field diary, which was also used for planning future workshops. The diary entries were enhanced by the inclusion of emails exchanged with the HCP co-designers and participants between workshops; group and private messages sent by participants on Microsoft Teams; and discussions with the co-facilitator and the researcher's supervisory team. Additionally, all workshops were audio-recorded using an audio device to allow the researcher to review the sessions in-depth for any additional information that was missed during the workshop. Between each workshop, the audio-recordings were reviewed by the researcher and transcribed segments from the recordings were added to diary entries.

Observational data was also collected in each of the co-design workshops. Observation provided an 'insider' view into how participants behave within this context (Spradley 1979; Ahmed and Asraf 2018). The researcher gathered observational data on the co-design processes, including participants interactions with one another; their engagement with the workshop activities; and any issues that arose. This data was used to examine the factors that could potentially be affecting a participant's engagement with co-design processes and to develop new probes for the topic guide used in Phase II (see section 3.6.1 for more detail).

Observational data was recorded as field notes. When compared to a field diary, field notes are more analytic and interpretive (Tenezk 2017). When writing field notes, the researcher used a template informed by the guidance of Merriam (2014) and Bowling (2014). Merriam (2014) and Bowling (2014) posit that field notes include the following: setting; participants; activities; participant interactions; frequency and duration of the workshop and each activity; direct or indirect quotes from participants; and the facilitators overarching comments. Field notes were written following the commencement of each workshop. Again, these notes were further enhanced by discussions with the co-facilitator, the audio-recordings, and the researcher's reflexivity journal.

Reflexivity is a key process within qualitative research to ensure transparency throughout the study (Dodgson 2019). It requires the researcher to reflect on their role within the research; question their influence on the data; and identify where biases may have occurred (Dodgson 2019). A reflexive summary of the workshops is provided in Chapters 4 and 5. A final reflexive account is provided in Chapter 7 that describes the researcher's interpretation of the data and discusses her influence on the research process.

This section has provided an in-depth description and explanation on the methods chosen for Phase I of this project. The following section presents the methods for Phase II.

3.6 PHASE II: QUALITATIVE EXPLORATION OF PARTICIPANT EXPERIENCES IN CO-DESIGN RESEARCH

The co-design process was moved from face-to-face to being completely online because of the COVID-19 pandemic (Beresford 2021). However, there is limited evidence on the perceptions of PLwIA taking part in asynchronous co-design research. Therefore, the purpose of this phase was to explore the participant co-designers' experience and perceptions in participating in co-design research to inform future similar studies. To achieve this, asynchronous focus groups were to be used as they are more cost-efficient (Rupert et al. 2017) and can collect more data in a shorter amount of time when compared to individual interviews

(Mayan 2016). This was considered an advantage due to the fact this was an unfunded study and the short study timeline for this Doctorate in Physiotherapy award. Additionally, participants were accustomed to this method, and they would be able to follow on immediately from the final workshop. However, IT-related issues caused two participants to have to reschedule, which resulted in the undertaking of two focus groups and three individual interviews.

3.6.1 Procedure

Upon completion of the fifth workshop, the qualitative exploration immediately commenced. A detailed account of the participants within each session is detailed in section 6.2. Each session was conducted on Microsoft Teams and was facilitated by the researcher. All participants were asked for their informed consent to participate in the qualitative exploration as per ethical approval. The role of the researcher acting as the facilitator was to encourage ongoing discussion; ensure all participants were given an equal opportunity to speak; and to keep the conversation relaxed and conversational (Taush and Menold 2016). At the end of each session, the researcher thanked participants for their time and contributions.

A topic guide (Table 3.5) was used to guide the sessions. It contained a series of open-ended questions to gather information regarding the experiences, barriers, and facilitators of co-design among participant groups (Kirk et al. 2020). Additional questions were used to probe for clarification, and to enable participants' experiences to be explored in-depth. Prior to the commencement of Phase II, the topic guide was reviewed and revised by one of the researcher's supervisors (LA).

Figure 3.1 Qualitative Exploration Topic Guide

Questions

1. Why did you want to participate in this study?
2. Tell me about your overall impressions/experiences during the workshops.
 - i. Did you enjoy working as part of the group?
 - ii. Did you learn anything from the workshops?
 - iii. Are you doing anything differently in your everyday life or your profession as a result of being a part of this team? If so, what are you doing differently?
3. What did you think about the layout of the workshops?
 - i. Did you find the activities helpful in developing the intervention?
 - ii. Why or why not?
4. Do you feel that the priorities agreed at the end of the day reflected your own experiences of what needs to be improved in service of care? If so, what contributed to this? If not, what do you think could have been done differently?
5. Did you feel able to participate fully? If so, what contributed to this? If not, what do you think could have been done differently?
6. What did you enjoy most about participating in the workshops?
7. What do you feel were the key challenges or barriers in working in a team such as this one?
8. What, if anything, would you change about the workshops?
9. Is there anything we have not talked about that you would like to comment on?

3.6.2 Data Analysis

3.6.2.1 *Transcription*

The audio data collected was transcribed. There are two primary types of transcription in qualitative research: verbatim and intelligent (McMullin 2021). Transcribing an audio-recording verbatim is the most time-consuming method as the transcriber includes hesitations, utterances, mistakes, and grammatical errors. In comparison, intelligent verbatim corrects these mistakes and the transcriber only annotates relevant pauses and details and was used in the present project to improve the readability of the transcript (McMullin 2021).

3.6.2.2 Analysis

There are three common approaches to qualitative data analysis as described by Bowling (2014): thematic, content, or framework analysis. Thematic analysis aims to generate meaningful themes or patterns within the data set. Content analysis entails coding data by the presence of certain words or concepts to quantify their presence within the data set or analyse their relationships. In framework analysis, a thematic framework is identified which reflects the study aims as well as key themes from the data (Bowling 2014). For this phase of the study, the framework method developed by Ritchie and Spencer (2014) was used as this approach allowed for a robust comparison of the data by themes across each session and existing literature base. Additionally, the structured nature of this approach is a suitable choice for novice researchers as it provides them with clear and systematic steps to follow (Gale et al. 2013).

Analysis followed a 6-step method for framework analysis (Ritchie and Spencer 2014). Firstly, a recursive process of reading and re-reading the data sets to familiarise oneself with the data was conducted (Ritchie and Spencer 2014). The second step required coding of the passages (Ritchie and Spencer 2014). Then, codes were grouped into meaningful themes and subthemes to develop a working framework in the third step; this step was undertaken on MS Excel to allow for a visual representation of the data to be created (Ritchie and Spencer 2014). The fourth step required the researcher to further refine and finalise their themes, subthemes, and analytical framework (Ritchie and Spencer 2014). To finalise themes, the researcher compared the themes with the entire data set to identify potentially missed data; assess whether the themes captured the most relevant aspects of the data; and determine if the themes comprehensively answer the research question (Ritchie and Spencer 2014). Lastly, the finalised themes and corresponding sub-themes were interpreted, and a detailed description and explanation of them was written up (Ritchie and Spencer 2014). The findings from the analysis is presented in Chapter 6.

The concept of data saturation is often used while undertaking focus groups and interviews. This concept refers to the point in which data no longer needs to be collected as no new information or themes are found during data analysis (Faulkner and Trotter 2017). Data saturation, however, was not appropriate as

this study only sought to explore the experiences of the participants taking part in these workshops, rather than the experiences of people who have ever taken part in co-design research.

3.6.3 Maintaining Quality in Qualitative Research

This project adopted the Lincoln and Guba (1985) framework for maintaining quality in qualitative research. This framework highlights four key aspects to ensuring quality in qualitative research: credibility, transferability, dependability, and confirmability. Credibility refers to the level of confidence in the truth of the research findings (Lincoln and Guba 1985; Shenton 2004). Transferability refers to the extent that the findings could be transferred to other contexts (Lincoln and Guba 1985; Shenton 2004). Dependability refers to the reliability of the findings; the study's findings should be consistent if the study was to be replicated (Lincoln and Guba 1985; Shenton 2004). Confirmability refers to the extent that the findings reflect participants' voices and not the researcher's perspective (Lincoln and Guba 1985; Shenton 2004). Actions taken to increase the quality of this research are described in Table 3.6.

This section has explored the procedures and data analysis methods for Phase II of this project. Additionally, the actions taken to ensure methodological rigour of each phase of the study were delineated. The following section discusses the ethical considerations of this project. It outlines the research approval process as well as the research governance principles and demonstrates how these were applied to this research study.

Table 3.5 Approaches to Ensuring Quality (Modified from source: Shenton 2004)

Criteria	Actions undertaken
Credibility	• Adoption of recognised research methods • Familiarity with PLwIA, HCPs, and NHS rheumatology services was established prior to data collection and during Workshop 1 • Triangulation of data in each workshop • Established rapport with participants and HCPs to promote honesty in informants • Iterative questioning used throughout both phases of the project • Frequent debriefing sessions with supervisory team • Supervisors, other PhD candidates, and institutional review boards were asked to review aspects of the study • Researcher kept an ongoing reflexive diary during data collection and arising issues were discussed with supervisor (LA) • Role of the researcher, including a description of her background, qualifications, and experiences are presented in Chapter 4 • Checks made by supervisors in relation to inferences made during data analysis for Phase I and II (Chapters 4-6) • Detailed description of the phenomenon of interest presented in Chapter 1 • Examination and comparison of previous research findings in similar studies explored in Chapters 2 and 4-7
Transferability	• Context of study established in Chapter 1 • Methods of each phase of the study are presented in detail in Chapters 3-5 • Quotes from participants included in Chapters 4-6 and Appendix 5.2
Dependability	• Methodology described in detail to allow the study to be repeated in Chapter 3 • Methods of data collection are detailed in Chapters 3-5 • Reflexive appraisal of the study provided in Chapters 4, 5, and 7
Confirmability	• Triangulation used to reduce investigator bias • Researcher's beliefs and assumptions are described in reflexive appraisals in Chapters 4, 5, and 7 • Limitations of the study are acknowledged in Chapter 7 • Audit trail of all aspects of research process kept

3.7 ETHICS

3.7.1 Approvals

Prior to commencement of the study, RGU, School of Health Sciences Research Review Group (SHS SRRG) (reference number: SHS/20/03, Appendix 3.4), NHS REC (ID: 278552, Appendix 3.4), and NHS R&D (ID: 2020RG0053, Appendix 3.4) approvals were sought. Approval for the second recruitment method was granted by NHS REC (reference number: 20/EE/0267, Appendix 3.5). The researcher also completed ethical training for Good Clinical Practice and obtained a research passport granted by NHS R&D (Appendix 3.4) prior to undertaking data collection.

3.7.2 Data Protection and Confidentiality

Data was collected, stored, and handled as per the data protection policies of RGU and the Data Protection Act (GDPR 2018). All data was securely stored on the project R Drive within the RGU organisational server, accessible only to the research team. All information collected during the study was kept confidential by adhering to the NHS Scotland Code of Practice on Protecting Patient Confidentiality. To ensure anonymity of participants, any potentially identifying information about participants was anonymised or removed. Participants were anonymised using a pseudonym to maintain a human element to participants (Saunders, Kitzinger and Kitzinger 2015).

All information and consent forms were created in accordance with the Health Research Authority (2017) advice. The PIS and the consent forms were given to participants prior to enrolment in the study. The researcher discussed both documents with participants and gave them the opportunity to ask questions prior to their enrolment. Before data collection commenced for Phase I and Phase II, the researcher gained verbal informed consent which was audio-recorded, and participants had an opportunity to ask any questions. All audio-recordings were exported to a secure research drive within the RGU server and the audio-recordings were deleted from the equipment. The audio-recordings were only accessed and listened to by the researcher.

Demographic data was collected on separate questionnaires and all identifying information was anonymised. Identifiable participant information was kept on a

separate password-protected spreadsheet on the research team's MS site (and backed up on the study research drive) and used for linking the anonymised data to a participant. This spreadsheet was restricted and only accessible by the research team.

3.8 CHAPTER SUMMARY

This chapter began by providing an outline of the philosophical paradigms and justification of the researcher's philosophical standpoint for this study. Following this, the chapter then described methodological approaches and the rationale for the use of co-design and IM. A detailed account of the methods undertaken in each phase were then reported. Finally, this chapter has described the ethical requirements for this study. The following chapter presents the findings from workshops 1-2.

4 UNDERSTANDING THE HEALTH PROBLEMS OF PEOPLE LIVING WITH INFLAMMATORY ARTHRITIS

4.1 CHAPTER INTRODUCTION

This chapter reports the findings from the first two workshops. The aim of these workshops was to develop a comprehensive understanding of the health problems of PLWIA residing in the northeast of Scotland. This chapter begins by introducing participants included in this study. The following section presents the work undertaken by the researcher prior to the workshop. The following two sections then present the methods and results for Workshop 1. These sections are organised by co-designer group (i.e., participants and HCPs). Subsequently, the findings are then discussed and compared against the scientific literature. Workshop 2 begins with a literature review using a pragmatic approach to identify the behaviours and environmental influences that influence the ability of PLWIA to self-manage. The methods and results from the participants are then presented followed by the methods and results from the HCPs. Findings from Workshop 2 are then discussed, and the chapter concludes with a reflexive summary of these workshops.

4.2 PARTICIPANTS

Ten participants were recruited from both recruitment methods. The first recruitment method resulted in two potential participants. However, when the potential participants were contacted, one participant did not respond, and the other did not consent to participation as they were unable to commit to the time requirements of the study. Therefore, the final sample consisted of 8 participants (see Table 4.1) who were recruited via the second recruitment method. These participants provided verbal informed consent prior to their participation in this stud

Table 4.1 Participant Demographics

Pseudonym	Gender	Age	Diagnosis	Disease Duration (years)	Educational Level	Working	Reason for Non-Work
Eilidh	F	46	PsA	23	University Undergrad	No	Receiving disability benefits
Isabella	F	41	PsA	13	NVQ Level 3	Yes	N/A
Louise	F	50	RA	23	University Undergrad	Yes	N/A
Iona	F	70	RA	30	University Undergrad	No	Retired
Fiona	F	63	RA	17	No answer	No	No answer
Fraser	M	49	Still's Disease	17	University Undergrad	No	Retired
Maisie	F	25	Enteropathic Arthritis	8	University Undergrad	Yes	N/A
Craig	M	41	AS	13	University Postgrad	Yes	N/A

Key: F-female; M-male; PsA-psoriatic arthritis; RA-rheumatoid arthritis; AS-ankylosing spondylitis; N/A-not applicable; NVQ- National Vocational Qualification

Of the 8 participants, 6 were female and 2 were male with a mean age of 48 years (SD 13.86). A range of conditions and disease durations were recruited. Three participants were diagnosed with RA; two with PsA; one with still's disease; one with AS; and one with enteropathic arthritis. Disease duration ranged from 8 to 30 years. Half of participants were still working, while two indicated that they were retired; one was receiving disability benefits; and one did not provide a reason for non-work. Seven participants completed all the workshops. One participant completed 4 workshops but was unable to participate in the final workshop and qualitative exploration secondary to other life circumstances.

4.3 WORKSHOP 1: PARTICIPANT INPUT

4.3.1 Participants

Consenting participants' availability was requested one week prior to the workshop. Additionally, they were emailed a document on how to access Microsoft Teams and the private Microsoft Teams page (Appendix 3.1). All participants were given the opportunity to practice using Microsoft Teams with the researcher prior to the first workshop. Participants were notified that the workshop was expected to take no longer than 90 minutes. In this workshop, two asynchronous sessions were held. Six participants (Eilidh, Isabella, Louise, Iona, Fiona, and Fraser) were placed in the first session, while two (Maisie and Craig) participated in the second session. The researcher's supervisor (LA) co-facilitated the first session to assist moderation and took notes.

4.3.2 Preparation for Workshop 1

The process for co-designing a novel SMI begins by understanding the health problems related to PLwIA (Bartholomew et al. 2016). Interventions should be designed around the target population's health problems (Kok et al. 2016). A poor understanding of the problems can result in type III error, which the intervention's design is inappropriate and/or ineffective (Sidani and Braden 2021). However, interventions that are designed to address the health-problems related to the target population in a manner that is acceptable to them are more likely to be found acceptable and effective (Yardley et al. 2015).

To understand the health problems related to PLwIA, the IM framework recommends exploring the theoretical and scientific literature as well as collect experiential data from the target population. The data collected is organised in a logic model of the problem (Bartholomew et al. 2016). A logic model illustrates the causal mechanisms of the problems related to PLwIA (Bleijenberg et al. 2018). While there are several types of logic models, this project used the PRECEDE model (Green and Kreuter 2005) recommended by the IM framework as this model differentiates potential causes of the health problems from a behavioural and environmental perspective that other logic models overlook (Bartholomew et al. 2016). An outline of the PRECEDE logic model can be seen in Figure 4.1.

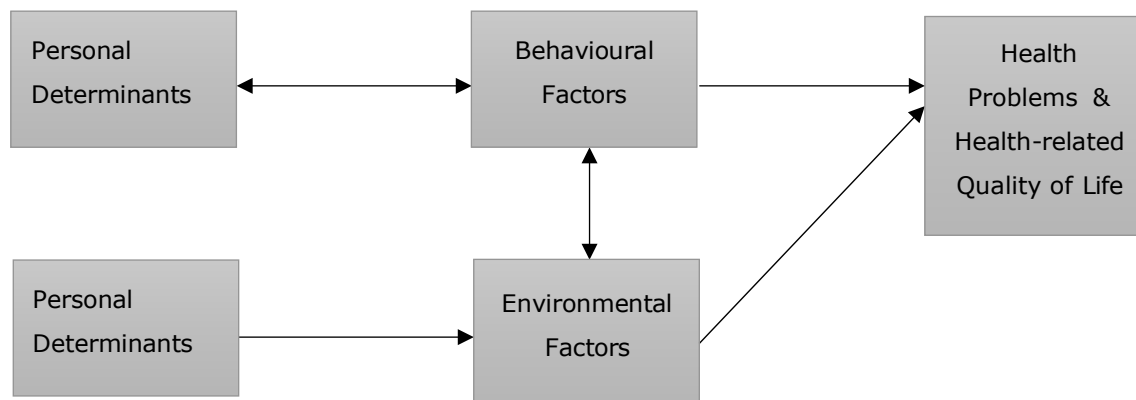


Figure 4.1 PRECEDE Logic Model (Modified from source: Bartholomew et al. 2016)

Prior to the first workshop, the researcher reviewed the scientific literature to identify the health problems that the decrease HRQoL for PLwIA (far right box in the PRECEDE model). Health problems related to PLwIA identified by the review were pain (Geenen et al. 2018), fatigue (Primdahl et al. 2019; Dures et al. 2019), decreased HRQoL (Michelsen et al. 2018; Geijer et al. 2021), functional and work-related disability (Myasoedova et al. 2019; Connolly et al. 2015; Chung et al. 2017), and co-morbidities (Baillet et al. 2016; Zhao et al. 2019). Each of these problems is presented in greater detail in section 1.3. Moving to the left in the model, the researcher then explored the scientific literature to identify potential behavioural and environmental causes of the identified health problems. Behavioural causes are the behaviours that raise the target population’s risk of experiencing the health problems, whereas the environmental causes include the environmental conditions that influence the health problems directly or the person’s ability to engage with the self-management behaviour. Lastly, the researcher identified the personal determinants (i.e., the factors or conditions) that contribute to the problem at both an individual and environmental level. Personal determinants were identified in the theoretical literature and can include knowledge, attitudes, beliefs, perceptions, and skills (Green and Kreuter 2005; Bartholomew et al. 2016). Personal determinants were not identified until Workshop 2 and will be discussed in more detail later in this chapter (see section 4.7).

4.3.3 Methods

The purpose of the first workshop was to explore the relevance of the identified health problems amongst the participants, and to identify their self-management support needs and preferences. This workshop began by introducing the researcher and the researcher's supervisor to the group of participants. Participants were also given an opportunity to introduce themselves. Following introductions, the researcher reiterated to the participant groups the purpose of the study; provided a brief explanation of what was to be expected throughout each of the workshops; and an overview of Workshop 1's agenda. A topic guide (Figure 4.1) was used to guide the discussion. The topic guide was developed by the researcher prior to the workshop and then sent to a supervisor (LA) to ensure quality and appropriateness. At the end of the workshop, the researcher summarised the main discussion points and gave participants an opportunity to state or clarify any final thoughts.

As highlighted in section 3.4.8, the workshop was audio-recorded and then subsequently transcribed. The researcher adopted a framework data analysis method to analyse the data gathered from this workshop. A detailed presentation of the framework method by Ritchie and Spencer (2014) is described in section 3.5.2. A framework-analysis method was adopted for a few reasons: (1) framework analysis was deemed to be an appropriate analytical process for this workshop as the lived experiences of participants were explored; (2) it would provide a rigorous approach for making sense of the data; and (3) it allowed for an easy comparison of the data by themes across each session and the existing literature base.

Figure 4.2 Workshop 1 Topic Guide

Questions

1. To begin, can I get you to think about your diagnosis and how this has impacted on your daily life? This could be the physical impact, emotional impact, your social life, your ability to engage in work, etc.
 - a. Prompts:
 - i. If you are having a flare, how does this change how your life is impacted? How frequently are flares occurring?
2. How do you manage the impact that your condition has on your everyday life? Do you have a day-to-day routine? This could be different across conditions and is very individual.
 - a. Prompts:
 - i. What have you found that makes it easier or harder to manage your condition?
 - ii. How has this changed throughout the years?
3. You all have been diagnosed with an inflammatory arthritis condition and have been navigating through how to live with it. Clinically, we define this as self-management. *Bring up whiteboard and then list the ones we have discussed-add to them and then list the ones we haven't yet discussed.*
 - a. Prompts:
 - i. Which ones are more important to you?
 - ii. What parts have you done before?
 - iii. Why do you behave in this way question? Why do you believe you are able/unable to participate in the behaviours that help you self- manage?
 - iv. Have you had self-management training?
 - v. Have you sought out self-management information?
4. What role, if any, does your social support network, such as family and friends, influence your ability to self-manage?
 - a. Prompts:
 - i. What do you feel like you can't do on your own and need help from your social support network?
 - ii. How well do you think people in your life understand the impact that your condition has on your life?
 - iii. What kind of support do you need from your healthcare practitioners?
 - iv. What, if any, community resources have you utilised? For example, outdoor gyms, running groups, or charities related to your condition?
5. Now let's work together to develop a self-management intervention. What would you like to get from a self-management intervention?
 - a. Prompts:
 - i. What topics would be covered in the intervention? Give them examples?
 - ii. Who would deliver it? Who would be the most important person and why?
 - iii. What else should be included in self-management?
 - iv. What do you think would encourage you in taking part in such an intervention? What might put you off?
 - v. How would you like it to be delivered? For example, group discussion, didactic passive teaching, workbooks, or diaries?
 - vi. How many sessions would it be?
 - vii. How long would the sessions last?
6. Is there anything else anyone would like to add?

4.4 Results

Participants reported a myriad of struggles related to their diagnosis. While each participant had their own personal issues they had to overcome, common challenges were identified amongst the group. Three overarching themes emerged from the data collected. These were: (1) living with IA; (2) experiences with clinical and third-sector services; (3) and self-management support. These themes and their corresponding subthemes are detailed in the following section. Illustrative quote examples are used to describe the identified themes and subthemes.

4.4.1 Theme 1: Living with IA

Four subthemes emerged relating to living with IA. These were impact on physical health; impact on mental health; impact on ability to participate socially; and impact on ability to work.

4.4.1.1 *Impact on physical health*

All participants reported that pain and fatigue significantly limited their ability to complete basic ADL, even with proper pharmacotherapy and non-pharmacological interventions. Participants attributed pain and fatigue as the main reason for a decline in their physical capabilities.

"I'm constantly in pain. I'm currently trying to sort that out, and I'm not getting very far." -Fraser

"The fatigue is there for me all the time. No matter what meds I'm on, the fatigue has never gone away." -Craig

Participants also described periods where their symptoms were exacerbated, that is 'flared'. Common triggers for a flare were stress, overexertion, and weather. Participants reported that it can be difficult to inhibit and manage a flare and that some flares can only resolve with time.

"When you're in so much pain and kind of at that point where no matter how many pain killers you take or hot baths or whatever, it's not going to help. You kind of have to ride through the pain until you get to the other side." -Maisie

"I'll get a flare whenever there's a drop in temperature." -Craig

"Just because I know what my triggers are, doesn't prevent [a flare] from happening." -Craig

All participants reported the importance of their medications to reduce the impact of their pain and improve their ability to function. However, they highlighted that it takes getting on the right medication before improvements are seen, and irreparable joint damage can occur during the interim.

"The medications have been helping me to be mobile. I know it has its side effects, but at least I can move." -Fiona

"Looking back, I thought it was arthritis and I'd be fine, and then it went downhill very quickly. (...) [My consultant] was actually very honest with me and told me that if I don't [use medications] then I was going to end up in a wheelchair." -Eilidh

"Because it took so long to get on the right medication you are still left with joint damage. [Iona]... that's where I am at too. [Fraser]"

A few participants also noted that changes in medications are common, and the side effects of the medications can come with its own set of challenges.

"I've been on Tramadol for years, but it's basically drug addiction. It's not helping with pain relief." -Fraser

4.4.1.2 Impact on mental health

A few participants reported that their mental health was adversely affected by their diagnosis. Specifically, some reflected on a turbulent time of living through a period of unexplained symptoms and difficulty accepting a diagnosis of an incurable disease.

"When your first diagnosed, it's very emotional and scary. (...) I was really struggling to get to grips with it." -Louise

"I was in denial, but then it had to be accepted. I had to realise my limitations and sort of admitting it, which I am still not very good at." -Eilidh

For some, however, the eventual diagnosis brought relief and validation.

"I was relieved when I was diagnosed. (...) I was initially treated in orthopaedics, and they were treating it as a sports injury. So, the first three or four years was really difficult because they didn't know what it was." -Craig

One participant spoke of the long-term effects that their condition has had on their mental health.

"A lot of the associated consequences of my condition is [my] mental well-being affected." -Craig

4.4.1.3 Impact on participants' ability to participate socially

This subtheme covers participants' feelings of being restricted in their ability to fulfil normal social roles. Participants portrayed how their relationships, particularly romantic and familial, were put under pressure or strain as a direct result of their condition.

"I was 27 years old when I was diagnosed. Within nine months of being married, my poor sod of a husband had this carefree happy girl that he married, and then within nine months it was someone completely different that he was living in the house with." -Louise

"Two of my relationships have broken down." -Isabella

Some participants also reported role changes within romantic and family relationships.

"She's my younger sister and normally you're the one having to look after your younger sister, and it's the other way around where she was the one that was having to look after me." -Maisie

Participants perceived others who are only familiar with 'typical' aches and tiredness are not fully able to recognise and understand the severity of their symptoms.

"Until they are in our position, they just don't get it. [Isabella] Yea. [Fraser]"

"You will have friends that will try and think they know what it's like, and it's like 'no you really don't'. (...) I know they are trying to be nice, but it just gets annoying. [Eilidh] Yea. [Group]"

Some participants also felt that it was difficult to gain support from society as there was a lack of public understanding about IA.

"People will take a look at you and go 'oh you can't be that bad', but they can't look inside of you to see the damage that is happening. (...) You are trying to live your life the best you can and not be down. You've got a family, you've got friends, you want to be normal. So, you do what you can in your own way, but then you get penalised by people's own viewpoints because they see you moving and think 'oh she can't be that bad'; but they can't see you got two fake knees, a fake shoulder, and on these really big drugs." -Eilidh

This often led to participants attempting to hide their condition or isolate themselves from others.

"You're a master at hiding the disease, (...) even when really you are dying inside. [Louise]... We have all done it. [Fiona]... Yup. [Iona]... That's a good point actually. [Fraser]"

"You often feel like you're the only person in the world that has this." - Craig

Fatigue was also reported as a barrier to social participation. The unpredictability of fatigue makes it difficult for participants to plan, and often results in the postponement or cancellation of plans. Consistent cancellation of plans and inability to do certain activities had led to feelings of guilt for some of participants. Guilty feelings were particularly evident in participants with children. Additionally, these participants highlighted that functional disability disrupted their ability to fulfil childcare responsibilities.

"I have huge guilt for my two kids. (...) We can't do this because mum can't manage, or we can't do that because mum is not able." -Iona

"When my daughter wants picked up and I can't pick her up, it's heart-breaking; it's my wife's support that I have to rely on." -Craig

"I am very lucky to have such a supportive family. (...) My mom has been to every single appointment and every hospital stay." -Maisie

4.4.1.4 Impact on ability to work

Participants widely reported the significant impact their condition had on their ability to work. Pain and fatigue often negatively affected participants' work

performance and made it difficult for them to fulfil their role at work. One participant reported having to change career paths or cease work because of their condition.

"I was working at the hospital as an auxiliary nurse and there was a lot of walking around. (...) I decided I had to switch the profession I was doing."
-Isabella

Participants reported that the expectations of their employer and co-workers influenced their ability to work. These expectations led to 'cycles of stress' in participants.

"One of my triggers is stress and then that cycle of 'I need to be at work and I'm stressed because I'm not at work' is a horrible cycle to get into." -
Craig

For these reasons, participants stressed the importance of having an understanding workplace to aid in helping them manage their condition.

"My work is extremely understanding. I know I can go and ask to take a break or take a seat." -Maisie

"[My job] gives me disability leave so all my appointments and stuff don't count negatively towards my attendance record." -Craig

4.4.2 Theme 2: Experiences with clinical and third-sector services

Two subthemes developed relating to participants' experiences with clinical and third-sector services. Subthemes that developed describe participants' experiences with their clinical care team and in joining support groups.

4.4.2.1 Clinical care

Participants in this study were overall satisfied with the current provision of their care by the rheumatology service. Participants collectively agreed that having a consultant that focuses on delivering patient-centred care is vital to their ability to manage. Specifically, participants highlighted that HCPs that are attentive to their personal story and needs improved their patient experience.

"I think having the right consultant... [Isabella]... is huge [Eilidh]... I absolutely agree with that statement. [Iona]"

"I'm now with a consultant that looks at the bigger picture. [My consultant] looks at how I live; how I want to live; and what I can cope with. (...) You often get medical people that just treat the symptoms. You don't get them looking at what the disease means to you and what you have lost." -Eilidh

"I have had three consultants and they were all superb. They looked at the background and they looked at the family, which made a big difference." -Iona

" (...) by asking about the family and making a point to remember stuff about me, so when you go in you are a person and not a file." -Isabella

Although participants primarily discussed the impact their consultants have had on them, one participant highlighted that all HCPs contribute to their care experience.

"Any healthcare professional you are working with makes a big difference to you." -Iona

Participants expressed less satisfaction and poorer quality of care with HCPs that do not consider their needs or preferences.

"Right after I was diagnosed, I had one consultant tell me to be more optimistic with my attitude and how I wasn't trying very hard. I had a lot of criticism. (...) I left in tears." -Louise

4.4.2.2 Third-sector support groups

Participants reported rarely utilising the support services offered by third-sector charities and groups. Some participants reported trying peer support groups in the past but did not find these groups to be helpful.

"It was possibly the most depressing thing I had ever done in my life because everyone at the table told me all the joints they had replaced and all the pillows they had to sleep with. I don't want to hear about all those things." -Louise

"I have joined other groups as well, and I don't find them on the same mind level as me because they want to be negative all the time and it sucks... it really sucks." -Eilidh

4.4.3 Self-management

Subthemes to develop from this theme included participant's current use of self-management strategies and their preferences for a new SMI.

4.4.3.1 Current use of self-management strategies

Participants reported using several self-management strategies to help them manage their condition in their daily lives. Prioritising and pacing activities were the most frequently adopted strategies to manage symptoms. These were particularly helpful for managing fatigue. Work and functional roles were often given higher priority than leisure activities and exercise.

"I have a family so that means that I have to work. Sometimes that means that friends are then ones that have to suffer, and that can be challenging." -Craig

However, prioritising and pacing were not always effective methods for coping with fatigue.

"It's not as 'if you've got a wedding on Saturday and you stay in bed all day Friday, you will manage'. No. It depends on what I wake up and feel like on Saturday morning. I might manage or I might feel like death. [Iona]... And even that day you may feel great when you wake up, but within an hour of waking up you may not feel well or vice versa. [Isabella]... And, also, if there is pressure on you to have rest day, it does not necessarily work. [Fraser]"

Other self-management strategies reported by participants included changes to daily routines, distraction, receiving help from others, rest, carry on regardless of the consequences, and having a positive attitude.

"I spent the entire Saturday in my bed just to rest because I needed that opportunity to recuperate, and my body needed that opportunity to recuperate. If I don't get the opportunity to do that every now and again my arthritis can become overwhelming." -Craig

"When I'm in a flare, I get up a little bit early to give the joints a little bit more time to get moving." -Maisie

"I get told all the time by my wife that I am doing too much, but I crack on through it and I suffer for it later." -Craig

"When it gets really bad and I'm squatting down to get something in the fridge, I can't get back up and I have to get my mom and sister to come help me." -Maisie

Participants' experiences with self-management techniques were primarily self-taught. However, most reported that it took them several years to feel at least somewhat confident in their ability to effectively self-manage their condition.

"I've had [Stills Disease] for 16 years and it's taken me about 15 years for me to be semi-managing." -Fraser

All participants expressed a desire to have more self-management support from their HCPs. Participants found that attention during appointment can be primarily focused on physical problems and disease activity, which led some to believe that little could be done about the wider implications that their condition has placed on their lives.

"I need help to know how to self-manage." -Craig

4.4.3.2 Preferences for a new SMI

Participants reported several information needs related to their condition, diet, exercise, and complementary therapies.

"I think it would be important, for when you are first diagnosed, to get more information on how the disease actually does what it does. (...) I like to know how the disease is affecting [my joints], and how it's going to progress and why intervention is important now." -Eilidh

Participants also reported they thought it is important for HCPs to explain that the road to effectively managing IA is unique to everyone, and that determining the best treatment path will be a 'trial and error' process.

"You have to understand that it is trial and error, and it's dreadful when you are in pain and waiting for something magical to happen. Every person's journey is different so it's very vague. (...) There are 15 ways to solve this disease and that's not explained to you. [Louise] Yea. [Group]"

Participants emphasised that the stage of disease should be considered while recruiting to the SMI. Participants recommended that newly diagnosed PLwIA should wait to be enrolled into the SMI to allow them the time and space to

process their diagnosis.

"[The intervention] would not be good to have at a first diagnosis. I think you would need to leave it till after your first 2 or 3 [consultant appointments] because your brain is scrambled after your first and second consultation. You take in nothing... absolutely nothing. [Iona]... If you leave it till further down the line, then you know there is a route out. As you say, after your diagnosis your life changes forever. So maybe [newly diagnosed individuals] should wait till after their third or fourth consultation. [Fraser]"

Participants collectively agreed that the SMI should be delivered in group format to allow them to meet others living with the same or similar condition. Some also reported they would like to be given information that they can take home with them and would like to have the ability to attend the intervention remotely.

"Have the opportunity to speak to one another. (...) talking to someone in our shoes who know exactly how we feel." -Maisie

"For the people that are travelling in [for the intervention], you have the physical time of getting there and getting parking, getting back, and then you are knackered." -Iona

4.5 WORKSHOP 1: HEALTHCARE PROFESSIONAL INPUT

4.5.1 Methods

Following the workshop sessions, an email was sent to the HCP co-designers (RH and AU) with an informal report on the findings from the workshop sessions and to obtain MDT members input on the following:

1. What factors do HCP/MDT believe affect the HRQoL in PLwIA the most?
2. Of the factors listed in question 1, which ones would they like addressed in the SMI? List in order of importance.
3. What other topics would they like to be covered in the SMI?

4.5.2 Results

Five members of the ARI rheumatology MDT were consulted: a specialist nurse, an occupational therapist, a podiatrist, a consultant, and a Band 7 specialist physiotherapist. The MDT considered pain, sleep, fatigue, reduced physical

activity, and socioeconomic status/economic deprivation to affect the HRQoL of PLwIA the greatest. They reported that of these factors, they wanted sleep, pain, fatigue, and reduced PA to be addressed during the SMI. Further, they reported that the SMI should provide education regarding IA, medication, diet, work, and provide them with an overview on the role of the MDT and rheumatology as a service.

This section has presented the methods and findings for Workshop 1. The following section will discuss the findings from this workshop in comparison to the relevant scientific literature.

4.6 WORKSHOP 1 DISCUSSION

This workshop revealed how participant co-designers have been impacted by their condition. Findings from the workshop highlighted the impact of IA on the physical and mental health for PLwIA as well as their ability to fulfil life roles at home, work, and in relationships. The health problems identified by participant and HCP co-designers correspond with the scientific literature presented in section 1.3 as well as other literature exploring the impact of IA on everyday life (Connolly et al. 2015; Oude Voshaar et al. 2015). The following subsections will discuss the findings from this workshop in relation to the literature.

4.6.1 Impact on Daily Life

Findings from this workshop suggested that pain and fatigue limit participants' ability to perform their ADL. Although the literature has indicated that early morning stiffness also acts a barrier to completing ADL (da Silva et al. 2011), this was not mentioned by either participant nor HCP co-designers. Rather, flares were reported to interfere with participants' ability to complete ADL. This finding is corroborated by previous qualitative literature in AS (Davies et al. 2013), PsA (Moverley et al. 2015), and RA (Hewlett et al. 2011; Flurey et al. 2012) that have also reported that flares can be disruptive to ADL.

Participants also highlighted that the physical consequences of IA can limit their ability to participate socially, especially in romantic and parenting roles. Inability

to participate in these life roles was associated with feelings of guilt and loss in participant co-designers. Several other studies have also found that physical disability can lead to an inability to fulfil parenting roles and causes psychosocial distress in PLwIA (Zelkowitz et al. 2013; Benka et al. 2016; Bergstrom et al. 2019; Cobb 2021). These findings emphasise that the physical consequences of IA can have wider implications on the well-being and HRQoL in those affected despite modern drug therapies (Ahlstrand et al. 2015).

Although participant co-designers openly discussed how their physical impairments affected their romantic relationships, the impact of IA on physical intimacy was not discussed. The impact of IA on intimacy has been previously identified in two other studies (Bergstrom et al. 2019; Codd 2021) in relation to a person's perceived closeness and connectedness to their partner resulting in wider implications to their self-identity and HRQoL.

The findings from this workshop suggest that IA can have a direct impact on participants' mental health/well-being. A few participant co-designers described the emotional distress associated with being diagnosed with an incurable condition. One participant reported that their mental health had been affected in the long-term. Interestingly, this was reported by a male participant which contradicts the research by Flurey et al. (2017) who reported that men are less likely to discuss the emotional impact of IA. Given the recognised prevalence of depression in IA in the literature (Matcham et al. 2013; Baillet et al. 2016), the researcher had expected that participant co-designers would have reported a greater impact on their mental and emotional health. It is possible that participant co-designers were reserved in discussing the emotional impact of their condition, which could potentially be attributed to the stoicism of northeast Scotland. Another potential explanation is that the participants may have expected the researcher or the other participants to have reacted negatively to them emotionally disclosing information (Greene and Faulkner 2002; Woodgate et al. 2022). People are less likely to disclose their emotions if they expect the recipient to act negatively. Negative expectations can be the result of a lack of social acceptance following previous attempts to emotionally disclose (Woodgate et al. 2022) and the stigma associated with having an invisible long-term condition (Ysasi, Becton and Chen 2018; Woodgate et al. 2022). Stigma is a

concept referring to the disapproval and devaluation of a person from others and has been previously linked to feelings of shame (Ysasi, Becton and Chen 2018). Poor understanding of illness by the public have also been associated with stigma (Hearn, Whorwell and Vasant 2020; Turnock, Langley and Jones 2022).

Although RA is a known condition to the general public, other forms of IA are virtually unheard of outside the medical profession (Bay et al. 2020). Findings from Workshop 1 highlight that many members of the participants' social networks usually have no prior knowledge of their condition. It is often extremely difficult for them to explain the nature of their arthritis to others. Even in cases in which the condition is known to others, evidence from this workshop indicated that others may not be able to fully understand the severity of their symptoms and the impact of this on their lives. This lack of public knowledge and understanding can cause PLwIA to not want to speak about the problems related to their diagnosis with others, which could carry over into situations like the workshop especially as this was the first workshop and the participants had not met the researcher before. Lack of public knowledge and understanding has also been attributed to loneliness in people living with long-term conditions and can cause some to isolate themselves (Bay et al. 2020). However, there is limited evidence on barriers to emotional disclosure in PLwIA and therefore more research is required in this area.

HCP co-designers also did not report that poor mental health was a main contributing factor to the decreased HRQoL in PLwIA. A potential explanation for this is that most clinic appointments are focused on remedying the physical consequences of IA. Due to time pressures placed by the NHS, rheumatology HCPs have limited time to discuss the psychosocial consequences of IA. HCPs may therefore be unaware of the extent that IA can have on a person's mental and emotional health; hence leading to underreporting of psychosocial consequences in PLwIA. However, it is possible that HCP co-designers did consider mental health to affect the HRQoL of PLwIA, but they did not believe it to be a main contributor to their decreased HRQoL.

Findings from this workshop have also highlighted how IA has affected participants' ability to attend and engage with work-based activities. Participants

in this study that were employed reported making several modifications at work, such as taking frequent breaks and modifying work-based activities. One participant also reported that her diagnosis forced her to change career paths. Findings from this study are in-line with other research that have explored ability of PLwIA to participate at work and retain employment (Looper et al. 2012; Hoving et al. 2013; van Vilsteren et al. 2015).

4.6.2 Preferences for Self-Management Support

Participants in this study described a wide range of self-taught, self-management strategies that they were already incorporating into daily life, however, participants and HCPs co-designers also described several self-management needs. Both co-designer groups reported that PLwIA need to be provided with additional information relating to their condition, lifestyle advice (e.g., diet and exercise), and non-pharmacological treatments (e.g., complementary therapies). The self-management needs identified in this study are consistent with that of previous research (Zuidema et al. 2015). Additionally, the findings from this workshop indicated a need for a peer support group in which PLwIA can meet and interact with one another in a safe, positive, and friendly environment.

Although participants in this study and other studies (Smolen et al. 2013) have highlighted that 'finding the right consultant' is central to the management of IA, evidence suggests that an MDT is best to provide disease management support and interventions (Bearne et al. 2016). Use of an MDT to support self-management in PLwIA is also supported by clinical guideline recommendations (National Institute for Health and Care Excellence 2017, 2018; Nikiphorou et al. 2021). These guidelines also recommend that IA interventions incorporate patient-centred approaches to adequately address the informational needs of PLwIA and empower them to self-manage. A person-centred model of care is an individualised approach to assessing and managing patient-identified needs (Coulter and Oldham 2016). In this model, the patient is at the heart of care and interventions are co-designed to meet their needs (Scottish Government 2017). A high-quality systematic review demonstrated that a person-centred model of care improves patient safety, patient experience, and clinical effectiveness in people living with long-term conditions (Doyle, Lennox and Bell

2013). Person-centred care is discussed in further in section 4.7.1.4.

Participant co-designers recommended that newly diagnosed PLwIA should wait to be enrolled in the SMI. This was an unexpected finding as literature exploring the impact of IA on everyday life has described similar health problems among those who are newly diagnosed (Bergstrom et al. 2019; Codd 2021) and those with established IA (Squire 2012; Ahlstrand et al. 2015; Connolly et al. 2015; Voshaar et al. 2015). However, this finding could help to explain why our initial recruitment strategy was unsuccessful. More research is needed to explore newly diagnosed IA patients' readiness to participate in a SMI and determine if their self-management support needs differ from the needs identified in this study and the literature.

This section has discussed the data collected from Workshop 1 in comparison to the scientific literature. The synthesised findings form an overall impression of the health problems related to PLwIA and their self-management support needs. These findings were integrated into the logic model developed in Workshop 2 (see section 4.7.1 below). The following section will present and explore the methods and findings from Workshop 2.

4.7 WORKSHOP 2

The purpose of this workshop was to develop and complete a logic model of the health problems related to PLwIA. The work undertaken in this workshop builds on the findings from Workshop 1. Prior to the second workshop, the researcher reviewed the literature on the self-management behaviours required of PLwIA; the environmental influences affecting their ability to self-manage; and their determinants (Bartholomew et al. 2016). The review took a pragmatic approach given the breadth of information available and the need to quickly continue onto the following workshop. The literature review mostly included systematic reviews and clinical guideline recommendations. Where systematic reviews weren't available, RCTs were sought. Although this approach potentially led to some relevant evidence being left out, it allowed for a literature review of robust study designs to be undertaken in a timely manner. The findings from the review were grouped into four categories (i.e., non-behavioural factors; self-

management behaviours; environmental influences; environmental determinants), which are presented in the following sub-sections and were used to develop a comprehensive logic model of the health problems related to PLwIA (Figure 4.3). Participant and HCP co-designers were consulted to explore the relevance and comprehension of the logic model in Workshop 2.

4.7.1 Literature Review

4.7.1.1 *Health outcomes and quality of life*

The health problems listed in the 'Health Outcomes & Quality of Life' box in Figure 4.3 are categorised by the nature of the problem, such as issues related to physical health, emotional health, and work. The problems listed in the box represent the identified problems from Workshop 1.

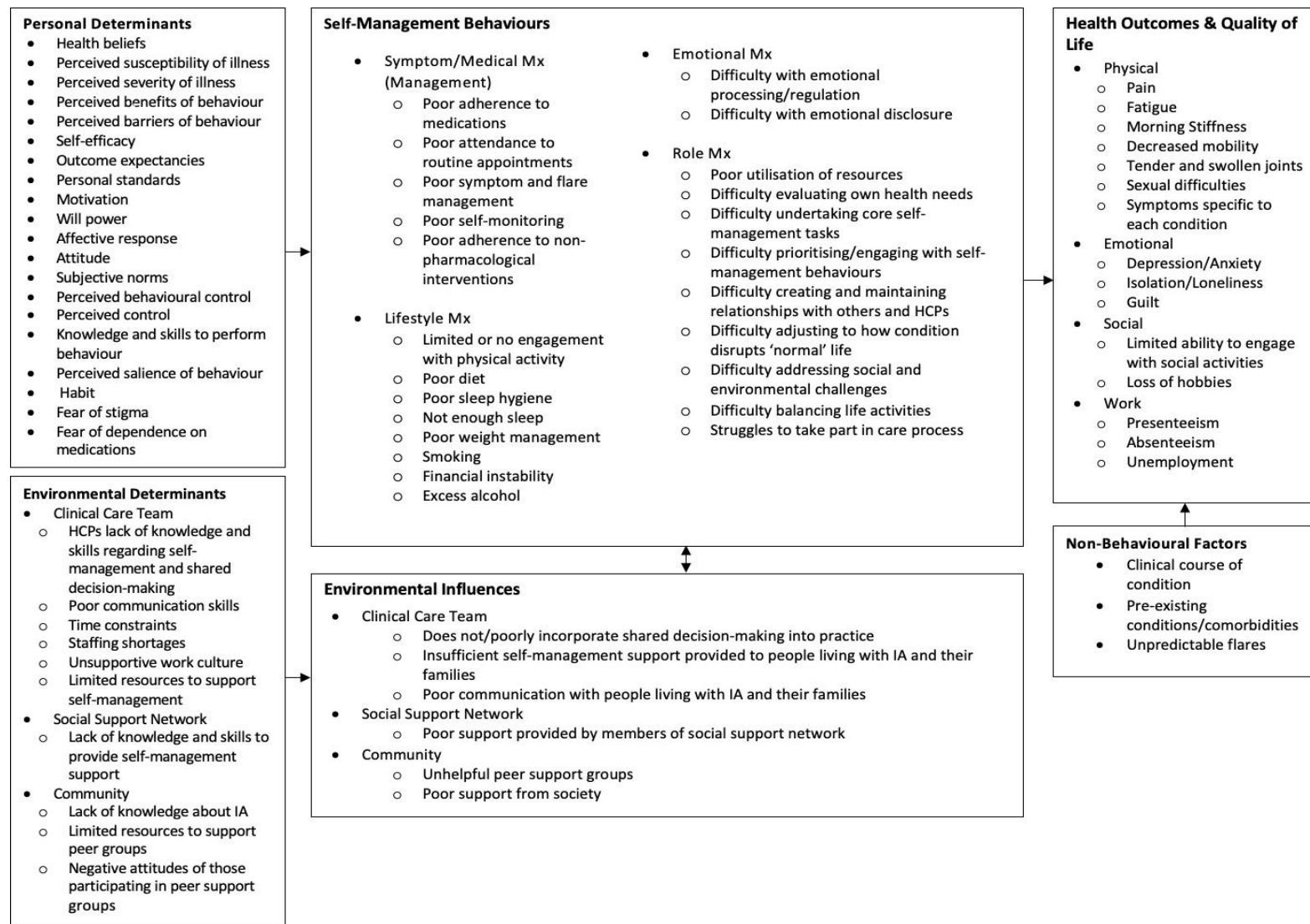
4.7.1.2 *Non-behavioural factors*

Non-behavioural factors are those that contribute to the health problem but are not the result of an individual's behaviour. Although non-behavioural factors are not included in the original PRECEDE diagram, it is important to recognise that these factors can and do greatly influence patient's experience of living with their condition (Sidani and Braden 2021). For this reason, the researcher included these factors within the logic model. Non-behavioural factors related to IA include the clinical course of the disease; any other pre-existing condition or comorbidities that PLwIA might have (Novella-Navarro et al. 2021); and unpredictable flares (Flurey 2012).

4.7.1.3 *Self-management behaviours*

To best encourage people to self-manage their health problems, it is key to understand the behaviours that positively and negatively affect these problems (Sassan et al. 2018; Sidani and Braden 2021). As highlighted in section 1.4.3, the self-management tasks required of PLwIA relate to the medical, emotional and role consequences of their diagnosis (Van de Velde et al. 2019). Adherence to drug therapy is an important aspect of medical management as it is key to achieving better outcomes and remission. Poor medication adherence increases the risk of flares; ongoing pain and stiffness; joint damage; and disability (Contreras-Yáñez et al. 2010; Bluett et al. 2015; Bullock et al. 2019). Poor

Figure 4.3 Logic Model of the Health Problems Related to PLwIA



medication adherence among PLwIA is frequently reported (Galo et al. 2016). There is a lack of high-quality evidence of medication adherence among PLwIA, however a recent RCT of 451 people with RA found that medication adherence ranged from 44-90% depending on the method used to measure adherence.

Medical management also includes PLwIA attending routine clinic appointments to have their disease activity and symptoms monitored (Van de Velde et al. 2019). A systematic review exploring the T2T approach and the frequency of monitoring in RA was unable to identify any evidence exploring the how often PLwIA should be monitored (National Institute for Excellence 2018). However, NICE guidelines recommend that people living with RA who are not in remission be monitored monthly and those in remission be monitored every 6 months (National Institute for Excellence 2020). NICE guidelines for SpA also recommend frequent monitoring, however this guideline recognises that the frequency of monitoring is dependent on the drug prescribed (National Institute for Excellence 2017). A recent RCT has also found that self-monitoring is an effective method for DMARD monitoring (McBain et al. 2018). Although, more research is required on the efficacy of self-monitoring in PLwIA.

Although drug therapy can significantly decrease the severity of symptoms and risk of long-term disability in PLwIA, pain and fatigue can still be prominent in daily life and therefore non-pharmacological interventions are warranted (Cramp 2019). Poorly controlled or uncontrolled pain and fatigue can lead to the development of maladaptive behaviours that can reduce mobility; diminish sleep quality; and increase the likelihood and/or severity of anxiety and depression (Vergne-Salle et al. 2020). Non-pharmacological interventions for the management of pain in IA includes electrotherapy; thermotherapy; complementary and alternative medicine (CAM); orthotics and assistive devices; physical activity and exercise; dietary interventions; and sleep hygiene education (Geenan et al. 2018). These interventions have been recommended by clinical guidelines (Scottish Intercollegiate Guidelines Network 2010, 2011; National Institute for Excellence 2018, 2020; Gwinnutt et al. 2021), and evidence regarding their effectiveness are presented elsewhere (see Appendix 5.2).

Healthy lifestyle behaviours must also be adopted in conjunction to medical management (Schulman-Green et al. 2013; Van de Velde et al. 2019). National and international clinical guidelines recommend that PLwIA receive support from HCPs on the benefits of exercise (Scottish Intercollegiate Guidelines Network 2010, 2011; National Institute for Excellence 2018, 2020; Gwinnutt et al. 2021; Nikiphorou et al. 2021). Most of the literature to-date has focused on the benefits of aerobic and strength training exercise in PLwIA. Several systematic reviews suggest that aerobic exercise and strength training have small- to moderate-effects on pain (Baillet et al. 2010), fatigue (Cramp 2013; Rongen-van Dartel et al. 2015; Kelley, Kelley and Callahan 2018), quality of life (Baillet et al. 2010), and function (Baillet et al. 2010, 2012; Bergstra et al. 2014; Lamb et al. 2015). Low impact forms of exercise, such as hydrotherapy (i.e., pool-based), T'ai Chi, and yoga are also frequently recommended to PLwIA to reduce stress on arthritic weight-bearing joints when compared to high impact exercises that can exacerbate pain and increase damage to the joint (National Institute for Excellence 2020; Gwinnutt et al. 2021; Nikiphorou et al. 2021). However, there is less robust scientific evidence to support the use of these forms of exercise. Two systematic reviews have also reported that hydrotherapy is beneficial over no exercise (Al-Quabaeissy et al. 2013; Siegal et al. 2017), but there was no significant benefit of hydrotherapy over land-based exercise (Siegal et al. 2017). Two older, high-quality systematic reviews exploring the effectiveness of T'ai Chi found limited effect on disease activity and symptoms (Han et al. 2004; Lee, Pittler and Ernst 2007). Lastly, only one meta-analysis of five RCTs found yoga to led to significant improvements in function (Wang et al. 2018).

Clinical guideline recommendations have also recommended that PLwIA receive support on healthy eating to help with weight management (National Institute for Excellence 2018, 2020; Gwinnutt et al. 2021; Nikiphorou et al. 2021). Popular diets for PLwIA include a vegetarian, gluten-free, Mediterranean diet, and intermittent fasting (Khanna, Jaiswal and Gupta 2017). To date, there are two high quality systematic reviews exploring dietary interventions for IA (Hagan et al. 2009; Philippou et al. 2021). Both reviews included an RA population. A 2009 Cochrane review were unable to determine the effects of diet as the included studies had small sample sizes. Moreover, the review included mostly single trials with moderate-to-high risk of bias and high attrition

rates in the intervention group, thus indicating that the potential adverse effects of dietary interventions for RA should be considered (Hagan et al. 2009). Another review published in 2021 produced similar findings, however authors found that consuming omega-3 polyunsaturated fatty acids (fish oil supplements) at high doses decrease disease activity and could be used in conjunction with a healthy diet (Philippou et al. 2021). The overarching consensus from the evidence, however, is that the findings on the effectiveness of dietary interventions is still ambiguous and most recommendations suggest that patients living with RA follow healthy eating guidelines (Nikiphorou et al. 2021).

Smoking cessation is particularly important for individuals living with IA (Gwinnett et al. 2021). A high-quality umbrella review found that PLwIA who smoke are at increased risk for CVD; less likely to respond to medication; have higher disease activity and severity (Wiczorek et al. 2022). There is also data from the umbrella review to suggest that increased alcohol consumption is associated with higher disease activity and radiographic damage in RA (Wiczorek et al. 2022).

Sleep is another important facet of an individual's health. In PLwIA, inadequate or disturbed sleep can exacerbate fatigue. Poor sleep can also increase stiffness and pain as well as decreases mood (Grabovac et al. 2018). A systematic review exploring the frequency sleep disturbance in RA compared to the general public found that people living with RA require more sleep; are more prone to sleep disorders; have more daytime dysfunction; and use more sleeping medication (Zhang, Shen and Liu 2021).

EULAR recommendations also promote the maintenance of the ability to work in individuals living with IA (Hoving 2013). For any working age adult, the ability to participate in work is important not only economically but also for physical and psychological health (Hoving 2013). There is limited evidence on the prevalence of unemployment and work disability in PLwIA. However, one older, moderate quality systematic review exploring work disability in PsA estimated the unemployment rate in this population is 20-50% and that work disability (i.e., absenteeism-time away from work and presenteeism-reduced

effectiveness at work) occurred in 16-39% (Tillett, de-Vries, and McHugh 2012). Predictive factors of work disability in PLwIA include jobs requiring manual work and heavy lifting; work conditions with excess exposure to cigarette smoke, fumes, or chemicals; older adults; lower educational level; female gender; and worse physical function (Tillett, de-Vries, and McHugh 2012; Papakonstantinou 2020).

Another task of self-management requires PLwIA to emotionally process and cope with the emotional sequeli of their diagnosis (Schulman-Green et al. 2013; Van de Velde et al. 2019). Findings from Workshop 1 and the literature (see section 4.6) indicate that depression, anxiety, isolation, loneliness, and guilt are all emotional consequences of IA. The findings also highlighted the importance of emotional disclosure. Another important aspect to emotional management indicated by the scientific literature is emotional processing and regulation, which refers to the ability of PLwIA to explore and express their emotions; cope with emotional consequences of their diagnosis; and grieve over the loss of their health and functioning (Schulman-Green et al. 2013). Wierenga, Lehto and Given (2018) identified that difficulty regulating or moderating emotional responses can contribute to a person living with a long-term condition's ability to effectively cope and self-manage.

Lastly, self-management requires people living with long-term conditions to maintain, change, and/or create new meaningful behaviours or life roles (Van de Velde et al. 2019). A qualitative meta synthesis of 101 studies identified several role processes related to self-management, including learning about their diagnosis; taking responsibility for their health needs; and engaging with self-management behaviours (Schulman-Green et al. 2013). The review also highlighted that people living with long-term conditions are required to utilise resources available to them to aid in self-management (Schulman-Green et al. 2013). EULAR recommendations suggest that important resources to PLwIA are clinical services; financial benefits; their social support network; and third-sector organisations (Nikiphorou et al. 2021). The self-management skills related to effectively utilising these resources include creating and maintaining relationship with others and HCPs; communicating effectively; shared-decision making with HCPs; ability to navigate the healthcare system; and address social and

environmental challenges (Schulman-Green et al. 2013). Furthermore, role self-management requires adjusting to a new 'normal' through finding pleasurable activities that PLwIA can participate in that doesn't exacerbate symptoms; self-monitoring behaviours and emotions; and balancing life activities (Schulman-Green et al. 2013). However, it is recognised that in order to adjust to their new 'normal', PLwIA will have to learn and adopt the core self-management skills of problem-solving, decision-making, goal setting, planning and prioritising, utilisation of resources, and form partnerships with their HCPs (Lorig and Homan 2003; Schulman-Green et al. 2013).

4.7.1.4 *Personal determinants of behaviour*

Social-cognitive determinants are the main contributing factors of self-management behaviour (Sassan et al. 2018). Social-cognitive determinants cause individuals to behave in a particular manner and can contribute to the cause and maintenance of the identified health problems of PLwIA (Sassan et al. 2018; Araújo-Soares et al. 2018). While other factors, such as socioeconomic status (Verstappen 2017; Nikiphorou et al. 2020), have been shown to contribute to the health problems for PLwIA, this project aims to identify modifiable determinants of behaviour as these have the greatest scope to change following exposure to the SMI (Bartholomew et al. 2016).

To determine the social-cognitive determinants of self-management behaviour, the researcher reviewed the literature for theoretical and conceptual papers (Bartholomew et al. 2016). Although a large body of literature exists on theories of behaviour, there are no systematic reviews to date that have determined which behavioural theory 'best' explains self-management behaviour in people living with long-term conditions. The MMSR presented in Chapter 2 identified theories to have been used to develop other IA SMIs which have included the Social Cognitive Theory (SCT) (Bandura 1986), Theory of Planned Behaviour (TPB) (Ajzen 1991), and Interaction Model of Client Health Behaviour (Cox 1982). While one study included in the MMSR (Shigaki et al. 2013) underpinned their intervention using the Social Learning Theory (Bandura 1977), this theory was later expanded on and replaced by Bandura's (1986) Social Cognitive Theory and was therefore not explored for the current study. The review of

theories undertaken by the researcher identified that the following theories also help to explain self-management behaviour: Health Beliefs Model (HBM) (Janz and Becker 1984), Self-Regulation Theory (SRT) (Baumeister, Schmeichel and Vohs 2007), and Integrated Theory of Health Behaviour Change (ITHBC) (Ryan 2010). Table 4.2 presents a summary of each of these behavioural theories and the aspects of each relevant to the identified IA health problems. These theoretical elements were also integrated into the logic model in Figure 4.3. Two additional personal determinants, 'fear of stigma' and 'fear of dependence on medications', arose from Workshop 1's finding and were also added to the logic model.

4.7.1.5 *Environmental influences*

Environmental influences are the factors and environmental conditions that directly affect the IA health problems or indirectly by influencing the person's ability to engage with self-management behaviours (Bartholomew et al. 2016). Interventions do not occur in a vacuum, therefore, the intervention's delivery characteristics must be shaped around the environmental factors influencing the self-management behaviour of PLwIA (Bartholomew et al. 2016). Findings from the previous workshop indicated that the social support network of PLwIA greatly impacts on their ability to cope with their condition. There was also some evidence to suggest that lack of awareness of IA from the general public and poorly facilitated peer support groups negatively impact on the self-management behaviours of PLwIA. EULAR recommendations have suggested that HCPs support families on how to reinforce self-management behaviours, but it is recognised that HCPs may require greater skills to effectively communicate with families (Nikiphorou et al. 2021). However, this literature review was unable to identify evidence on how or the extent that families, friends, and the community influence the ability of PLwIA to self-manage. More research is therefore needed exploring how the environment influences PLwIA ability to self-manage.

As highlighted in 4.6.2, HCPs are also required to provide support that is tailored to the individual needs of patients (Scottish Government 2012). A key tenet of person-centred care is that all decisions related to the selection of tests, treatments, and the care goals and plan are made through a shared decision-

Table 4.2 Summary of Behavioural Theories

Theory	Summary	Elements Integrated into Logic Model
Health Belief Model (Janz and Becker 1984)	This model suggests that people decide to engage with health-promoting behaviour based on their health beliefs and their perceived benefits and barriers to engaging with the behaviour.	Health beliefs; perceived susceptibility; perceived severity; perceived benefits; perceived barriers; self-efficacy
Social Cognitive Theory (Bandura 1986)	Social cognitive theory is a learning theory used to explain human behaviour. It posits that behaviour is learned through observing others and is influenced by personal and environmental factors.	Outcome expectancies; self-efficacy
Self-Regulatory Theory (Baumeister, Schmeichel and Vohs 2007)	This theory suggests that self-management and the pursuit of personal goals requires a dynamic process of self-monitoring and evaluating one's thoughts, feelings, and behaviours.	Standards of desirable behaviour; motivation; willpower
Interaction Model of Client Health Behaviour (Cox 1982)	In the Interaction Model of Client Health Behaviour, a patient's health is influenced by their interactions with their HCPs. Particularly, affective support, health information, decisional control, and professional competencies directly impacts the patient's health outcomes.	Motivation; cognitive appraisal; affective response
Theory of Planned Behaviour (Ajzen 1991)	This theory suggests that attitude, subjective norms, and perceived behavioural control influence a person's behavioural intentions.	Attitude; subjective norms; perceived behavioural control
Integrated Theory of Health Behaviour Change (Ryan 2010)	This theory posits that a health behaviour change can occur if an intervention increases a patient's knowledge and self-regulation skills; provides opportunities for social facilitation; and fosters positive beliefs of health-promoting behaviours.	Knowledge; beliefs; self-efficacy; outcome expectancy; goal congruence

making (SDM) process between the HCPs and patients (Murray et al. 2020). SDM encourages PLWIA to identify their own goals and collaboratively work with HCPs to achieve them. A Cochrane review demonstrated that SDM led to improvements in physical and psychological health in patients living with long-term conditions and strengthened their confidence and skills to self-manage (Coulter et al. 2015).

4.7.1.6 Environmental determinants

Findings from Workshop 1 and the review identified determinants that cause or affect the environmental influences. Specifically, these determinants were related to the clinical care team and social support networks of PLWIA, and their community. Those in the social support network of PLWIA who lack knowledge and skills for providing support for self-management indirectly influence their ability to self-manage (Rat et al. 2021). Their clinical care team also requires more training and greater skills to support PLWIA to self-manage (Dures et al. 2016; McBain, Shipley and Newman 2018); to use shared decision-making processes (Morrison et al. 2011); and communicate effectively (Owensby et al. 2020; Coates et al. 2021). This is compounded by organisational time constraints (Morrison et al. 2022; Mathijssen et al. 2020), staffing shortages (Coulter et al. 2016), work culture (Coulter et al. 2016; Mathijssen et al. 2020), and limited resources (Coulter et al. 2016). Further, the findings from Workshop 1 also suggested that the general community's lack of knowledge about IA; the community's negative attitude of support; and limited resources to support peer groups also indirectly affects participants' ability to self-manage their conditions.

4.7.2 Methods: Participant Co-Designers

Following the initial development of the logic model, it was presented to participants in Workshop 2 to determine the model's comprehension and relevance of the factors listed in the logic model. Additionally, participant co-designers were asked to prioritise the problems and self-management behaviours that should be addressed by the proposed SMI. Participants were contacted one week prior to the workshop to obtain their availability and were notified that the workshop was expected to take 2 hours. Upon receipt of their availability, three asynchronous workshop sessions were scheduled. Three participants were to attend the first (Iona, Fiona, and Fraser) and second session

(Eilidh, Isabella, and Louise), while two participants (Craig and Maisie) were scheduled to attend the third. One participant was unable to attend their session secondary to poor health and was unable to attend the other scheduled sessions. A fourth session was scheduled to accommodate them. The researcher's supervisor (LA) attended the fourth session and took notes during it.

To begin, the researcher provided participants with a brief overview on the purpose and agenda for Workshop 2. The researcher shared the logic model on a Microsoft Word document using the *share* function on Microsoft Teams. Participants were given an explanation on the purpose and function of the logic model; how it was developed; and its relevance to developing a SMI. The researcher also explained each box of the logic model and defined relevant terms. The logic model presented to participants was edited slightly from the one presented in Figure 4.3. Where appropriate, the listed factors were rewritten to neutral language to respect participants ability to engage and understand (Figure 4.4).

Participants were consulted on the factors listed in the 'Health Outcomes & Quality of Life' and 'Self-Management Behaviours' boxes. These boxes are outlined by a bold, black-dotted line in Figure 4.4. Participants were not consulted on the factors listed in the 'Non-behavioural Factors', 'Environmental Influences', and 'Environmental Determinants' boxes as these factors are often out with participant's control and will therefore not be able to be changed by the SMI. Additionally, the researcher deemed it inappropriate to consult participants about the theoretical constructs of behaviour as they were likely to have minimal knowledge and understanding of behavioural theories. The discussions around theoretical constructs were conducted with the supervisory team.

Participants' attention was initially directed to the 'Health Outcomes & Quality of Life' box. Participants were asked to examine the health problems listed in the box and assess whether each of the health problems were relevant. Additionally, they were asked whether the items listed in the box represented a comprehensive list of problems and if there were any health problems not listed. Missing health problems were included, and irrelevant ones were struck-through. A priority list of problems was then developed by each of the participants by

individually asking them to name the top 5 health problems impeding on their life the greatest. These factors were highlighted by the researcher.

Participants' attention was then directed to the 'Self-Management Behaviours' box. Participants were again asked to determine the comprehension and relevance of all the listed behaviours and the logic model was adjusted based on participants' feedback. They were then asked to indicate which strategies in this box they found to be helpful in alleviating their top 5 health problems and to identify which behaviours they need self-management support for. An example of the logic model from session 4 can be seen in Figure 4.

Participants and the researcher then worked together to develop a loose blueprint of the SMI. Participants were engaged in a discussion that explored their preferences for the SMI's content; how they would like this information to be delivered (e.g., group discussion, didactic passive teaching, workbooks, etc.); and who they believed was best suited to facilitate the intervention. Following the workshop sessions, the researcher reviewed the audio-recordings and consolidated the statements obtained from each session. These statements were then integrated into a comprehensive logic model and a preliminary blueprint of the SMI. Changes and new additions to the logic model are highlighted in green.

Figure 4.4 Logic Model with Neutral Language

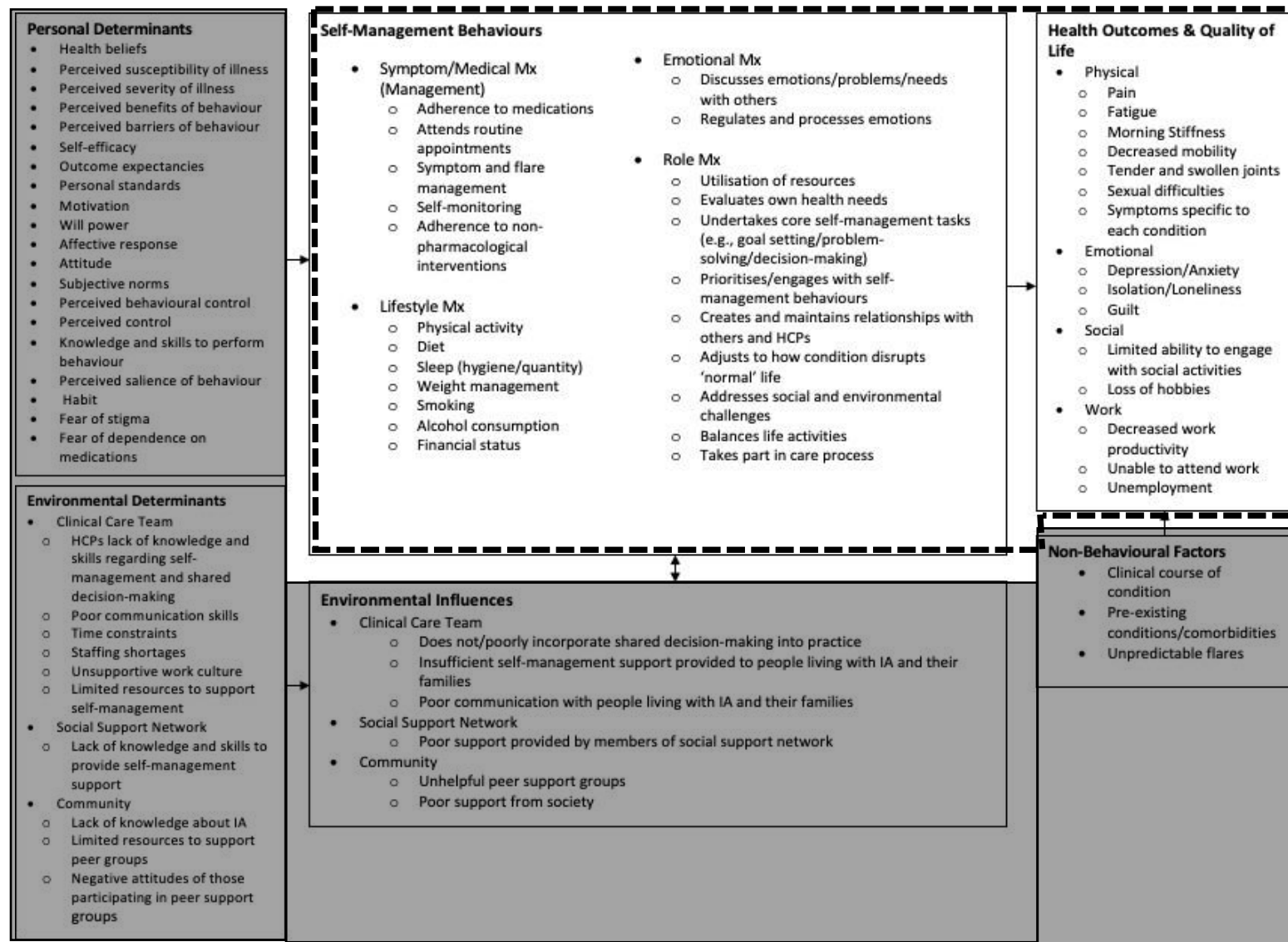
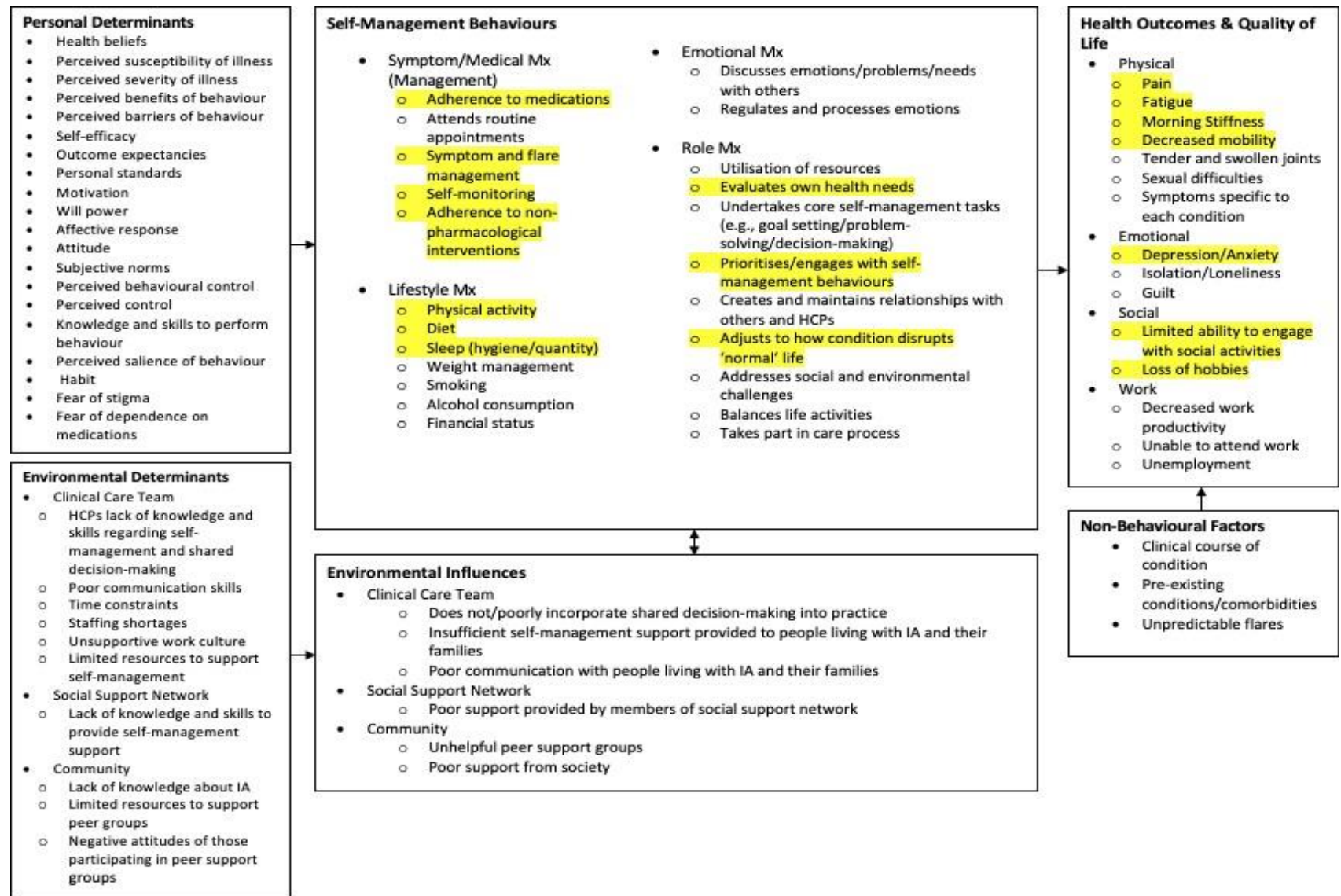


Figure 4.5 Logic Model from Session 4



4.7.3 Results

4.7.3.1 *Logic model*

During the workshops, participants reported that some of the health problems in the 'Health Outcomes & Quality of Life' box need to be edited to better reflect participants' personal experience. Originally, depression and anxiety as well as isolation and loneliness were grouped together in pairs. Although some participants did experience these health problems co-occurring, some participants had reported only experiencing one of the health problems without experiencing the other. Loss of work productivity was also changed to decreased work productivity as this word choice was more acceptable to participants. Additional health problems reported by participants included: general stiffness, nausea, decreased mobility, disturbed sleep, low mood, embarrassment, change of career paths, and loss of work.

Participants also added several factors to the 'Self-Management Behaviours' box. Three participants reported their ability to self-manage a flare influenced their experience of pain and fatigue. Under lifestyle management, one participant reported that having a busy work and lifestyle made it more difficult to cope with the unpredictability of fatigue. Several participants also reported that comfort strategies, such as indulging in their favourite comfort foods, had short-term benefits. When discussing emotional management, some participants reported that a negative mindset (or attitude) and low resilience led them to dwell on their problems and engage in unhealthy coping mechanisms. Two other participants agreed that poor body image and low self-compassion also impeded on their ability to emotionally cope with their condition. One participant highlighted that self-compassion was a particularly useful practice when they had to cancel plans with someone to mediate their feelings of guilt. These factors were added into the logic model and can be seen in Figure 4.6.

4.7.3.2 *Intervention content*

The top health problems reported by participants (in order of greatest impact) were pain, fatigue, low mood, stiffness, and decreased mobility. Participants reported they found the following self-management behaviours to be the most helpful in

mediating these problems: self-monitoring; ability to evaluate their own health needs; prioritise and engage with self-management behaviours; and adjust to living with IA. Participants reported a need for additional support with the following: pain, medication, fatigue, non-pharmacological interventions (particularly podiatry and complementary therapies), flare management, diet, exercise, sleep, communication with friends and family, communicating with HCPs, work, and coping with the emotional impact.

Participants reported that they preferred a rheumatology HCP to facilitate the SMI, and where possible, to be delivered by multiple HCPs. An 'expert patient' was also recognised as an acceptable facilitator for imparting information and providing emotional support. However, participants preferred that the expert patient was accompanied by an HCP and would not deliver the intervention solo.

The preferred format of the modules varied depending on the topic. Participants preferred a passive didactic teaching method for information provision. Small group discussions or workshops were the preferred format for topics discussing sensitive information, such as emotional coping. A comprehensive list of participant's preferences established in this workshop are organised into the SMI modules in Table 4.4. The sessions are listed in no particular order and were developed further in the remaining workshops.

This section presented the methods and results regarding the participants' input for Workshop 2. The following section presents the methods and results in relation to the HCPs' input.

Figure 4.6 Comprehensive Logic Model

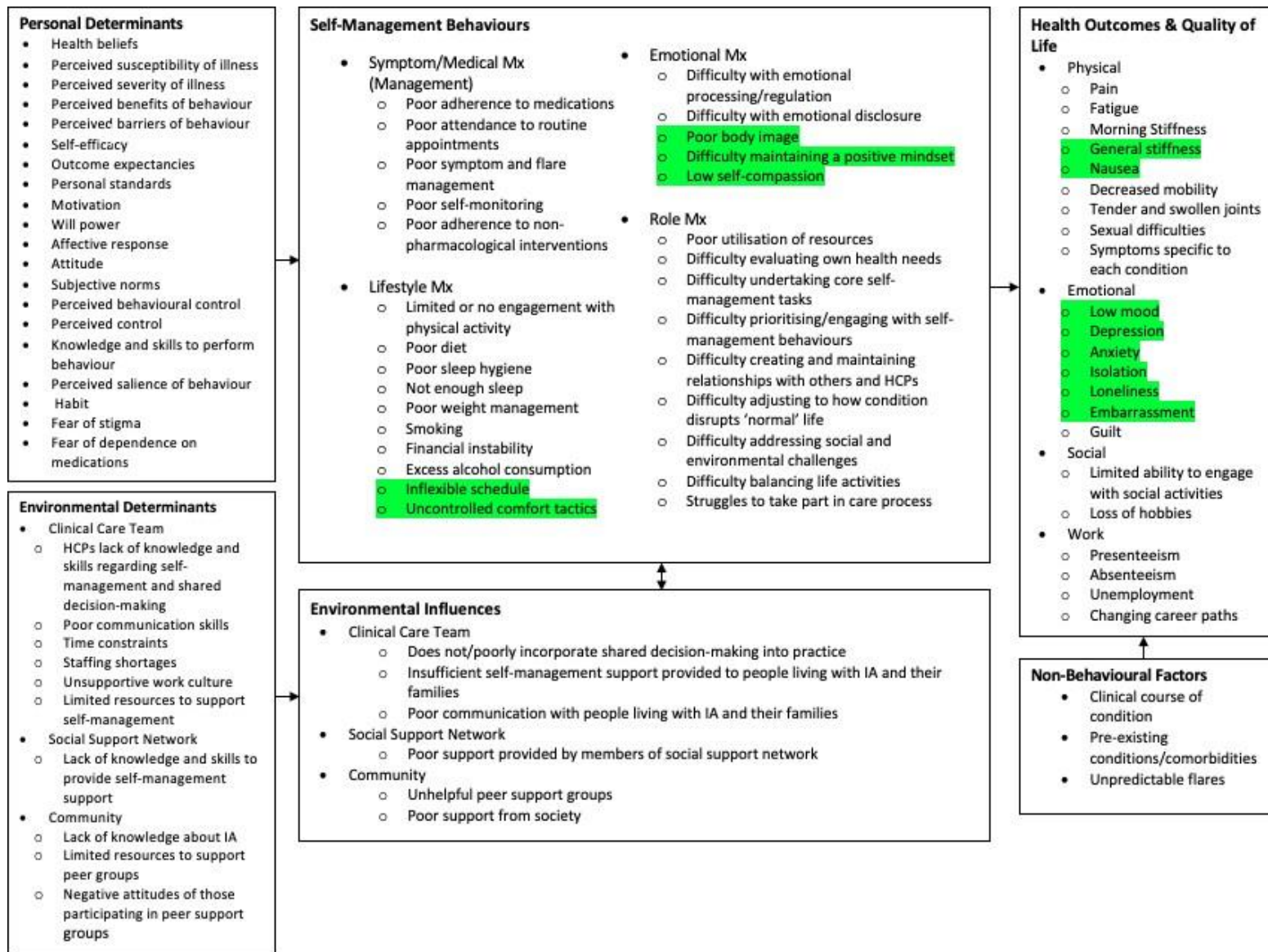


Table 4.3 Participant Preferences for the SMI's Content

Topic	Preferred Format	Information Covered
Newly Diagnosed Session	Didactic passive teaching	• Information regarding what IA is and how its diagnosed • The feelings experienced at time of diagnosis are completely natural • What to expect • Who will be involved in their care and rheumatology care pathways • Treatment and self-management Introduction to resources (charities, apps, online forums)
Pain/Medication	Didactic passive teaching with ability to ask questions	• What causes IA pain? • Medication ◦ Types ◦ Hierarchy of meds ◦ How to take ◦ Side effects
Lifestyle Management	Didactic passive teaching or workshop	• Diet ◦ Healthy eating ◦ Supplements ◦ Signposted to credible online resources • Physical activity/appropriate exercise ◦ Benefits of PA ◦ Pacing ◦ Goal setting ◦ Returning to physical activity after a flare ◦ Re-engagement strategies ◦ Support tools (e.g., wearable devices, apps, etc.) ◦ Demonstration of gentle exercises ◦ Signposting to community resources • Sleep hygiene
Fatigue	Group discussion or workshop	• What is fatigue and what causes it? • Coping/managing a flare • Pacing and activity regulation • Energy management strategies

Flare Management	To be determined	• What is a flare? • Importance of self-monitoring • Identifying/understanding triggers • Relapse prevention • Coping/managing a flare
Podiatry	Didactic passive teaching	• Types of appliances • How to use appliances • Up-to-date info
Complementary Therapies	To be determined	• Types • Benefits • Signposting to credible online
Emotional Management	Small group discussion or workshop	• Coping with negative emotions • Who to seek help from? • Signpost to credible online resources
Communication	Small group discussion or workshop	• Communication with family/friends ◦ Communicate about condition ◦ Communicate needs • Communicating with HCPs ◦ Shared decision-making
Work	To be determined	• Discussion of how the condition can affect ability to work • When to get help with your job • Financial benefits • Rights of work • Signposting to credible resources

4.7.4 Methods: Healthcare Professional Input

Following the workshop, the same HCPs were contacted. The purpose for this session was to explore HCPs preferences and thoughts related to the intervention content developed in Workshop 2. HCPs were provided with a copy of the logic model; an overview of the workshop's agenda; and a draft of the intervention sessions (Figure 4.7). HCPs were then consulted on:

1. The comprehensiveness and relevance of the SMI's topics and content.
2. What did HCPs believe to be the best format for delivery of the SMI.

4.7.5 Results: Healthcare Professional Input

HCPs reported that the SMI should have a flexible design in which HCPs could assign modules in a 'pick and mix' fashion to meet the individual needs of patients. Additionally, a flexible approach was also considered more likely to sustain and contend with the ever-changing healthcare system and demands placed on healthcare staff. HCPs' commentary regarding each of the topics is presented verbatim in Table 4.5.

Table 4.4 HCP Feedback on Intervention Sessions

Topic	Participant Preferences	HCP Comments
Newly Diagnosed	- Information regarding what IA is and how its diagnosed - The feelings experienced at time of diagnosis are completely natural - What to expect - Who will be involved in their care and rheumatology care pathways - Treatment and self-management - Introduction to resources (charities, apps, online forums)	- This session already exists as a service in the rheumatology department - Revise to be an introduction session - Remove 'what IA is' and 'how it is diagnosed' topic points as these are already discussed by charity organisations—signpost to organisations alternatively - Allow all patients to attend this session
Pain/Medication	- What causes IA pain? - Medication - Types - Hierarchy of meds - How to take - Side effects	- Pain and medication should be separated and made into individual sessions - Address different types of pain - Remove 'how to take medication' as a topic point as PLwIA receive individual drug education from consultant and specialist nurse—consider making this into a paper or online resource
Flare Management	- What is a flare? - Importance of self-monitoring - Identifying/understanding triggers - Relapse prevention - Coping/managing a flare	- Consider discussing that flares can also occur without a trigger - Remove 'relapse prevention' as prevention may not be possible
Fatigue	- What is fatigue and what causes it? - Coping/managing a flare - Pacing and activity regulation - Energy management strategies	Discuss fatigue and then follow up with fatigue management (e.g., pacing and activity regulation)
Podiatry	- Types of appliances - How to use appliances - Up-to-date info	No comments were added

Lifestyle Management	• Diet ◦ Healthy eating ◦ Supplements ◦ Signposted to credible online resources • Physical activity/appropriate exercise ◦ Benefits of PA ◦ Pacing ◦ Goal setting ◦ Returning to physical activity after a flare ◦ Re-engagement strategies ◦ Support tools (e.g., wearable devices, apps, etc.) ◦ Demonstration of gentle exercises ◦ Signposting to community resources • Sleep hygiene	• Cover this information over multiple sessions—too much to discuss in one session • Discuss common barriers to exercise
Complementary Therapies	• Types • Benefits • Signposting to credible online	• Consider removing as healthcare professionals may have a difficult time navigating this topic
Emotional Management	• Coping with negative emotions • Who to seek help from? • Signpost to credible online resources	No comments were added
Communication	• Communication with family/friends ◦ Communicate about condition ◦ Communicate needs • Communicating with HCPs • Shared decision-making	No comments were added
Work	• Discussion of how the condition can affect ability to work • When to get help with your job • Financial benefits • Rights of work • Signposting to credible resources	• Consider having this an online/paper resource as not everyone works, and those not working may require different support

This section discussed the methods and results regarding the HCPs' input for Workshop 2. The following section will discuss the key findings from this workshop in relation to the literature.

4.8 WORKSHOP 2 DISCUSSION

To the authors best knowledge, this is the first study to systematically map the health problems related to PLwIA and the factors contributing to the identified problems. Participant and HCP co-designers reported pain, fatigue, low mood, stiffness, and decreased mobility as the top health problems related to PLwIA impeding on their daily life. They recommended that the IA SMI be centred around supporting PLwIA to make positive changes in the management these problems. The logic model (Figure 4.6) developed in this workshop went on to inform the specification of the SMI's intervention methods. This will be discussed in more detail in section 5.3.

Participants in this study reported preferring HCPs to deliver the developed SMI (aiM) as they were perceived to possess the required qualifications; are likely to understand the conceptualisation of the intervention; and have the generic skills required to deliver the SMI. However, there is an ongoing debate in the scientific literature regarding who should deliver SMIs. Both, HCPs and expert patients, have been shown to be able to deliver SMIs effectively (Foster et al. 2007; Hiller-Venegas et al. 2022; van Zanten 2022), however, they have different strengths and assets. A strength of having HCPs facilitate the SMI is that they have expertise in the pathology and medical management of IA. This expertise may make some PLwIA more receptive to receive self-management education (Scarpello et al. 2011). HCPs also have direct access to PLwIA, and they already possess, at least somewhat, the skills required to support the self-management of IA conditions. These strengths could explain why EULAR endorsed HCPs as the favoured facilitator of SMIs for PLwIA (Nikiphorou et al. 2021). A potential challenge, however, is that HCPs are constrained for time with their current case load and care responsibilities.

Having the HCP as a facilitator may therefore require an organisational shift, which can be time-consuming and have cost implications (Hooft 2017).

A potential solution to this challenge is to outsource the position of intervention facilitator to expert patients. An added benefit of expert patients is that they could potentially serve as a role model for PLwIA by providing practical knowledge on how to implement self-management skills in daily life (Scarpello et al. 2011; Lorig et al. 2014). Additionally, they can be recruited as volunteers and there would not be a direct cost associated with their involvement (van Zanten 2022). Expert patients will, however, require ongoing training, recruitment, and an infrastructure to support them as facilitators (Cordier 2014). These challenges would require close collaboration and communication with HCPs (Boulet 2016), putting into question the extent that the implementation of expert patients can save the NHS time and money. Furthermore, there is limited qualitative research available on the perspectives and attitudes of HCPs, PLwIA, and people living with long-term conditions' regarding the use of expert patients compared to HCPs as facilitators of SMIs. More qualitative research is therefore required on the acceptability of expert patients as facilitators of SMIs.

Taking all of this into consideration, it is recommended that the developed SMI is facilitated by rheumatology HCP(s), and expert patients are recruited to act in a supporting role. The decision for the facilitator is, however, ultimately the decision of the implementation site. Participant co-designers also highlighted that personal attributes should be taken into consideration while recruiting and selecting facilitators. Specifically, they recommend recruiting an HCP that demonstrates expertise in IA conditions, good communication skills, charisma, empathy, and are confident in managing a group of people. These characteristics are thought to help PLwIA feel comfortable in the facilitator's presence and reassures them that the facilitator is a credible source of information.

There was considerable agreement between the co-designer groups in their desires and preferences for the design and content of the SMI. The primary difference

between the co-designer groups was that HCPs were reluctant to include complementary therapies in the SMI. The HCP co-designers reported that potential HCP facilitators may have decreased confidence in teaching PLwIA about these therapies. This finding is consistent with the literature reporting that complementary and alternative medicine (CAM) is generally viewed positively by PLwIA, but is frequently contested among rheumatology HCPs (Yang, Sibbritt and Adams 2017). While a few CAM therapies (particularly acupuncture and meditation) are being increasingly prescribed by rheumatology HCPs (Grainger and Walker 2014; Wong, Litwic and Dennison 2015), evidence suggests that HCPs opinion toward specific CAM therapies is dependent on the evidence demonstrating the effectiveness of the CAM therapy and HCPs familiarity with the CAM therapy (Grainger and Walker 2014).

A potential explanation for why HCPs are reluctant to discuss CAM therapies is that the NHS does not offer them support on how to discuss CAM therapies or refer PLwIA to CAM therapists, therefore, it wasn't an area frequently discussed in their daily clinical practice. The HCP co-designers also reported being unfamiliar with the literature regarding CAM therapies, and this may also be the reason for their decreased confidence in discussing these therapies with PLwIA. Considering, however, that some PLwIA need additional symptom relief and are interested in pursuing CAM therapies, this is a conversation that should be had by HCPs and PLwIA if a service is to be truly patient-centred. However, it is recognised that HCPs will require organisational support to feel confident and competent in navigating these discussions.

Findings from this workshop have highlighted participants' need for more education regarding their condition and treatment options. Participants were partial to this information being delivered in a didactic passive teaching format. Clinical guideline recommendations for IA have advocated for the use of patient education to help PLwIA better understand their diagnosis and improve adherence to medical advice and treatment (Zangi et al. 2015; Nikiphorou et al. 2021). However, findings from the MMSR in Chapter 2 highlighted that imparting information alone is not sufficient

in achieving short- or long-term positive health outcomes for PLwIA. A potential explanation for this finding is that self-management behaviour is more complex than simply adhering to medical advice (Harrington and Valerio 2014; Heijmans et al. 2015; Rust, Davis and Moore 2015). Rather, self-management is an active and iterative process of self-monitoring, decision-making, goal setting, making action and coping plans, self-evaluation, and reflective thinking; and is influenced by a wide range of environmental and non-behavioural factors (Ryan and Sawin 2009; Clark and Zimmerman 2014). Clinical guideline recommendations (Nikiphorou et al. 2021) and systematic review evidence (Taylor et al. 2015) suggests that the SMIs that are the most effective in changing the health behaviours of PLwIA educate participants on their condition; provide support for their physical and psychological needs; improve their ability to self-regulate; and foster social support.

For these reasons, the developed SMI was underpinned by the Integrated Theory for Health Behaviour Change (ITHBC) (Ryan 2010) as it is the only theory that directs the design of the intervention to increasing participant's knowledge and self-regulation skills as well as fostering positive health beliefs and social support. Applying the ITHBC to this study, the goal of the developed SMI is to improve the health status of PLwIA through increasing their level of engagement with self-management behaviours. The theory purports that PLwIA engage in self-management behaviours if they understand how their level of engagement with self-management behaviours influences the severity of their health problems; believe that engaging in self-management behaviours will improve their health problems; and feel confident in being able to undertake the required self-management behaviours. The likelihood for improving the health status of PLwIA is increased if they learn to use resources to meet their goals; use self-regulation skills; utilise their social support network; develop self-management goals that are consistent with their personal life goals; and collaboratively and actively take part in the care process (Ryan 2010). A conceptual model of the ITHBC can be seen in Figure 4.7.

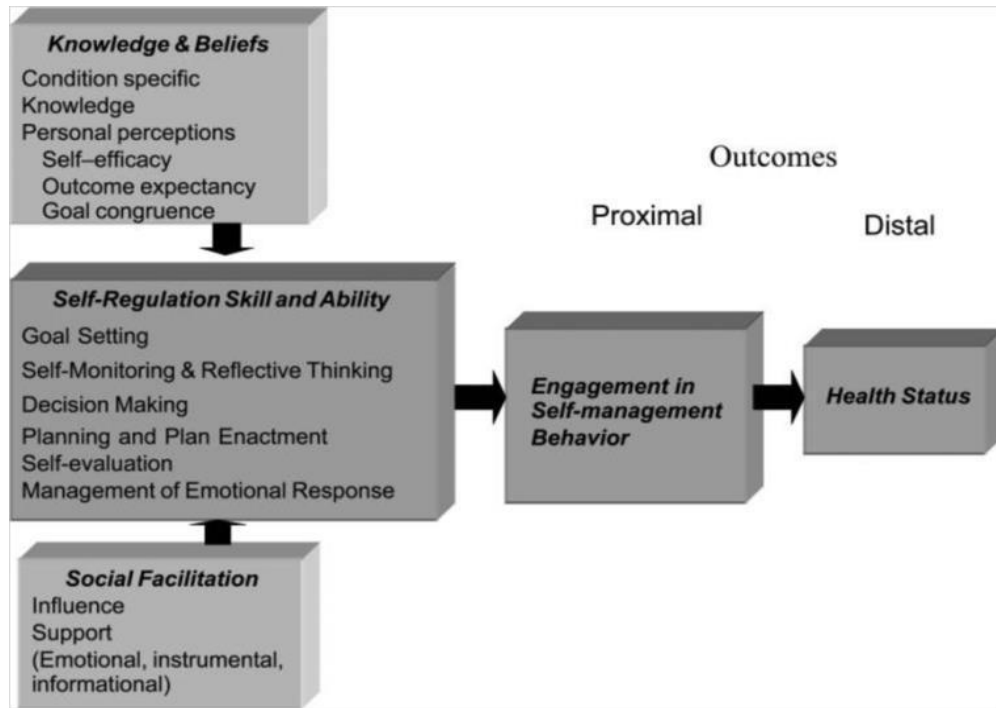


Figure 4.7 Conceptual Model of the Integrated Theory of Health Behaviour Change (Source: Ryan 2010)

This section has discussed the findings from Workshop 2 in context to PLwIA and HCPs involved in their care. The following section presents a reflexive account of the researcher’s experience in Workshops 1 and 2.

4.9 CHAPTER 4 REFLEXIVITY

Before beginning my DPT journey, I had little to no experience working with a rheumatology population. I was interested in this topic due to its applied research nature and having multiple family members diagnosed with various autoimmune conditions. Conscious of my lack of experience with this population, I did some background reading and spoke with family members who were diagnosed with an autoimmune condition. The reading helped me to understand the clinical symptoms and presentation of IA, while speaking to family members provided insight into what it truly means to be diagnosed with a turbulent long-term condition and the

impact that this has had on their lives. Additionally, speaking with family members brought to light the sensitive nature of discussing personal experiences and its potential to cause distress. This background research helped to build my confidence to effectively engage with participants during the workshops. I attempted to facilitate candid conversations with participants and provide them with a safe environment so that they would feel comfortable and be more willing to discuss their experiences freely, which was aided by my training during physiotherapy school on how to communicate with people experiencing different health conditions and how to approach people with empathy and respect.

My greatest concerns going into the workshops were technology failure and participants having trouble accessing or using Microsoft Teams. To avoid or at least limit IT issues, I offered participants a step-by-step guide with pictures on how to access Microsoft Teams (Appendix 3.1) and reminded them several times that a secure connection to the internet was necessary to participate. This seemed to have helped mitigate some issues with the technology. However, a few unforeseen technology-related difficulties did occur. An issue that we ran into during the first workshop was failure of the Microsoft Team's white board function. I had originally hoped to use this function as part of an activity to aide in the design of the SMI. However, the function was not able to be viewed by some of the participants and I was required to adjust the activity on the spot. Some participants also had trouble with their camera and had to participate using audio only or had to participate on their phone. Participants using their phones were unable to participate fully in the activities in which I shared my screen to present and discuss material.

I was also concerned about my ability to act as a facilitator in the workshops. Prior to this project, I did not have much experience in facilitating workshops. I undertook several tasks to improve my confidence as a facilitator prior to the workshops. I undertook a series of pilot workshops with peers. I reviewed the workshop agendas with my primary supervisor for feedback. I also did quite a bit of background reading on how to conduct workshops and facilitate group discussions. This reading helped me to realise that I had to adjust from the clinical

conversations that I normally have with patients in my role as a physiotherapist to that of a qualitative researcher. As a physiotherapist, I can assume a position in which I can offer advice to patients if I am competent in the topic area, and it is within the scope of my practice. However, it is the role of the qualitative researcher to explore in-depth about lived experiences rather than consult with patients and offer advice, and I therefore often tried to claim a position as a research student. By assuming this position, I was able to come from a place in which I was wanting to learn from participants and foster a culture in which participants were seen and treated as the experts of their condition. I also believed assuming this position would overcome my shortcoming of having minimal understanding of the NHS as I come from a different country where healthcare is capitalised. Overall, I found that my preparation helped me at least feel more confident as a facilitator. At the time, however, it was difficult to know if I had done enough or if I should have done something differently because of my lack of experience.

Starting at Workshop 2, I also began to schedule more workshop sessions with smaller groups to make it easier to facilitate. During the first session of Workshop 1, I scheduled six participants into a workshop. I found this number of participants too difficult to facilitate online. The conversation felt clunky at times. Some participants would accidentally speak over each other, while others would not have the opportunity to share their opinions. Thus, my aim for this workshop was to schedule no more than 4 participants per workshop session. I did find that a smaller number of participants in each group made facilitating conversation easier. The interaction between participants improved, and more people were able to contribute.

Over the course of the two workshops, I collected a wealth of qualitative evidence on the health problems and self-management needs and preferences of PLwIA. Participants emphasised their desire and willingness to self-manage their condition, however they were not always sure of the best means for self-managing and that learning how to manage their condition was a 'trial and error' process. As the

workshops progressed, my desire to create a resource to help my participants became greater, and I was very determined to try to make that happen. However, I also began to realise that my scope of influence was relatively small in the larger picture. An effective and acceptable resource is dependent on several influential stakeholders, including but not limited to the research team, HCPs, healthcare systems, commissioners, the government, and even PLwIA. I realised that the scope of my ability within this study was to develop a SMI centred around empowering PLwIA to become confident self-managers.

4.10 CHAPTER SUMMARY

This chapter explored the perceived self-management needs and preferences of co-designers (PLwIA and HCPs). The findings from the first two workshops were used to develop a comprehensive logic model of the health problems related to PLwIA and the preliminary content of the developed SMI. The following chapter presents the methods and findings for Workshops 3-5, which focus on the process for designing the SMI.

5 CHAPTER 5: DESIGNING THE aiM INTERVENTION

5.1 CHAPTER INTRODUCTION

The previous two workshops focused on developing an understanding of the health problems in PLwIA. The latter three workshops focus on developing recommendations for a SMI that addresses the identified problems. The chapter begins by presenting the developed SMI's goals, objectives, and intervention methods. This is followed by a presentation of the methods and results for Workshops 3, 4, and 5. The chapter concludes with a discussion of the results and a reflexive piece written by the researcher.

The process for designing the SMI was dynamic and iterative. It entailed a series of brainstorming, idea generation and analysis, evaluation, and refinement over the course of Workshops 3-5. The nature of this process makes it difficult to report the methods and findings of each individual workshop as set of consecutive steps. For this reason, the methods and findings from Workshops 3-5 were amalgamated to reduce redundancies and enhance readability.

5.2 WORKSHOP 3, 4, and 5 PRE-WORKSHOP

5.2.1 Goals and objectives

The process for designing the IA SMI began by conceptualising its goals and objectives. An intervention goal is a statement of what the intervention is expected to achieve (Bartholomew et al. 2016). The goals of the SMI are based on the proximal and distal outcomes of the ITHBC (Ryan 2010). Thus, the SMI's short-term goal is to improve the uptake and engagement of self-management behaviours in PLwIA with a long-term goal of improving their health status.

The objectives of the SMI are to:

1. Heighten the awareness of PLwIA regarding the self-management behaviours that influence their IA-related health problems.
2. Improve the understanding of PLwIA regarding the relationship between their level of engagement with self-management behaviours and the severity of their IA-related health problems.
3. Enhance the self-confidence of PLwIA in applying self-management behaviours and self-regulation skills.

The IM framework then recommends specifying the behaviours or actions that the service user must undertake to achieve the intervention's goals and objectives.

The specification of behaviours is known in IM as 'change objectives'. Change objectives are delineated by developing a matrix in which the objectives of the intervention are placed in the left-hand column of the matrix with the prominent social-cognitive determinants of the ITHBC across the top row (Table 5.1). The change objectives are then stated in the intersections of the rows and columns.

5.2.2 Specifying Intervention Methods

The next step in the IM framework entails delineating the intervention methods for each aspect of the health problems the SMI intends to address (Bartholomew et al. 2016). A definition of intervention methods can be seen in section 2.7.2.2.

Intervention methods were identified using the taxonomy of theory- and evidence-based methods developed by Bartholomew et al. (2016). The process for identifying intervention methods began by reviewing the taxonomy for applicable methods for each determinant (i.e., knowledge, skills and self-efficacy, and outcome expectancies). Additionally, methods that have been shown to influence attitude and motivation were also identified from the taxonomy as the ITHBC assumes these determinants to be prerequisites to behaviour change (Ryan 2010). The identified methods and a description of each method can be seen in Table 5.2. The methods were subsequently assessed for their acceptability amongst the co-designers during the workshops.

Table 5.1 Matrix of Change Objectives

Objectives	Knowledge	Skills and Self-Efficacy	Outcome Expectancies
OBJ.1. Heighten the awareness of PLWIA regarding the self-management behaviours that influence their IA-related health problems	K.1. Indicate that they are aware of self-management strategies to manage their IA- related health problems		
OBJ.2. Improve the understanding of PLWIA regarding the relationship between their level of engagement with self-management behaviours and the severity of their IA-related health problems	K.2. Indicate that they understand how engaging in self-management behaviours reduces the severity of their IA-related health problems		OE.2. Recognise that making the decision to use self- management strategies reduces the severity of their IA-related health problems
OBJ.3. Enhance the self-confidence of PLWIA in applying self-management behaviours and self-regulation skills	K.3. Indicate that they understand how to implement relevant self-management strategies and self-regulation skills	SSE.3. Express confidence in being able to effectively implement relevant self-management strategies and self-regulation skills	OE.4. Recognise that self- management strategies and self-regulation skills are important to improve their health status

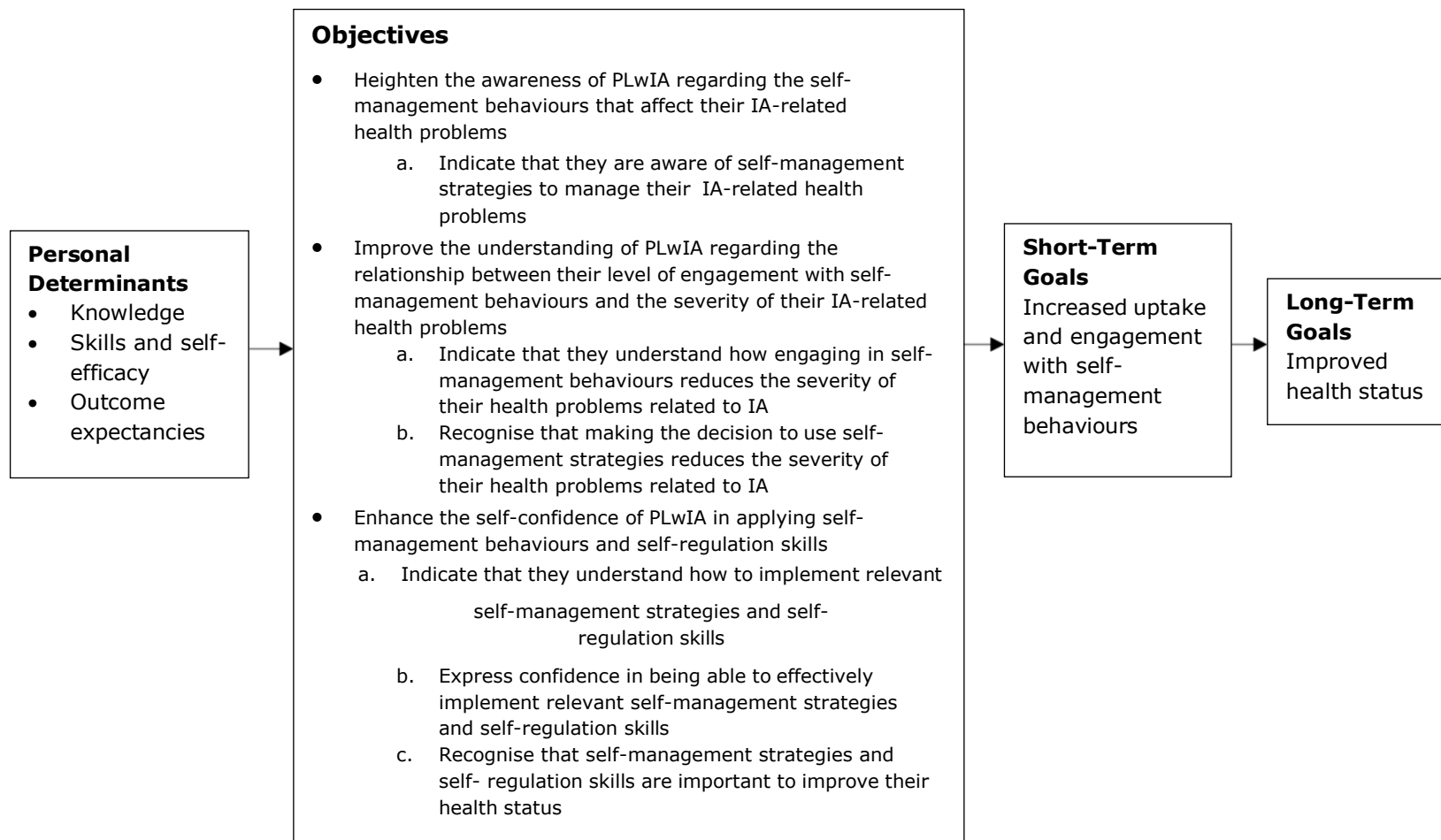


Figure 5.1 Logic Model of Change (Modified from source: Bartholomew et al. 2016)

This section has presented the work that was undertaken to prepare for Workshops 3-5. The following section outlines the methods undertaken during the workshops.

5.3 WORKSHOP 3, 4, and 5 METHODS

5.3.1 Participant Methods

Participants' availability was identified one week prior to each of the workshops as per previous workshop sessions. Workshop 3 was intended to last 1.5 hours.

Three asynchronous workshop sessions were initially scheduled. Three participants (Iona, Fiona, and Fraser) were to attend the first session; three (Eilidh, Louise, and Craig) in the second; and two (Isabella and Maisie) in the third. Two participants, however, were unable to attend their sessions secondary to poor health and other time commitments. An additional two sessions were scheduled to accommodate them. Each of the additional sessions only had one participant in each as they were unable to attend the other sessions or with one another.

For Workshop 4, the sessions were intended to last 1.5 hours. Three workshop sessions were initially scheduled. Two participants (Iona and Fiona) were to attend the first session; two (Isabella and Maisie) in the second; and three (Eilidh, Fraser, and Louise) in the final session. One participant was unable to attend their session and was unable to reschedule. As an alternative method for participating in the workshop, the participant was emailed with an overview of the workshop's agenda as well as five questions exploring their preferences for the acceptability of the intervention's content and delivery. At this point, one participant (Craig) dropped out of the study secondary to extenuating life circumstances.

Workshop 5 was undertaken in three sessions and was to last one hour. Two participants (Iona and Fraser) were to attend the first session; two (Maisie and Isabella) in the second; and three (Louise, Isabella, and Iona) in the third. Two participants were unable to attend their sessions secondary to poor health and wi-fi issues. An additional session was scheduled for each of these participants.

Table 5.2 Potential Intervention Methods (Modified from source: Bartholomew et al. 2016)

Determinant	Method	Definition
Knowledge	Chunking	Taking smaller pieces of information and categorising them into meaningful groups
	Discussion	Conversing or debating about a topic to exchange ideas
Skills and Self-Efficacy	Verbal persuasion	Using positive messages to encourage PLwIA they are able perform a given behaviour
	Self-monitoring	Being aware of and recording symptoms and behaviours
	Goal setting	PLwIA set a target or desired outcome they wish to achieve and take active steps to achieve it
	Action planning	Design a plan of behaviours or actions to meet a goal
	Coping plans	Design a plan of behaviours or actions to overcome anticipated barriers that may prevent PLwIA from achieving their goal
	Decision-making	The cognitive process for making a choice to perform a behaviour
	Mobilising social support	Linking PLwIA to the IA community or others living with IA and supporting them to build social relationships
	Social comparison	Providing opportunities for PLwIA to evaluate oneself or their performance to people they view as similar to them

Determinant	Method	Definition
Outcome Expectancy	Self-evaluation	The process of appraising oneself to assess if one's beliefs and behaviours are in line with their identity and goals
	Environmental evaluation	Analysing one's environment to determine factors that act as barriers and facilitators to goal-directed behaviour
	Direct experience	Developing new knowledge and understanding through active engagement with a behaviour or phenomenon
	Elaboration	The process of adding personal meaning to imparted information
	Anticipated regret	Encouraging PLwIA to foresee the negative emotional reactions about deciding to engage with unhealthy behaviours
	Cultural similarity	Tailoring intervention messages to the personal and cultural characteristics of the intervention PLwIA
Individual Level Methods	Persuasive communication	Present arguments that motivate PLwIA to adopt self-management behaviours and positive health beliefs
	Active learning	Encouraging PLwIA to learn by reflecting on their experiences and goal-directed behaviour or by engaging with others to discuss ideas and solve problems
	Individualisation	Providing opportunities for PLwIA to ask questions or by adapting the content of intervention to individual PLwIA
	Belief selection	Presenting messages to strengthen positive beliefs and weaken negative beliefs
	Feedback	Intervention facilitators assess the performance of PLwIA and provide advice about their performance
	Modelling	Learning how to perform a behaviour through observing others
	Reinforcement	Encourage PLwIA to perform a behaviour through supportive communication or a reward system
	Motivational interviewing	Individualised approach to behaviour change; used by the facilitators to address ambivalence and encourage PLwIA to engage with healthy behaviours

The purpose of Workshops 3-5 was to design the SMI. Participants preferences for the identified methods were initially explored, and the methods that were found to be acceptable were then operationalised into intervention activities. In this study, the intervention methods and activities were operationalised into intervention modules as per the HCP co-designers' feedback in Workshop 2 (refer to section 4.7). Participants were also consulted about their preferences for the intervention's mode, structure, and dose. Mode of delivery is characterized by the format in which the modules are delivered (e.g., face-to-face, telephone, online, etc.). The structure of the intervention is the sequence of the intervention modules. Dose specifies the amount and frequency the intervention is intended to be delivered (e.g., twice a week for eight weeks) (Bartholomew et al. 2016). The following subsections presents the research methods used to delineate the following aspects of the SMI: intervention modules, structure, mode and dose, and the intervention name.

5.3.1.1 *Intervention modules*

The process for designing the modules occurred over the course of Workshops 3 and 4. Participants were initially asked to review the goals and objectives of the SMI; revisions were made based on participant's feedback. Then, the researcher reviewed the blueprint of the modules (Table 4.4) with participants using the *share* function on Microsoft Teams, and participants were informed of HCPs' feedback. Participants were then engaged in a brainstorming exercise to exchange thoughts and ideas about how the content of the module could be improved. Again, revisions to the modules were made based on participants' feedback. This process of brainstorming, idea generation and analysis, evaluation, and refinement was completed for each module until every module was found to be acceptable to both co-designer groups.

Once the content of the module was established, the intervention activities could be developed. Participants were introduced to the intervention methods (Table 5.1), and the researcher highlighted the methods that were applicable to the module being discussed. Participants were also provided with an example of how each relevant method could be translated into an intervention activity. The researcher then explored participants' perceptions of the methods. Methods that were found to be acceptable were translated into intervention activities by

engaging participants in a brainstorming exercise. The same process of brainstorming, idea generation, evaluation, and refinement was used to develop the intervention activities.

Upon finalisation of the intervention modules content and activities, participants were asked to prioritise the modules and each of the modules' content. Using the same methods described to establish participants 'top 5 health problems related to IA' in Workshop 2 (see section 4.7.2), each participant was asked to choose the modules they believed were to be of the upmost importance to deliver and the top key messages in each of the modules.

5.3.1.2 *Structure*

Upon finalisation of the intervention modules, participants were engaged in an active discussion to explore their preferences for the sequence of module delivery. Participants in each session were asked to reach an agreement on the sequence of the modules. Answers from each group answers were collated to generate the structure of the intervention. The acceptability of the structure was then explored and refined a final time during Workshop 5.

5.3.1.3 *Mode and dose*

Participants were engaged in a discussion to determine the mode of delivery and how long each session should last. Additionally, participant preferences for the duration and scheduling of the intervention were explored (for example, one session held biweekly on a Monday evening). Revisions were made regarding the mode and dose several times during the workshops.

5.3.1.4 *Intervention name*

Participants were asked to think of a name for the intervention at the end of Workshop 3, and they were informed that this would be a topic of discussion during the following workshop. Participants could email or message the researcher prior to Workshop 4 if they had any ideas for a name; however, participants were unable to generate a name. For this reason, the researcher generated a list of potential names and terms that could potentially be used in the name (Appendix 5.1). Participants were asked during Workshop 5 to review

the list of terms and identify the terms they found to be appropriate to be used in the intervention name. Participants were also asked if they were able to generate a name for the intervention from the terms and for their preferences regarding the names generated by the researcher. Vote counting was used to analyse which terms and names were most acceptable to participants.

5.3.2 Methods: Healthcare Professionals

The researcher worked exclusively with two HCPs (AU and RH) throughout Workshops 3-5. As per previous workshops, HCPs were emailed with a progress report and a series of questions requiring their feedback. They were initially updated on the participants' revisions to the module blueprint. HCP co-designers were then asked to feedback on their perceptions of the updated module blueprint and make revisions accordingly. Their revisions were primarily made on a Microsoft Word document using *track changes*, which was emailed back and forth between the researcher and HCPs. Additionally, the researcher had a remote meeting on Microsoft Teams with HCP co-designers to discuss the intervention modules in more detail and to explore their reasons for the revisions. During the meeting, the researcher explored their preferences for the sequence of the modules, mode of delivery, dose, and the intervention name.

This section has presented the methods undertaken during Workshops 3-5. The findings from the workshops are presented in the following section.

5.4 WORKSHOP 3, 4, and 5 RESULTS

The findings from Workshops 3-5 were used to develop recommendations for an implementation manual of the developed SMI (Appendix 5.2), which outlines the key features of the developed SMI (i.e., methods, activities, content, structure, recruitment, mode, and dose) (Bartholomew et al. 2016). Each of these key features is outlined in the following subsections. The GUIDED guidelines for reporting intervention development in health research were used to help develop the recommendations document to ensure all relevant aspects of the developed SMI were reported (Duncan et al. 2020). The recommendations document was reviewed and evaluated by all co-designers one final time following Workshop 5.

5.4.1 Specifying the Intervention Name

The chosen name was inflammatory arthritis self-Management (aiM) intervention. Participant co-designers preferred names that made it obvious that the target audience was for PLwIA. Names using the terms 'heal' and 'mend' were not perceived favourably by participant co-designers as there is not yet a cure for IA. Other popular names were Ease-IA, (IA)lleviate, and Self-Management for Inflammatory Arthritis (S.M.I.A.). From this point forward, the developed SMI will be addressed as the aiM intervention or 'aiM' for short.

5.4.2 Chosen Methods and Their Applications

The aiM intervention employs several methods to achieve its goals and objectives. Table 5.3 presents the methods and applications that were included and maps them to the objectives and determinants. The intervention methods that were found to be acceptable to both co-designer groups were added onto the logic model of change (Figure 5.2). The revised logic model is known as the 'intervention logic model' in the IM framework (Bartholomew et al. 2016), which is a conceptual model of the SMI that represents the mechanisms that explain how and why aiM produces the hypothesised outcomes (O'Cathain et al. 2019).

5.4.3 Recruitment of PLwIA

Participant co-designers recommended a member from their support network, such as a trusted family member or friend, to attend the modules. However, HCP co-designers were hesitant on the inclusion of family members as they thought additional attendees would make group facilitation more challenging and could shift focus away from the intervention PLwIA. Some participant co-designers were also reluctant for external members to attend certain modules, particularly the emotional well-being module. For these reasons, recommendations for the presence of a support network member were made in the recommendations document.

Table 5.2 aiM Methods and Activities

Objectives	Determinants	Methods	Application
Heighten the awareness of PLwIA regarding the self-management behaviours that influence their IA-related health problems	Knowledge	Chunking	Key messages were grouped together based on the self-management task (i.e., medical, lifestyle, emotional, and role management)
			Recommended self-management strategies were grouped together based on the module's topic
Improve the understanding of PLwIA regarding the relationship between their level of engagement with self-management behaviours and the severity of their IA-related health problems	Knowledge	Chunking	Module topics were based on the health problems reported by HCP and participant co-designers to be a priority of the SMI and the self-management strategies shown to be effective in improving the symptom
		Discussion	Facilitators are recommended to open informal conversations with PLwIA to ensure they understand the relationship between self-management behaviours and the severity of their IA-related health problems
	Outcome expectancies	Self-evaluation	PLwIA are encouraged to reflect on their own behaviours to determine links between their engagement with self-management strategies and the severity of their IA-related health problems
			PLwIA are encouraged to reflect on their own health beliefs to determine the extent that they believe engaging with self-management strategies improves their IA-related health problems
		Elaboration	PLwIA are encouraged to reflect on their quality of life, what is important to them in life, and what they would want to achieve in life. PLwIA are then encouraged to reflect on how self-management can help them achieve a better quality of life
		Anticipated regret	PLwIA are encouraged to anticipate worsening symptoms or a possible flare if they make the decision to engage with unhealthy behaviours
		Cultural similarity	Facilitators are recommended to tailor key messages to their target audience

Objectives	Determinants	Methods	Application
Improve understanding cont.	Individual methods	Persuasive communication	Facilitators are recommended to discuss the evidence base with PLwIA using lay terminology
		Active learning	PLwIA are encouraged to reflect on their past experiences with the recommended self-management strategies and assess the extent they were helpful in improving their IA-related health problems
		Belief selection	Key messages were designed to inform PLwIA on the benefits of self-management on symptoms and promote the use of self-management strategies
			Key messages were designed to inform PLwIA on behaviours that have been shown to worsen symptoms
Enhance the self-confidence of PLwIA in applying self-management behaviours and self-regulation skills	Knowledge	Chunking	Self-management strategies and self-regulation skills are broken down into steps for PLwIA to follow
		Discussion	Facilitators are encouraged to open informal discussions with PLwIA to ensure that they understand how to perform the self-management strategies
	Skills and self-efficacy	Verbal persuasion	Facilitators are encouraged to use positive and supportive communication when discussing self-management strategies
		Self-monitoring	PLwIA are encouraged to self-monitor symptoms and behaviours
		Goal setting	PLwIA are encouraged to set self-management goals
		Action planning	PLwIA are encouraged to develop action plans
		Coping plans	PLwIA are encouraged to develop coping plans
		Decision-making	PLwIA are informed that they will be presented with a variety of self-management strategies and they are encouraged to implement the self-management strategies most acceptable to them
		Mobilising social support	Facilitators are recommended to allocate time at the end of each session for PLwIA to speak to one another
			PLwIA are provided with links to community resources

Objectives	Determinants	Methods	Application
Enhance self-confidence cont.	Skills and self-efficacy cont.	Social comparison	PLwIA are encouraged to speak to other PLwIA regarding their experience with IA and use of self-management strategies. Facilitators are recommended to use small group discussion throughout the modules
	Outcome expectancies	Self-evaluation	PLwIA are encouraged to reflect on their own behaviours to determine if their current behaviours and actions are in line with their self-management goals
		Environmental evaluation	PLwIA are encouraged to analyse their environment and life circumstances to determine potential barriers and facilitators to engaging with self-management strategies
	Individual methods	Active learning	PLwIA are encouraged to reflect on past experiences engaging in self-management behaviours and analyse how the behaviour was performed and the outcome of performing the behaviour
			PLwIA are encouraged to speak to other PLwIA about self-management strategies that they have found to be effective
		Individualisation	PLwIA select self-management strategies that are acceptable to them
			Facilitators are recommended to prescribe modules according to the individual needs and preferences of PLwIA
		Feedback	PLwIA are encouraged to speak to facilitators and ask for feedback regarding the performance of self-management behaviours
		Modelling	Where appropriate, facilitators are recommended to demonstrate how to apply self-management strategies
			Expert patients help facilitate the intervention and act as role models to other PLwIA
		Reinforcement	Facilitators are recommended to use supportive communication to encourage PLwIA to engage with self-management strategies
			PLwIA are recommended to reward themselves following accomplishment of a goal.

5.4.4 Mode and Dose

Both co-designer groups recommended that aiM be offered in a variety of formats, specifically face-to-face, remote, online, or any combination of the three. The recommendations document specifies that the choice of delivery mode is ultimately determined by the rheumatology site. If possible, the sites are recommended to offer multiple modes. Co-designer preferences for face-to-face and remote delivery are specified in the recommendations document. Although it was out of scope for this project to develop an online version of aiM, the participant co-designer preferences for features and content of the online version were explored and are also reported in the recommendations document. Regarding the intervention dose, the participant co-designers preferred that aiM was scheduled once a week or biweekly with sessions lasting 1.5 hours.

5.4.5 Modules and Structure

The aiM intervention consists of 5 modules aiming to promote and improve the self-management of PLwIA. Each of the modules were designed to address a specific health problem. Every module contains an education section and a self-management section. The education section provides PLwIA with information related to the health problem; this information is presented as 'key messages'. The key messages were developed from co-designer recommendations, clinical guideline recommendations, and the scientific literature. The self-management section outlines self-management strategies shown to be effective in managing the health problem. The modules can be implemented individually or collectively. Prescription of the modules is intended to be determined via SMD processes and based on the individual needs of the patient. The modules were also designed to be self-tailoring, meaning that PLwIA can select the self-management strategies that are most acceptable to them. Participant co-designers recommended that PLwIA are allowed re-entry to individual modules or the entire intervention, rather than providing booster sessions.

Participants' priorities for the modules and health messages (known as the 'key messages' in the recommendations document) were explored during the workshops. The priority modules identified by participant co-designers were: *Introduction to aiM, inflammatory arthritis, and self-management; Pain & flares;*

and *Living a healthy lifestyle*. The priority key messages for each module are discussed below in the following sections. The priorities for key messages and modules agreed upon by participant co-designers are denoted by this symbol in the recommendations document (Appendix 5.2): . Although HCPs were asked what they believed to be the key priorities to be, HCPs felt that the participants' opinion held more weight and therefore opted to not disclose their priorities.

5.4.5.1 Introduction to aiM, inflammatory arthritis, and self-management

The purpose of the introductory module is to introduce PLwIA to the concept of self-management and the rheumatology service implementing aiM. Additionally, it aims to help PLwIA develop a better understanding of their condition. The key messages of the module include: introducing PLwIA to the facilitator, their rheumatology MDT, and the rheumatology department as a service; provide education on IA and how it is managed; and inform them on the importance of self-management. The self-management strategies included in this module were: techniques for medication adherence (e.g., dosette boxes and setting alarms), decision-making, problem-solving, goal setting, action plans, and coping plans. The latter four strategies are considered as core self-management skills (Lorig and Holman 2003) and were addressed in the recommendations document as applicable for all modules. Key messages 1-4 were the priority messages for this module.

5.4.5.2 Pain and flares

This module helps participants to develop a better understanding of their experience of pain, flares, and non-pharmacological management strategies for each. The key messages of this module include informing PLwIA on what pain and flares are and the different mechanisms of pain. The self-management strategies included were electrotherapy, thermotherapy, complementary and alternative medicine, and orthotics and assistive devices. The priority key messages are messages 1 and 3.

5.4.5.3 *Fatigue and work*

The fatigue and work module informs PLwIA on the causes of fatigue and the prevalence of work disability. The self-management strategies for fatigue included joint protection techniques, pacing, asking others for help, rest, and developing an energy management plan. The self-management strategies for work included pacing, establishing boundaries, planning, finding a flexible approach to work, and finding a work and home life balance. Participant co-designers considered all key messages to be important within this module.

5.4.5.4 *Living a healthy lifestyle*

The purpose of the living a healthy lifestyle module is to educate PLwIA on how to reduce their risk for co-morbidities; maintain their mobility; and decrease early morning stiffness. The key messages educate PLwIA on the importance of living a healthy lifestyle; introduces them to exercise guidelines; and educates them on healthy eating. The self-management strategies included were self-monitoring, reduce screen time, setting exercise goals, action plans, coping plans, monitoring/recording progress, rewarding oneself, and eating and diet advice. The priority key messages were messages 2 and 3.

5.4.5.5 *Emotional well-being and communication*

The final module introduces PLwIA to the common emotional issues related to IA and how to manage them. The module also teaches PLwIA how to navigate difficult conversations with their family, friends, and employers as well as how to take a more active role in their care. The self-management strategies for emotional well-being included were practicing self-compassion; relaxation; spending time socialising and in nature; and prioritising time. Advice on navigating difficult conversations and how to communicate needs and feelings were also included as self-management strategies in this module. The priority key messages were key messages 2 and 3.

This section has discussed the results of Workshops 3-5 and how they were implemented into recommendations for the implementation of aiM. The following section will discuss the key findings from these workshops in relation to the scientific literature to provide a better understanding for the choices that

were made by co-designer groups and the researcher during these workshops. Each of the key findings are discussed individually in the following sub-sections.

5.5 DISCUSSION

5.5.1 Recommendations for the Implementation of the aiM intervention

The purpose of the recommendations document (Appendix 5.2) is to guide the implementation of the aiM intervention in Scottish rheumatology departments. It also can serve as reference for aiM facilitators and be used to develop or select outcome measures for subsequent evaluation testing (Bartholomew et al. 2016; Sidani and Braden 2021). It is important to note that the recommendations document is not a fit-for-purpose manual, rather it was written as a set of key principles, values, and recommendations for implementation to allow rheumatology departments to contextualise the aiM intervention to meet the needs of their patients and IA service.

The decision to develop a recommendations document rather than a standardised intervention manual was two-fold. Firstly, results of evaluation studies have demonstrated that standardised healthcare interventions seldom have clinically meaningful benefits (Heckler et al. 2018). Qualitative research has found that individual differences, such as personality, life circumstances, severity of symptoms, and acceptability of certain aspects of the intervention influence the service users' opinion and engagement with the intervention and the likelihood of achieving clinically meaningful benefits (Reach 2016). Secondly, the recommendations document was co-designed by HCPs working in and PLwIA attending an outpatient rheumatology department in the Northeast of Scotland. It is therefore possible that aiM's content and features is biased towards this context and that PLwIA and HCPs outside of this context may find certain features of the aiM intervention unacceptable.

Following contextualisation of the recommendations document, it can be used to promote fidelity during subsequent evaluation testing (Sidani and Braden 2021). Interventions are considered to be delivered with high fidelity if the intervention facilitator(s) apply the intervention's components as intended (Forberg et al.

2015; Wojewodka et al. 2017; Berkel et al. 2019). It is important for intervention facilitators to deliver high fidelity interventions to ensure that PLwIA achieve the expected outcomes (Masterson-Algar et al. 2014; Wiltsey-Stirman et al. 2015). Variations in delivery, if not planned, might affect the validity of the conclusions drawn about aiM's ultimate effectiveness (Toomey et al. 2019). Adding or omitting components to aiM, even if they are positively perceived by PLwIA, can confound aiM's effects. This can lead to type 2 error, which is falsely concluding that the intervention is ineffective (Toomey et al. 2019).

5.5.2 Choice of Intervention Methods

All the methods listed in Table 5.2 were incorporated into the aiM except for direct experience and motivational interviewing. Direct experience was excluded because participant co-designers did not find the inclusion of assignment, workbooks, and skills training (e.g., mindfulness and progressive muscle relaxation) to be acceptable, and direct experience requires PLwIA to undertake training or perform an activity to learn new knowledge (Bartholomew et al. 2016). Motivational interviewing was also eliminated as an option as it would require the intervention facilitators to undertake additional training which may not be practical or feasible for them (Langlois and Goudreau 2022). A systematic review exploring the effects of MI training determined that three to four subsequent supervision sessions within a six-month period are needed to maintain training effects (Schwalbe et al. 2014). In an effort to keep the resources and costs associated with the implementation of aiM to a minimum, persuasive communication was chosen over motivational interviewing as it would not require the intervention facilitators to undertake additional training. Sheeran et al. (2016) previously demonstrated that persuasive communication has a moderate effect on changing a person's attitudes, intentions, and health behaviour in a general population; however, there is no evidence available on the effects of persuasive communication on changing the attitudes, intentions, and health behaviours in an IA population and more research is needed.

5.5.3 Social Support Network

Although the inclusion criteria for aiM was established early in the workshops (see section 4.5.2), participant co-designers expressed an interest in extending the inclusion criteria to allow one social support network member (e.g., a

trusted family member or friend of PLwIA) to attend the modules. There is some evidence to suggest that interventions incorporating a social network member has some beneficial effects on changing health behaviour in a general population (Tilter et al. 2017; Lou et al. 2019). However, the evidence base for these interventions is very limited. There is no evidence on the effects of incorporating a social network member into an SMI for PLwIA. Future research is therefore needed to evaluate the effectiveness, feasibility, and acceptability of dyad interventions for self-management in PLwIA. More research is needed on if and how the presence of support network members impacts on the intended outcomes of an intervention. Implementation sites choosing to include support network members will likely need to provide their intervention facilitators with additional training to manage complex group dynamics (Titler et al. 2017); however, developing this training programme was out of scope for the current study.

5.5.4 Mode of Delivery

The recommendations document specifies that the aiM intervention can be delivered face-to-face, remote, online, or any combination of the three. The decision for mode of delivery is recommended to be made by considering the needs and preferences of PLwIA (e.g., their demographics, caregiving responsibilities, and ability to access aiM) (de Thurah et al. 2022), and by weighing up the advantages and disadvantages of each mode.

Face-to-face sessions offer the best opportunity for social support; however, these sessions can be costly; resource intensive; and difficult to schedule. Remote delivery could include the entire intervention being delivered over a videoconferencing platform or the ability for PLwIA to 'tune in' to face-to-face sessions (de Thurah et al. 2022; Nikiphorou et al. 2021). Remote intervention delivery has the advantages of being cost-effective as it doesn't require facilitators or interventions users to travel; offers greater scheduling flexibility; and is a low-risk delivery method in light of the recent COVID-19 pandemic (Carey et al. 2017). An online (internet-based) could also be developed for aiM as recent systematic reviews have indicated that online SMIs are efficacious (Ariza-Mateos et al. 2020; Klein et al. 2018; Williams et al. 2019). However, challenges related to remote and online versions of aiM include IT issues,

technical skills, and computer literacy of PLwIA (Carey et al. 2017; de Thurah et al. 2022).

There is a lack of consensus in the literature on the mode and dose most appropriate for SMIs. However, EULAR recommends that patient education be made available in a variety of delivery formats to accommodate the needs and preferences of all PLwIA (Zangi et al. 2015). Findings from the workshops indicate that the decision for mode and dose will ultimately be based on the capacity of the rheumatology site. In making this decision, aiM implementation sites will need to balance the preferences and needs of PLwIA with the logistics, costs, and team skills associated with each mode of delivery (Bartholomew et al. 2016).

5.5.5 Modules

The content of the modules is represented as 'key messages'. The sequence of the key messages and the modules was determined by the HCP and participant co-designer preferences. Key messages were written following best-practice guidance (Center for Disease Control 2015; Health Literacy Place Scotland 2022); specifically, the messages were written using non-didactic language; conversational writing style; easy to read fonts; clear layouts; bullet points; and signposting. Medical terminology and certain treatments (e.g., thermotherapy, electrotherapy, CBT, etc.) were not defined in the recommendations document as these are assumed to be known to HCPs. The aiM facilitators are given autonomy to decide which key messages and recommendations they are to deliver. It has been suggested that giving the intervention facilitators autonomy builds trust and increases acceptability towards an intervention (Yardley et al. 2015). To support intervention facilitators in their decision-making, each of the key messages were supported by clear explanations and evidence (i.e., co-designer recommendations, clinical guideline recommendations, and the scientific literature).

Each of the modules includes recommended self-management strategies. The aiM intervention was designed to allow PLwIA to self-select the strategies most appropriate to them. Other literature has referred to this approach as 'self-tailoring' (Morrison et al. 2014). The rationale for this decision was three-fold.

Firstly, it encourages PLwIA to take more responsibility for the management of their health. Secondly, PLwIA will have different needs, and this approach allows them to select strategies that are most relevant for them (Lorig and Holman 2003). Lastly, self-tailoring is suggested to improve the personal relevance of aiM to PLwIA and prevents them from viewing its' content as off-putting; thus, improving their engagement with and adherence to aiM as well as improving the acceptability of aiM to PLwIA (Sidani and Braden 2021).

This section has discussed the findings from Workshops 3-5. The following section presents a reflexive piece developed from the researcher's reflexive journal during Workshops 3, 4, and 5.

5.6 CHAPTER 5 REFLEXIVITY

The process for designing the intervention yielded a rich quantity of data for the development of the aiM intervention. The development process usually began with knowledge generation, which came in the form of experiential knowledge from the co-designer groups as well as literature reviews of the scientific and theoretical literature. However, this presented a key challenge to the design process. I needed to figure out how to proceed when knowledge from different sources conflicted. I was confronted with a paradoxical problem of not wanting to privilege the scientific evidence over the needs and preferences of the co-designer groups; however, I was also aiming for the aiM intervention to be theory- and evidence-based. This problem was further compounded by not wanting to privilege the needs and preferences of one co-designer over another nor one co-designer group over another.

To help solve this problem, I reviewed the co-production literature for equitable decision-making approaches. I initially planned that decisions regarding the aiM intervention would be made via consensus amongst all co- designers, however this approach can be slow, and I was on a tight timeline (Farr et al. 2021). For this reason, I opted for a pragmatic decision-making process. For each decision that needed to be made during the co-design process, each of the co-designer

groups' needs and preferences were explored and compared to the evidence base. Both co-designer groups were provided with synopses of the evidence. I would communicate my findings using language appropriate to the group I was speaking to. Depending on what the evidence indicated, I would negotiate and reach a compromise with one or both groups.

This method proved to be effective for the current study as all participants highlighted that they felt they contributed to the decision-making processes. This decision-making approach was facilitated by the high intra-group agreement in each of the co-designer groups, meaning that there were very few differences of opinions, needs, and preferences within each group. The groups were also able to come to an agreement with minimal or no facilitation required by myself. This approach was also facilitated by the commitment of both co-designer groups and my supervisory team to developing recommendations for the implementation of an SMI that could meet the needs of PLwIA and HCPs. I was not met with any institutional or culture barriers that impeded on the co-design process. However, I would have to frequently filter the information to determine its relevance and appropriateness before presenting it to co-designers. I therefore was always privileged to more knowledge than the HCP and participant co-designers. To help mitigate this, I always tried to provide co-designers with enough knowledge to participate fully and make decisions. I tried to be very transparent with my thought process; provide justifications for my thinking; and create an open dialogue throughout the design process for them to ask questions.

I also gave participant co-designers ownership over the design process and aiM, which they acquired gradually in the workshops. In this approach, I facilitated openness by providing them with a physical space that allowed a diverse group of people to come together and share their knowledge, skills, viewpoints, and resources (Moore and Evans 2021). This was facilitated by a wide range of workshop activities that sparked creativity and idea generation, and small groups allowed all participants to have a chance to share their experiences and viewpoints with minimal facilitation required by the researcher. Participant co-designers were then empowered to use that knowledge to define the content and features of the aiM intervention. These were then presented as a blueprint

in the recommendations document, which was peer reviewed by the HCP and participant co-designers upon development and revisions were made accordingly.

5.7 CHAPTER SUMMARY

This chapter has presented the methods and results for Workshops 3-5. The features of the recommendations document that arose from the workshop findings have been discussed. The chapter concludes with a reflexive piece of the work undertaken in these workshops. The following chapter presents the findings from the qualitative exploration of the participants' experience in participating in co-design research (Phase II).

6 FINDINGS FROM THE QUALITATIVE EXPLORATION OF PARTICIPANTS' PERCEPTIONS AND EXPERIENCES PARTICIPATING IN CO-DESIGN RESEARCH

6.1 INTRODUCTION TO THE CHAPTER

This chapter explores the experiences of participants who took part in the co-design workshops in Phase I. Methods for Phase II are described elsewhere (see section 3.5). The framework analysis identified four main themes with corresponding subthemes. The main themes identified were (1) reasons for participation; (2) perceptions of the co-design workshops; (3) facilitators to the co-design process; and (4) barriers to the co-design process. This chapter concludes by discussing the researcher's interpretation of the findings as well as the strengths and limitations of this study.

6.2 FINDINGS

Initially, three focus groups were scheduled. Two participants (Iona and Fraser) were to attend the first session; two (Maisie and Isabella) in the second; and three (Louise, Fiona, and Eilidh) in the third. Two participants were unable to attend their sessions secondary to poor health and wi-fi issues. An additional session was scheduled for each of these participants. Thus, two focus groups and three individual interviews were undertaken. Demographics for participants can be seen in section 4.2.1.

The duration of the qualitative exploration lasted between 20 and 40 minutes. Those participating in the focus groups tended to engage more in the discussions than those in the individual interviews, although everyone was engaged resulting in free-flowing discussion and all interviews were relaxed and informal. The establishment of this relaxed social atmosphere was likely aided by the fact that the researcher had already established a good rapport with participants.

Table 6.1 Participant Schedule

Session	Participants
1	Iona and Fraser
2	Isabella
3	Louise and Fiona
4	Eilidh
5	Maisie

Due to a malfunction in the audio recorder, session 4 was unfortunately not recorded on the device even though the interview was undertaken. For this reason, only four of the sessions underwent framework analysis. The analysis identified four dominant themes. These were: (1) reasons for participation; (2) perceptions of the co-design workshops; (3) facilitators to the co-design process; and (4) barriers to the co-design process. These themes and their corresponding subthemes are detailed in the following section. Illustrative quote examples are used to describe the identified themes and subthemes.

6.2.1 Theme 1: Reasons for Participation

Two subthemes were identified relating to reasons for participation which were meeting others and altruistic motives.

6.2.1.1 Meeting others

One of the most common motives for participation in this study was to meet others living with the same or similar condition. As seen in an exchange between two of participants,

"I thought it would be nice to speak to other people who have the same condition to see if their condition has progressed or what similarities we had or what we have gone through. [Fiona]... It was similar for me as well. With any illness, it can be quite lonely. [Louise]"

Another participant also expressed that meeting new people could help them to learn more about their diagnosis.

"I wanted to speak to people that were also going through a similar thing and talk to them about it. (...) Sometimes I think I put my arthritis diagnosis on the back burner, and I think I need to be more proactive about it. I [thought] that this would be a more interesting way to learn more about it as well as meeting and speaking with people who are also going through a similar thing." -Maise

6.2.1.2 Altruistic motives

Many of participants highlighted that they were motivated to participate in the study to give back to their rheumatology HCPs.

"I have been very fortunate. I have had superb treatment from the rheumatology team all together. So, any small thing I can give back, I am more than happy to give back. [Iona]... The treatment I have received has been excellent. My consultant, my doctor, and the whole team has been excellent. (...) As you have said, I would like to give back as much as I can sort of thing to the department. [Fraser]"

Participants were also motivated to participate out of concern for other PLwIA. Participants' hope was that others would benefit from their contributions to this study.

"I wanted to help other suffers and improve [the services]." -Isabella

"When you are first diagnosed and present with these diseases, (...) it takes your life away and a lot of people don't realise how damaging these diseases can be. In the very early stages, if I knew what I knew now, I could have made it a lot easier for myself and saved a lot of physical and mental suffering you know. (...) I would really like to help if I could." - Fraser

Another participant added,

"If people don't take part in research or workshop programmes like this, there is no future. You often don't have to think about yourself. You must think about the people coming after you. Just knowing that there is a programme planning to be instigated in the first instance is a huge positive for me. That was the main driver for me. [For] the future of inflammatory arthritis, this is clearly the way to go because there are so many patients now that I am sure there is a massive backlog in the department. So, if there is some way that others can benefit from a self-management programme rather than contributing to the log jam of patients actually needing to be seen in the clinic, then it's got to be a good thing." -Iona

6.2.2 Theme 2: Perceptions of the Co-Design Workshops

Three subthemes were identified relating to perceptions of the co-design workshops which were overall impressions and experiences; acceptability of workshop mode of delivery and structure; and acceptability of the workshop activities.

6.2.2.1 Overall impressions and experiences

All of participants reported that they enjoyed taking part in the workshops and were satisfied with their overall experience.

"It's been very interesting, and it's been very organised. It makes you think. (...) It's been an enjoyable process overall, and it's been very informative. [Iona]... I agree with that. (...) I think there has been a lot of good energy coming from it. Whenever you get a lot of arthritis folks in a room, there is always a danger of negativity, and I think that everyone that has been [participating] has been doing it for the right reasons and trying to move it forward and to help I think. I have found it to be a very positive thing. [Fraser]... Yes! [Iona]"

Other participants commented that being a part of the co-design team had provided them with opportunities for positive learning experiences.

"I think I found it really interesting listening to other people's stories. (...) I think it's been good to kind of speak to someone who just kind of gets it. (...) It's given me a lot more knowledge on the subject and has given me advice about a lot of things I didn't know I needed advice on." -Maisie

6.2.2.2 Acceptability of workshop mode of delivery and structure

For the most part, participants liked having the workshops on Microsoft Teams, and a few commented that the platform made it 'easy' to take part in the study.

"I liked having it on Microsoft Teams. It would have been nice meeting people in person, but because of COVID I don't think that people would have been comfortable doing that. I liked it because it meant that I didn't have to travel somewhere after work and then be late home. It just kind of fit really well with my schedule, and I didn't have to sacrifice anything." -Maisie

Participants preferred workshops with smaller groups of two or three people, rather than larger groups of six or more. As seen in the following excerpts,

"It was a good idea on [the researcher's] part to cut the size of the number of people participating at a time. It is certainly easier with two or three, rather than with five, six, or seven. [Iona]... Yea. [Fraser]"

"I think when it's smaller groups it gives you the opportunity to speak and maybe speak more freely." -Maisie

The duration and layout of the workshops was also perceived to be acceptable among participants. A few participants also mentioned the importance of a small break half-way through the workshop.

"The length of time the workshops were and how they were laid out was appropriate." -Louise

"It's not too long and you have the break in the middle, which is quite nice. It's not too short where you feel like you wanted to say more. I think it's been really easy to understand and follow." -Maisie

"I think it was good that [the researcher] broke things up. You would have a face-to-face bit, then you would look at a document for 15 minutes, then you would have a break, then you would have a face-to-face bit again. (...) It was a quick 2 hours. [Fraser]... It was, yes. It never dragged. [Iona]"

6.2.2.3 Acceptability of the workshop activities

Overall, participants reported enjoying the workshop activities and felt that all the activities were relevant for developing the aiM intervention. Although some of participants reported some confusion around Workshop 2, they believed that this was the nature of the co-design process and their confusion resolved as the workshops progressed.

"Nothing was a waste of time. [Iona]... It was all very good yea. [Fraser]... It's only by talking things through that you get a perspective of what is more important and what is less important, but nothing was a waste of time. [Iona]... I was a wee bit confused the second meeting, but things came together once you had something tangible to look at. You are able to work from that framework. [Fraser]... It was such early days though that you had to kind of work your way through it in order for it to make sense. [Iona]... If it's too structured and you provide too much of a framework, you may be driving people down a certain path. (...) There's a balance to be struck there. [Fraser]"

Another participant added,

"If you not got a structure, you can go off and talk about everything and anything that's got nothing to do with anything." -Isabella

All participants reported feeling that aiM met each of their needs, even though participants were living with different IA conditions. Additionally, they reported feeling that their contributions to this study were reflected in the content of aiM.

"It was good. My thoughts and feeling were always taken into account." -Isabella

"Ordinarily, rheumatology is dominated by rheumatoid arthritis and osteoarthritis. Still's [disease] is a kind of weird and wonderful ones on the edges. The good thing for me is that this intervention is still relevant to me as well." -Fraser

"I have generally found that we all have very similar opinions of what we want out of it, and how it would be helpful for us." -Maisie

6.2.3 Theme 3: Facilitators of the Co-Design Process

Four subthemes were identified relating to facilitators of the co-design process. These were fostering new relationships; personal growth; the workshop facilitator's demeanour; and asynchronous remote workshops.

6.2.3.1 Fostering new relationships

Developing new relationships with others contributed to participants' ongoing motivation to continue in the study and high attendance rate at the co-design workshops.

"Because of the conditions that we have (...), you can feel a bit abandoned. (...) Just speaking to people with different conditions, it can help you." -Fraser

Two participants were even keen to continue their new friendship and meet up following the end of the study.

"I was laughing because I think that we could exchange email addresses and go for a coffee. [Fiona]... Haha! I am good with that! [Louise]"

6.2.3.2 Personal growth

Personal growth was also considered to be an important motivating factor for their ongoing engagement.

"Just by speaking to folk and exchanging things. It's amazing! They can learn from you, and you can learn from them, and that is a great help for me!" -Fiona

"I think that I have gained a little bit of confidence in myself in asking questions that I would have previously just moved on from. Not even knowing what my arthritis was called [at the beginning of this study]. After speaking to the couple of people that I have meet and finding out about their stories, I have found it really helpful to be honest. I'm kinda learning more about what it is like to live with arthritis. (...) [This experience] has made me be more accepting of my diagnosis and be kinder to myself." -Maisie

Participants highlighted that they felt inspired by their co-design team members to review their own health and make changes to how they were managing their condition.

"...some of their reactions when I said I have been struggling with pain for 14 years made me kinda think that maybe that's not the norm, and I should do something about it. In conjunction with my GP and pharmacist, I have started to reduce [the number of opioids I have been taking]. So, that is a positive for me that's come out of it." -Fraser

"I am keeping a health diary better." -Isabella

"I came away feeling extremely lucky because I didn't have to endure as much as other people had gone through. To me, I was sort of thanking my lucky stars to be quite honest. It made me reassess." - Fiona

6.2.3.3 The workshop facilitator's demeanour

Most participants mentioned that the workshop facilitator plays a large role in the conduct of the workshops, and they can greatly influence the outcomes. Specifically, they highlighted that the facilitator needs to be well organised; knowledgeable on the topic; skilled at group dynamics; and able to prevent schedule slippage. Two participants also reported the personality of the facilitator plays an important role in the co-design process.

"But a lot of it also had to do with the [workshop facilitator's] own personality. [They] have a personality such that [they] make it interesting, and [they] make people want to carry it forward, and that was a huge help. [Iona]... [They] are very good at driving things forward and keeping people on track. [Fraser]"

6.2.3.4 Asynchronous workshops

The asynchronous remote workshops were also seen as a facilitator to the co-design processes as it allowed participants (even those with busy schedules and other responsibilities) to take part in the study at a time that was convenient for them.

"I, from week to another, can be either really busy or really quiet so it was quite good that it wasn't anything too structured." -Isabella

"I think that was a good way of doing it. If you were to schedule it every second Monday or so, it doesn't work as well. [Fraser]... It was a very good way of doing it, asking people when they were available. [Iona]"

The remote format also made it easier for some to discuss sensitive topics.

"I liked the flexibility because I don't think that I am particularly flexible. (...) Although I would have said that I would have liked meeting face-to-face. When we have had these sorts of workshops, the topics have been a little bit tricky so been a little not so personal being online." -Louise

All participants reported that they liked the 'mixing' of the groups during the workshops, meaning that they were able to work with different people for each workshop. This gave them an opportunity to speak and learn from different people.

"Actually, it was very good being with different people and not being with the same people all the time. [Iona]... Yea, actually, that is a very good point! (...) If you got somebody that is not really interested or being very negative, they can take over the meeting but mixing people up that would negate that if that was an issue. Not that has very been an issue here, but in the future. [Fraser]"

Other participants added,

"I thought it was very good being mixed up. (...) You talk about different things when it is different sexes. [Louise]... Oh, definitely! [Fiona]"

"I think it's important having a good kind of mix of people." -Maisie

One participant reported a caveat to mixing groups was that compatible members have less opportunities to foster relationships with one another.

"That was good and bad because I enjoyed speaking to ones that I never saw again." -Louise

However, this participant also reported that they did not believe it was the responsibility of the workshop facilitator to match compatible individuals, and that mixing of the small groups was overall beneficial to the co-design process.

6.2.4 Theme 4: Barriers to the Co-Design Processes

For the final theme of barriers to the co-design processes, two subthemes were identified. The first was barriers related to the structure, activities, and format of the workshops, while the second was barriers related to asynchronous remote delivery.

6.2.4.1 Barriers related to the structure, activities, and format of the workshops

All participants reported minimal to no barriers in relation to the procedures, structure, activities, or format of the workshops. One participant, however, did report that they found it difficult to share personal experiences about certain topics, such as sexual health and emotional wellbeing. They said,

"I find it difficult sharing because this isn't a topic you discuss much. (...) I did notice that there was a part in the [recommendations document] that you had that was all about your sexual health. I know that nobody in any of the workshops I was in discussed it. (...) It was something that I was aware of that was never discussed, and I wasn't particularly about to discuss it either." -Louise

Although, two participants reported that it was easier to discuss sensitive topics with people they were more compatible with.

"I found it easier with one or two of the gents, we seemed to kind of gel and laugh and talk about it more. [Louise]... I agree with you. [Fiona]... I bet I wasn't the most popular with some either. With a different group of people, you have no idea if you are going to gel with them or not. [Louise]"

One participant also reported an issue with the scheduling of the workshops. They found it difficult to schedule in the time to participate as they work full-time and have childcare responsibilities.

"I have a lot packed into my week. I did find the timing very difficult because I have a family to feed, and it was always on at teatime. So, I found that very difficult. (...) It just wasn't always the easiest to schedule for the actual working it into the day." -Louise

6.2.4.2 Barriers related to asynchronous remote delivery

This subtheme relates to the IT issues experienced by participants during the workshops. Several participants reported being unable to use the Microsoft Teams application on Apple tablets and computers.

"I have had to persevere on my little iPhone. Sometimes I cannot see so I have had to hear you, but that is the thing that has annoyed me because I like to see." -Fiona

"I wanted to initially have it set up on my laptop because it has a big screen. But Apple doesn't talk to Microsoft Teams if you don't have a business account. [Fiona]... That's why I am using the browser because I have a Mac as well. (...) I tried the [Microsoft Teams] app as well, but it just didn't work and I didn't want to mess about with it. [Fraser]"

Although these participants were able to still attend the workshops using the Microsoft Teams browser or on their smartphones, they reported they would have preferred using the app or a different device. Their smartphones limited their ability to participate in the workshop activities that required the facilitator to 'share their screen' or view a document. One participant also reported issues logging into Microsoft Teams because of Wi-Fi difficulties following a large storm.

This section has presented the key findings of Phase II, the following section will now discuss these findings in relation to the literature. The strengths and weaknesses of this phase of the study will also be discussed.

6.3 DISCUSSION

Participants in this study reported that they were overall satisfied with the workshops and enjoyed taking part in the study. This finding is reflected in participants' high attendance rate in each of the workshops and the study's low attrition rate. The findings indicated that participants got involved in this study for altruistic reasons where participants felt their contributions could impact the lives of others or broaden the scientific field. Altruism has also been reported in another study as a reason for participation in co-design research in people who had been exposed to endocrine-disrupting chemicals or suffered a chemical burn (Carrera et al. 2016).

Participants reported wanting to participate to meet others living with the same or similar condition as another reason for participating in this study. Living with IA is a physically and emotionally intense experience, and many participants described wanting to meet other PLWIA to gain a better understanding of their own diagnosis. The workshops provided an opportunity for them to come together and learn more about their conditions through sharing their experiences and viewpoints with others. This was highly valued by participants as it offered them an opportunity to connect emotionally and socially with others (Fisher et al. 2018). This also proved highly advantageous to the researcher as it provided unique social and cultural insights (Neubauer, Witkop and Varpio 2019), which allowed the researcher to tailor the workshops and aiM to participants preferences (Sidani and Braden 2021).

There is an ongoing debate in the literature about how co-designers (both HCP and participants) should be compensated for their time and involvement. One of the key principles of co-production is reciprocity, meaning that co-designers should be compensated for their time and contributions (Social Care Institute for Excellence 2015). Payment is widely considered to be the most appropriate form of compensation for co-production activity (Co-Production Collective 2021; Farr et al. 2021). Payment is also thought to equalise the power dynamic between researchers and participants (Farr et al. 2021). Where possible, future researchers should consider paying co-designers for their time and contributions. However, in cases like this study, where payment was not possible due to a lack of funding, these findings indicate that there are other

benefits to participants that may not be financial. Our participants reported getting involved in co-design research for personal gain rather than financial compensation. These findings are reflected by Voorberg et al. (2018) who reported that there are more motivating factors for why people get involved in co-production research than financial gain.

Participants highlighted that the asynchronous remote method contributed to their ability to take part in the study as it allowed them to schedule at a time that was convenient for them. For this reason, future researchers should consider this method when facilitating co-design research. The Microsoft Teams software was found to be an inexpensive, easy, and intuitive platform to use by participants and the researcher. However, the researcher found that it takes some practice to take advantage of its full functionality. If deciding to use this method in future research, it is recommended that meeting etiquette is established early on. Specifically, it is recommended that co-designers mute their microphones if they are not speaking and asking people to switch off notifications that might interrupt them. This stops any background noise being projected into the meeting which can have the potential distract co-designers. Workshop facilitators will also need to decide on the process for allowing co-designers to speak. This could be using the *hands up* function or the facilitator calling on co-designers individually.

Despite the advantages of asynchronous remote workshops, the most common reported barrier to participation in this study was IT issues. Participants reported that the Microsoft Teams software had trouble communicating with Apple hardware. Participants that had Apple tablets and computers had to participate in the workshops on their phones, which limited their ability to change their display settings (e.g., size of text, display resolution, colour, etc.) to make it easier for them to view their screen. It also made it more difficult for them to participate in the workshop activities that involved the researcher sharing her screen. There were no reported issues for those using Microsoft Teams on other computer hardware brands. Actions taken by the researcher that appeared to help combat technical problems in this study included: practice testing of software with the research prior to the first workshop; provision of support guides; using a software that is widely used; familiarisation with the software;

being flexible; and making people feel at ease when technology failed. Future researchers should be aware of these IT issues and consider asking participants prior to data collection how they plan on accessing the co-design activity to prepare for possible barriers to participation.

The findings from Phase II also highlight the practical costs to participant co-designers. To take part in this study, participants had to take time and resources away from their primary responsibilities (such as work and family). Moreover, the co-design processes required participants to make themselves vulnerable by sharing personal experiences and opinions. While discussing sensitive subject matters, the researcher found it beneficial to initiate the conversation and allow participant co-designers to decide if they would like to share. In cases in which participant co-designers did share their experiences, the researcher tried to make the participant feel comfortable and provide them with reassurance that they were in a supportive, non-judgemental, and safe environment. In cases where no participants wished to share their experiences or viewpoints, the researcher would ask participant co-designers as a group whether they thought a particular topic was relevant and if it should be included in the content of aiM. An example of the latter situation can be seen in Workshop 2 (see section 4.6.2). When trying to explore participants' experiences and perceptions on issues related to sexual health, the researcher asked the group in an open-dialogue context whether they believed that sexual health should be discussed during one of the intervention modules. No participants disclosed personal experiences about issues they have had, however all participant co-designers agreed that it was an important topic to cover. The researcher moved on to the next topic of business. It is advised that these practical costs are considered while developing the study methods in future co-design research. These implications to participants were limited by using asynchronous workshops; small co-designer groups; fostering a non-judgemental, safe environment were found to facilitate the co-design processes; and maintaining flexibility in decision-making processes.

6.3.1 Strengths and Limitations

To the author's knowledge, this is the first qualitative approach to explore the experiences and perceptions of PLWIA co-designing a SMI. Through this study,

the researcher has demonstrated that it is possible to (1) develop recommendations for the implementation of a SMI that meets the needs and preferences of PLwIA and (2) for people to collaborate and form strong bonds with others using remote asynchronous co-design methods. The findings presented here strengthen the evidence base on the utility of asynchronous workshops to co-design healthcare intervention as well as the factors that facilitate and inhibit the use of co-design in the development of SMIs.

Another strength of this study was the use of asynchronous qualitative methods (i.e., focus groups and individual interviews), which allowed PLwIA, who can be required to limit their potential exposure to the COVID-19 virus, the opportunity to be fully participate in research (Rupert et al. 2017). Additionally, the asynchronous methods allowed the study to be conducted at a minimal cost. However, participants and the researcher were already equipped with the hardware needed to participate (i.e., laptops or computers fitted with web cameras). Future research, especially those including participants from low socioeconomic areas, may need to factor in costs related to purchasing web cameras, accessing wi-fi, and administrative fees associated with scheduling participants (Rupert et al. 2017).

There were a few limitations to this study, however. Bias could have potentially been introduced into the study considering the researcher acted as the facilitator for Phase I (i.e., the co-design workshops) and Phase II (i.e., the qualitative exploration). Another limitation is that some participants were not able to be grouped together resulting in three semi-structured interviews rather than focus groups. This was largely due to IT-issues, study time constraints, and limited availability of the participants.

It is possible that the use of semi-structured interviews may have limited the amount of data collected given that focus groups (when compared to individual interviews) are able to collect more 'rich' data from participants (Hennink, Kaiser and Weber 2019). However, the individual interviews allowed the research to have in-depth conversations with participants and helped to ensure that all participant co-designers were included in the study. There is no agreement on

what the ideal asynchronous focus group size should be. Other studies employing this method typically recruited six to nine participants per group (Tran et al. 2021), although this was not possible in this study as the participant co-designers preferred smaller groups (i.e., ≤ 3 people per group).

The findings from this study could have been made more robust if HCPs perspectives were explored and if the data from the fourth interview had been included and analysed. Although, the fourth session wasn't analysed due to IT failure rather than a limitation of the study methods. Additionally, the findings could have been made more robust if the emerging themes and subthemes were developed in collaboration with a member from the supervisory team; this would have improved the credibility of this study's findings (Shenton 2004). Themes and subthemes were, however, reviewed and checked by the supervisory team (LA and EH).

This section has discussed the findings as well as the strengths and limitations of the qualitative exploration. The following section will present the researcher's conclusions.

6.4 CONCLUSION

The purpose of this qualitative study was to explore participants' experiences in participating in co-design workshops to develop the aiM intervention. The findings presented in this chapter illustrate the utility of asynchronous workshops as a co-design method in developing complex healthcare interventions. To enable co-design methods to be successful in future research, these findings suggest that researchers should build on the motivations of the research participants to foster participation, collaboration, and innovation; create an open and supportive environment for co-designers to share their experiences and viewpoints; and provide opportunities for co-designers to build and foster new relationships. Remote co-design is not without limitations, however. Researchers should be aware of and address the potential IT issues that can occur throughout the co-design process. Additionally, researchers should be aware of the practical and financial costs to co-designers that can impede their participation.

6.5 CHAPTER SUMMARY

This chapter has described the experiences of PLwIA who have taken part in co-design workshops. The themes describing these co-design experiences include reasons for participation; perceptions of the co-design workshops; facilitators of the co-design process; and barriers to the co-design process. The following and final chapter revisits the project's research questions, aims, and objectives and discusses the key findings of each phase in relation to the scientific literature.

7 DISCUSSION

7.1 CHAPTER INTRODUCTION

The final chapter begins by exploring the key findings from Phase I: co-designing the aiM intervention and Phase II: qualitative exploration of the participants' experience in comparison to the research question and with the existing literature. This is followed by a discussion of this project's overall results; reflections on the research design; and the strengths and limitations of the project. The chapter closes with suggestions and recommendations for future research and concluding remarks.

7.2 REVIEW OF KEY FINDINGS

7.2.1 Aims and Objectives

This project sought to answer the following research question: *Is it possible to co-design a SMI for PLwIA?*

The overarching aim of this research was to co-design a draft SMI for PLwIA based on participant and HCP co-designer needs and preferences as well as the scientific literature. The research study took a pragmatic approach that is based on a multi-method sequential design in which a qualitatively driven study was followed by a second qualitative study (QUAL $\square$ qual). The first phase used co-design workshops guided by the IM framework (Bartholomew et al. 2016) to develop the aiM intervention. The second phase qualitatively explored participants' experience in participating in co-design research.

7.2.2 Key Findings from Phase I

The aiM intervention was co-designed alongside HCPs and PLwIA in five asynchronous remote workshops. The first two workshops aimed to develop an understanding of the health problems related to PLwIA and their self-management support needs (Chapter 4). The latter three workshops aimed to design a SMI to address the identified problems and needs (Chapter 5).

The following sub-sections will discuss the key findings from each of these

chapters in relation to the existing literature.

7.2.2.1 *Understanding the Health Problems of PLwIA*

The first workshop explored participant and HCP co-designers' perceptions of the health problems and self-management needs of PLwIA. The findings highlighted the negative impact that IA can have on physical and emotional well-being for PLwIA. It was also found that IA can inhibit their ability to participate in important life roles, such as parental, romantic, and vocational. These findings led to parallels being drawn between the problems reported in the literature that are experienced amongst people living with different IA conditions (Hewlett et al. 2011; Flurey et al. 2012; Davies et al. 2013; Moverley et al. 2015). These parallels highlighted that people living with different IA conditions do in fact experience similar biopsychosocial problems; thereby strengthening the argument that an intervention targeting all IA conditions is possible to develop.

A logic model of the problem was developed using the findings from Workshop 1 and a literature review identifying behavioural, social, and contextual factors shown to directly or indirectly influence the problems identified by participant and HCP co-designers. The logic model was subsequently reviewed by participant co-designers in Workshop 2 to determine the appropriateness and relevance of the listed factors. This process helped to identify the health problems that are the most important to address by the aiM intervention, and the potential environmental factors that may influence the uptake (e.g., HCPs with poor communication skills) and implementation of aiM (e.g., time constraints). The logic model proved to be a useful tool to establish a shared understanding among the HCP and participant co-designers about the problems to be addressed by aiM.

Upon finalisation of the logic model, an analysis of the model led to the selection of the ITHBC (Ryan 2009) for aiM's underpinning theory. The ITHBC was used to guide the development of aiM's goals and objectives; key determinants to be targeted by aiM's methods; and its hypothesised causal mechanisms of effect. The use of the ITHBC is unique to the SMI developed in this study. Although the findings from the MMSR in Chapter 2 highlighted a variety of theories that

have previously underpinned IA SMIs, the SCT (Bandura 1986) is the most widely used theory to underpin SMIs for PLwIA as well as other long-term conditions (Davis et al. 2015). The strength of the ITHBC (Ryan 2009) when compared to the SCT (Bandura 1986), however, is that it contains a core set of constructs and associated predictions related to self-management behaviour. In comparison, the SCT is limited in that the causal mechanisms of self-management behaviour aren't clearly delineated; thereby limiting the ability to make predictions about the service user's self-management behaviour. Future research will, however, need to establish the effectiveness of aiM's methods on the constructs of the ITHBC.

7.2.2.2 *Designing the aiM intervention*

Preliminary work was undertaken in Workshops 1 and 2 regarding participant and HCP co-designers' preferences for the design and content of aiM. Findings from these workshops indicated several educational needs of PLwIA and were used to develop the aiM modules. The development of these modules was aided by the EULAR recommendations for the implementation of self-management strategies (Nikiphorou et al. 2021). The content of the modules is in line with the previously developed IA SMIs (Chapter 2).

Participants reported that they preferred aiM to be delivered by a rheumatology HCP with prior experience working with PLwIA. However, an expert patient was also considered to be an acceptable assistant facilitator. These findings guided the development of aiM's content as well as helped to define its facilitators. Again, these findings are in line with the findings of the MMSR reported in Chapter 2 and EULAR recommendations (Nikiphorou et al. 2021).

The latter three workshops focused on further developing and refining aiM (Chapter 5). Three modes of delivery were found to be acceptable to participant and HCP co-designers: face-to-face, remote, and online. Although the MMSR was unable to identify SMIs that use remote delivery, this research study considered this to be an important feature to incorporate into the aiM intervention given the push for use of digital technology by national policies in the recent years (Scottish Government 2021a, 2022b). Therefore, the findings

from this study provide new evidence to support the use of telehealth interventions. Subsequent versions of aiM could include a mobile app or have a blended delivery approach (i.e., consisting of both face- to-face and online). These modes of delivery will, however, require additional resources to support HCPs and PLwIA and mitigate technical issues that arise (Soloman and Rudin 2020; Marques et al. 2022). Implementation sites for aiM will need to consider these factors prior to implementation to determine how to best overcome them. Further development, testing and contextualisation of aiM in subsequent research studies will help to address and answer these points.

Another key finding of the workshops was participants' preference for a member of their social support network (such as a family member or friend) to attend the modules. This was a unique finding of this study. The inclusion of a support network member could be a useful strategy given that social factors influence behaviours (Ryan 2009). However, the presence of a support network member has the potential to have a positive or negative impact on the health behaviour of the target population (i.e., PLwIA) (Ryan 2009). There are also practical implications associated with their presence that will need to be taken into consideration, such as group sizes; resources required; and the facilitators level of comfort delivering aiM to two groups with likely different needs. The guidance written in the aiM recommendations document recommends facilitators consider the inclusion of support network members and to deliver the content to both the target population (PLwIA) and their families/friends. However, it specifies that aiM is not intended to be a dyadic intervention as it's methods and activities are only intended for PLwIA. It is uncertain how support network members will affect the outcomes of aiM and whether it is appropriate to allow them to attend some or all the modules. Future research is therefore needed to evaluate the feasibility and acceptability of aiM as an individual and dyadic intervention.

The findings from Workshops 3-5 also highlighted the need to have a modular and flexible design to allow facilitators to tailor aiM to meet their PLwIA' needs. This finding is in line with recent literature suggesting that tailored interventions are more acceptable to HCPs (Mignogna et al. 2018). Previous qualitative studies have reported that HCPs believe standardised interventions and stringently adhering to protocols can lead to deterioration in the rapport with

their patients (Mignogna et al. 2018). There is also an increasing amount of quantitative evidence suggesting that standardised interventions only produce statistically significant improvements in the outcomes but rarely demonstrate clinically meaningful results (Hekler et al. 2018). Qualitative research has demonstrated that tailored interventions reduce treatment burden (Deshpande et al. 2014) and are more acceptable to HCPs and patients (DeRosier 2019; Mauricio et al. 2019).

At this point in time, it is uncertain whether aiM is cost-effective. There is some evidence to suggest that SMIs are cost-effective when compared to usual care (Manning et al. 2015). Intervention development teams are recommended to estimate the resource use of the resulting intervention (Skivington 2021). However, this was not possible within this study due to a limited number of resources available to the researcher and the focus of this study being on the initial development of the SMI. Economic considerations, however, were discussed by the researcher and the supervisory team throughout the development process. Several attempts were made to reduce relative costs or offer more cost-effective solutions. For example, it is recommended that facilitators email the appendices of the recommendations document that signpost participants to third-sector organisations rather than printing the appendices off as handouts. Additionally, aiM was developed to be facilitated by personnel who already possess the necessary knowledge and skills to deliver the intervention. Future research will need to undertake a cost-effectiveness analysis of aiM to determine intervention costs and cost-benefit of the aiM intervention (Skivington 2021).

7.2.3 Key Findings from Phase II

Following on from Phase I, the participants' experience in co-design research was explored. The findings from this study highlighted the need to build on the motivations of the research participants to foster participation, collaboration, and innovation. Participants reported that this study offered an opportunity for them to give back to the rheumatology department and to others living with the same condition. Some participants also reported getting involved to broaden the scientific community's understanding of the lived experiences and needs of PLwIA.

The findings from this study also suggest that the success of the co-design process was in-part related to the participants' ability to form new relationships with others. These relationships are important for encouraging participants to share stories and experiences during the workshop activities (Pallesen et al. 2019). Furthermore, these types of relationships can help combat the loneliness and social isolation associated with having a long-term condition as it encourages engagement with other people who might not ordinarily be in their social support network (Weiss 1973; Greenhalgh et al. 2016). These supplementary relationships are easy for PLWIA to manage outside of their existing social support network, and there is less consequence to PLWIA if the supplementary relationship is unable to be maintained or fails (Weiss 1973). The researcher in this study sought to contribute to the development of these relationships by allowing time for informal chat; using video conferencing for face-to-face communication; and group discussion and group work to promote social interaction. However, the co-design team seemed to foster relationships with one another organically and with minimal problems or disagreements arising (Bowen et al. 2013).

Advantages of the remote workshops as highlighted by participants included reduced travel time and enabled the workshops to take place at a time that was convenient for them. Asynchronous workshops were attributed to participants high attendance rates at the co-design workshops and the study's low attrition rate. These findings necessitate the need for workshop facilitators to create an inclusive space for participant co-designers to collaborate. These conditions also helped to embed the core co-production values (section 3.4.1.2) into the research process.

Asynchronous workshops were not without limitations. Issues related to IT were frequently reported as barrier to participation. This finding is in-line with a recent high-quality scoping review that also identified that IT issues were the largest obstacle to receiving virtual healthcare (Li, Borycki and Kushniruk 2021). Actions taken by the researcher that appeared to help combat technical problems in this study included: practice testing of software with the research prior to the first workshop; provision of support guides; familiarisation with the software; being flexible; and making people feel at ease when technology failed.

Future researchers should be aware of these IT issues and consider asking participants prior to data collection how they plan on accessing co-design activities to prepare for possible barriers to participation.

7.2.4 Triangulation of Key Findings from Phase I and II

When taken together, the findings from both phases of this project have demonstrated that it is possible to develop a SMI alongside PLwIA and HCPs using co-design methods. The use of participant and HCP co-designers was thought to support the development of aiM in several ways. Firstly, it improved the understanding of health problems and self-management needs for PLwIA. They were also helpful in determining content and features of aiM that might be unnecessary or off-putting to PLwIA or HCPs. Discussions with the co-designer groups also led to the selection of intervention components that are novel to aiM, such as the inclusion of all PLwIA and a support network member, remote delivery, signposting to third-party organisations, and the use of the ITHBC. Furthermore, the HCP co-designers provided valuable insight into the factors affecting future implementation, such as ensuring existing structures at the local setting and organisational level (healthcare system) were considered; aiM undertook a flexible approach that allowed for the individualisation of treatment; and limited the costs and amount of training associated with aiM.

7.3 STRENGTHS AND LIMITATIONS

One of the main strengths of this project was the MMSR, which explored the effectiveness of IA SMIs on several outcome measures and was the first review to explore the acceptability of these interventions. The findings from the workshops provide a greater understanding of the wider implications that IA can have on a person's life and has widened the lens on the behavioural, psychosocial, and environmental factors influencing the health problems for PLwIA. Additionally, the workshop findings led to the development of a novel SMI for PLwIA. Furthermore, this study adds knowledge to the existing, albeit limited, evidence base on the usefulness of co-design methods in developing SMIs; mechanisms through which co-design operates; and the impact co-design can have on those involved.

Another strength of this project was the rigorous methodological approach adopted for the research. This study was able to yield an extensive amount of rich data. The researcher contributes these findings to three key methodological decisions: pragmatism, qualitatively driven multi-methods, and asynchronous co-design workshops. A qualitatively driven multi- methods approach helped to broaden the scope of the research by allowing for in-depth exploration of participant and HCP co-designers' perspectives on how IA impacts daily life; their preferences for aiM's content and features; participants' experiences of co-designing aiM; how their involvement impacted them; and the challenges of co-design in practice.

However, the pragmatic paradigm allowed for other methods to be employed when required. This was found to be particularly useful during Phase I of the study as the IM framework requires the integration of the scientific and theoretical literature with the experiential data collected throughout the workshops (Bartholomew et al. 2016). Thus, the pragmatic approach ultimately led to a more thorough and comprehensive understanding of PLwIA needs; the development of a detailed logic model that can be used as a framework to guide future evaluation studies; and an intervention that was carefully designed to meet the identified needs in a manner that is acceptable to participant and HCP co-designers. These outcomes would not have been possible if only qualitative methods were employed.

The use of asynchronous co-design workshops is a further methodological strength of this project. This project demonstrated that it is possible to co-design virtually, which was important for this population as many of them had to shield during the COVID-19 pandemic and it allowed practice to move forward. Co-design also allowed for a wide range of PLwIA and HCPs to be highly involved in aiM's development, which increases the likelihood that aiM will be found acceptable in future evaluation studies (Bartholomew et al. 2016; Sidani and Braden 2021). This method also allowed participants to take part at a time and place that was convenient to them; the researcher to rapidly respond to arising problems; rapport to develop between the researcher and the co-designers; and aiM to develop through an iterative process of design and refinement in which participant and HCP co-designers were able to continuously think and reflect on

the concept and content of aiM. The findings from the workshops provide a greater understanding of the wider implications that IA can have on a person's life and has widened the lens on the behavioural, psychosocial, and environmental factors influencing the health problems for PLwIA. Additionally, the workshop findings led to the development of a novel SMI for PLwIA.

Another strength of this project was the inclusive representation of PLwIA involved in the development of aiM. Participants included a wide range of IA conditions, gender, ages, employment, and education levels. This representation was made possible by maximum variation purposive sampling. The benefit of recruiting a broad and diverse range of PLwIA is that they offer unique insights that collectively ensure the content and features of aiM respond to the self-management needs of those in the local context. Although HCPs were not recruited to this study as the rheumatology HCPs were already participating in this study as supervisor and advisor within the doctoral supervision team, it is important to highlight that several rheumatology HCPs were also consulted during the workshops, including a specialist nurse, an OT, a podiatrist, a consultant, and a Band 7 specialist physiotherapist.

As with all methodological choices, however, there were limitations to the methods chosen for this project. The use of the IM framework meant that the development of aiM was labour and time intensive (Croot et al. 2019), which was a particularly difficult undertaking given the time constraints of the project and limited capacity associated with being a lone doctoral researcher. There was also a substantial administrative burden placed on the researcher as the asynchronous methods required a significant amount of planning and scheduling. Additionally, the researcher found that managing group dynamics could, at times, be difficult. Particularly, not letting some participants dominate the conversations, which required interpersonal skills that the researcher had no previous training on. This was a driving factor for reducing the size of the participant groups during the workshops.

There were also difficulties in recruitment of participant co-designers because of the COVID-19 pandemic's impact on the rheumatology out-patient service. The initial recruitment method was unsuccessful. Those who initially showed interest

in this study, did not go on to participate as they felt that their new diagnosis was too overwhelming, and they did not feel they could commit to participating in this study. This may reflect the difficulty in recruiting newly diagnosed and acute PLwIA in the future, and further strengthens the argument that aiM might be more useful for certain subgroups. However, this limitation was overcome by receiving ethical approval for an amendment made to the recruitment strategy.

Another limitation was that the small sample size and use of convenience sampling led to an underrepresentation of certain groups (Creswell 2007). This includes those of a non-white ethnicity, and those not within the NHS Grampian health board. The sample inclusion criteria also introduced a 'digital divide' selection bias towards those with access to the internet and technology as well as those that possessed a computer or a laptop (Stewart, Shamdasani and Rook 2011). For these reasons, the findings of this study may have limited transferability to these groups or to other contexts (Creswell 2007). Expanding the recruitment strategy to include those of a more diverse group of PLwIA or to other NHS Scotland health boards would have been beneficial. However, the demographic characteristics of participants reflect to some extent PLwIA in the northeast of Scotland.

It is also acknowledged that the needs and preferences of the co-designer group are not reflective all PLwIA. This project was unable to recruit people living with reactive arthritis or uSpA, and only one person living with Still's disease was recruited. Although, the inclusion of only one person with Still's Disease may be reflective of its relatively rare prevalence (Rao et al. 2022). Nevertheless, the needs and preferences of these populations may be underrepresented in the aiM intervention. It may therefore also be possible that the chosen intervention methods for aiM (see section 5.4) are skewed towards the preferences of the co-designers participating in this research and are not acceptable to all PLwIA.

It may also be argued that the use of semi-structured interviews may have limited the amount of data collected given that focus groups (when compared to individual interviews) are able to collect more 'rich' data from participants (Hennink, Kaiser and Weber 2019). However, the individual interviews allowed the research to have in-depth conversations with participants and helped to

ensure that all participant co-designers were included in the study. The data collected could have been strengthened if the perspectives of HCPs were sought as they may have provided further insights; this is acknowledged as a study limitation. Although absent from the qualitative exploration sample, their presence in the co-design processes is visible throughout Phase I. Their involvement as co-designers and as part of the researcher's supervisory team helped to shape and inform the content and format of the aiM intervention.

It is also possible that the researcher acting as the lead facilitator for Phase I and Phase II introduced bias to the findings from the qualitative exploration (Chapter 6). Participants may have reported more favourable responses or socially desirable answers because of the rapport that was created between the researcher and participants. To reduce the potential for social desirability bias, the researcher explained to the participants the purpose and objectives of the study and emphasised the importance of providing honest answers. Under ideal circumstances, the workshop facilitator would have been different from the researcher exploring the participants' perceptions and experiences of the workshops; however, this was not possible as a doctoral project requires the research to be undertaken alone.

7.4 RECOMMENDATIONS FOR PRACTICE

This study has identified recommendations for practice:

- Contextualise the recommendations document to the rheumatology department the aiM intervention is to be implemented in.
- Determine and select HCPs to deliver aiM.
- HCPs facilitating the aiM intervention will need to undertake training.

Although aiM was intentionally developed so HCPs would already have the knowledge and skill set to deliver content and activities of aiM, facilitators will still need to be trained in the delivery of aiM to ensure intervention fidelity. The need for facilitator training is echoed in the EULAR recommendations for self-management support (Nikiphorou et al. 2021), which highlights that training can have a positive impact on the HCP's confidence in providing the intervention.

7.5 RECOMMENDATIONS FOR FUTURE RESEARCH

This study has identified recommendations for future research:

- Upon contextualisation, future research will need to test for feasibility prior to a large-scale intervention evaluation study (i.e., RCT trial). Future feasibility trial(s) can use the logic models and matrices developed as part of this project to guide the development or selection of outcomes measures (Bartholomew et al. 2016). Decision-making related to outcome measures can be aided by the findings from the MMSR (Chapter 2).
- Examination of acceptability will also be crucial during a feasibility trial to explore the perceived acceptability of the aiM intervention to PLwIA and HCPs and determine the social validity of aiM (Greenhalgh et al. 2016). Future research can use frameworks of acceptability like the one developed by Sekhon, Cartwright, and Francis (2017) to guide the assessment of acceptability.
- Cost-effectiveness of the aiM intervention also needs to be established using a health economic cost-benefit analysis.
- Qualitative research exploring the readiness of newly diagnosed PLwIA to participate in a SMI and determine if their self-management support needs differ from the needs identified in this study.
- Establish the effectiveness of aiM's methods on the constructs of the ITHBC.
- Qualitative research exploring the experiences and perceptions of PLwIA regarding intervention methods to determine acceptability.
- Determine how the presence of support network members impacts on the intended outcomes of aiM.
- Determine the prevalence of seropositive and seronegative RA.
- Qualitative research exploring the barriers to emotional disclosure in PLwIA.
- Qualitative research exploring the self-management support needs of people living with SpA, especially those with rarer forms (e.g., reactive arthritis and adult-onset still's disease).
- Determine if aiM is acceptable to people living with reactive arthritis and uSpA.
- Determine the acceptability of aiM's intervention methods among PLwIA.

- Quantitative research exploring the efficacy of DMARD self-monitoring for PLwIA.
- Qualitative research exploring how the environment influences the ability of PLwIA to self-manage.

7.6 PERSONAL REFLECTIONS

I have found this doctoral research experience to be both rewarding and challenging. Undertaking this study, allowed me to gain a tremendous amount of experience with different research methods. My favourite part of this process was working with participants who I have been fortunate enough to learn from. The methods undertaken in this study were also thought to contribute to better working relationships locally. Despite my initial fears of undertaking the workshops, I believe that these co-design workshops shaped the aiM intervention and allowed me to meet the research aims and objectives. Through this process, I have a better understanding of my strengths as researcher. I believe that I have strong communication and problem-solving skills. I also think I am good at organising and time management. Many of these strengths were honed during my clinical training as a physiotherapist. This process has also helped me to improve on my weaknesses. Undertaking such a multi-component piece of work has allowed me to grow immensely as a health researcher and taught a lot about research methodologies. Conducting this study during the COVID-19 pandemic was very challenging. The study changed several times and forced me to problem solve a lot of the time. It also forced me to become more resilient and made me more comfortable with 'learning by doing'.

7.7 CONCLUSIONS

This project developed a novel prototype SMI for PLwIA and has explored the experience of PLwIA participating in co-design development workshops. The MMSR conducted in-part of this project demonstrated that IA SMIs are effective and produced a clinically meaningful reduction in fatigue and pain in PLwIA. There was also some data to suggest that IA SMIs have a beneficial effect on self-efficacy, HRQoL, knowledge, engagement with self-management

behaviours, and communication. Additionally, the MMSR found that IA SMI are generally acceptable to PLwIA and HCPs. Using an innovative pragmatic, multi-method approach, this research project was able to develop a new theory- and evidence-based SMI for PLwIA (aiM). These findings have provided new knowledge regarding PLwIA self-management needs and preferences for self-management support. Additionally, the results from Phase II have provided evidence on the participants' perceived acceptability of asynchronous co-design methods as well as mechanisms that support and hinder co-design processes. This research has the potential to benefit PLwIA and HCPs wanting to support these patients in the self-management of their conditions. To realise this potential benefit, recommendations for future clinical practice and research have been identified.

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9 APPENDICES

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Appendix 2.1 MMSR PROSPERO Protocol



Systematic review

Fields that have an **asterisk (*)** next to them means that they **must be answered**. **Word limits** are provided for each section. You will be unable to submit the form if the word limits are exceeded for any section.

Registrant means the person filling out the form.

* Review title.

Give the title of the review in English

A mixed-methods systematic review of self-management interventions for patients living with inflammatory arthritis

Original language title.

For reviews in languages other than English, give the title in the original language. This will be displayed with the English language title.

* Anticipated or actual start date.

Give the date the systematic review started or is expected to start. 28/01/2021

* Anticipated completion date.

Give the date by which the review is expected to be completed. 22/01/2022

* Stage of review at time of this submission.

Tick the boxes to show which review tasks have been started and which have been completed. Update this field each time any amendments are made to a published record.

Reviews that have started data extraction (at the time of initial submission) are not eligible for inclusion in PROSPERO. If there is later evidence that incorrect status and/or completion date has been supplied, the published PROSPERO record will be marked as retracted.

This field uses answers to initial screening questions. It cannot be edited until after registration. The review has not yet started: No

Review stage	Started Completed
Preliminary searches	Yes
Piloting of the study selection process	Yes
Formal screening of search results against eligibility criteria	No
Data extraction	No
Risk of bias (quality) assessment	No
Data analysis	No

Provide any other relevant information about the stage of the review here.

*** Named contact.**

The named contact is the guarantor for the accuracy of the information in the register record. This may be any member of the review team.

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Full title of the organisational affiliations for this review and website address if available. This field may be completed as 'None' if the review is not affiliated to any organisation.

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Review team members and their organisational affiliations.

Give the personal details and the organisational affiliations of each member of the review team. Affiliation refers to groups or organisations to which review team members belong. **NOTE: email and country now MUST be entered for**

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* Funding sources/sponsors.

Details of the individuals, organizations, groups, companies, or other legal entities who have funded or sponsored the review.

Self-funded Grant number(s)

State the funder, grant, or award number and the date of award

* Conflicts of interest.

List actual or perceived conflicts of interest (financial or academic). **None**

Collaborators.

Give the name and affiliation of any individuals or organisations who are working on the review but who are not listed as review team members. **NOTE: email and country must be completed for each person, unless you are amending a published record.**

* Review question.

State the review question(s) clearly and precisely. It may be appropriate to break very broad questions down into a series of related more specific questions. Questions may be framed or refined using PI(E)COS or similar where relevant.

(1) To what extent are self-management interventions for patients living with inflammatory arthritis effective? (2) How appropriate do patients, their families and healthcare providers perceive self-management interventions to be in terms of the intervention's ability to address and manage their condition and fit their lifestyle?

The overarching aim of this review is to construct an integrated synthesis of the quantitative and qualitative evidence on self-management interventions for people living with inflammatory arthritis (i.e., rheumatoid arthritis and spondyloarthropathies) in an effort to infer their value in clinical practice.

* Searches.

State the sources that will be searched (e.g., Medline). Give the search dates, and any restrictions (e.g., language or publication date). Do NOT enter the full search strategy (it may be provided as a link or attachment below.)

This review will be conducted in accordance with the JBI methodology for mixed methods reviews (Lizarondo et al. 2020). A search of the following databases will be undertaken: CINAHL, MEDLINE, EMBASE and AMED. The search for unpublished studies will include Center for Disease Control and Prevention (CDC), British Library for E-Theses Online Service (EThOS), National Institute for Health and Care Excellence (NICE) Evidence, International Standard Randomised Controlled Trials Number (ISRCTN) Registry, National Institute for Health Research, the EULAR recommendations references, and Google Scholar. Studies will be limited to a start date of January 2000 as it was not until around the turn of the century that the current pharmacological treatment practice for IA, biologic response therapies, was introduced (Upchurch and Kay 2012). Searches will be re-run prior to the final analysis. Only studies published in English will be considered for inclusion.

URL to search strategy.

Upload a file with your search strategy, or an example of a search strategy for a specific database, (including the keywords) in pdf or word format. In doing so you are consenting to the file being made publicly accessible. Or provide a URL or link to the strategy. Do NOT provide links to your search **results**.

https://www.crd.york.ac.uk/PROSPEROFILES/225944_STRATEGY_20210107.pdf
Alternatively, upload your search strategy to CRD in pdf format. Please note that by doing so you are consenting to the file being made publicly accessible.
Do not make this file publicly available until the review is complete

* Condition or domain being studied.

Give a short description of the disease, condition or healthcare domain being studied in your systematic review.

Inflammatory arthritis, specifically rheumatoid arthritis and spondyloarthropathies.

* Participants/population.

Specify the participants or populations being studied in the review. The preferred format includes details of both inclusion and exclusion criteria.

The quantitative and qualitative components of this review will consider studies that include male or female adult participants (aged 18 or over) who have a confirmed diagnosis of Rheumatoid Arthritis (RA) or a Spondyloarthropathy (SpA) (axial and peripheral) will be included. Common types of spondyloarthritis include ankylosing spondylitis and psoriatic arthritis. Participants of all ethnic origins, disease duration and disease severity (e.g., in remission or experiencing a flare-up) will be considered. This review will include mixed- population studies if the participants (1) have a diagnosis of an inflammatory arthritic condition, such as juvenile idiopathic arthritis, polyarthritis, or undifferentiated arthritis, (2) make up ? 35% of the participant group and (3) are ?18 years of age. Studies that include patients who are under the age of 18 or diagnosed with a non-inflammatory musculoskeletal condition (e.g., osteoarthritis) will be

excluded.

*** Intervention(s), exposure(s).**

Give full and clear descriptions or definitions of the interventions or the exposures to be reviewed. The preferred format includes details of both inclusion and exclusion criteria.

The quantitative component of the review will consider studies that include a structured self-management intervention (SMI) as defined by relevant literature (Jonkman et al. 2016; Lorig and Holman 2003). Jonkman and colleagues (2016) define SMIs as: "Interventions that aim to equip patients with skills to actively participate and take responsibility in the management of their chronic condition. This includes knowledge acquisition, and a combination of at least two of the following: (1) stimulation of independent sign and/or symptom monitoring; (2) medication management; (3) enhancing problem-solving and decision-making skills for treatment or disease management; (4) or changing physical activity, dietary and/or smoking behaviour."

The review will include studies matching this definition or incorporate at least two of the following self- management skills as defined by Lorig and Holman (2003): problem- solving, decision making, utilisation of resources, forming or enhancing patient and healthcare relationships and taking action. Purely exercise- based interventions will be excluded.

The qualitative component of this review will consider studies that explore the perceptions and experiences of the effectiveness and appropriateness of self-management interventions amongst patients living with inflammatory arthritis and/or their families or the facilitators delivering the intervention.

*** Comparator(s)/control.**

Where relevant, give details of the alternatives against which the intervention/exposure will be compared (e.g., another intervention or a non-exposed control group). The preferred format includes details of both inclusion and exclusion criteria.

This review will include studies in which the intervention is compared with no treatment or usual care.

*** Types of study to be included.**

Give details of the study designs (e.g., RCT) that are eligible for inclusion in the review. The preferred format includes both inclusion and exclusion criteria. If there are no restrictions on the types of study, this should be stated.

For the quantitative component of this review, RCT and cross-sectional designs will be considered for inclusion. The qualitative component of this review will consider qualitative studies of experience and perceptions including designs such as interview studies, focus group studies, phenomenology, and ethnography.

Mixed- methods studies will be included if the data can be extracted.

Context.

Give summary details of the setting or other relevant characteristics, which help define the inclusion or exclusion criteria.

Interventions that are delivered by health professionals, lay-leaders, or a combination via any mode of delivery (e.g., face-to-face, digital, post, etc.) will be included. This review will only include interventions that took place in a developed nation as defined by the top 59 countries on the United Nations Development Programme's Human Development Index (2019).

* Main outcome(s).

Give the pre-specified main (most important) outcomes of the review, including details of how the outcome is defined and measured and when these measurements are made, if these are part of the review inclusion criteria.

The quantitative component of this review will consider studies that use an outcome measure that can be categorised under any of the following: disease-specific, self- efficacy, health-related quality of life (HRQoL), functional status or disability, psychosocial metrics, knowledge of the disease, use of self-management strategies or acceptability of the intervention.

Measures of effect

Please specify the effect measure(s) for your main outcome(s) e.g., relative risks, odds ratios, risk difference, and/or 'number needed to treat.

Not applicable

* Additional outcome(s).

List the pre-specified additional outcomes of the review, with a similar level of detail to that required for main outcomes. Where there are no additional outcomes please state 'None' or 'Not applicable' as appropriate

to the review Not applicable Measures of effect

Please specify the effect measure(s) for your additional outcome(s) e.g., relative risks, odds ratios, risk difference, and/or 'number needed to treat.

Not applicable

* Data extraction (selection and coding).

Describe how studies will be selected for inclusion. State what data will be

extracted or obtained. State how this will be done and recorded.

All searches will be exported to RefWorks and then into Covidence for screening. Two reviewers will independently screen titles, abstracts, and full texts of relevant studies. The data from included quantitative and qualitative studies will then be extracted concurrently. One reviewer will extract data with 10% consistency checks made by a second. Quantitative data will be extracted from papers included in the review using the standardized data extraction tool from Joanna Briggs Institute Meta-Analysis of Statistics Assessment and Review Instrument (JBI-MASARI). The data extracted will include specific details about the country the study took place in, study method used (i.e., RCT or cross-sectional), target population, sample size, type of intervention, type of comparison, mode of delivery (i.e., one-to-one or in groups), delivery method (e.g., face-to-face, digital, etc.), setting (e.g., community centre or hospital), duration (e.g., number of sessions and the total duration of programme), facilitator of the intervention (e.g., lay-led, physiotherapist-led, nurse-led, etc.), components of the intervention, primary and secondary outcome measures, results and the authors' conclusions. Extracted data will be presented in narrative form and in tables. Details of the intervention's characteristics will be reported in accordance with the template for intervention description and replication (TIDieR) checklist.

Qualitative data will be extracted from papers included in the review using the standardized data extraction tool from the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI). Data collected will include details of the country the study took place in, study method used (i.e., phenomenological, or ethnographic), target population, phenomena of interest, setting, cultural relevance, data analysis technique, study findings and the authors' conclusions. Reviewers will then assign a level of validity or credibility, such as unequivocal, credible, or unsupported evidence, to each finding.

*** Risk of bias (quality) assessment.**

State which characteristics of the studies will be assessed and/or any formal risk of bias/quality assessment tools that will be used.

Quantitative papers selected for retrieval will be assessed by two independent reviewers for methodological validity prior to inclusion in the review using standardized critical appraisal instruments from the Joanna Briggs Institute critical appraisal instruments for quantitative study designs. Appraisal tools will be used according to each study design. Qualitative papers selected for retrieval will also be assessed by two independent reviewers for methodological validity prior to inclusion in the review using standardized critical appraisal instruments from the JBI Critical Appraisal Checklist for Qualitative Research (JBI-QARI). Mixed-method studies will be appraised using a combination of the above tools. Any disagreements that arise between the reviewers will be resolved through discussion or with a third reviewer. Authors of papers will be contacted to request missing data, where required. All studies, regardless of their methodological quality, will undergo data extraction and synthesis.

***Strategy for data synthesis.**

Describe the methods you plan to use to synthesise data. This **must not be generic text** but should be **specific to your review** and describe how the proposed approach will be applied to your data. If meta- analysis is planned, describe the models to be used, methods to explore statistical heterogeneity, and software package to be used.

This review will follow a two-stage convergent segregated approach to synthesis and integration as per the JBI methodology for mixed-methods systematic reviews. This entails separate quantitative meta- analysis/narrative and qualitative meta-aggregation followed by integration of the single-method syntheses into an overall configured analysis.

Stage 1: Individual quantitative and qualitative syntheses

Quantitative synthesis

A meta-analysis will be conducted depending on the homogeneity of the interventions, populations, and outcomes. For dichotomous data, effect sizes will be expressed as odds ratios. Mean difference with standard deviations (SD) and 95% confidence intervals (CI) between baseline and follow-up will be calculated for continuous data. Clinical and methodological heterogeneity will be assessed using χ^2 and I^2 statistics. Statistical analyses will be performed using a model (random-effect or fixed-effect) appropriate for the level of heterogeneity. If appropriate, subgroup analyses and/or meta-regression approaches will be undertaken. Where statistical analysis is not possible due to heterogeneity, findings will be narratively synthesised using text and tables to present the quantitative data.

Qualitative synthesis

Following data extraction, qualitative data will be pooled using a meta-aggregation approach. Findings from the included studies will be categorised based on similarity in meaning. Developed categories will be generated from the aggregation of at least two like findings. Categories will then be synthesised to produce a comprehensive set of synthesised findings. Where meta-aggregation is not possible, findings will be presented in a narrative.

Stage 2: Integration of quantitative evidence and qualitative evidence

The findings from the quantitative and qualitative synthesis will then be aggregated together to produce an overall analysis. Where configuration is not possible, the findings will be presented in a narrative.

*** Analysis of subgroups or subsets.**

State any planned investigation of 'subgroups'. Be clear and specific about which type of study or participant will be included in each group or covariate investigated. State the planned analytic approach.

Subgroup analysis may be performed according to disease diagnosis.

* Type and method of review.

Select the type of review, review method and health area from the lists below.

Type of review

Cost effectiveness No

Diagnostic No

Epidemiologic No

Individual patient data (IPD) meta-analysis No

Intervention Yes

Living systematic review No

Meta-analysis No

Methodology No

Narrative synthesis No

Network meta-analysis No

Pre-clinical No

Prevention No

Prognostic No

Prospective meta-analysis (PMA) No

Review of reviews No

Service delivery No

Synthesis of qualitative studies No

Systematic review Yes

Other No

Health area of the review Alcohol/substance misuse/abuse No

Blood and immune system No Cancer
No

Cardiovascular No

Care of the elderly No

Child health No

Complementary therapies No

COVID-19

No

Crime and justice No

Dental No

Digestive system No

Ear, nose and throat No
Education No
Endocrine and metabolic disorders No
Eye disorders No
General interest No
Genetics No
Health inequalities/health equity No
Infections and infestations No
International development No
Mental health and behavioural conditions No
Musculoskeletal No
Neurological No
Nursing No
Obstetrics and gynaecology No
Oral health No
Palliative care No
Perioperative care No
Physiotherapy No
Pregnancy and childbirth No
Public health (including social determinants of health) No
Rehabilitation No
Respiratory disorders No
Service delivery No
Skin disorders No
Social care No
Surgery No
Tropical Medicine No
Urological No
Wounds, injuries and accidents No
Violence and abuse No

Language.

Select each language individually to add it to the list below, use the bin icon to

remove any added in error. English

There is not an English language summary

*** Country.**

Select the country in which the review is being carried out. For multi-national collaborations select all the countries involved.

Scotland

Other registration details.

Name any other organisation where the systematic review title or protocol is registered (e.g., Campbell, or The Joanna Briggs Institute) together with any unique identification number assigned by them. If extracted data will be stored and made available through a repository such as the Systematic Review Data Repository (SRDR), details and a link should be included here. If none, leave blank.

Reference and/or URL for published protocol.

If the protocol for this review is published provide details (authors, title and journal details, preferably in Vancouver format)

Add web link to the published protocol.

Or upload your published protocol here in pdf format. Note that the upload will be publicly accessible. **Yes, I give permission for this file to be made publicly available**

Please note that the information required in the PROSPERO registration form must be completed in full even if access to a protocol is given.

Dissemination plans.

Do you intend to publish the review on completion?

Yes

Give brief details of plans for communicating review findings.?

Keywords.

Give words or phrases that best describe the review. Separate keywords with a semicolon or new line. Keywords help PROSPERO users find your review

(keywords do not appear in the public record but are included in searches). Be as specific and precise as possible. Avoid acronyms and abbreviations unless these are in wide use.

Inflammatory arthritis, self-management, intervention

Details of any existing review of the same topic by the same authors.

If you are registering an update of an existing review, give details of the earlier versions and include a full bibliographic reference, if available.

* Current review status.

Update review status when the review is completed and when it is published. New registrations must be ongoing, so this field is not editable for initial submission. Please provide anticipated publication date Review_Ongoing Any additional information.

Provide any other information relevant to the registration of this This review is in-part of a doctoral thesis. Details of final report/publication(s) or preprints if available.

Leave empty until publication details are available OR you have a link to a preprint (NOTE: this field is not editable for initial submission). List authors, title, and journal details preferably in Vancouver format. Give the link to the published review or preprint.

Appendix 2.2 MMSR Database Search Results

DATABASE	SEARCH TERMS	SEARCH HITS 31/3/2020	SEARCH HITS 21/8/2022
CINHAL	1. TX inflammatory arthriti* OR MH "Arthritis, Rheumatoid" OR TX rheumatoid arthriti* OR MH "Spondyloarthritis" OR TX spondyloarthriti* OR MH "Arthritis, Psoriatic" OR TX psoriatic arthriti* OR TX ankylosing spondyliti* OR TX spondyloarthropath* 2. MM "Self-Management" OR TX self-management OR MM "Self Care" OR TX self care OR TX self-management program* OR MH "Patient Education+" OR TX patient education OR TX self care education OR MH "Disease Management" OR TX disease management OR TX self-management intervention* 3. 1 AND 2	1. 43,260 2. 238,006 3. 4,414	1. 8,109 2. 44,683 3. 952
EMBASE	1. rheumatoid arthrit* OR psoriatic arthrit* OR spondyloarthriti* OR ankylosing spondylit* OR spondyloarthropath* OR inflammatory arthrit* 2. self-management OR self-management program* OR self-management intervention* 3. 1 AND 2	1. 205,042 2. 228,339 3. 789	1. 1 2. 479 3. 0
MEDLINE	1. MH "Arthritis, Rheumatoid" OR TX rheumatoid arthrit* OR MH "Arthritis, Psoriatic" OR TX psoriatic arthrit* OR MH "Spondylarthritis" OR TX spondyloarthriti* OR MH "Spondylitis, Ankylosing" OR TX ankylosing spondylit* OR MH "Spondyloarthropathies" OR TX spondyloarthropath* OR TX inflammatory arthrit* 2. MH "Self-Management" OR TX self-management OR TX self-management program* OR MH "Self Care" OR TX self care OR MH "Disease Management" OR TX disease management OR MH "Patient Education as Topic" OR TX patient education as topic OR TX self-management intervention* 3. 1 AND 2	1. 91,784 2. 167,859 3. 2,049	1. 29,235 2. 58,918 3. 1,899
AMED	1. TX rheumatoid arthrit* OR TX psoriatic arthrit* OR TX spondyloarthriti* OR TX ankylosing spondylit* OR TX spondyloarthropath* OR TX inflammatory arthrit* 2. TX self-management OR TX self-management program* OR TX self care OR TX disease management OR TX patient education OR TX self-management intervention* 3. 1 AND 2	1. 1,888 2. 2,528 3. 68	1. 85 2. 95 3. 1

Key: MH-Mesh heading; TX-Text

Appendix 2.3 MMSR Grey Literature Search Results

SOURCE	SEARCH TERMS	SEARCH HITS (2000-2020) 15/4/2020	SEARCH HITS (2020-2022) 21/8/2022
Center for Disease Control and Prevention	1. Arthritis self-management	1. 150	1. 150
British Library for E-Theses Online Service	1. Arthritis AND self-management OR patient education	1. 21	1. 23
National Institute for Health and Care Excellence Evidence	1. Arthritis self-management	1. 2,347	1. N/A
National Institute for Health Research Journal Library	1. "Self-management"	1. 39	1. 2
Google Scholar	1. "self-management" OR "patient education" AND "inflammatory arthritis" 2. "self-management" OR "patient education" AND "rheumatoid arthritis" 3. "self-management" OR "patient education" AND "psoriatic arthritis" 4. "self-management" OR "patient education" AND "ankylosing spondylitis"	1. 150 2. 150 3. 150 4. 150	1. 150 2. 150 3. 150 4. 150
International Standard Randomised Controlled Trials Number Registry	1. self-management OR patient education within Condition: Rheumatoid arthritis 2. self-management OR patient education within Condition: Psoriatic arthritis 3. self-management OR patient education within Condition: Ankylosing spondylitis 4. self-management OR patient education within Condition: Spondyloarthritis	1. 28 2. 2 3. 1 4. 0	1. 13 2. 1 3. 0 4. 1

SOURCE	SEARCH TERMS	SEARCH HITS (2000-2020) 15/4/2020	SEARCH HITS (2020-2022) 21/8/2022
The European Alliance of Associations for Rheumatology Recommendation References	1. EULAR recommendations for patient education for people with inflammatory arthritis	1. 108	1. N/A
	2. EULAR recommendations for cardiovascular disease risk management in patients with rheumatoid arthritis and other forms of inflammatory joint disorders: 2015/2016 update	2. 164	2. N/A
	3. 2010 update of the ASAS/EULAR recommendations for the management of ankylosing spondylitis	3. 96	3. N/A
	4. 2016 update of the ASAS-EULAR management recommendations for axial spondyloarthritis	4. 112	4. N/A
	5. 2016 update of the EULAR recommendations for the management of early arthritis	5. 88	5. N/A
	6. EULAR recommendations for the role of the nurse in the management of chronic inflammatory arthritis	6. 80	6. N/A
	7. EULAR recommendations for the health professional's approach to pain management in inflammatory arthritis and osteoarthritis	7. 80	7. N/A
	8. EULAR recommendations for patient education for people with inflammatory arthritis	8. 80	8. N/A
	9. 2021 EULAR recommendations for the implementation for self-management strategies in patients with inflammatory arthritis	9. 108	9. 85
	10. 2021 EULAR recommendations regarding lifestyle behaviours and work participation to prevent progression of rheumatic and musculoskeletal diseases	10. N/A	10. 119
	11. 2022 EULAR points to consider for remote care in rheumatic and musculoskeletal diseases	11. N/A	11. 63

	12. EULAR points to consider for the management of difficult-to-treat rheumatoid arthritis	12. N/A	12. 184
	13. EULAR Points to consider for designing, analysing, and reporting of studies with work participation as an outcome domain in patients with inflammatory arthritis	13. N/A	13. 36

Appendix 2.4 MMSR Reasons for Study Exclusion

Citation	Exclusion reason
John et al. (2013) A randomized controlled trial of a cognitive behavioural patient education intervention vs. a traditional information leaflet to address the cardiovascular aspects of rheumatoid disease	Wrong outcomes
Revenas et al. (2016) Mobile internet service for self-management of physical activity in people with rheumatoid arthritis: evaluation of a test version	Lack of participant voices in qualitative data
Parlar et al. (2013) The effects of self-pain management on the intensity of pain and pain management methods in arthritic patients	Wrong study design
Hoving et al. (2014) E-health to improve work functioning in employees with rheumatoid arthritis in rheumatology practice: a feasibility study	Wrong study design
El Miedany et al. (2012) Arthritis education: The integration of patient-reported outcome measures and patient self-management	Wrong rank on HDI
Lineker et al. (2015) Getting a grip on arthritis online: Web-based continuing education supports the dissemination of arthritis clinical practice guidelines among rural/remote primary care providers	Wrong study design
des Bordes et al. (2018) Assessing information needs and use of online resources for disease self-management in patients with rheumatoid arthritis: a qualitative study	Wrong phenomena of interest
Ajeganova, Wörnert and Hafström (2016) A four-week team-rehabilitation programme in a warm climate decreases disability and improves health and body function for up to one year: a prospective study in Swedish patients with inflammatory joint diseases	Wrong study design
Logan and Magem (2012) Group cognitive-behavioural therapy aimed at self-management reduced fatigue impact in people with rheumatoid arthritis is better than fatigue information alone	Abstract only
Kett et al. (2010) Self-management strategies used during flares of rheumatoid arthritis in an ethnically diverse population	Wrong phenomena of interest

Dures et al. (2015) Patient experiences of psychological support in inflammatory arthritis: Open-ended responses in a national survey	Wrong phenomena of interest
Barton et al. (2018) Experience and Context Shape Patient and Clinician Goals for Treatment of Rheumatoid Arthritis: A Qualitative Study	Wrong phenomena of interest
van Riel et al. (2019) Patient Self-Management and Tracking: A European Experience	Wrong study design
Lacaille et al. (2015) Proof of concept study of the arthritis health journal: An online tool to promote self-monitoring in people with rheumatoid arthritis (RA)	Abstract only
Zwikker et al. (2014) Effectiveness of a group-based intervention to change medication beliefs and improve medication adherence in patients with rheumatoid arthritis: a randomized controlled trial	Wrong intervention
Yousefi et al. (2015) Epidemiological evaluation quality of life in patients suffering from early rheumatoid arthritis: a pragmatic, prospective, randomized, blind allocation controlled of a modular program group intervention	Wrong rank on HDI
Vilsteren et al. (2017) One Year Effects of a Workplace Integrated Care Intervention for Workers with Rheumatoid Arthritis: Results of a Randomized Controlled Trial	Wrong study design
Untas et al. (2020) What Is Relatives' Role in Arthritis Management? A Qualitative Study of the Perceptions of Patient-Relative Dyads	Wrong phenomena of interest
Shao, Yu and Chen (2020) Feasibility and Acceptability of a Self-Management Program for Patients With Rheumatoid Arthritis	Wrong rank on HDI
Smarr et al. (2011) Online self-management in rheumatoid arthritis: a patient-centered model application	Wrong study design
Li et al. (2020) Efficacy of a Physical Activity Counselling Program With Use of a Wearable Tracker in People With Inflammatory Arthritis: A Randomized Controlled Trial	Duplicate
Leung et al. (2016) A pilot evaluation of arthritis self-management program by lay leaders in patients with chronic inflammatory arthritis in Hong Kong	Wrong study design

Masiero et al. (2014) Supervised training and home-based rehabilitation in patients with stabilized ankylosing spondylitis on TNF inhibitor treatment: a controlled clinical trial with a 12-month follow-up	Wrong study design
Inderjeeth et al. (2016) Ankylosing spondylitis (AS-P) patient centred education program improves disease activity and quality of life up to 12 months	Wrong study design
Kennedy et al. (2017) A prospective comparison of telemedicine versus in-person delivery of an interprofessional education program for adults with inflammatory arthritis	Wrong study design
Kennedy et al. (2011) Prescription for education: development, evaluation, and implementation of a successful interprofessional education program for adults with inflammatory arthritis	Wrong study design
Kukkurainen et al. (2011) Improving the quality of rheumatoid arthritis patients' education using written information	Wrong study design
Hammer et al. (2020) Preferences for Self-Management and Support Services in Patients with Inflammatory Joint Disease - A Danish Nationwide Cross-Sectional Study	Wrong phenomena of interest
Geuens et al. (2019) Mobile Health Features Supporting Self-Management Behavior in Patients with Chronic Arthritis: Mixed-Methods Approach on Patient Preferences	Wrong patient population
Geryk et al. (2016) Medication-related self-management behaviors among arthritis patients: Does attentional coping style matter?	Wrong intervention
Dufour et al. (2015) Physiotherapists supporting self-management through health coaching: a mixed methods program evaluation	Wrong patient population
Dougados et al. (2015) Impact of a nurse-led programme on comorbidity management and impact of a patient self-assessment of disease activity on the management of rheumatoid arthritis: Results of a prospective, multicentre, randomised, controlled trial (COMEDRA)	Wrong intervention
Blaney et al. (2019) Improved anxiety, depression, and emotional distress for rheumatoid arthritis patients following the completion of an online mental health intervention	Wrong study design
Beauvais et al. (2019) Development, acceptability and usability of hiboot: A smartphone app to improve medication adherence, safety and self-assessment in patients with inflammatory arthritis	Wrong study design

Azevedo et al. (2015) Smartphone application for rheumatoid arthritis self-management: cross-sectional study revealed the usefulness, willingness to use and patients' needs	Duplicate
Avery et al. (2016) The Impact of a Telephone-Based Chronic Disease Management Program on Medical Expenditures	Unable to identify specific relevant data
Hough et al. (2015) Identifying patients' preferences regarding education sessions for self-management of newly diagnosed rheumatoid and inflammatory arthritis	Abstract only
Dale et al. (2012) An evaluation of patients' perspectives of participating in a two-week inpatient ankylosing spondylitis rehabilitation programme	Abstract only
Bartlett et al. (2012) Flare self-management strategies used by patients with rheumatoid arthritis	Abstract only
Cox et al. (2014) The benefits of a multidisciplinary group education session for patients with newly diagnosed rheumatoid arthritis and psoriatic arthritis	Abstract only
Abou-Raya and Abou-Raya (2012) Disease self-management in adolescents with chronic musculoskeletal and rheumatic diseases	Abstract only
Stockl et al. (2010) Outcomes of a rheumatoid arthritis disease therapy management program focusing on medication adherence	Wrong study design
Wang et al. (2020) Efficacy of comprehensive technology-assisted home-based exercise in ankylosing spondylitis: A randomized, controlled trial	Abstract only
Rongen-Van Dartel et al. (2018) Introduction and evaluation of an online self-management tool and personal health environment for patients with rheumatoid arthritis (RA)	Abstract only
Nordgren (2015) Challenges in supporting behavior change in a two-year real-life physical activity program	Abstract only
Manning et al. (2014) Education, self-management, and upper extremity exercise training in people with rheumatoid arthritis: A randomized controlled trial	Duplicate

Molto et al. (2018) Impact of a nurse-led program of patient self-assessment and self-management axial spondyloarthritis: Results of a prospective, multicentre, randomised, controlled trial (comedspa)	Duplicate
McNicol et al. (2020) Integrated referral of newly diagnosed rheumatoid arthritis patient to education and support resources delivered by patient led organisation	Abstract only
Li et al. (2016) A qualitative study exploring participants' perception of the making it work program, an online program to help people with inflammatory arthritis maintain employment	Duplicate
Li et al. (2019) Efficacy of a counselling program to promote physical activity in people with inflammatory arthritis	Duplicate
Leung et al. (2014) A pilot evaluation of arthritis self-management program by lay leaders in patients with chronic inflammatory arthritis in Hong Kong	Duplicate
Lenzsinck et al. (2012) Which strategies adopt patients with early inflammatory arthritis to address their problems with work performance?	Abstract only
Inderjeeth et al. (2016) 12-month follow-up of patient satisfaction and outcomes of a novel ankylosing spondylitis patient centered education project	Duplicate
Hewlett et al. (2010) Sustained reduction in fatigue impact in rheumatoid arthritis: RCT of cognitive behavioural therapy	Duplicate
Hammond, Young and Kidao (2005) A preventative occupational therapy program for people with early rheumatoid arthritis increased the use of some self-management strategies but did not improve pain or perceived health status over 2 years	Too old
Haglund et al. (2017) Educational needs in patients with spondyloarthritis in Sweden - a mixed-methods study	Duplicate
Dures, Hammond, and Hewlett (2018) As a practitioner I feel enriched: Rheumatology tutors' experiences of delivering a manualised group cognitive-behavioural fatigue programme to patients with rheumatoid arthritis	Duplicate
Beaulieu et al. (2020) Mindfulness-based stress reduction to improve depressive symptoms and rheumatoid arthritis-related clinical outcomes: Results from a feasibility and acceptability trial	Abstract only

Bearne et al. (2012) A brief exercise and self-management programme improves upper limb disability in people with early rheumatoid arthritis	Duplicate
Azevedo et al. (2015) Smartphone application for rheumatoid arthritis self-management: cross-sectional study revealed the usefulness, willingness to use and patients' needs	Duplicate
Shao, Yu and Chen (2020) Feasibility and Acceptability of a Self-Management Program for Patients with Rheumatoid Arthritis	Wrong rank on HDI
Zickuhr et al. (2017) Impact of patient education tool to increase cardiovascular risk knowledge, attitudes, and behaviors in patients with rheumatoid arthritis	Abstract only
Wilson et al. (2020) The experiences of and preferences for delivery of outpatient rheumatology services in adults diagnosed with AXSPA living in the UK: A qualitative study	Abstract only
Tziatzou et al. (2019) Patients perspectives on self-management of axial spondyloarthritis fatigue	Abstract only
Tiliakos et al. (2011) The effect of arthritis self-management program on outcome in African Americans with rheumatoid arthritis served by a public hospital	Duplicate
Seah et al. (2016) Process evaluation of "employment & arthritis: Making it work", an online program to help people with inflammatory arthritis maintain employment	Abstract only
Tan et al. (2010) Immediate impact of an education programme for patients with early rheumatoid arthritis	Abstract only
Piperno et al. (2016) Efficiency of an education program on the safety knowledge and skills of patients with rheumatoid arthritis treated by biologics	Abstract only
Passalent et al. (2017) Impact of e-learning on knowledge, self-efficacy and exercise behaviours of patients with axial spondyloarthritis: Results from a longitudinal randomized control trial	Duplicate
Manning et al. (2013) "I definitely would recommend it...I think it's been quite amazing really": Experiences of an upper limb education, self-management, and exercise training programme (the extra programme) among people with early rheumatoid arthritis	Duplicate

Manning et al. (2013) 'i think having a programme like that for people who have got rheumatoid arthritis is well worth doing': Experiences of an upper limb education, self-management and exercise programme among people with early rheumatoid arthritis	Duplicate
Manning et al. (2014) Education, self-management and upper extremity exercise training in people with rheumatoid arthritis: A randomised controlled trial.	Duplicate
Liu and Zhuang (2016) Chronic disease management mode are benefit for the rheumatoid arthritis patients treated by the biological agents	Abstract only
Kristjansdottir et al. (2020) Mobile app to help people with chronic illness reflect on their strengths: Formative evaluation and usability testing	Wrong patient population
Kang et al. (2013) Utilization of an informational needs assessment to develop an education program for patients with ankylosing spondylitis and related axial spondyloarthritis	Abstract only
Jamal et al. (2018) Early arthritis self-management sessions: Does it have a role?	Abstract only
Grønning et al. (2017) Patients Perceptions of Having a Good Life One Year after Arthritis Patient Education: A Qualitative Study Nested within a Randomized Controlled Trial	Duplicate
Hindley and MacPhie (2019) Promoting self-management in patients with inflammatory arthritis: How do patients want education on self-management to be delivered?	Abstract only
Dougados et al. (2013) Impact of a nurse led program of patient self-assessment of disease activity on the management of rheumatoid arthritis: Results of a prospective, multicentre, randomized, controlled trial (comedra)	Duplicate
Conn et al. (2013) The effect of the Arthritis Self-Management Program on outcome in African Americans with rheumatoid arthritis served by a public hospital	Wrong patient population
Dures, Hammond, and Hewlett (2018) 'as a practitioner I feel enriched': rheumatology tutors' experiences of delivering a manualised group cognitive behavioural fatigue programme to patients with rheumatoid arthritis (RA)	Duplicate
Druett et al. (2015) Personal experiences of the 'living well with arthritis' self-management course	Abstract only

Cuss et al. (2010) Goal setting for managing rheumatoid arthritis fatigue: A qualitative exploration	Abstract only
Cheung, Lee and Tang (2016) Starting care at the peep of rheumatoid arthritis-a patient education and empowerment program	Abstract only
Beauvais et al. (2017) Clefs De dos: A unique pare-led video program to improve coping skills of people living with axial spondyloarthritis	Abstract only
Austin, Jones and Prasad (2019) Patient education in psoriatic arthritis: Addressing an unmet need	Abstract only
Zuidema et al. (2018) HPR effectiveness of an e-health tailored self-management program for patients with rheumatoid arthritis: An explorative RCT	Duplicate
Xhaxho et al. (2019) Patients' perspectives on self-management of axial spondyloarthritis fatigue	Duplicate
Vermaak et al. (2013) Evaluation of a disease specific rheumatoid arthritis self-management education program	Duplicate
Salmon et al. (2015) Acceptability of a novel physical activity and self-management intervention for managing fatigue in rheumatoid arthritis	Duplicate
Phillips and Harris (2019) Helping people to help themselves: an eight-week mindfulness course for people living with a long-term inflammatory condition	Abstract only
Molto et al. (2018) Impact of a nurse-led program of patient self-assessment and self-management axial spondyloarthritis: Results of a prospective, multicentre, randomized, controlled trial	Duplicate
Li et al. (2017) Participants' experience of the making it work program, an online program to help people with inflammatory arthritis remain employed	Abstract only
Lawson et al. (2018) Longitudinal outcomes and predictors of e-Learning effectiveness in patients with axial spondyloarthritis: A randomized controlled trial	Abstract only

Jones et al. (2019) Participation in the stanford university chronic pain self-management program in a population with a high prevalence of arthritis	Abstract only
Hewlett et al. (2010) Reducing the impact of rheumatoid arthritis fatigue: A randomized controlled trial of cognitive behavioural therapy	Duplicate
Hewlett et al. (2019) Reducing arthritis fatigue impact: two-year randomised controlled trial of cognitive behavioural approaches by rheumatology teams (RAFT)	Duplicate
Gencturk, Eren and Yuksel (2015) Evaluation study for self-management of patients with ankylosing spondylitis (AS) through a personal health system	Abstract only
Claassen et al. (2015) Factors influencing the use of a self-management care booklet for patients with rheumatoid arthritis	Abstract only
De Angelis et al. (2017) The use of social media by arthritis health professionals to disseminate a self-management program to patients: A feasibility study	Wrong patient population
Bain et al. (2011) The role of the patient ambassador in support of the identified theme of hope in the needs of patients attending an inflammatory arthritis education program at the arthritis program (TAP)	Abstract only
Austin, Sanders and Dixon (2017) Patients' experiences of remote monitoring of rheumatoid arthritis using a smartphone app	Abstract only
Briffa et al. (2013) The development of a community-based education/self-management program for people with ankylosing spondylitis	Abstract only
(2012) Assessment of knowledge progression after the educational program in rheumatoid arthritis and ankylosing spondylitis patients	Abstract only
Flurey et al. (2014) It's like a juggling act: Rheumatoid arthritis patient perspectives on daily life and flare while on current treatment regimes	Duplicate
Zhao and Chen (2019) Effectiveness of health education by telephone follow-up on self-efficacy among discharged patients with rheumatoid arthritis: A randomised control trial	Wrong rank on HDI

Shinde and Varadharajulu (2017) Effect of Therapeutic Exercise Programme in Adults with Early Rheumatoid Arthritis	Wrong rank on HDI
Song et al. (2019) A randomized controlled trial of the Effects of a telehealth educational intervention on medication adherence and disease activity in rheumatoid arthritis patients	Wrong rank on HDI
Feldthusen et al. (2013) Perception, consequences, communication, and strategies for handling fatigue in persons with rheumatoid arthritis of working age--a focus group study	Wrong intervention
Shao, Yu and Chen (2020) Effectiveness of a self-management program for joint protection and physical activity in patients with rheumatoid arthritis: A randomized controlled trial	Wrong rank on HDI
Barkham and Ersser (2017) Supporting self-management by Community Matrons through a group intervention; an action research study	Wrong patient population
Vermaak et al. (2015) Evaluation of a disease specific rheumatoid arthritis self-management education program, a single group repeated measures study	Wrong study design
Jisha, Suneetha and Skandhan (2016) The Effect of Structured Teaching Programme among Patients with Ankylosing Spondylitis	Wrong rank on HDI
Thomas et al. (2019) Keeping physically active with rheumatoid arthritis: semi-structured interviews to explore patient perspectives, experiences and strategies	Wrong intervention
Townsend et al. (2013) A qualitative interview study: Patient accounts of medication use in early rheumatoid arthritis from symptom onset to early postdiagnosis	Wrong intervention
Helland et al. (2011) Rheumatic diseases and sexuality: Disease impact and self-management strategies	Wrong intervention
Flurey (2012) Capturing daily fluctuations, flare and self-management in rheumatoid arthritis: The patient perspective	Wrong intervention
Passalent et al. (2016) Impact of e-learning on knowledge, self-efficacy and exercise behaviours of patients with axial spondyloarthritis: Results from a longitudinal randomized control trial	Duplicate

Dougados et al. (2013) Nurse-led programmes for self-management of rheumatoid arthritis	Abstract only
Anvar et al. (2018) Effectiveness of self-management program on arthritis symptoms among older women: A randomized controlled trial study	Wrong rank on HDI
Shankpal (2012) Development of lifestyle suitable for rheumatoid arthritis sufferers	Abstract only
Martin and Fiddler (2016) Axial spondyloarthritis know-how: What are the benefits of a brief exercise and self-management education group programme? a qualitative investigation	Abstract only
Ferwerda et al. (2017) A tailored-guided internet-based cognitive-behavioral intervention for patients with rheumatoid arthritis as an adjunct to standard rheumatological care: results of a randomized controlled trial	Duplicate
Liu et al. (2019) Effects of a 4-week Omaha System transitional care programme on rheumatoid arthritis patients' self-efficacy, health status, and readmission in mainland China: A randomized controlled trial	Wrong rank on HDI
Wang and Hu (2016) Influence of self-care training on disease uncertainty and quality of life of patients with rheumatoid arthritis	Wrong rank on HDI
Manning et al. (2013) Upper limb exercise, education and self-management in early rheumatoid arthritis (the extra programme)-results from a randomised controlled trial	Duplicate
Khoury, Kourilovitch and Massardo (2015) Education for patients with rheumatoid arthritis in Latin America and the Caribbean	Wrong study design
McQuade et al. (2015) Patient satisfaction and outcomes of a novel ankylosing spondylitis education and self-management project	Wrong study design
Inderjeeth et al. (2015) Improving ankylosing spondylitis specific outcomes at 6 months utilising a novel self-management education program	Wrong study design
Inderjeeth et al. (2015) Ankylosing spondylitis(as) self-management education program-6-month follow-up results	Wrong study design

Inderjeeth et al. (2015) Ankylosing spondylitis (AS) self-management education program-6-month follow-up results	Wrong study design
Inderjeeth et al. (2016) Ankylosing spondylitis patient-centred education program improves disease activity and quality of life up to 12 months	Wrong study design
Inderjeeth et al. (2019) Patients enrolled in an ankylosing spondylitis (AS-P) patient centred education program had improved disease activity outcomes up to 12 months	Wrong study design
Koksvik et al. (2016) Shared understanding and high intensity-the patients' perspectives of attending a rehabilitation program in warm climate specially designed for young adults	Wrong study design
Martin (2020) Getting the know-how: The feasibility of delivering a digital self-management programme for axspa	Wrong study design
Martin (2020) Getting the know-how: the feasibility of delivering a digital self-management programme for axial spondyloarthritis	Duplicate
Luquini et al. (2020) Effectiveness of the making it WorkTM program at improving presenteeism and work cessation in workers with inflammatory arthritis-results of a randomized controlled trial	Wrong study design
Stockl et al. (2010) Clinical, economic, and humanistic benefits of a rheumatoid arthritis disease therapy management program	Wrong study design
Li et al. (2017) A qualitative study exploring participants' perception of the making it work program, an online program to help people with inflammatory arthritis maintain employment	Duplicate
Gordhan et al. (2012) The evaluation of an arthritis education outreach programme for black and ethnic minority communities	Wrong study design
Yu, Lin and Zhang (2015) Influence of authorized education on treatment compliance and quality of life of patients with rheumatoid arthritis	Unable to locate

Appendix 2.5 MMSR Reference List

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Appendix 2.6 MMSR Participant Demographics

Citation	Participants	Gender (% Female)	Age (μ ±SD)	Disease Duration (years; μ ±SD)	Ethnicity (%)	Currently employed or studying (full- or part-time; %)	Married/Living with partner (n)	Current Medication (n)	BMI (kg/m ² ; μ ±SD)
Aksoy et al. 2017	AS (n=41)	IG: 25% CG: 19%	IG: 37.9±9.8 CG: 37.4±11.1	IG: 9.4±7.1 CG: 8.6±6.7	NR	NR	NR	NR	NR
Allam et al. 2015	RA (n=157)	I: 43% SS: 10% G: 14% SS+G: 46% CG: 18%	I: 55.1±10.5 SS: 53.2±13.3 G: 54.5±12.0 SS+G: 53.5±9.9 CG: 69.3±6.4	I: 9.9±9.3 SS: 10.5±9.8 G: 8.9±8.2 SS+G: 18.1±15.9 CG: 18.1±15.9	NR	N/A	NR	NR	NR
Arvidsson et al. 2012	IA (n=120)	IG: 71% CG: 73%	IG: 56.4±7.2 CG: 55.2±13.2	NR	NR	NR	IG: 30 CG: 102	NR	NR
Bain et al. 2016	IA (n=30)	83.3%	N/A	NR	NR	30%	NR	NR	NR
Barsky et al. 2010	RA (aged 20-75) (n=168)	CBT: 90% RR: 82% AE: 87%	CBT: 54.3±13.1 RR: 54.0±12.3 AE: 51.9±13.4	CBT: 12.4±11.3 RR: 13.9±10.2 AE: 14.1±13.1	White CBT: 85% RR: 75% AE: 77% Black CBT: 9% RR: 14% AE: 16% Other CBT: 6% RR: 11% AE: 7%	CBT: 50% RR: 57% AE: 64%	CBT: 51 RR: 48 AE: 46	Steroids CBT: 29; RR: 34; AE: 23 DMARDs CBT: 63; RR: 59; AE: 57 Biologics CBT: 44; RR: 36; AE: 50	NR
Berdal et al. 2018	RA and SpA (n=389)	IG: 75.8% CG: 65.1%	IG: 58 CG: 57 (SD NR)	IG: 19.1±13.3 CG: 21.0±13.3	NR	IG: 39.4% CG: 35.8%	IG: 129 CG: 138	NSAIDs IG: 98; CG: 104 Synthetics IG: 83; CG: 92 Biologics IG: 39; CG: 44 Analgesics IG: 130; CG: 120 Other IG: 114; CG: 129	IG: 27.7±5.7 CG: 27.5±4.7

Citation	Participants	Gender (% Female)	Age ($\mu\pm$ SD)	Disease Duration (years; $\mu\pm$ SD)	Ethnicity (%)	Currently employed or studying (full- or part-time; %)	Married/ Living with partner (n)	Current Medication (n)	BMI (kg/m ² ; $\mu\pm$ SD)
Breedland et al. 2011	RA (n=34)	IG: 63% CG: 80%	IG: 45 $\pm$ 11.9 CG: 51.8 $\pm$ 9.4	IG: 9.7 $\pm$ 14.0 CG: 5.9 $\pm$ 7.2	NR	NR	NR	NSAIDs IG: 0; CG: 4 DMARDs IG: 4; CG: 4 NSAIDs+ DMARDs IG: 13; CG: 9 Biologics + DMARDs IG: 2; CG: 0 No medication IG: 0; CG: 1	NR
Bearne et al. 2017	RA (n=12)	83%	57.8 $\pm$ 16.6	N/A	Black Caribbean 25% White 59% Pakistani 8% Black African 8%	66.6%	5	NR	NR
Beauvais et al. 2022	RA, axSpA, and pSpA (n=129)	IG: 64% CG: 63%	IG: 48.6 $\pm$ 12.6 CG: 45.4 $\pm$ 13.0	N/A	NR	IG: 56.5% CG: 76.7%	IG: 109 CG: 104	NSAIDs IG: 32; CG: 29 Glucocorticoids IG: 13; CG: 18 DMARDs IG: 23; CG: 27	NR
Change et al. 2014/ Gilbert et al. 2018	RA (n=185)	All participants: 84%	All participants: 54.8 $\pm$ 13.7	All participants: 13.2 $\pm$ 10.0	White 72% African American 12% Other 16%	NR	NR	NR	All participants: 27.9 $\pm$ 6.6
Cramp et al. 2020	RA (n=12); Band 6 Physios (n=3)	RA: 75% Physios: NR	RA: 57.6 $\pm$ 14.5 Physios: NR	RA: N/A Physios: N/A	RA: NR Physios: NR	RA: 41.7% Physios: N/A	RA: NR Physios: N/A	RA: NR Physios: N/A	RA: NR Physios: N/A

Citation	Participants	Gender (% Female)	Age (μ ±SD)	Disease Duration (years; μ ±SD)	Ethnicity (%)	Currently employed or studying (full- or part-time; %)	Married/Living with partner (n)	Current Medication (n)	BMI (kg/m ² ; μ ±SD)
Davis et al. 2015	RA (aged 21-86) (n=143)	All participants: 68.5%	All participants: 54.3±13.8	NR	All participants: 85% Caucasian	NR	NR	NR	NR
Dures et al. 2012	RA (n=38)	78.9%	60.9±9.4	14.0±11.5	NR	NR	NR	NR	NR
Feldthusen et al. 2015	RA (aged 20-65) (n=70)	IG: 88.9% CG: 88.2%	IG: 54.2±8.5 CG: 52.7±10.9	IG: 14.2±11.2 CG: 11.6±7.7	NR	IG: 72.3% CG: 70.6%	NR	NR	IG: 26.2±5.3 CG: 28.3±5.3
Ferwerda et al. 2017	RA + a psychological risk profile of elevated levels of distress (n=133)	IG: 61% CG: 66%	IG: 55.5±10.7 CG: 57.1±9.4	NR	NR	NR	NR	NR	NR
Grønning et al. 2012	RA, PsA, and UA (aged 18-80) (n=141)	IG: 68% CG: 70%	IG: 58±12 CG: 58±11	IG: 13±14 CG: 11±12	NR	IG: 32% CG: 26%	IG: 58 CG: 59	DMARDs IG: 59; CG: 55 NSAIDs/coxibs IG: 22; CG: 14 Oral cortisone IG: 27; CG: 19 Analgesics IG: 30; CG: 24	NR
Grønning et al. 2014	RA, PsA, and UA (aged 18-80) (n=141)	All participants: 69%	All participants: 58±11	All participants: 12±13	NR	All participants: 29%	NR	All participants: DMARDs 114 NSAIDs/coxibs 36 Oral cortisone 46 Analgesics 54	NR
Grønning, Midttun, and Steinsbekk 2016	RA, PsA, and UA (n=26)	88%	58 (SD NR)	NR	NR	20%	24	NR	NR
Grønning, Lim and Bratås 2019	RA, PsA, and UA (n=98)	All participants: 71.3%	All participants: 58.7±9.9	All participants: 11.5±9.3	NR	NR	83	All participants: DMARDs 83%	NR
Haglund et al. 2017	SpA (n=11)	36%	N/A	N/A	NR	NR	NR	NR	NR
Hammond et al. 2017	RA, PsA, and UA (n=55)	IG: 75.9% CG: 76.9%	IG: 47.7±10.4 CG: 50.5±6.4	N/A	NR	IG: 58.6% CG: 61.5%	IG: 24 CG: 16	Steroids IG: 12; CG: 7 DMARDs IG: 26; CG: 20 Biologics IG: 8; CG: 9	NR

Citation	Participants	Gender (% Female)	Age ($\mu \pm$ SD)	Disease Duration (years; $\mu \pm$ SD)	Ethnicity (%)	Currently employed or studying (full- or part-time; %)	Married/ Living with partner (n)	Current Medication (n)	BMI (kg/m ² ; $\mu \pm$ SD)
Hewlett et al. 2011	RA (n=168)	IG: 75.4% CG: 71%	IG: 61.1 $\pm$ 10.5 CG: 58.3 $\pm$ 12.0	IG: 14.2 $\pm$ 11.6 CG: 14.6 $\pm$ 10.6	NR	NR	NR	NR	NR
Hewlett et al. 2019 (QUAN)	RA with severe fatigue (n=333)	IG: 80.1% CG: 79.6%	IG: 63.7 CG: 61.8 (SD NR)	IG: 10 CG: 10 (SD NR)	White IG: 151; CG: 147 Asian/Asian British IG: 5; CG: 3	NR	NR	NR	NR
Hewlett et al. 2019 (QUAL)	Nurses (n=12) OTs (n=10)	NR	NR	N/A	NR	NR	NR	NR	NR
Kaya et al. 2016	AS (n=80)	IG: 7.5% CG: 5%	IG: 43.1 $\pm$ 9.1 CG: 40.9 $\pm$ 9.3	IG: 9 CG: 5 (SD NR)	NR	IG: 15% CG: 21.3%	IG: 19 CG: 23	NR	NR
Kjeken et al. 2013	AS (n=100)	IG: 21.7% CG: 46.9%	IG: 49.4 $\pm$ 10.3 CG: 48.6 $\pm$ 9.4	IG: 14.9 $\pm$ 9.6 CG: 16.1 $\pm$ 12.0	NR	IG: 71.8% CG: 68.2%	NR	NSAIDs IG: 34; CG: 38 DMARDs IG: 3; CG: 1 Biologics IG: 1; CG: 6	NR
Kristiansen and Antoft 2016	RA (n=17)	100%	NR	NR	NR	NR	NR	NR	NR
Lumley et al. 2014	RA (n=262)	WED+CST: 80.6% WED+CT: 81.2% CW+CST: 84.1% CW+CT: 78.8%	WED+CST: 56.0 $\pm$ 10.4 WED+CT: 55.2 $\pm$ 12.3 CW+CST: 54.0 $\pm$ 13.7 CW+CT: 55.3 $\pm$ 11.9	WED+CST: 11.9 $\pm$ 11.5 WED+CT: 12.6 $\pm$ 10.9 CW+CST: 14.4 $\pm$ 11.4 CW+CT: 13.7 $\pm$ 11.2	White WED+CST: 12.5% WED+CT: 16.4% CW+CST: 16.8% CW+CT: 19.1% Black WED+CST: 8.0% WED+CT: 9.1% CW+CST: 6.8% CW+CT: 4.2% Other WED+CST: 0.4% WED+CT: 0.8% CW+CST: 0.4% CW+CT: 1.5%	NR	WED+CST: 46 WED+CT: 44 CW+CST: 41 CW+CT: 42	Biologics WED+CST: 31; WED+CT: 34; CW+CST: 34; CW+CT: 32 DMARDs WED+CST: 50; WED+CT: 48; CW+CST: 41; CW+CT: 40 Steroids WED+CST: 31; WED+CT: 23; CW+CST: 29; CW+CT: 34 Opioids WED+CST: 20; WED+CT: 15; CW+CST: 15; CW+CT: 23 NSAIDs WED+CST: 45; WED+CT: 42; CW+CST: 47; CW+CT: 40	NR

Citation	Participants	Gender (% Female)	Age (μ $\pm$ SD)	Disease Duration (years; μ $\pm$ SD)	Ethnicity (%)	Currently employed or studying (full- or part-time; %)	Married/Living with partner (n)	Current Medication (n)	BMI (kg/m ² ; μ $\pm$ SD)
Manning et al. 2014	RA (n=108)	IG: 84.6% CG: 67.8%	IG: 53 $\pm$ 16 CG: 57 $\pm$ 15	IG: 20 $\pm$ 18 CG: 20 $\pm$ 19	NR	IG: 19% CG: 18%	NR	N/A	IG: 29 $\pm$ 7 CG: 30 $\pm$ 7
McBain et al. 2015	RA and PsA (n=128)	IG: 46.2% CG: 64.6%	IG: 54.8 $\pm$ 11.2 CG: 58.8 $\pm$ 12.2	N/A	White IG: 88.5%; CG: 89.6% Indian IG: 3.9%; CG: 4.2% Chinese IG: 0%; CG: 2.1% Black-African IG: 0%; CG: 2.1% Black-Caribbean IG: 2%; CG: 0% Other IG: 5.8%; CG: 2.1%	NR	IG: 37 CG: 33	All participants taking an oral steroid	NR
Mollard and Michaud 2018	RA (n=12)	NR	NR	NR	NR	NR	NR	NR	NR
Molto et al. 2021	axSpA (n=502)	IG: 40% CG: 34%	IG: 47 $\pm$ 12 CG: 47 $\pm$ 12	IG: 14 $\pm$ 11 CG: 13 $\pm$ 11	NR	NR	NR	NR	N/A
Ndosi et al. 2016	RA (n=132)	IG: 68% CG: 63%	IG: 54 $\pm$ 12.3 CG: 56 $\pm$ 13.3	IG: 5.2 $\pm$ 4.9 CG: 6.7 $\pm$ 8.9	NR	NR	NR	NR	NR
Niedermann et al. 2011, 2012	RA (n=53)	IG: 85% CG: 82%	IG: 62.1 $\pm$ 12.6 CG: 53.4 $\pm$ 15.7	IG: 10.2 $\pm$ 7.6 CG: 8.3 $\pm$ 9.8	NR	NR	NR	Biologics IG: 8; CG: 9 DMARDs IG: 22; CG: 20 Steroids IG: 11; CG: 13 NSAIDs IG: 9; CG: 11 Analgesics IG: 7; CG: 2	NR

Citation	Participants	Gender (% Female)	Age (μ $\pm$ SD)	Disease Duration (years; μ $\pm$ SD)	Ethnicity (%)	Currently employed or studying (full- or part-time; %)	Married/ Living with partner (n)	Current Medication (n)	BMI (kg/m ² ; μ $\pm$ SD)
Nilssen et al. 2017	RA, PsA, AS, and UA (aged 20-35) (n=64)	IG: 66% CG: 59%	IG: 27.1 $\pm$ 5.3 CG: 28 $\pm$ 4.6	IG: 7.5 $\pm$ 9.7 CG: 8.4 $\pm$ 8.2	NR	IG: 44% CG: 53%	IG: 40 CG: 30	DMARDs IG: 27; CG: 27 Corticosteroids IG: 4; CG: 0 NSAIDs/Coxibs IG: 11; CG: 13 Other analgesics IG: 10; CG: 11	IG: 26.9 $\pm$ 6.3 CG: 24.8 $\pm$ 5.8
Pot-Vaucel et al. 2016	RA (n=54)	NR	IG: 58.2 $\pm$ 10.7 CG: 62.4 $\pm$ 9.8	IG: 11.6 $\pm$ 9.4 CG: 14.5 $\pm$ 13.0	NR	NR	NR	Biotherapy IG: 26; CG: 25 Corticotherapy IG: 35; CG: 31 DMARDs IG: 44; CG: 48	N/A
Prior et al. 2015	Band 6, 7, and 8 OTs (n=9);	NR	NR	N/A	NR	N/A	NR	NR	NR
Prior et al. 2017	IA, RA, and PsA (n=32)	71.9%	49.4 $\pm$ 8.5	NR	NR	100%	23	Biologics 8 Mono/combination therapy 18	NR
Rodríguez-Lozano et al. 2013	AS (n=756)	IG: 29% CG: 27%	IG: 45 $\pm$ 12 CG: 46 $\pm$ 11	IG: 17 $\pm$ 10 CG: 18 $\pm$ 11	NR	N/A	NR	Analgesics IG: 49; CG: 38 NSAIDs IG: 284; CG: 286 Corticosteroids IG: 13; CG: 17 DMARDs IG: 59; CG: 86 Oral steroids IG: 24; CG: 41 Biologics IG: 146; CG: 149	NR
Salmon 2019	RA (n=9)	88.9%	58.3 $\pm$ 11.0	4.9 $\pm$ 3.0	NR	22.2%	NR	DMARDs 9 NSAIDs 2 Biologics 1	NR
Sharpe and Schreiber 2012	RA (n=104)	All participants: 78%	CT: 55.2 $\pm$ 13.3 BT: 57.9 $\pm$ 12.9 CBT: 57.7 $\pm$ 15.4 CG: 54.2 $\pm$ 11.0	CT: 11.5 $\pm$ 12.7 BT: 9.8 $\pm$ 11.5 CBT: 20 $\pm$ 20.3 CG: 12.4 $\pm$ 11.6	NR	Part-time CT: 19% BT: 23% CBT: 20% CG: 31% Full-time CT: 19% BT: 11% CBT: 16% CG: 27%	CT: 13 BT: 10 CBT: 16 CG: 19	DMARDs WLC: 16 CT: 14 BT: 18 CBT: 14	NR

Citation	Participants	Gender (% Female)	Age ($\mu \pm SD$)	Disease Duration (years; $\mu \pm SD$)	Ethnicity (%)	Currently employed or studying (full- or part-time; %)	Married/ Living with partner (n)	Current Medication (n)	BMI (kg/m ² ; $\mu \pm SD$)
Shigaki et al. 2013	RA (n=106)	IG: 93% CG: 92%	IG: 50.3 $\pm$ 11.6 CG: 49.3 $\pm$ 12.3	IG: 7.4 $\pm$ 8.6 CG: 8.5 $\pm$ 10.3	White IG: 93% CG: 96%	IG: 62% CG: 69%	IG: 33 CG: 34	NR	NR
Unk and Bransington 2014	RA (n=108)	IG: 85.2% CG: 74.1%	IG: 50.1 $\pm$ 12.9 CG: 50.5 $\pm$ 11.3	IG: 7.3 $\pm$ 8.7 CG: 8.0 $\pm$ 10.2	Black IG: 29.6% CG: 31.5% White IG: 70.4% CG: 68.5%	NR	IG: 31 CG: 35	NR	NR
Zangi et al. 2011	RA, AS, PsA, and IA (aged 20-70 years) (n=45)	87.5%	N/A	N/A	NR	55.6%	38	NR	NR
Zangi et al. 2012	RA, AS, PsA, and IA (aged 20-70 years) (n=71)	IG: 77.8% CG: 80.0%	IG: 53.0 $\pm$ 9.4 CG: 54.9 $\pm$ 8.9	IG: 14.4 $\pm$ 11.3 CG: 18 $\pm$ 14	NR	IG: 38.9% CG: 40.0%	IG: 63.9% CG: 65.7%	NR	NR
Zuidema et al. 2019a	RA (n=157)	IG: 65.0% CG: 66.0%	IG: 61.0 $\pm$ 11.3 CG: 62.9 $\pm$ 10.2	N/A	NR	IG: 23.6% CG: 18.5%	NR	NR	NR
Zuidema et al. 2019b	RA (n=21)	NU: 50.0% LU: 100% HU: 57.1% HUP: 50.0%	NU: 57 LU: 64 HU: 50 HUP: 66.5 (SD NR)	N/A	NR	NU: 50.0% LU: 50.0% HU: 85.7% HUP: 50.0%	NR	NR	NR

KEY: AE= arthritis education; AS= ankylosing spondylitis; axSpA=axial spondyloarthritis; BMI= body mass index; BT= behavioural therapy; CBT= cognitive behavioral therapy group; CG= control group; CST= behavioral coping skills training; CT= arthritis education control training (Lumley); CT= cognitive therapy (Sharpe and Schreiber); CW= control writing; DMARDs= disease-modifying antirheumatic drugs; G= gaming group; HUB=high-user; HUP=high-user plus; I= information group; IA= inflammatory arthritis; IG= intervention group; LU= low-user; N/A= not applicable; NR= not reported; NSAIDs= non-steroidal anti-inflammatory drugs; NU=non-user; OT= occupational therapist; pSpA=peripheral spondyloarthritis; RA= rheumatoid arthritis; RR= relaxation response training group; SD= standard deviation; SpA= spondyloarthritis; SS+G= social support and gaming group; SS= social support group; UA= unspecified polyarthritis; WED= written emotional disclosure

Appendix 2.7 MMSR Intervention Characteristics (Modified from source: Hoffmann et al. 2014)

Citation	Brief Name	Theory	Materials	Facilitator	Mode of delivery	Setting	Duration	Tailoring	Modifications	Fidelity
Aksoy et al. 2017	N/A	NR	Pamphlet containing educational information and exercises	Physio	Group; remote	Hospital	5 days	NR	NR	NR
Allam et al. 2015	ONESELF	NR	NR	Doctors and researchers	Combination; online	Website	2 months	NR	NR	Yes
Arvidsson et al. 2012	NR	NR	NR	Nurses	Group; face-to-face	NR	1 year	NR	NR	NR
Bain et al. 2016	IA TEP	NR	NR	NR	Group; face-to-face	Outpatient rheumatology clinic	10 days	NR	NR	NR
Barsky et al. 2010	NR	NR	NR	Therapists	Group; face-to-face	NR	8-12 weeks + 12 months of telephone booster calls	NR	NR	Yes
Berdal et al. 2018	NR	NR	Self-management booklet	HCP (not specified)	Individual; combination	Multi-centre; rehabilitation clinics	time spent in rehab + 5 months post D/C	Yes	NR	NR
Breedland et al. 2011	FIT	SCT	NR	MDT-led; psychologist, physio, OT, dietitian, and a social worker	Group; face-to-face	Outpatient	8 weeks	NR	NR	NR
Beauvais et al. 2022	NR	NR	Booklet outlining key messages	Nurses	NR; face-to-face	Multi-centre; hospital	3 months	NR	NR	NR
Chang et al. 2014/ Gilbert et al. 2018	IMPAACT	IMCHB	NR	Physician	Individual; face-to-face	NR	2 years	Yes	NR	NR
Cramp et al. 2020	PEPA-RA	SDT	NR	Band 6 Physio	Combination; face-to-face	Primary care clinic	12 weeks	Yes	NR	NR
Davis et al. 2015	NR	NR	30 daily diary booklets	Clinical health psychologist and clinical psychologist	Group; face-to-face	NR for education modules; diary assessments completed at home	12 weeks	NR	NR	Yes

Citation	Brief Name	Theory	Materials	Facilitator	Mode of delivery	Setting	Duration	Tailoring	Modifications	Fidelity
Feldthusen et al. 2015	NR	NR	NR	Physio	Individual; face-to-face	Hospital outpatient rheumatology clinic	12 weeks	Yes	NR	NR
Ferwerda et al. 2017	NR	NR	NR	CBT-trained therapists	Individual; online	Website	8 weeks	Yes	NR	NR
Grønning et al. 2012, 2014; Grønning, Midttun and Steinsbekk 2016; Grønning, Lim and Bratås 2019	NR	NR	Unspecified handouts	Nurses	Combination; face-to-face	Hospital outpatient clinic	8 weeks	NR	NR	NR
Hammond et al. 2017; Prior et al. 2015, 2017	WORK-IA	NR	NR	OT	Individual; combination	OT dept, participant's home, or their workplace	4 weeks	Yes	NR	Yes
Hewlett et al. 2011; Dures et al. 2012	NR	SCT	Versus Arthritis fatigue booklet	Clinical psychologist and specialist OTs	Group; face-to-face	Multi-centre; hospital rheumatology clinics	6 weeks + booster session at week 14	NR	Yes	Yes
Hewlett et al. 2019	RAFT	SCT	Arthritis Research UK Leaflets	Rheumatology nurses and/or OTs (Band 6 or 7)	Group; face-to-face	Multi-centre; hospital rheumatology clinics	6 weeks + booster session at week 14	Yes	NR	NR
Kaya et al. 2016	NR	NR	Educational booklet including information about AS	Expert patients	Group; face-to-face	Hospital outpatient clinic	4 weeks	NR	NR	NR
Kjeken et al. 2013	NR	NR	NR	Physician, nurse, physio, and OT	Individual; face-to-face	In-patient rehabilitation	Length of stay in rehab	NR	NR	NR
Kristiansen and Antoft 2016	NR	NR	NR	Unspecified HCPs and expert patients	Group; face-to-face	NR	10 weeks	NR	NR	NR

Citation	Brief Name	Theory	Materials	Facilitator	Mode of delivery	Setting	Duration	Tailoring	Modifications	Fidelity
Lumley et al. 2014	NR	NR	Blank journal	Research assistant and advanced doctoral students or post-doctoral fellows in clinical psychology, and nurses	Individual; combination	Laboratory, clinic, and home	10 weeks	NR	NR	Yes
Manning et al. 2013; Bearne et al. 2017	EXTRA	SCT	Programme handbook containing informational related to exercises, intervention content, and an exercise diary	Physio	Group; face-to-face	NR	12 weeks	NR	NR	Yes
McBain et al. 2015	NR	NR	NR	Rheumatologist and health psychologist	Group; face-to-face	NR	One-off training session	NR	NR	NR
Mollard and Michaud 2018	LiveWith Arthritis	NR	NR	N/A	Online	Mobile app and website	6 months	Yes	NR	NR
Molto et al. 2021	COMEDSPA	NR	NR	Nurses	Individual; face-to-face	Multi-centre; Secondary and tertiary rheumatology clinics	One-off consultation	Yes	NR	NR
Ndosi et al. 2016	NR	NR	NR	Rheumatology nurse	Group; face-to-face	Rheumatology clinic	One-off consultation	Yes	NR	NR
Niedermann et al. 2011, 2012	NR	SCT	NR	OT	Individual; face-to-face	Multi-centre; rheumatology clinics	3 weeks	Yes	NR	Yes
Nilssen et al. 2017	NR	NR	NR	Physiotherapists and nurses	Group; face-to-face	Treatment centre	2.5 weeks	Yes	NR	NR
Pot-Vaucel et al. 2016	NR	NR	NR	Combination of 2: rheumatologist, PTE instructor, rheumatologist, OT, physio, social worker, dietician, and psychologist	Combination; face-to-face	NR	6 months	Yes	NR	NR

Citation	Brief Name	Theory	Materials	Facilitator	Mode of delivery	Setting	Duration	Tailoring	Modifications	Fidelity
Rodríguez-Lozano et al. 2013	NR	NR	Yes	Rheumatologist, rheumatology nurse, psychologist, and physiotherapist	Group; face-to-face	Outpatient rheumatology clinic	8 weeks	NR	NR	NR
Salmon et al. 2019	NR	SDT	Handouts	Physiotherapist	Group; Face-to-face	Hospital	12 weeks	Yes	Yes	Yes
Sharpe and Schreiber 2012	NR	NR	NR	Psychologists	Individual; face-to-face	Hospital outpatient clinic	8 weeks	NR	NR	Yes
Shigaki et al. 2013	RAHelp	SLT	NR	CBT-trained counsellor	Individual; combination	Online	10 weeks	Yes	NR	NR
Unk and Bransington 2014	NR	NR	CD copy of the SMI	Nurse	Individual; face-to-face	Outpatient rheumatology clinic	One-off session	NR	NR	NR
Zangi et al. 2011, 2012	VTP	NR	NR	Physiotherapist, OT, nurses and social workers	Group; face-to-face	Rheumatology clinic	15 weeks	NR	NR	NR
Zuidema et al. 2019a, 2019b	NR	TPB	NR	N/A	Individual; online	Website	12 months	NR	NR	NR

KEY: AS= ankylosing spondylitis; D/C= discharge; IMCHB= Interaction Model of Client Health Behaviour; MDT= multi-disciplinary team; N/A= not applicable; NR= not reported; OT= occupational therapist; SCT= Social Cognitive Theory; SDT= Social Determination Theory; SLT= Social Learning Theory; TPB= Theory of Planned Behaviour; UK= United Kingdom

Appendix 2.8 MMSR HRQoL Meta-Analysis Results

HRQOL- Overall

4 studies and 21 data points

Meta-analysis

Mean controlled difference= 0.24 [95%CrI: -7.46 to 8.46]

Between study standard deviation= 6.04 [75%CrI: 1.97 to 11.70]

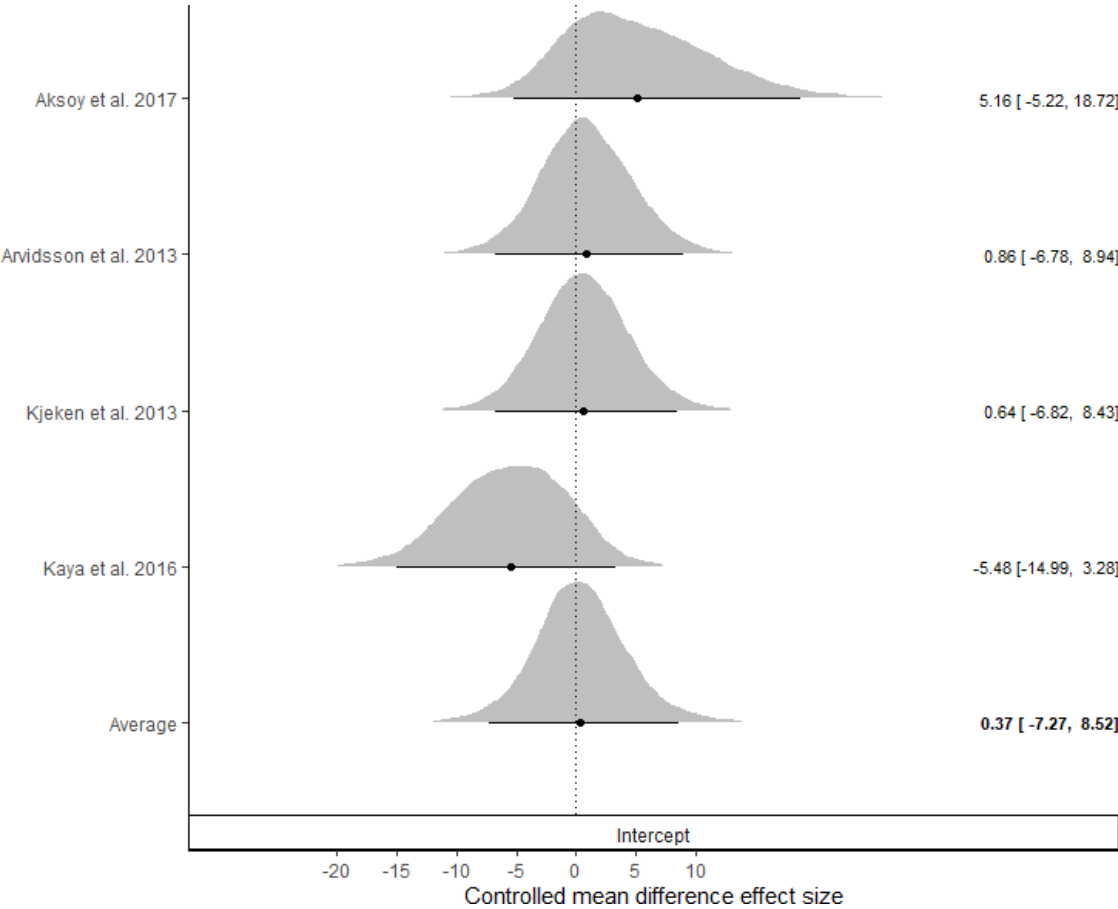


Figure 2.5 Forest Plot Comparison: IA SMI versus comparator, outcome HRQoL (Overall)

HRQOL-SOCIAL FUNCTIONING

4 studies and 7 data points

Meta-analysis

Mean controlled difference= 4.19 [95%CrI: -4.43 to 12.82]

Between study standard deviation= 9.54 [75%CrI: 5.40 to 15.09]

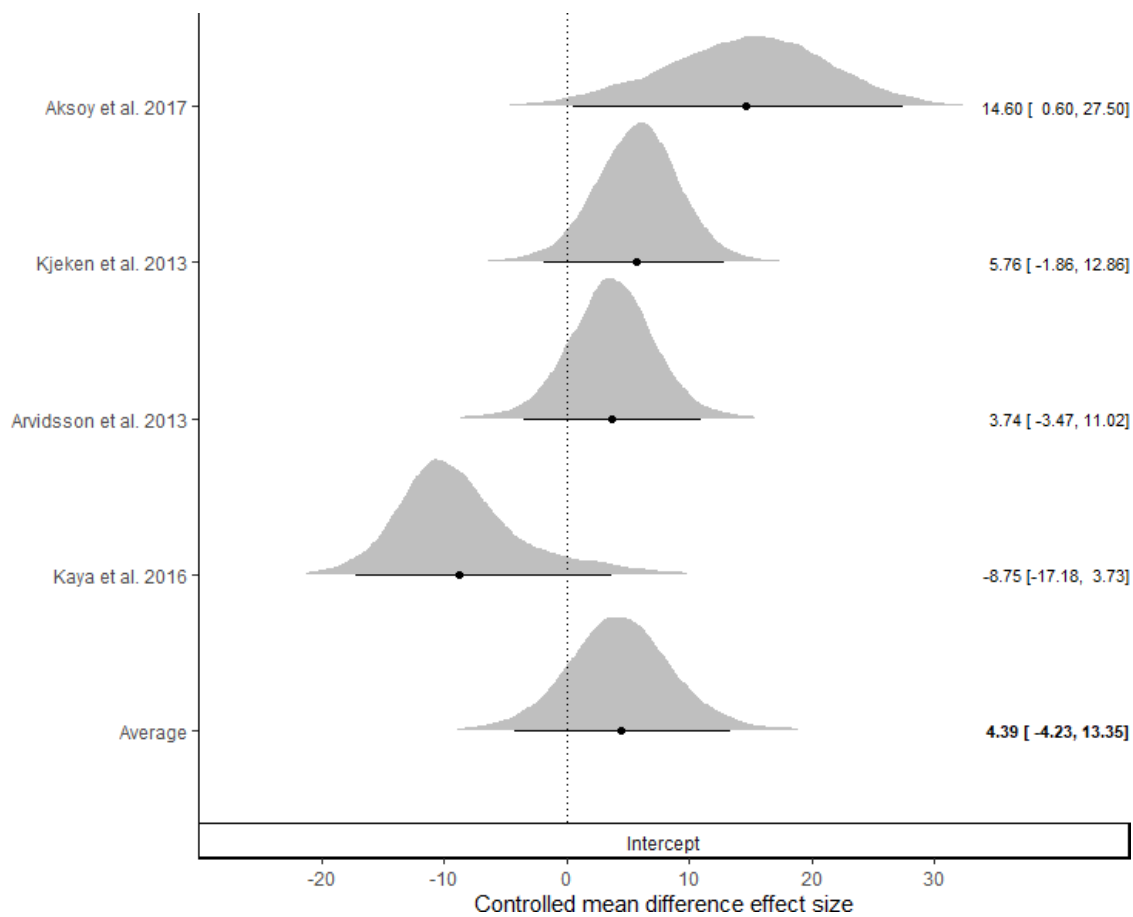


Figure 2.6 Forest Plot Comparison: IA SMI versus comparator, outcome HRQoL-Social Functioning Subscale

HRQOL-ROLE PHYSICAL

4 studies and 7 data points

Meta-analysis

Mean controlled difference= -5.25 [95%CrI: -26.61 to 15.80]

Between study standard deviation= 17.25 [75%CrI: 8.11 to 30.72]

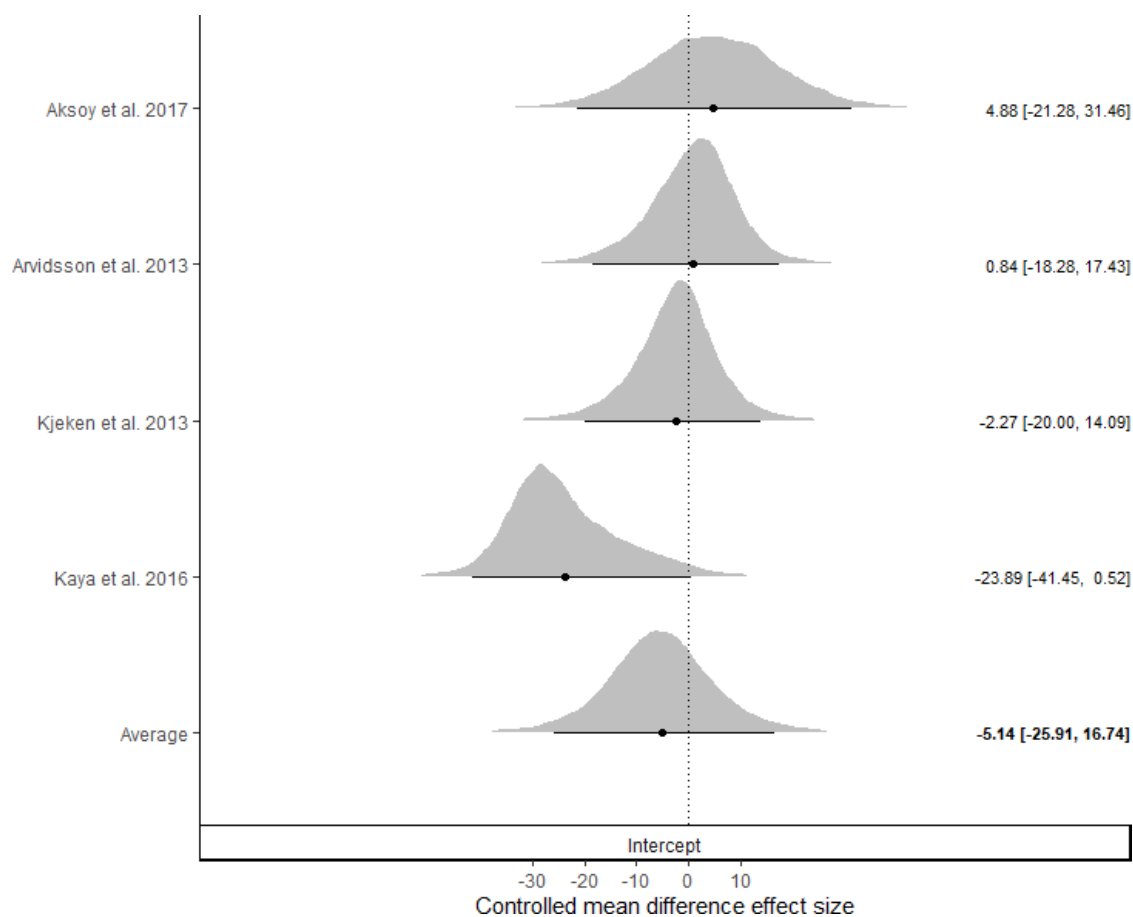


Figure 2.7 Forest Plot Comparison: IA SMI versus comparator, outcome HRQoL-Role Physical Subscale

HRQOL- MENTAL HEALTH

4 studies and 7 data points

Meta-analysis

Mean controlled difference= 2.04 [95%CrI: -4.01 to 8.22]

Between study standard deviation= 5.05 [75%CrI: 2.20 to 8.94]

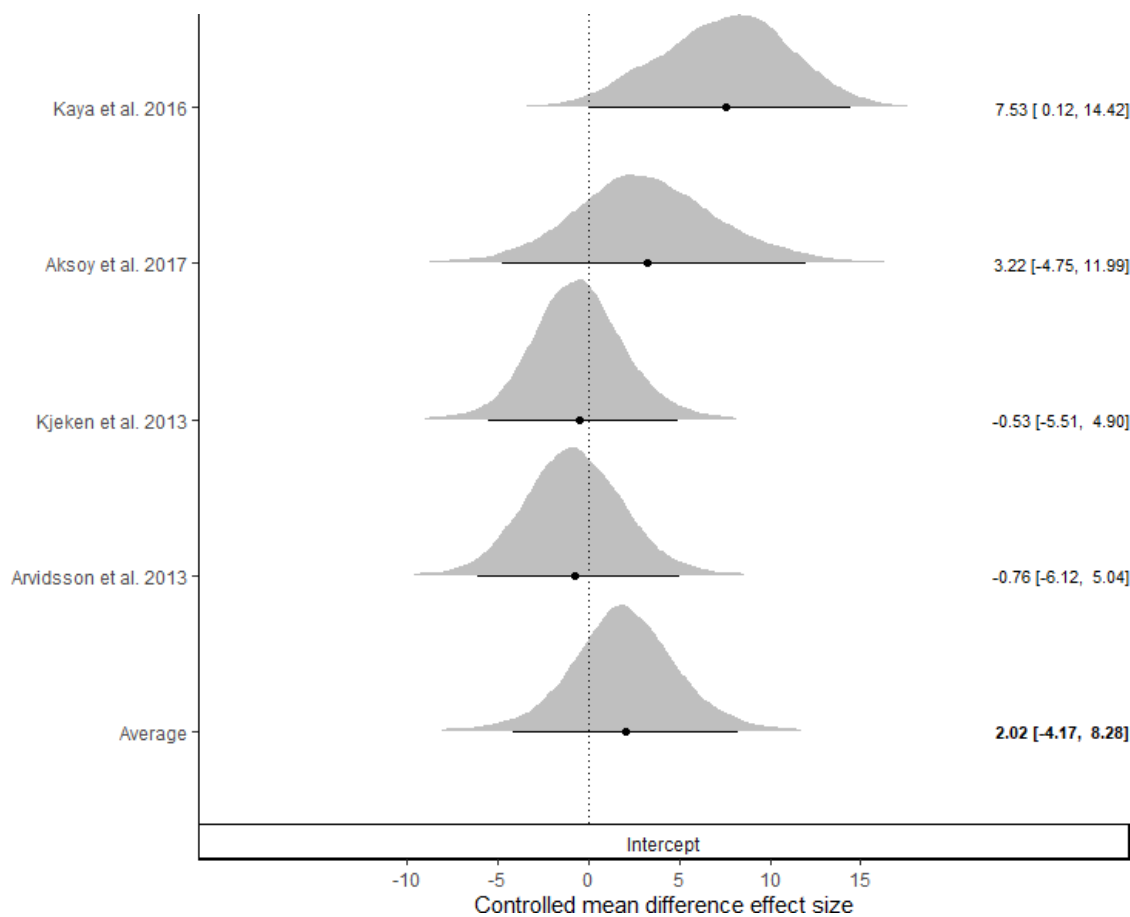


Figure 2.8 Forest Plot Comparison: IA SMI versus comparator, outcome HRQoL-Mental Health Subscale

Appendix 3.1 Creating a MS Teams Account Guide

A GUIDE TO ACCESSING MICROSOFT (MS) TEAMS

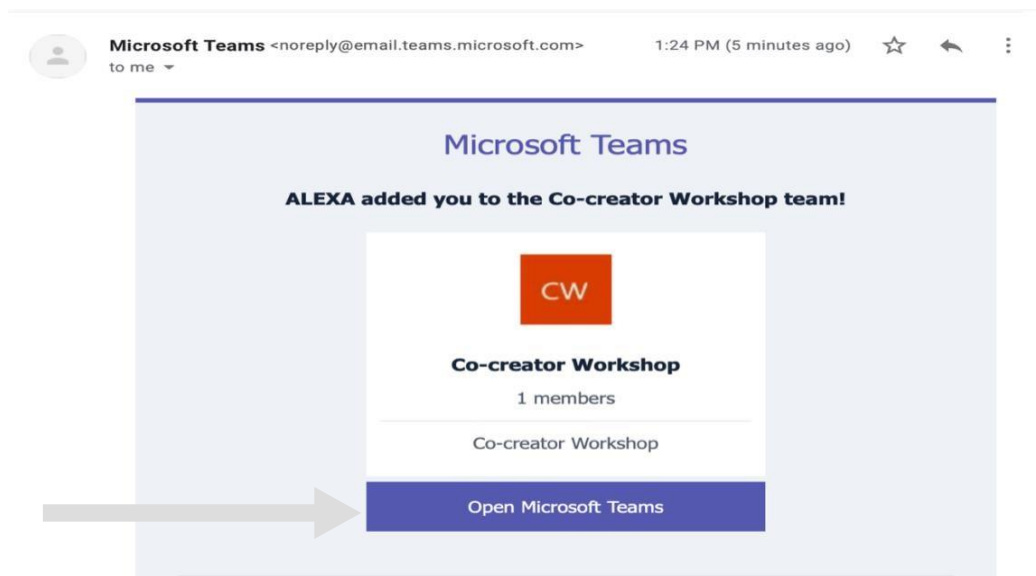


There are two main ways of accessing MS Teams –a desktop/laptop, or on an iPad/mobile app. The following steps explain how to set up an account and how to access Teams by either of these means.

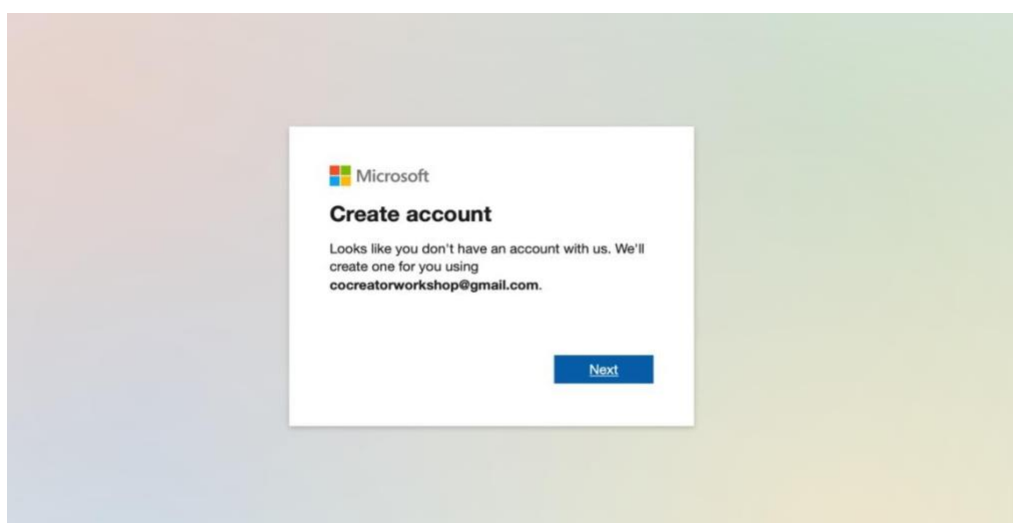
- If you do not yet have an **MS Teams Account**, please begin on **page 2**. If you are accessing **MS Teams on a Mac**, please begin on **page 6**.
- If you are accessing **MS Teams on a Windows** computer, please begin on **page 9**.
- If you are accessing **MS Teams on an iPhone/iPad**, please begin on **page 12**. If you are accessing **MS Teams on an Android**, please begin on **page 16**.

How to Create an MS Teams Account

1. You will receive an email from me with an invite onto our private MS Teams page. Click **Open Microsoft Teams**.



2. If you already have a Microsoft Sign In, you will need to click **Sign In** and then enter your password. Once you have successfully signed in, you can skip to step 8 on page 5 of this document. If you **do not** yet have a Microsoft Sign In, Teams will ask you to create an account. Click **Next**.

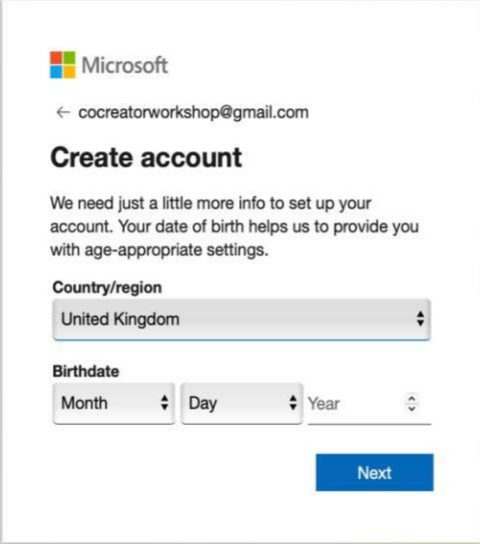


3. Create a password and then click **Next**.



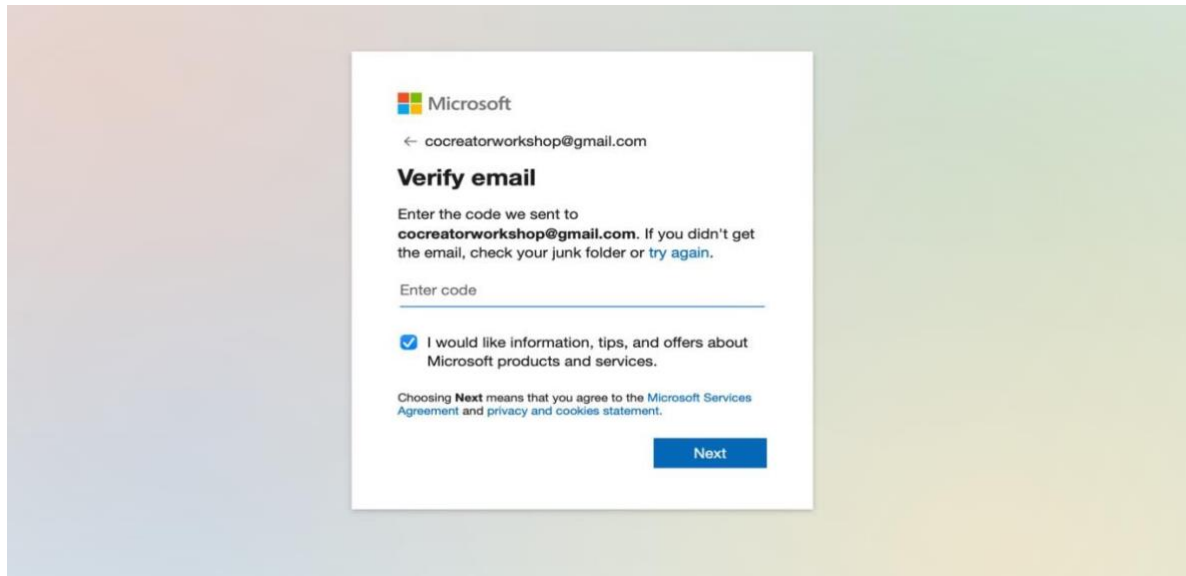
The screenshot shows the Microsoft account creation interface. At the top is the Microsoft logo and the email address 'cocreatorworkshop@gmail.com'. The main heading is 'Create a password'. Below it, a message states: 'Enter the password you would like to use with your account.' There is a text input field labeled 'Create password'. Below the field is a checkbox labeled 'Show password'. A blue 'Next' button is located at the bottom right of the form.

4. Enter **UNITED KINGDOM** under the **Country/region** section and then your **Birthdate**. Click **Next**.

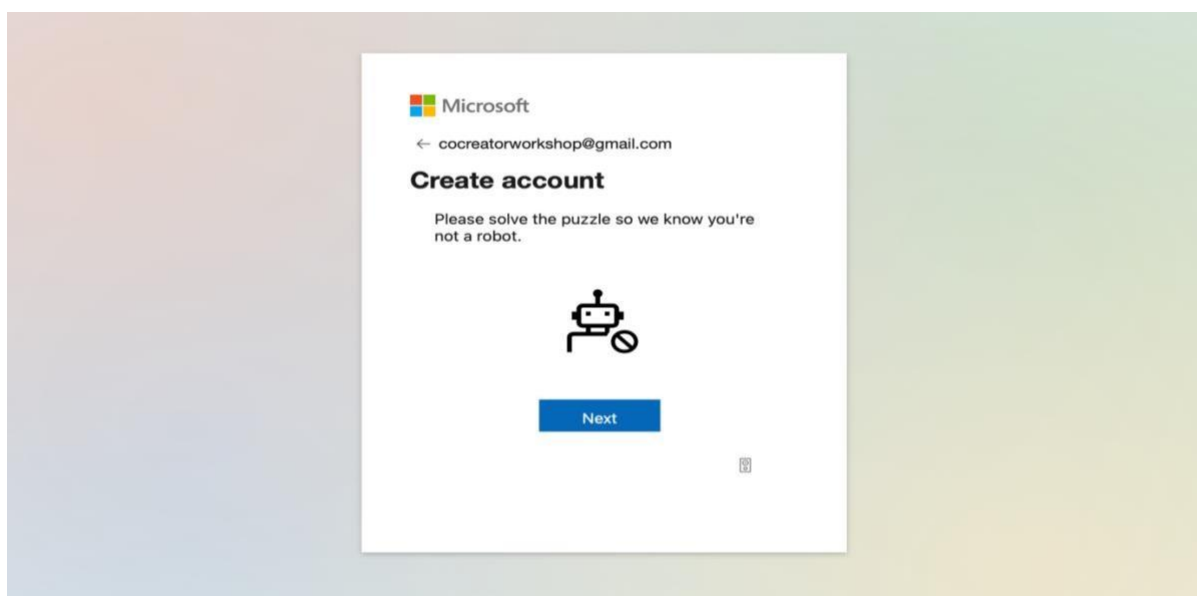


The screenshot shows the Microsoft account creation interface. At the top is the Microsoft logo and the email address 'cocreatorworkshop@gmail.com'. The main heading is 'Create account'. Below it, a message states: 'We need just a little more info to set up your account. Your date of birth helps us to provide you with age-appropriate settings.' There are two sections: 'Country/region' with a dropdown menu showing 'United Kingdom', and 'Birthdate' with three dropdown menus for 'Month', 'Day', and 'Year'. A blue 'Next' button is located at the bottom right of the form.

5. You will then be asked to verify your email. Return to the email inbox which you have received your MS Teams invite in. You should have received another email from Microsoft with a 4-digit code. Return to the MS Teams set-up page and **enter your 4-digit code**. Click **Next**.

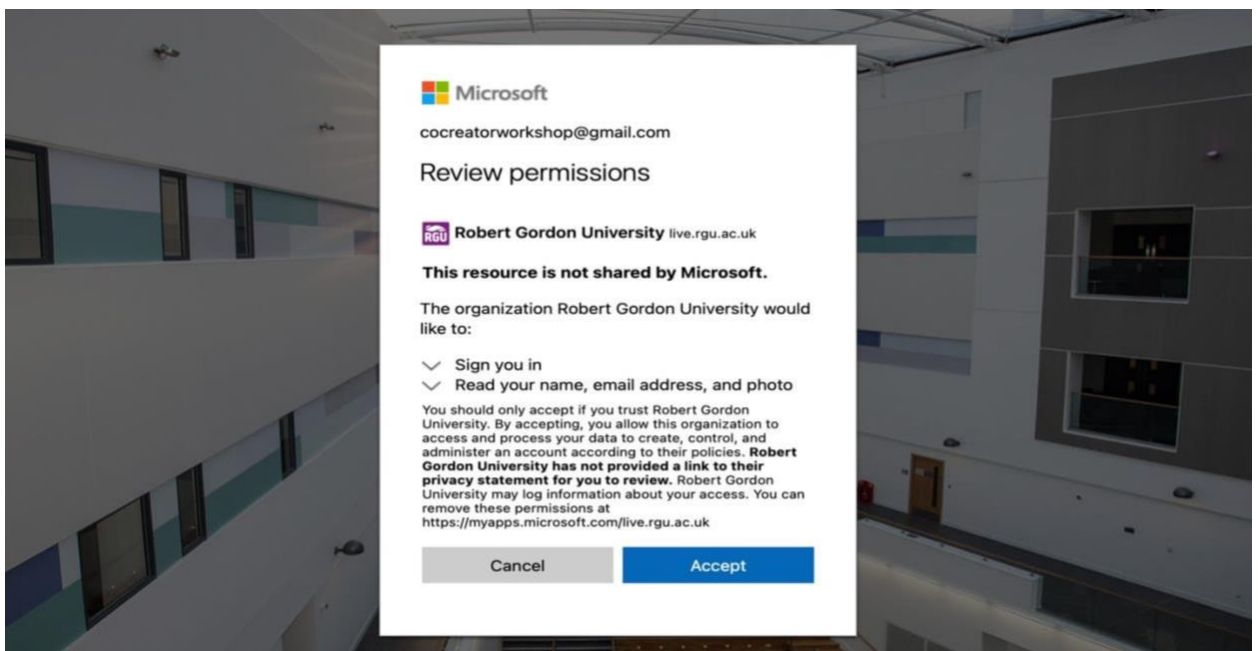


6. You may then need to complete a series of security puzzles. If the following screen does not show up on your screen, please skip to Step 6. If the following screen does show up on your screen, please complete the required puzzles then click **Next**.



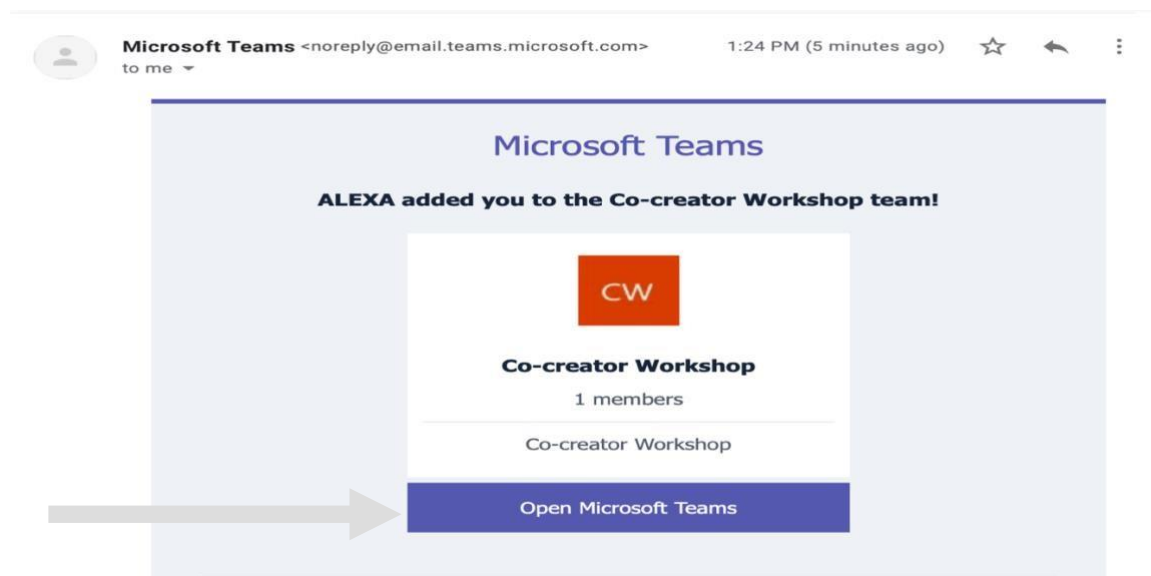
7. You can choose whether you would like to stay signed into your MS Teams account. Either tick or untick the **Do not show this again**, then choose **Yes** or **No**.

8. Following a successful log in, you will have reached this page. Please review the permissions. If you are happy to proceed, click **Accept**. You can access MS Teams on your desktop or mobile phone. The rest of this document explains how to access Teams by either of these means.



How Access MS Teams on a Mac

1. You will receive an email with an invite onto our private MS Teams page. Click **Open Microsoft Teams**.

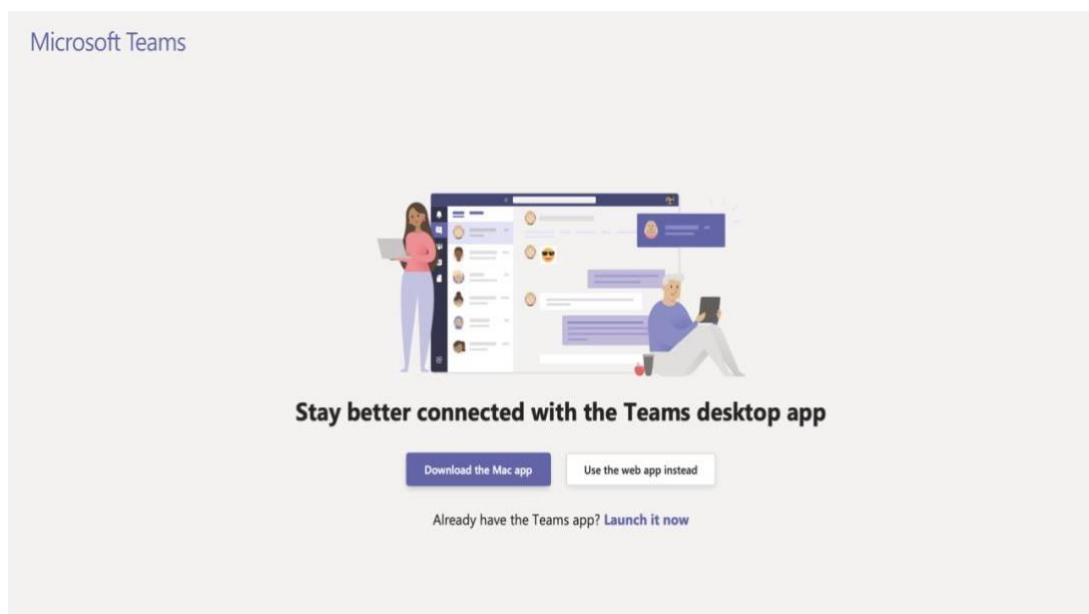


2. You will then be directed to the page below (see pg. 7 for picture).
Safari does not support the use of the web app. You will either need to install the desktop app or use the Mac-version of Google Chrome or Firefox (these need to be installed onto your computer as desktop apps) to use MS Teams on the web browser. I find, however, that the MS Teams desktop app offers slightly more functionality.

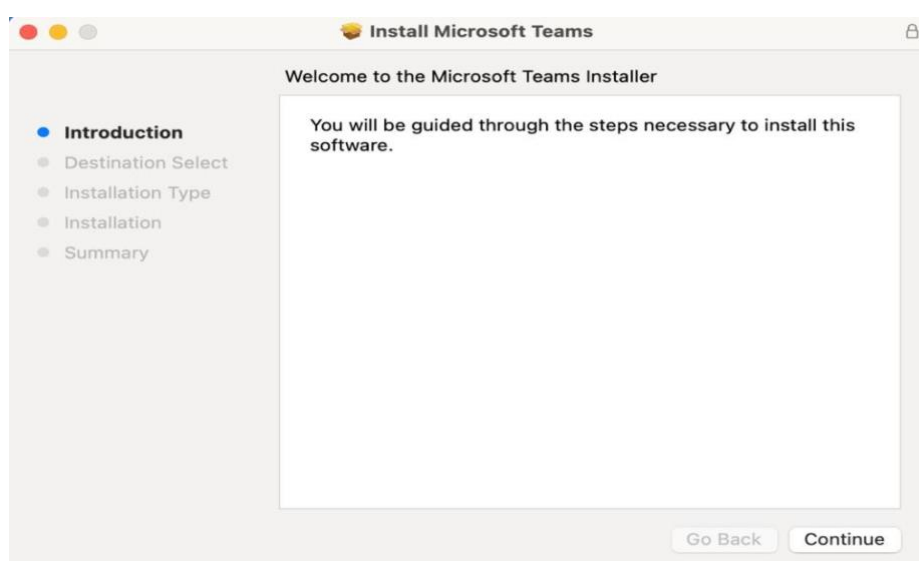
- a. If you are interested in downloading the app, click **Download the Mac App** and proceed to step 3 on page 7 of this document.
- b. If you are interested in using the web browser, click **Use the web app instead**. If you already have a Microsoft Sign In, you will need to click **Sign In** and then enter your password. If you **do not** yet have a Microsoft Sign In, please begin on pg. 2 of this document. You will select **Robert Gordon University (Guest)** from the drop-down menu, then click **Continue**. You should then be able access the full Teams application and our private Teams page on your desktop. Our

Team's page is called 'Co- creator Workshop'. View step 5 for a picture of what the page will look like.

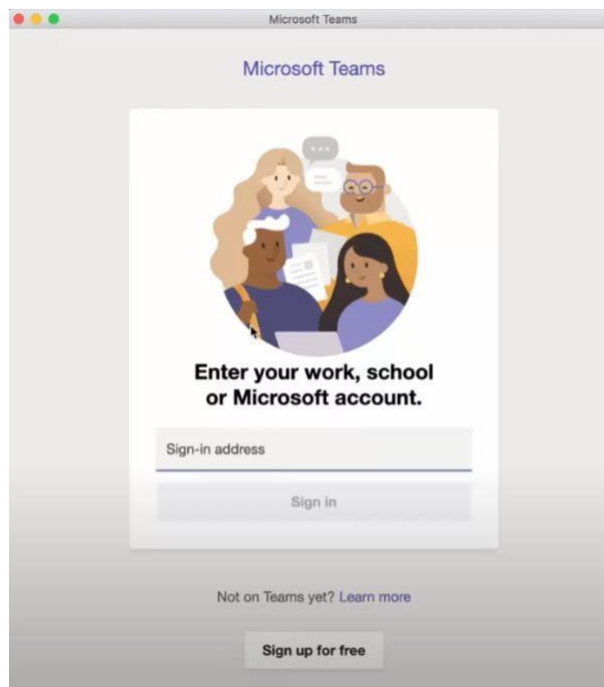
- c. **If you already have the Teams app**, click **Launch it now**. Sign into your account, if applicable. You should then be able access the full Teams application and our private Teams page on your desktop. Our Team's page is 'Co-creator Workshop'. View step 5 for a picture of what the page will look like.



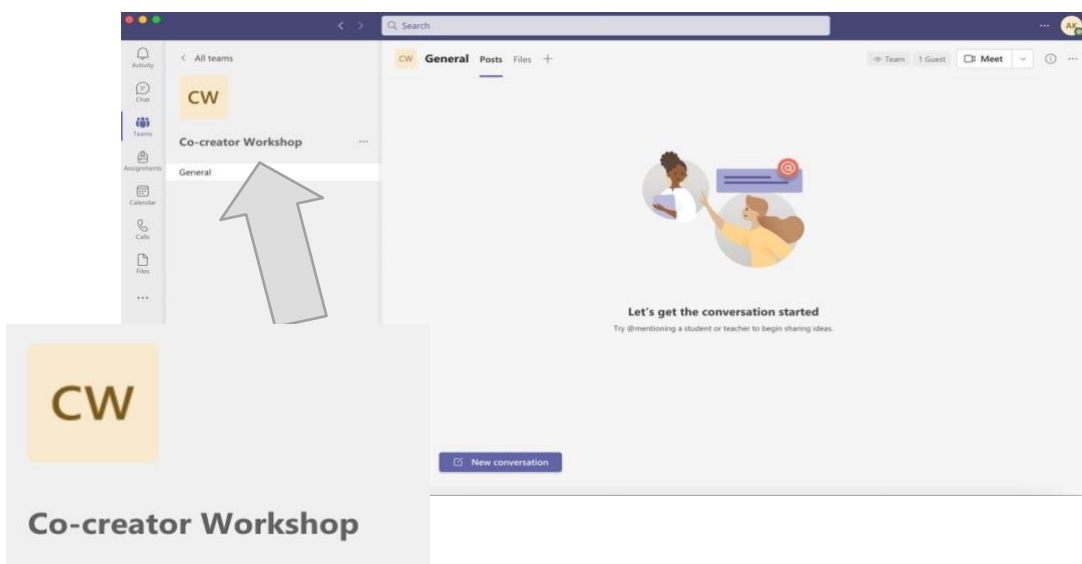
3. Click the downloaded file to launch it – this should bring up the Microsoft Teams Installer. Click **Continue**, then click **Install**.



4. Once the application has installed, this should automatically bring up the desktop app. Sign in using your **email and password**.

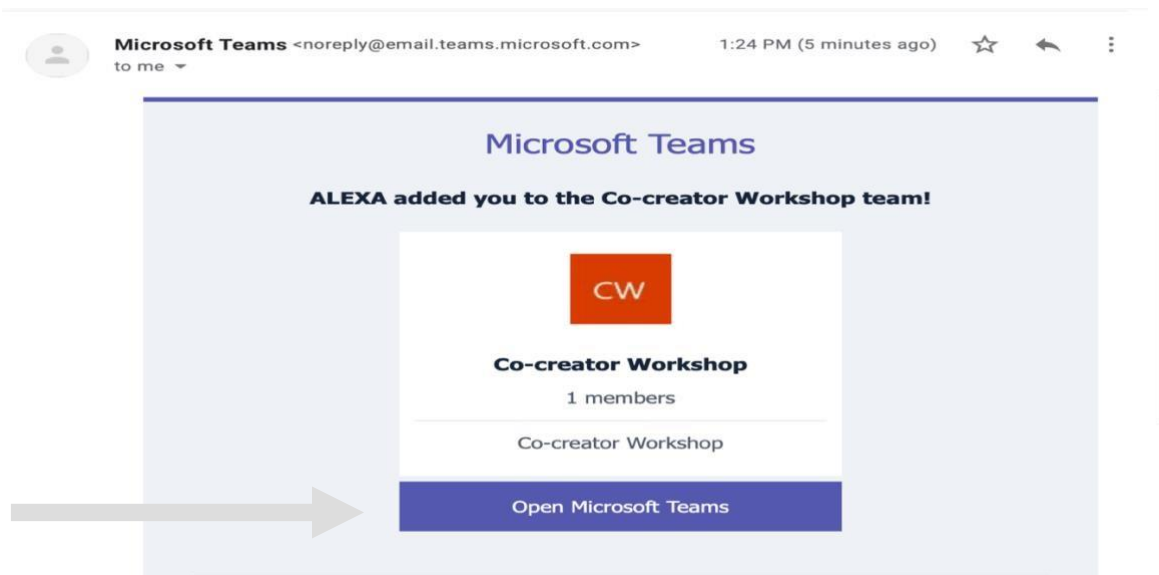


5. You should then be able access the full Teams application and our private Teams page on your desktop. Our team's page is 'Co-creator Workshop'.



How Access MS Teams on a Windows Computer

1. You will receive an email from with an invite onto our private MS Teams page. Click **Open Microsoft Teams**.

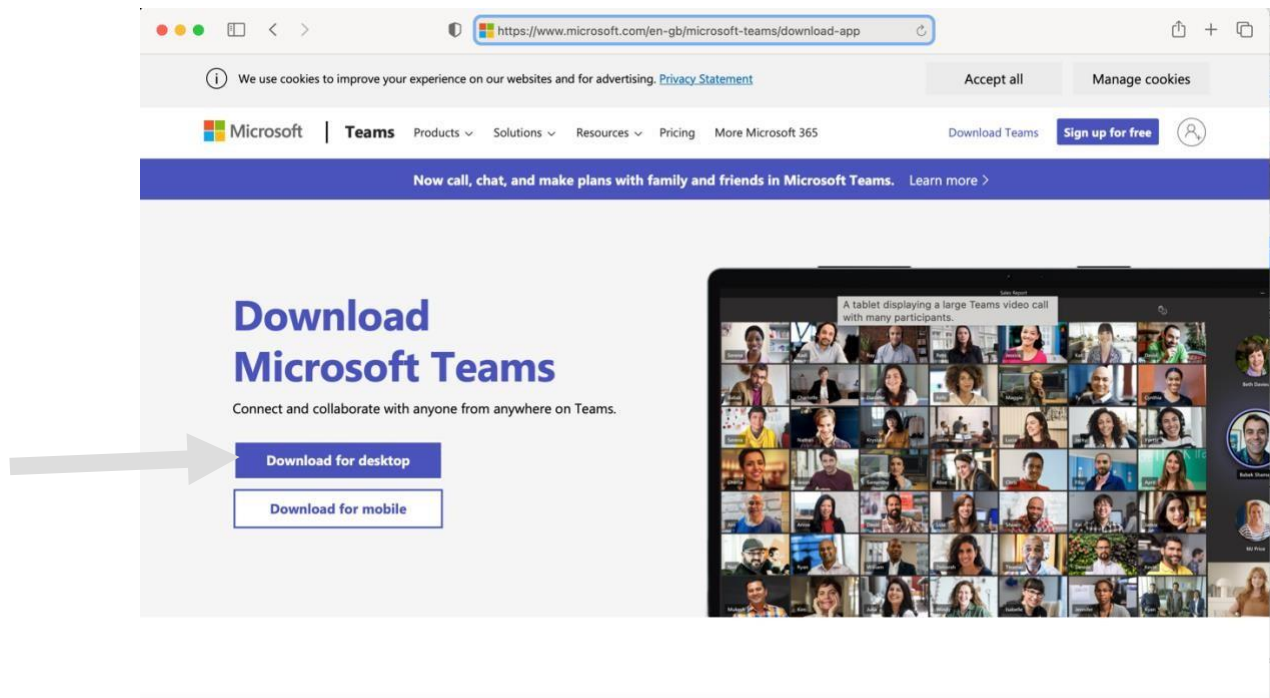


2. You can use MS Teams on your favourite web browser (e.g., Google Chrome, Firefox, etc.) or download the desktop application—which I think offers slightly more functionality.

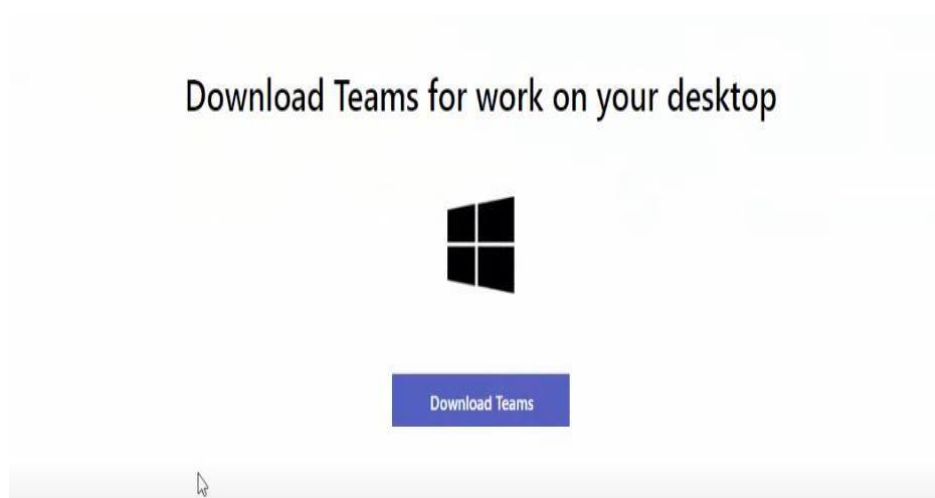
- a. If you are interested in downloading the app, proceed to step 3 on page 10 of this document.
- b. If you are interested in using the web browser, you will need to click **Sign In** and then enter your password. If you **do not** yet have a Microsoft Sign In, please begin on pg. 2 of this document. It may ask you to select **Robert Gordon University (Guest)** from the drop-down menu, then click **Continue**. You should then be able access the full Teams application and our private Teams page on your desktop. Our team's page is 'Co-creator Workshop'. View step 6 for a picture of what the page will look like.

c. If you already have the Teams app, click **Launch it now**. Sign into your account, if applicable. You should then be able access the full Teams application and our private Teams page on your desktop. Our team's page is 'Co-creator Workshop'. View step 6 for a picture of what the page will look like.

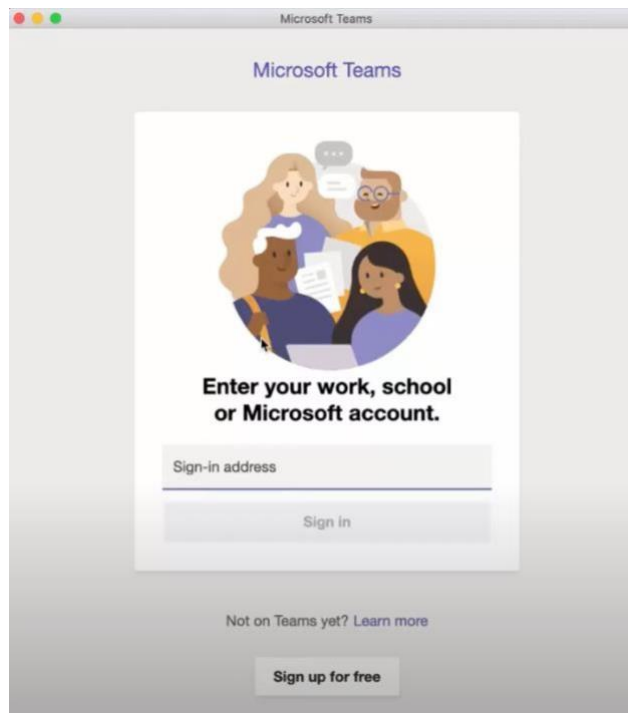
3. Go to <https://teams.microsoft.com/downloads> and click **Download for desktop**.



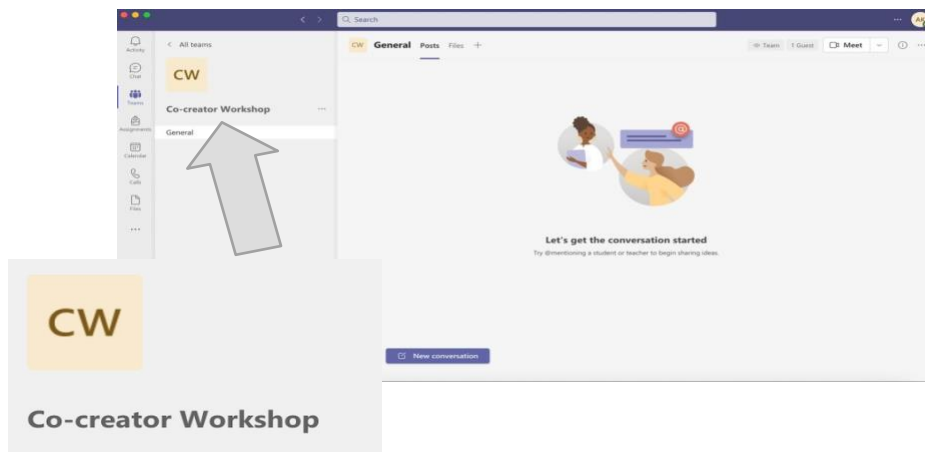
4. Then click **Download Teams**.



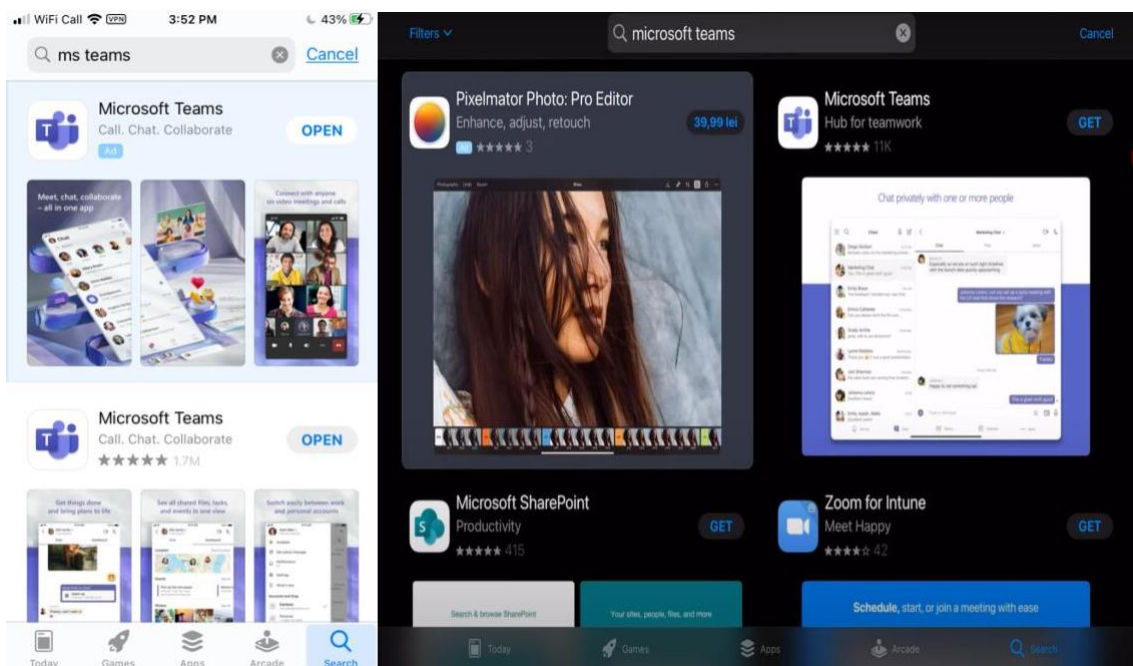
5. Click the downloaded file to launch it – this should bring up the desktop app. Sign in using your **email and password**.



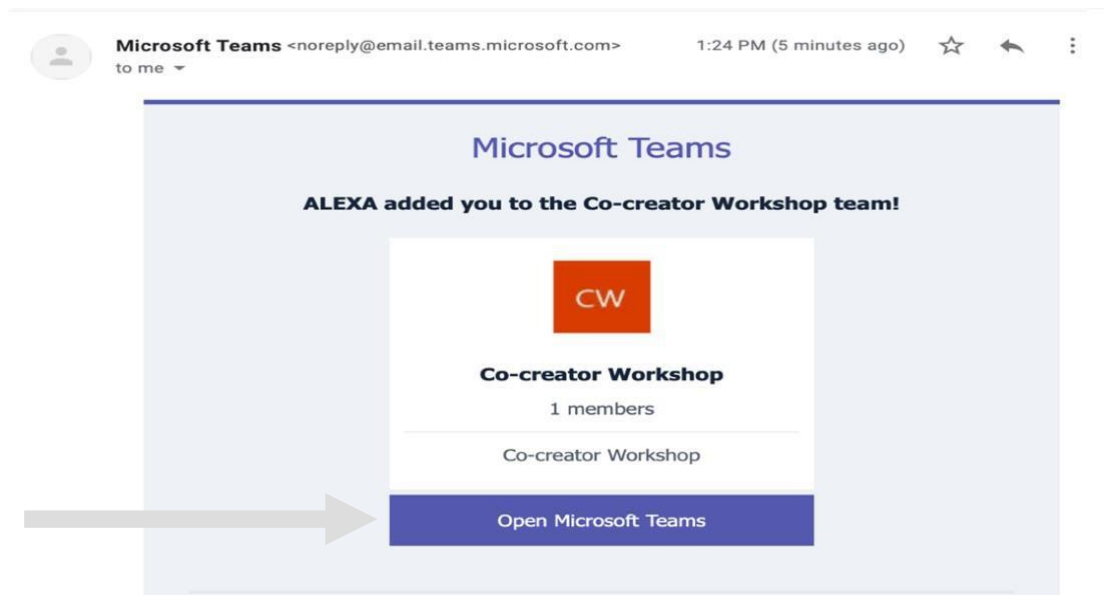
6. You should then be able access the full Teams application and our private Teams page on your desktop. Our team's page is 'Co-creator Workshop'.



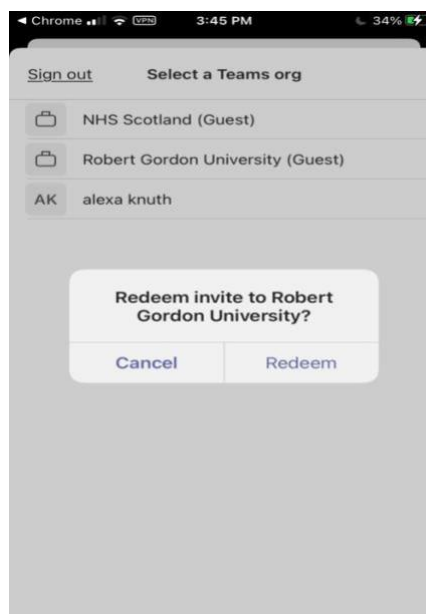
7. You will need to go the App Store and type in 'Microsoft Teams' in the search bar. Click the '**Get**' button and sign in with your fingerprint, face ID or Apple ID username/password. Once the application has finished downloading, click **OPEN** or flip through your home screens to find the MS Teams application icon.



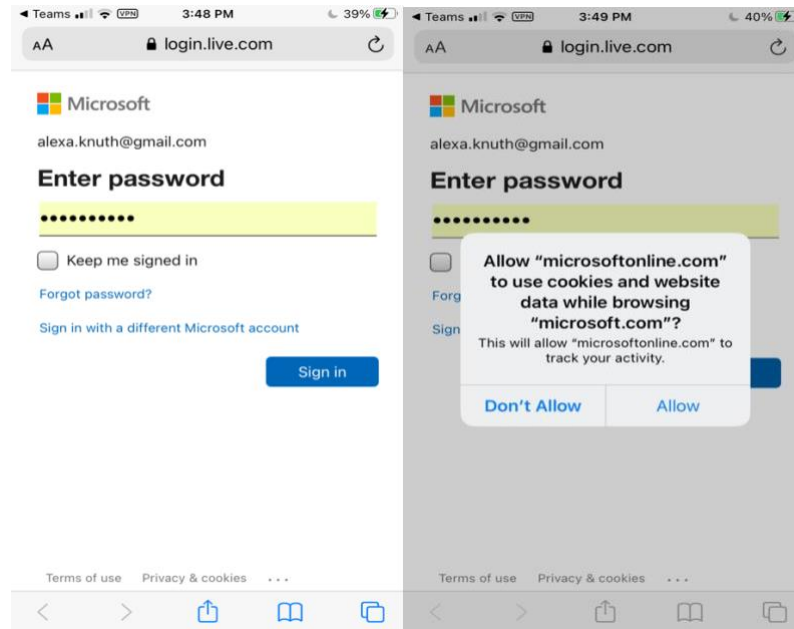
8. Go to your email inbox. You will receive an email with an invite onto our private MS Teams page. Click **Open Microsoft Teams**.



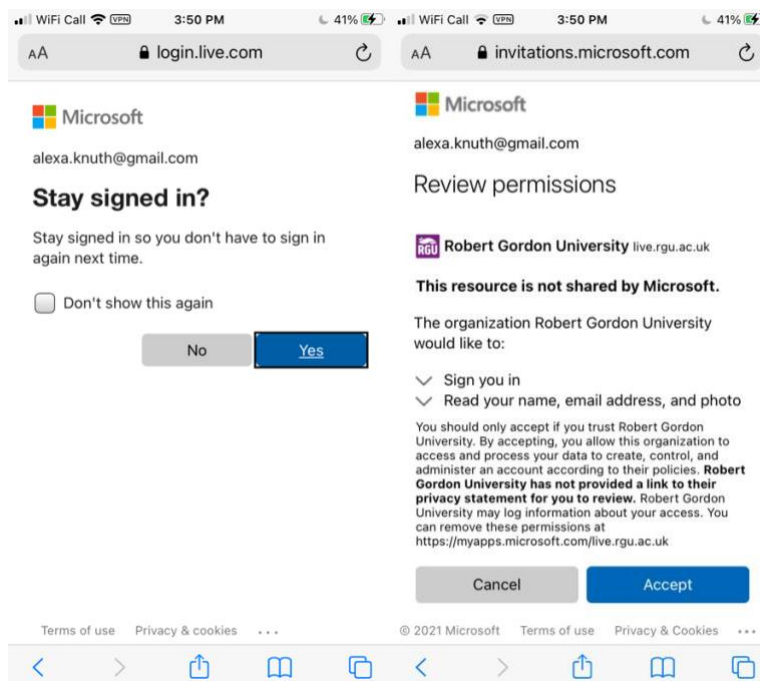
9. Sign in using your MS Teams account. If you **do not** yet have a Microsoft Sign In, please begin on pg. 2 of this document. You will select **Robert Gordon University (Guest)** from the menu. A message will appear asking you to redeem invite to Robert Gordon University, click '**Redeem**'.



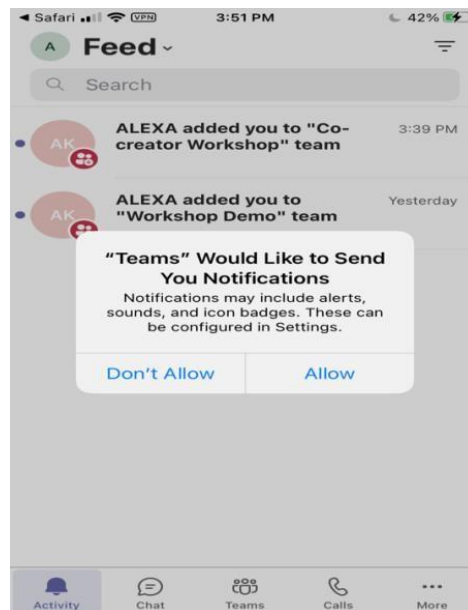
10. Your phone/iPad may open your web browser and ask you to re-enter your MS Teams password. Re-enter your password and click **Sign in**. If you receive this cookie message, you can click **Don't Allow**. If this does not happen, please move onto the next step.



11. Please either tick or untick the **Do not show this again** box and then choose **Yes** or **No** on the stay signed in page. Review the permissions. If you are happy to proceed, please click **Accept**.



- 12.** Teams will then ask you if you would like to receive Notifications. Click **Allow** or **Don't Allow**, depending on what your preference is. I find that it is helpful to allow for notifications to easily know if someone is trying to reach you.



- 13.** If using an iPad, teams will ask if it can use your microphone and video. Click **Ok (this is essential)**. It may also take you through a series of screens of the different features you can use on MS Teams (i.e., collaborate with others, chat one-on-one/group chats, and make 1:1/group calls). Click **Next** through each of these screens.
- 14.** You should now be able to access our private MS Teams page called '**Co-creator Workshop**' (see next page for picture).



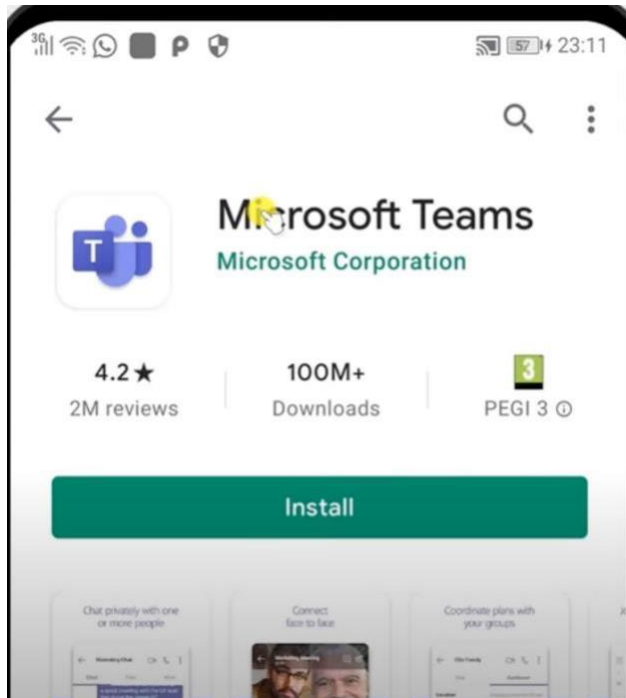
No one has sent any messages yet

Try @mentioning the people you want
to participate in this channel.

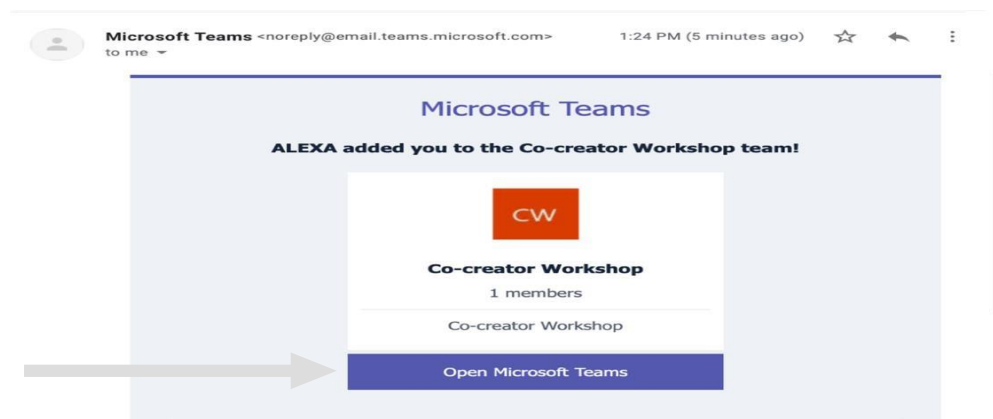
 New post

How Access MS Teams on an Android

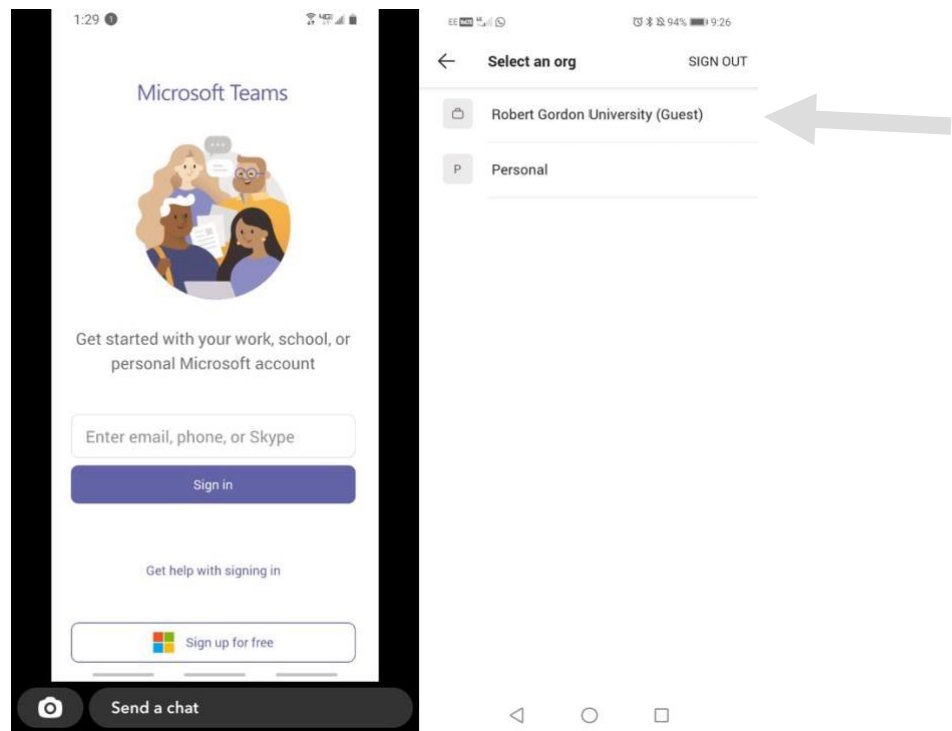
1. You will need to go the Play Store and type in 'Microsoft Teams' in the search bar. Click **Install** button. Once the application has finished downloading, click **OPEN**.



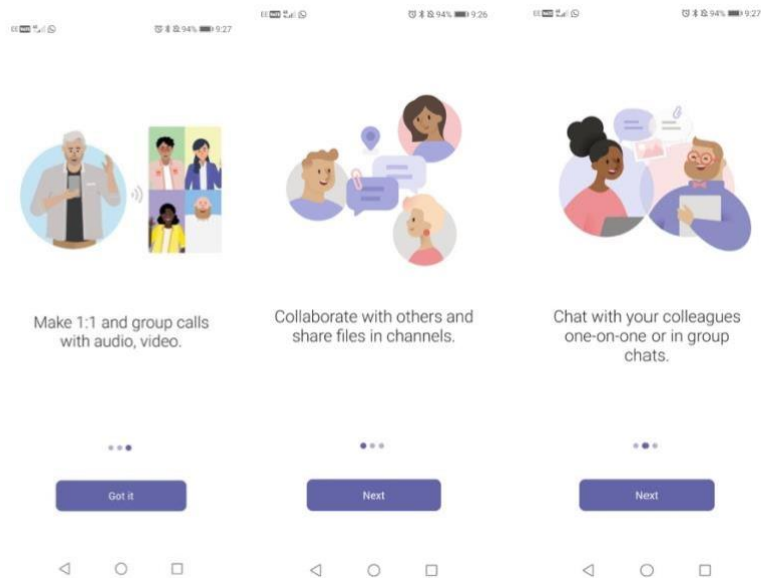
2. Go to your email inbox. You will receive an email from with an invite onto our private MS Teams page (see picture below). Click **Open Microsoft Teams**.



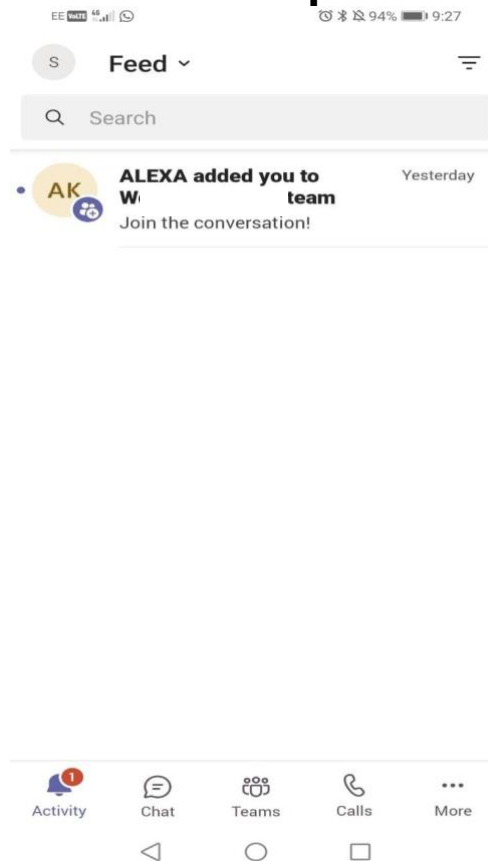
3. Sign in using your MS Teams account. Sign in using your MS Teams account. If you **do not** yet have a Microsoft Sign In, please begin on pg. 2 of this document. You will then select **Robert Gordon University (Guest)** from the menu.



4. Once you have successfully logged in, it will take you through a series of screens of the different features you can use on MS Teams (i.e., collaborate with others, chat one-on-one/group chats, and make 1:1/group calls). Click **Next** through each of these screens.



5. You should now be able to access our private MS Teams page called '**Co-creator Workshop**' under the Activity tab.



Appendix 3.2 Study Letter of Invitation



LETTER OF INVITATION – CO-CREATOR

IRAS ID: 278552

Reference number: SHS/20/03

[DATE]

Study title: Co-Production of a Virtual IA SMP v2

Dear [NAME],

I am writing to you because I would like to invite you to participate in the development of a virtual self-management programme for patients living with inflammatory arthritis. Please find enclosed a 'Co-Creator Information Sheet' relating to the study for more details. As part of this study, we would like you to help co-develop this programme alongside our research team and participate in a focus group to interview you about your experience in co-producing the programme. The entire study will be conducted online and will not require you to travel. We consider your experience with an inflammatory arthritic condition as a valuable and important resource to developing this new service. The information sheet provides further details and makes it clear that your involvement in this study is entirely voluntary and your responses will be confidential. If you feel that you would be interested in taking part of the study, please get in touch on the email provided below.

Kind Regards,

Alexa Knuth

Doctorate of Physiotherapy Student

School of Health Sciences, Robert Gordon University, Garthdee Road, Aberdeen
AB10 7QG

Email: a.knuth@rgu.ac.uk

Appendix 3.3 Participant Information Sheet



Co-Creator Information Sheet IRAS ID: 278552

[DATE]

Reference number: SHS/20/03

Study title: Co-Production of a Virtual IA SMP v2

Introduction:

We'd like to invite you to take part in a research study. Joining the study is entirely up to you before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team members will go through this information sheet with you, to help you decide whether or not you would like to take part and answer any questions you may have. Please read the following information carefully and, if you wish, discuss it with others, such as your family. You can ask us if there is anything that is not clear or if you would like more information. Take time to decide whether you wish to take part. Thank you for reading this.

We are asking patients who are living with rheumatoid arthritis or a spondyloarthropathy to co-create a virtual self-management programme for other individuals living with these conditions alongside our research team. This study consists of two phases. The first phase will be the co-production of the self-management programme that will subsequently be tested for its feasibility and acceptability in the second phase. We are asking you to take part in the first phase and become a co-creator of the programme. As a co-creator, you help to provide our research team with knowledge of what it means to live with inflammatory arthritis and your healthcare needs, as well as any tips or tricks you have found to be helpful in managing your condition day-to-day.

Why have I been chosen?

We are looking to involve people that are interested in contributing to the research field and becoming a representative for other patients with your

condition. As a co-creator we are requesting that you are able to attend ALL of the five online remote workshops. Workshop dates are TBC.

Additionally, people have been invited to join this study because:

- You are aged 18 years or older
- Have a confirmed diagnosis of either Rheumatoid Arthritis or a Spondyloarthropathy

Do I have to take part?

No. It is up to you to decide whether to take part. If you do decide to take part, please contact Alexa Knuth who can be contacted using the details below. If you decide to take part, you are still free to withdraw at any time and without giving a reason. Deciding to withdraw at any time, or not to take part, will not affect the standard of care you receive. If you notify us that you wish to withdraw from the study, we will not contact you again. However, we will use the data collected prior to your withdrawal. All answers you give will be anonymous and confidential and you will not be identified in any way by your responses.

What is the purpose of the study?

Inflammatory arthritic conditions frequently cause joint pain, muscle weakness and difficulty doing everyday activities. Self-management programmes have been developed by researchers and healthcare professionals as a method for delivering patient education and teaching self-management strategies. However, a self-management programme has yet to be created for individuals living with inflammatory arthritis. Therefore, this study wants to develop a self-management programme alongside patients living with inflammatory arthritis and physiotherapists. Sharing your experience as a person living with inflammatory arthritis helps to provide valuable information to our research team. Together we will be able to create a programme that is reflective of the daily struggles of inflammatory arthritis and create strategies that help others to live better lives. Following the programmes development, it will be assessed for its feasibility and acceptability for patients.

What will happen to me if I decide to take part?

If you do decide to take part, a member of our research team will phone you to go over what is involved, answer any questions you may have. All the workshops will take place remotely via Microsoft Teams. Before the workshops commence,

we will ask you to provide verbal consent to take part that we will audio-record and store securely as evidence of your consent and complete a general information questionnaire (such as contact details, age, condition, date of diagnosis, etc.). You will be joined at all of the workshops by a small group of other patients living with inflammatory arthritis, a Band 7 Specialist Rheumatology Physiotherapist from Aberdeen Royal Infirmary (ARI) and members of our research team. Collaboratively, all attendees will co-design the programme. We anticipate that workshops will be ran over the course of 3 months and will each last around 2 to 3 hours. The final workshop will include a focus group at the end to explore your experiences with co-producing a self-management programme. All workshops and the focus group will be video- and audio-recorded so that the research team will be able to review the sessions in-depth. The focus group will be later transcribed for analysis. The transcribed interview will be anonymised and stored securely in a password protected site in the University server that only the research team can access. All information and data gathered during this study will be kept securely within password protected files for 3 years and then destroyed.

What are the possible disadvantages and risks of taking part?

You will not be disadvantaged in any way by joining the study. Nothing about the way your physiotherapist treats you will change as a result of taking part in the study. There are no insurance implications.

What are the possible benefits of taking part?

We hope that through the workshops we develop a remote self-management programme for patients living with inflammatory arthritis.

What will happen to the results of the research study?

Results from the study will be publicised in academic conferences and journals. If you wish to receive a summary of the research findings, please let a member of the research team know, but it may be some time before these are available.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called Cambridgeshire and Hertfordshire Research Ethics Committee, to

protect your interests. This study has been reviewed by Robert Gordon University, School of Health Sciences Research Review Group (SRRG No: SHS/20/03) and NHS [IRAS reference: 278552].

Who can I talk to about the study?

The study research student, Alexa Knuth, who can be contacted using the details at the end of this information sheet.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. Dr Lyndsay Alexander the study principal investigator, can be contacted via the details at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this through the NHS complaints procedure. Details can be found at: <http://www.nhs.uk/nhs.uk/your-nhs/complaints>

You can also make a complaint to Arthur Stewart convenor of the School of Health Sciences Research Review Group, Robert Gordon University, Garthdee Road, Aberdeen AB10 7QG a.d.stewart@rgu.ac.uk or Laura Binnie, Head of School of Health Sciences, Robert Gordon University, Garthdee Road, Aberdeen AB10 7QG l.m.binnie@rgu.ac.uk.

Will my taking part in the study be kept confidential?

Yes. Here are the steps we will take to ensure this:

- All study materials will identify you using only a unique ID number.
- Your name and contact details will be stored separately from other study materials and all data storage will be kept secure at all times.
- Only study personnel who need to send you something will have access to your contact details.
- Electronic data will be kept securely on university computers with password-protected access, and we will comply with all Data Protection legislation.
- We will never report study results in a way that could identify you.

Robert Gordon University is the sponsor for this study based in the United Kingdom. We will be using information from you to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Robert Gordon University will keep identifiable information about you for 3 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally identifiable information possible.

The researchers will keep your name and contact details confidential and will not share this information with any other organisation. The research team will use this information as needed, to contact you about the research study, and make sure that relevant information about the study is recorded for your care and to oversee the quality of the study. Certain individuals from Robert Gordon University, NHS Grampian and regulatory organisations may look at your research records to check the accuracy of the research study. Robert Gordon University will only receive information without any identifying information. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details.

What will happen if I don't want to carry on with the study?

You can choose to withdraw from all or part of the study at any time by contacting the researchers using the contact details below. These will be printed on all paperwork that you receive from us.

Further information and contact details:

Alexa Knuth

School of Health Sciences, Robert Gordon University, Garthdee Road, Aberdeen AB10 7QG

Email: a.knuth@rgu.ac.uk

Dr Lyndsay Alexander

School of Health Sciences, Robert Gordon University, Garthdee Road, Aberdeen AB10
7QG

Email: l.a.alexander@rgu.ac.uk Telephone: 01224 263264

Appendix 3.4 Ethical Approval

Research and Development

Foresterhill House Annexe
Foresterhill
ABERDEEN
AB25 2ZB



Dr Rosemary Hollick
University of Aberdeen
1st Floor Health Sciences Building
Foresterhill
Aberdeen
AB25 2ZD

Date 09/02/2021
Project No 2020RG005E
Enquiries to Louise/Isobel
Extension 53846
Direct Line 01224 553846
Email gram.randdpermissions@nhs.scot

Dear Dr Hollick

Management Permission for Non-Commercial Research

STUDY TITLE: Co-Production of a Virtual Self-Management Programme for Patients Living with Inflammatory Arthritis
PROTOCOL NO: v2, 20/01/21
REC REF: 20/PR/0691
IRAS REF: 278552

Thank you very much for sending all relevant documentation. I am pleased to confirm that the project is now registered with the NHS Grampian Research & Development Office. The project now has R & D Management Permission to proceed locally. This is based on the documents received from yourself and the relevant Approvals being in place.

All research with an NHS element is subject to the UK Policy Framework for Health and Social Care Research (2017 v3), and as Chief or Principal Investigator you should be fully committed to your responsibilities associated with this.

R&D Permission is granted on condition that:

- 1) The R&D Office will be notified and any relevant documents forwarded to us if any of the following occur:
 - Any Serious Breaches in Grampian (Please forward to pharmaco@abdn.ac.uk).
 - A change of Principal Investigator in Grampian or Chief Investigator.
 - Any change to funding or any additional funding
- 2) When the study ends, the R&D Office will be notified of the study end-date.
- 3) The Sponsor will notify all amendments to the relevant National Co-ordinating centre. For single centre studies, amendments should be notified to the R&D office directly.

We hope the project goes well, and if you need any help or advice relating to your R&D Management Permission, please do not hesitate to contact the office.

Yours sincerely



Susan Ridge
Non-Commercial Manager

cc: CI/Sponsor
Research Monitor

Sponsor: RGU

East of England - Cambridgeshire and Hertfordshire Research Ethics Committee

The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

18 December 2020

Dr Lyndsay Alexander
Vice Principles Office
Robert Gordon University
Garthdee House, Garthdee Road, Aberdeen
AB10 7QE

Dear Dr Alexander

Study title:	Co-Production of a Virtual Self-Management Programme for Patients Living with Inflammatory Arthritis
REC reference:	20/EE/0267
Protocol number:	N/A
IRAS project ID:	278552

Thank you for responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved on behalf of the PR sub-committee.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in

the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database. For this purpose, 'clinical trials' are defined as the first four project categories in IRAS project filter question 2. Registration is a legal requirement for [clinical trials of investigational medicinal products \(CTIMPs\)](#), except for phase I trials in healthy volunteers (these must still register as a condition of the REC favourable opinion).

Registration should take place as early as possible and within six weeks of recruiting the first research participant at the latest. Failure to register is a breach of these approval conditions, unless a deferral has been agreed by or on behalf of the Research Ethics Committee (see here for more information on requesting a deferral:

<https://www.hra.nhs.uk/planning-and-improving-research/research-planning/research-registration-research-project-identifiers/>

As set out in the UK Policy Framework, research sponsors are responsible for making information about research publicly available before it starts e.g. by registering the research project on a publicly accessible register. Further guidance on registration is available at:

<https://www.hra.nhs.uk/planning-and-improving-research/research-planning/transparency-responsibilities/>

You should notify the REC of the registration details. We routinely audit applications for compliance with these conditions.

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter.

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit:

<https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/>

N.B. If your study is related to COVID-19 we will aim to publish your research summary within 3 days rather than three months.

During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you haven't already done so,

A Research Ethics Committee established by the Health Research Authority

please register your study on a public registry as soon as possible and provide the HRA with the registration detail, which will be posted alongside other information relating to your project. We are also asking sponsors not to request deferral of publication of research summary for any projects relating to COVID-19. In addition, to facilitate finding and extracting studies related to COVID-19 from public databases, please enter the WHO official acronym for the coronavirus disease (COVID-19) in the full title of your study. Approved COVID-19 studies can be found at: <https://www.hra.nhs.uk/covid-19-research/approved-covid-19-research/>

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report

The latest guidance on these topics can be found at <https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/>.

Ethical review of research sites

The favourable opinion applies to all NHS/HSC sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see “Conditions of the favourable opinion” above).

Approved documents

The documents reviewed and approved by the Committee are:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of advertisement materials for research participants [leaflet]	V1	31 March 2020
Copies of advertisement materials for research participants [leaflet 2]	V1	31 March 2020
Covering letter on headed paper [letter]		24 March 2020
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [RGU insurance]	1	01 August 2020
Interview schedules or topic guides for participants [FG]	V1	04 September 2020
Interview schedules or topic guides for participants [Interview]	V1	04 September 2020
IRAS Application Form [IRAS_Form_28102020]		28 October 2020
Letters of invitation to participant [Invite]	V1	24 June 2020
Letters of invitation to participant [Invite 2]	V1	24 June 2020
Non-validated questionnaire [demographics]	V1	21 March 2020
Non-validated questionnaire [demographic 2]	V1	21 March 2020

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Organisation Information Document [OID]	V1	20 October 2020
Other [workshop]	V1	04 September 2020
Participant consent form [Consent]	V1	24 June 2020
Participant consent form [Consent 2]	V1	24 June 2020
Participant information sheet (PIS) [PIS]	V1	24 June 2020
Participant information sheet (PIS) [PIS2]	V1	24 June 2020
Participant information sheet (PIS) [PIS]	V2	06 December 2020
Participant information sheet (PIS) [PIS2]	V2	06 December 2020
Referee's report or other scientific critique report [SHSREC]		24 March 2020
Research protocol or project proposal [protocol]	V1	24 June 2020
Response to Request for Further Information [Response to Provisional Opinion]		15 December 2020
Schedule of Events or SoECAT [Schedule of events]	V1	08 September 2020
Summary CV for Chief Investigator (CI) [CV]		06 April 2020
Summary CV for student [CVAK]		21 March 2020
Summary CV for supervisor (student research) [CVRH]		06 April 2020
Summary CV for supervisor (student research) [liz hancock CV]	V1	28 May 2020
Summary, synopsis or diagram (flowchart) of protocol in non technical language [flow chart]	V1	10 February 2020

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at:

<https://www.hra.nhs.uk/planning-and-improving-research/learning/>

IRAS project ID: 278552
correspondence

Please quote this number on all

With the Committee's best wishes for the success of this project.

Yours sincerely

A Research Ethics Committee established by the Health Research Authority

pp f.slaOe

Dr Mauro Buraglio
Chair

Email: cambsandherts.rec@hra.nhs.uk

Enclosures: "After ethical review – guidance for researchers" [SL-AR2]

Copy to: Ms. Jill Johnston

Lead Nation England: approvals@hra.nhs.uk

East of England - Cambridgeshire and Hertfordshire Research Ethics Committee

Attendance at PRS Sub-Committee of the REC meeting on 11 November 2020

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Ms Eva Anthopoulou	Regulatory Sciences Associate	Yes	
Dr Mauro Buraglio	Independent Consultant in Clinical Pharmacology and Clinical Development	Yes	Chaired the Meeting
Dr Aoibhinn McDonnell	Safety Risk Lead	Yes	
Dr David Rawlins	Retired Pharmaceutical Consultant	Yes	

Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>
Miss Faye Slade	Approvals Administrator

Miss Alexa Knuth
Department of Physiotherapy
Robert Gordon University
Garthdee Road
Aberdeen
AB10 7QE

Date 02/02/2021
Enquiries to Dr Isobel Ford
Extension 59452
Direct Line 01224 559452
Email
Gram.researchpassports@nhs.scot

Dear Miss Knuth

Letter of access for research

This letter confirms your right of access to conduct research through NHS Grampian for the purpose and on the terms and conditions set out below. This right of access commences on 02 February 2021 and ends on 17 December 2021 unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

The information supplied about your role in research at NHS Grampian has been reviewed and you do not require an honorary research contract with this NHS organisation. We are satisfied that such pre-engagement checks as we consider necessary have been carried out.

You are considered to be a legal visitor to NHS Grampian premises. You are not entitled to any form of payment or access to other benefits provided by this NHS organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research through NHS Grampian, you will remain accountable to your employer, Robert Gordon University but you are required to follow the reasonable instructions of Dr Rosemary Hollick of this NHS organisation or those given on her behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with NHS Grampian policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with NHS Grampian in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on NHS Grampian premises. You must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of any other contract holder and you must act appropriately, responsibly and professionally at all times.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (<http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf>) and the current Data Protection legislation. Furthermore you should be aware that under the legislation, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

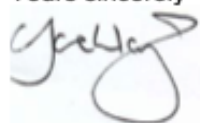
You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

NHS Grampian will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the current Data Protection legislation. Any breach of the current Data Protection legislation may result in legal action against you and/or your substantive employer.

If your current role or involvement in research changes, or any of the information provided in your Research Passport changes, you must inform your employer through their normal procedures. You must also inform your nominated manager in this NHS organisation as well as the Research and Development Office.

Yours sincerely



Jane Lloyd
Assistant HR Manager, NHS Grampian

cc: R&D office at NHS Grampian
HR department of the substantive employer

NHSG letter of access for university researchers who do not require an honorary research contract
Version 1

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Appendix 3.5 Ethics Amendment



Health Research Authority

East of England - Cambridgeshire and Hertfordshire Research Ethics Committee

The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

27 July 2021

Ms Alexa Knuth
School of Health Sciences
Robert Gordon University
Ishbel Gordon Building, Garthdee Road, Aberdeen
AB10 7QE

Dear Ms Knuth

Study title: Co-Production of a Virtual Self-Management Programme for Patients Living with Inflammatory Arthritis
REC reference: 20/EE/0267
Protocol number: N/A
Amendment number: 278552 – AM02
Amendment date: 19 May 2021
IRAS project ID: 278552

The above amendment was reviewed at the meeting of the Sub-Committee held in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Completed Amendment Tool [Amendment tool]	v1.5	19 May 2021

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

Amendments related to COVID-19

We will update your research summary for the above study on the research summaries section of our website. During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you have not already done so, please register your study on a public registry as soon as possible and provide the HRA with the registration detail, which will be posted alongside other information relating to your project.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

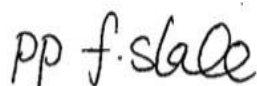
HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: <https://www.hra.nhs.uk/planning-and-improving-research/learning/>

IRAS Project ID - 278552:

Please quote this number on all correspondence

Yours sincerely



Professor Barry Hunt
Chair

E-mail: cambsandherts.rec@hra.nhs.uk

Enclosures: List of names and professions of members who took part in the review

Copy to: Ms Alexa Knuth

East of England - Cambridgeshire and Hertfordshire Research Ethics Committee

Attendance at Sub-Committee of the REC meeting on 28 June 2021

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Mrs Kornelia Hathaway	Previous Education & Training Manager	Yes	
Professor Barry Hunt	Pro-Vice Chancellor (International) (Retired)	Yes	Chaired the Meeting

Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>
Miss Faye Slade	Approvals Administrator

Appendix 5.1 Intervention Name

Inflammatory Arthritis	Self-management	Intervention	Help	Improve	Health
IA Joint	SM Self Autonomy Management Control Treatment Own	Programme Guidance Service Support Advice Care Mediation Counsel	Assist Alleviate Advice Aid Benefit Comfort Cooperation Cure Remedy Empowerment Ease Relief/Relieve Mitigate	Amend Better Enhance Rehabilitate	Well-being Wellness Heal Mend

Examples:

Self-management for Inflammatory Arthritis (S.M.I.A.) OR AIMS

Ease-IA

IA Support

(IA)lleviate

OWN-IA*

Improve

Recommendations for an
Implementation Manual of the
inflAmmatory arthrItis self-
Management (**aiM**) Intervention

PREFACE

Recognising the imperative to provide self-management support for people living with inflammatory arthritis (IA) and to bridge the gap between available resources, the inflammatory arthritis self-Management (**aiM**) intervention was developed as part of a doctoral thesis in 2021. The aiM intervention was co-produced by a team of people living with IA, members of the rheumatology multidisciplinary team at Aberdeen Royal Infirmary, and researchers at Robert Gordon University. Several IA conditions made up the patient co-designer group, specifically three living with rheumatoid arthritis (RA), two living with psoriatic arthritis (PsA), one living with axial spondyloarthritis (axSpA), one living with adult-onset Still's disease, and one living with enteropathic spondyloarthritis. The diversity of the patient co-designers makes aiM applicable to people across the IA spectrum.

The purpose of aiM is to empower and provide support for people living with IA to effectively self-manage their condition. This document was developed as a resource to aid rheumatology staff wishing to deliver aiM. It was designed so that it can be easily adapted and contextualised to deliver in your rheumatology clinic. It is my hope that it will be a useful and effective tool for delivering self-management support for people living with IA across Scotland.

ACKNOWLEDGEMENTS

I gratefully acknowledge each of the aiM co-designers. Thank you for your insight and knowledge that has guided me through this research. If it wasn't for their contributions, this work would not have been possible.

ABBREVIATIONS

Activities Of Daily Living (ADLs)

Axial Spondyloarthropathies (axSpA)

Body Mass Index (BMI)

Cardiovascular Disease (CVD)

Cognitive Behavioural Therapy (CBT)

European Alliance of Associations for Rheumatology (EULAR)

General Anxiety Disorder (GAD)

Healthcare Professionals (HCPs)

Inflammatory Arthritis (IA)

Inflammatory Arthritis Self-Management Intervention (aiM)

Multi-Disciplinary Team (MDT)

National Institute for Health and Care Excellence (NICE)

Psoriatic Arthritis (PsA)

Randomised Controlled Trial (RCT)

Range of Motion (ROM)

Rheumatoid Arthritis (RA)

Scottish Intercollegiate Guidelines Network (SIGN)

Spondyloarthropathies (SpA)

Transcutaneous Electrical Nerve Stimulators (TENS)

United Kingdom (UK)

INTRODUCTION

The aiM intervention comprises of 5 modules to support the self-management of people living with IA. The ethos of aiM is that successful management of IA is dependent on healthcare professionals (HCPs) supporting them to take an active role in the management of their condition. The aiM intervention teaches people living with IA how to become better self-managers by:

- Providing an opportunity to learn about their condition and treatment options.
- Encouraging and supporting them to make gradual, sustainable changes.
- Supporting the development and application of self-management skills.
- Providing an opportunity for them to share their experiences with others living with the same or similar condition.
- Introducing them to community resources

Excerpts from the Patient Co-designers that Inspired aiM

"So much of the time [at an appointment] is taken up talking about medication. By the time you are done talking about medication, there isn't time left to discuss anything else."-Iona

"When you're diagnosed with a condition that you can't control, you need to get back to the feeling that you can control something."-Louise

"I need to be told how to self-care. I need to see results and they need to be supported. I need someone to champion me."-Craig

"I know everyone's journey is different, but they should be prepared for what their journey could be."-Eilidh

"But I think as well that there is an awful lot of choice. If you look at the rheumatology service right now, it's a case of... 'Do I change my diet?' 'Do I cut out tomatoes?' 'Do I try complementary therapies?' What you are being told is that each person's journey is different so it's very vague. So, then you are like... 'alright, so then what do I do?' It takes months and years till you trial all these things, and you, after all these years, discover that one thing worked. So, I find the amount of information quite overwhelming as there is not one path to follow. You find out that there are 15 ways to manage this disease and I don't think that is explained to you."-Louise

"Lack of knowledge I think and lack of information when I was first diagnosed was my problem. (...) I was diagnosed about 22 years ago,

psoriatic arthritis for me. At the time, I didn't know anything about it. I thought it was just 'arthritis' and I would be fine. It went downhill very quickly. (...) I had no idea what to expect.”-Eilidh

Underpinning Theory

The aiM intervention is based on the Integrated Theory of Health Behaviour Change. According to this theory, engagement with self-management strategies influences a person living with a chronic disease's health status. It is suggested that the decision of whether to engage in self-management strategies is influenced by a person's attitude, personal agency, and perceived social norms. Thus, interventions are aimed at increasing knowledge and beliefs about their condition and management; developing self-regulation skills; and fostering positive social bonds^{1,2}.

References

1. Ryan P. Integrated Theory of Health Behavior Change: background and intervention development. Clin Nurse Spec [Internet]. 2009;23(3):161–70.
2. Health behavior and health education [Internet]. Upenn.edu. [cited 2022 Jul 4]. Available from: <https://www.med.upenn.edu/hbhe4/part2-ch4-integrated-behavior-model.shtml>

WHO CAN PARTICIPATE AND WHEN?

The aiM intervention was designed for any adult (>18 years) diagnosed with RA or SpA. Individuals of all disease severities (e.g., in remission or experiencing a flare-up) can participate.

When Should They be Considered for Enrolment?

It was recommended by the co-designers that newly diagnosed individuals are not enrolled into the intervention. Some of the information being presented in aiM could potentially be overwhelming and further distressing those who are newly diagnosed. Co-designers also highlighted that those that have had the time to process their diagnosis will be more likely to actively participate. It is therefore recommended that individuals are enrolled 4 to 6 months after diagnosis.

"Everything about tackling [the disease] goes out the window if you don't realise that your life has now changed dramatically and it's not going to go away."-Iona

Co-designers and clinical management guidelines^{1,2} recommend that participants are allowed re-enrolment to the intervention's modules throughout the disease course. The fluctuating cycle of the disease and wellbeing for people living with IA can make certain modules more relevant depending on their life stage.

"I think as your disease changes, you can revisit [the intervention]. Things are different for me now then 5 years ago. (...) You also don't always recognise things at time that you should."-Louise

"As life goes on and things continue, things will hit you from out of the blue that you never expected would be a problem. Until [my daughter] was born, I didn't think [my diagnosis] would affect me emotionally."-Craig

"The disease is a journey."-Fraser

Presence of Family or Friends at Sessions

Some co-designers expressed that they would like the option for a trusted friend or family member to be with them during some of the modules. Including the

social support network could also be helpful for family and friends in understanding the participant's condition and may help them feel better equipped to support their loved one in the future. However, other co-designers expressed that extra people in a session will increase complexity of the group dynamics thereby making it more difficult to facilitate. It is therefore recommended that the decision for allowing a friend or a family member to participate is made by weighing up the advantages and disadvantages of their attendance and by assessing your level of confidence in facilitating a larger group³. If you decide to allow family or friends to join, here are some important things to consider:

- You are not focusing on the problems of the family member or friend. The role of the other person is to support the participant.
- Some modules, such as emotional management and communicating with family/friends, may be inappropriate for the participant's family or friend to attend as the participants may disclose personal thoughts or feelings about their loved ones that could be hurtful or damaging to their relationship.

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1. Management of inflammatory arthritis | NICE impact arthritis | Reviewing the impact of our guidance | Measuring the use of NICE guidance | Into practice | What we do | About | NICE. [cited 2022 Aug 4]; Available from: <https://www.nice.org.uk/about/what-we-do/into-practice/measuring-the-use-of-nice-guidance/impact-of-our-guidance/nice-impact-arthritis/management-of-inflammatory-arthritis>
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3. Ezhumalai S, Muralidhar D, Dhanasekarapandian R, Nikketha BS. Group interventions. *Indian J Psychiatry* [Internet]. 2018;60(Suppl 4):S514–21.

DELIVERING aiM

It is recommended that aiM is delivered by at least one rheumatology HCP that has experience working with people living with IA. This recommendation is based on co-designer and clinical guideline recommendations¹, and the Scottish Government's Active and Independent Living Programme (AILP)².

"If it is something that needs to be shown how to do properly, I hate being referred to a workbook or a leaflet. Its needs to be shown by a professional. (...) You think you are doing it right, but you have absolutely no idea."-Iona

A Word about Expert Patients

It is up to you whether you decided to have expert patients (or lay leaders) help deliver aiM. All the co-designers were receptive to having an expert patient. However, the co-designers recommend that the expert patient act in a supporting role and should not be leading the intervention.

"If it comes from [an expert patient] then you are more inclined to listen to some advice."-Isabella

"(...) actually listening to practical advice from people going through similar issues as yourself is inspiring to me."-Craig

Evidence suggests that expert patients can deliver self-management interventions effectively^{1,3,4} by serving as positive role models for the participants³. If deciding to use expert patients, be mindful of the logistics for recruiting and retaining expert patients. Involving expert patients can be difficult to sustain as they will require ongoing recruitment and training as well as compensation for their involvement⁵.

References

1. Zangi HA, Ndosi M, Adams J, Andersen L, Bode C, Boström C, et al. EULAR recommendations for patient education for people with inflammatory arthritis. *Ann Rheum Dis* [Internet]. 2015;74(6):954–62. Available from: <http://dx.doi.org/10.1136/annrheumdis-2014-206807>
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References

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MODULE OVERVIEW

"These are the things that we have went and gone all our own research on that should be more accessible to people like us. I think that is the most important part. (...) It's this package that I hope can make the experience for others easier [Craig]... It's the ability to have everything in one place and have access to it without spending hours of having to go through random stuff on the internet [Maisie]."

The modules were designed to introduce the participants to several topics that are important to the self-management of their condition. Each of the modules are organised into two sections:

1. The first section introduces you to the topics that will be covered and provides a brief overview of the key messages.
2. The second section contains the recommended key messages to be delivered to the participants. The key messages are based on one or more of the following: co-designer needs, the scientific literature, or clinical guideline recommendations. Each of the messages will vary in scope, level of guidance, and detail provided. Additionally, each message will have a list of suggested talking points.

Prescribing Modules and Messages

Each of the modules can be prescribed in a 'pick and mix' manner. The choice of modules should be a collaborative decision between the patient and the HCP. You also can 'pick and mix' key messages you would like to deliver. You may choose to include all or only some of the messages but be aware that some messages are reoccurring and appear in multiple modules.

Priorities for key messages were established by the co-designers. For those with limited time to deliver aiM, the talking points denoted with this symbol  were considered by the co-designers as essential to cover.

Self-Management Strategies

Some of the key messages will discuss self-management strategies that are designed to either increase the participant's engagement with healthy behaviours or decrease unhealthy behaviours. All the modules were designed to be self- tailoring, meaning that each participant will be working on different behaviours and problems depending on their own needs and preferences. Autonomy is given to the participants to decide which self-management strategies they would like to try.

Signposting to Additional Resources

"Being signposted to credible resources is important to me."-Craig

In Appendix I, you can find a series of tables that signposts participants to patient organisations as well as other third-sector organisations. The chosen organisations can provide credible and reliable advice for the participants. Each table provides the name of relevant organisations, their website URL, and which social media platforms they are on. These tables can be printed out or emailed to each of the participants.

Supporting Social Bonds

"Just for somebody to say that 'I have actually been there too' is just as much a comfort to me when somebody else can go 'yea that period was tough'."-Louise

"Just having an opportunity to share experiences would be excellent because you do often feel that you are on your own and you are the only person in the world that has this. (...) I like the idea of a community feel [for the intervention]. Let's get people learning about self-management with confidence and reassure people that they are doing the right thing. I think that a support network would be hugely beneficial."-Craig

Providing opportunities for participants to meet and chat to one another is highly recommended by the co-designers. It is important to encourage the participants to not go through this 'journey' alone. The other participants will understand first-hand the struggles of coping and managing IA that even the most supportive friends and family members may never understand. The other participants may also be able to offer practical tips or offer insight on what to expect in the future.

The co-designers recommend that facilitators leave 30 minutes at the end of each session for participants to informally meet and talk to one another. This time could also be an opportunity for the participants to discuss with you about any questions or concerns they may have regarding the module or key messages. Providing tea, coffee and biscuits at the sessions could further encourage participants to stay and chat.

When Should Questions be Allowed?

Co-designers recommend that questions be allowed while the module content is being presented instead of waiting until the end to take questions. The participants may forget their questions, think their question is no longer relevant or may no longer care to ask their question if they wait till the end of the module.

MODE OF DELIVERY

"A blended model has to be the way."-Craig

Each of the modules can be delivered face-to-face, remotely, online, or a combination of any of the three. The online version of aiM will need to be developed for your service. If wishing to develop an online platform, co-designer preferences for developing this resource can be found in the following section. Co-designers recommend a blended approach, delivering the intervention in at least two of the modes. To help in deciding which mode(s) of delivery is best for your clinic, the advantages and disadvantages of each mode are outlined in Table 1. The decision for which mode of delivery best suits the participant should be tailored to their needs and preferences¹.

Co-Designer Recommendations for Delivery

Face-to-face

- Group Size, Duration, and Scheduling
 - Co-designers recommend hosting between 6 to 10 participants per group.
 - Sessions are suggested to be run weekly or fortnightly with each session lasting between 1.5 to 2 hours.
 - While scheduling the time of the sessions, you will have to consider the capacity of the facilitator as well as the demographics of your patient population before scheduling a time that works best for both parties.
- Location
 - It is recommended that aiM be delivered at a healthcare facility, such as a hospital or clinic, or well-known community setting.
 - The room in which the session is held should be big enough that all the participants and facilitator(s) fit and move around comfortably; allow for participants to tune in remotely (if applicable); be in a place with minimal distractions; and is easily accessible to all (especially those with physical limitations).
 - Consider parking and access to public transportation.
 - The rooms are kept at a comfortable temperature and have adequate lighting.

- Ideally, the room has a round table to allow for interaction of the participants. If a table is not available, you can position the chairs in a U-shape or a circle.

Remote

- Those that are in rural and remote areas should be offered remote delivery.
- You will need to develop a system in which participants can ask questions during the session, such as the 'hand raise' function on MS Teams.
- All participants should be on mute while the facilitator is speaking.
- You will need IT staff to ensure proper operation of equipment.
- You will need to prepare a document for how the participants can access the video conferencing account and use specific functions (e.g., the hand raises function).
- Provide contact information for help with IT-related issues.

Online

- Content
 - Content should follow the information provided in each of the modules.
 - Provide the participants with an opportunity to ask an HCP a question, such as a 'chat forum' or 'encrypted email'.
 - Links to patient organisations
 - Contact information regarding the rheumatology clinic
 - Include recorded videos and quotes from people living with IA about their experience of living with IA.
 - Provide contact information for help with IT-related issues.
- Features
 - Content is presented in a variety of different formats, such as graphs, tables, charts, personal experience videos, educational videos, bullet points, paragraphs, and whiteboard animation.
 - Interactive tools to assist the participants in self-managing. These could include a diary, symptom monitoring log, and goal setting sheets.
 - Be able to access the online version on their computer, tablet, and phone.
 - Web pages are downloadable and print friendly.

- Web pages should also be easy to navigate.
- Webpages to be maintained by regular revisions and updates based on new scientific literature; adding modules over time to reflect new developments and research.
- The colour palette should be engaging and vibrant. Avoid using colours that can symbolise low mood, such as dark blue or black. Font styles and size should be easy to read.

Table 1. Strengths and Weakness of Each Mode of Delivery¹⁻³

	Face-to-Face	Remote	Online
Advantages	Offers a better opportunity to meet and build relationships with others Additional support provided by the HCP Allows for interaction with others	Provides greater accessibility to participants Eliminates travel time Allows for interaction with others	It is cost-effective and eliminates travel time Offers the participant greater flexibility in engaging with the intervention material Needs to be developed prior to implementation Offers the ability to self-pace
Disadvantages	Costly and difficult to schedule Highly structured	Less interaction with others compared to face-to-face Highly structured Setting up equipment takes time Computer or smartphone required Requires moderate digital literacy Fast internet connection needed	Participants are unable to interact with one another Misunderstandings undetected No direct access to HCP Computer or smartphone required Requires moderate digital literacy

References

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aiM Modules

MODULE ONE- INTRODUCTION TO aiM, INFLAMMATORY ARTHRITIS, and SELF-MANAGEMENT

Introduction to the Module

The module begins by introducing you, your rheumatology service, and the intervention to the participants. The key messages of this module recommend educating the participants about IA, its treatment, and basic self-management skills. Participants can begin to improve their ability to effectively self-manage their condition by using self-monitoring, goal setting, action planning, and coping plans. Participants will be encouraged to use these foundational self-management skills throughout the aiM modules.

Key Message Recommendations

The first key message of this module is for the facilitator(s) to introduce themselves and other members of the MDT to the participants as well as share information regarding the clinic, such as clinic hours, numbers to call, research being conducted at the site, and other relevant

procedures/news. [This recommendation is based on co-designer needs and clinical guideline recommendations]. 

- Clinical guideline recommendations:
 - The National Institute for Health and Care Excellence (NICE) guidelines recommend that adults with SpA should be given information about which HCPs will be involved with their care, how and when to get in touch with them, and opportunities to get involved in research¹.
- Suggested talking points:
 - The facilitator(s) can begin by introducing themselves. If possible, other MDT members can come to the beginning of this session to introduce themselves. If conducting the intervention remotely or MDT members are unavailable, you can introduce them to the participants by providing their name, credentials, and picture on a word doc, PowerPoint slide, or the like.
 - Share important information about the logistics of the intervention, including where, when, and how often the group will meet.

- Share information regarding the clinic, such as clinic hours, numbers to call, research being conducted at the site, and other relevant procedures/news.
- Participants can introduce themselves to the group and provide information regarding their diagnosis and how long ago they were diagnosed. If wishing to play an icebreaker game, now would be a good time.
- Advise on the pathways of care.
- Introduce the purpose of aiM and explain to the participants how it was developed.
 - The aiM intervention was co-produced by a group of people living with IA, members of the Aberdeen Royal Infirmary rheumatology MDT, and researchers at Robert Gordon University.
 - While developing aiM, each of the co-designers participated in a series of workshops to identify the self-management support needs of people living with IA. The design of aiM is centred around and addresses the identified needs.
- The purpose of aiM is to provide an opportunity for the participants to:
 - Learn more about their condition and what to expect in the future.
 - Provide them with the most up-to-date evidence on treatment, lifestyle, and self-management strategies.
 - Introduce them to others living with same or similar condition and credible third-sector organisations that they can use to look up information regarding their condition.
 - A variety of self-management strategies will be covered throughout each of the modules and that not all the strategies will be acceptable to each person. This intervention was specifically designed to introduce strategies that have been proven to be effective and that others living with IA have found helpful. It is up to each participant which ones they would like to try.

The second key message of this module is to educate the participants on

IA and how it can present. [This recommendation is based on co-designer needs and clinical guideline recommendations].

"I think it would be important to get information on how the disease actually does what it does. (...) I like to know how the disease is affecting me, how it could progress, and why intervention is important early."-
Eilidh

- Clinical guideline recommendations:
 - NICE guidelines for the management of IA recommend that people living with SpA should be given information about their condition, diagnosis, and symptoms¹.
 - The European Alliance of Associations for Rheumatology (EULAR)² recommend providing education about the disease, comorbidities, and possible outcomes.
 - The Scottish Intercollegiate Guidelines Network (SIGN) for PsA recommend provision of education regarding their condition, how it is diagnosed, symptoms, and comorbidities¹³.
- Suggested talking points:
 - Explain what IA is and its classifications/subgroups
 - Provide information on how IA is diagnosed
 - Explain the basic pathophysiology
 - You may find it useful to have a picture or model representing the anatomy of a synovial joint.
 - Explain the unpredictable and reoccurring nature of IA and that flares are likely to occur
 - Emphasise that IA is a long-term and progressive condition but can be managed with appropriate treatments
 - Discuss that the aiM modules will provide management strategies for the following issues whilst reassuring participants that these may not be present in every case
 - Pain and fatigue
 - Flares
 - Employment issues
 - Impact on activities of daily living (ADLs)

- Family life and relationships
- Emotional issues
- Advise on the risk for certain comorbidities
 - EULAR guidelines³ state that people living with IA are at increased risk for developing cardiovascular disease, kidney diseases, lung diseases, infections, malignancies, osteoporosis, gastrointestinal diseases, and depression.
 - Fibromyalgia is also estimated to be prevalent in 18-24% of people living with RA, 14-16% in axSpA, and 18% in PsA⁴.
 - Discussions of comorbidities should be handled sensitively to avoid further stigmatisation or anxiety¹³.
- Co-designers recommend being careful when discussing the prognosis of IA and to not discuss 'worst case scenarios' as everyone living with IA will have a different journey.

The next key message focuses on how IA is managed. [This recommendation is based on co-designer needs and clinical guideline recommendations]. 

"My rheumatoid arthritis was heredity. (...) I could see what my mother went through, and I was determined no drugs. I had to give in in the end, so hence it was [taking] different medications. What I am working with now is helping me to be mobile. It has its side effects, I know, but at least I can move."-Fiona

"I am not a big fan of taking drugs. (...) I was a bit like 'oh I won't need drugs I will be fine' and I realised that was foolish. (...) I didn't realise I had a disabling [condition]." -Eilidh

- Clinical guideline recommendations:
 - EULAR guidelines² recommend providing education about treatment options.
- Suggested talking points:

- Advise that IA conditions are treated through pharmacological and non-pharmacological interventions. Medications have an important role but will not solve everything.
- Emphasise that the aim of treatment is to control joint pain, stiffness, and damage, thereby improving their quality of life and preventing long term disability.
- Inform that types of medications will not be covered in this intervention as choice of medication is highly individualised. However, the decision for medications will be made in partnership with them and strategies for the decision-making process will be covered in Module 5.
- Emphasise that medication adherence will be important.
- Reassure that fear of medication or dependency is normal in the beginning, but others have found it extremely beneficial to their overall quality of life in the long-term.
- Self-management strategies for medication adherence found useful by co-designers:
 - Dosette boxes and pill organisers
 - Setting alarms on their phones to remember to take their medication at the same time every day.
 - These strategies are particularly useful when medication frequency changes.
 - Remembering to take their medication gets easier with time and will start to become second nature.
 - A record of the type of medication they are on, what it is for, and the dosage can be beneficial to bring to consultant visits

Although all the co-designers emphasised the importance of medication and the improvement they had seen in their everyday life, they all expressed that medication was not the be all, end all. There were other parts of their condition they still must manage every day. Therefore, the next key message of this module recommends educating the participants on self-management and how to do it. [This recommendation is based on co-designer needs, clinical guideline recommendations, and the scientific literature].

"I'm on a medication now and my life drastically turned around, but that doesn't mean that [the disease] went away."-Craig

"It's not just your joints. It's the soft stuff around your joints that gets damaged as well. That was a bit of a shock to me. (...) I got on a biologic, but I was still in pain and still stiff and that's the stuff we can't do anything about. (...) I didn't realise because it took so long [to get on the right medication] that there was damage being done that can't be reversed. That's another battle in your head that you have to come to terms with."-

Eilidh

"Because it takes so long to find what [medication] will work, the joint damage is already done [Iona]... that's where I am, yea [Eilidh]... you still have to contend with the fact that even though you have found the correct medication, you're left with the joint damage [Iona]".

"Nobody knows the answer at the moment, and I think that is a powerful thing to be told. We are going to have to do a lot of trial-and-error to find out what works."-Louise

- Guideline Recommendations:
 - NICE guidelines for SpA recommend educating people living with SpA on self-help options¹.
 - EULAR guidelines⁵ recommend self-management interventions should include problem-solving and goal setting.
- Additional supporting evidence:
 - A systematic review found that self-management interventions incorporating self-monitoring are more likely to improve clinical outcomes and reduce healthcare utilisation compared to interventions not using self-monitoring⁶.
 - Action and coping plans are theory-based strategies that are frequently used in self-management interventions⁷. Preliminary

evidence suggests that these strategies are effective in improving medication adherence⁸, exercise engagement⁹, and work productivity¹⁰.

- Suggested talking points
 - Advise on the importance and benefits of self-management

How to self-manage

- Successful self-management is undertaken 6 steps^{7,11}:
 1. Identify the problem
 2. Decide what strategies to use
 3. Decide how to implement the strategy
 4. Practice until it is a habit
 5. Revise as needed
 6. Reward themselves
- 1. Identify the problem. The first step to successful self-management is for participants to gain an understanding of their condition and how it affects them. The best way of doing this is through self-monitoring.
 - Self-monitoring allows them to identify their biggest problems and can be useful in understanding the behavioural patterns of their symptoms. These patterns help to provide clues to understanding how their condition affects them and how to manage their symptoms^{7,11}.
 - There are many ways to self-monitor. Popular methods used by the co-designers included: writing it down in a diary or computer log, apps, or websites. Even making a mental note was found to be helpful by some co-designers. Facilitators are recommended to encourage participants to try a variety of tools to find which ones they like best.
 - Important information to track when self-monitoring¹¹:
 - Presenting symptoms and their severity (rate on a scale of 0- 10)
 - Joints affected
 - Flares and how long they last
 - Emotions
 - Self-management strategies used and whether or not the strategy helped reduce their symptom(s)
 - Participants wishing to use self-monitoring tools can be encouraged to

bring their records into their consultant visits as the information gathered from self-monitoring records can be helpful for deciding treatment.

2. Decide on a self-management strategy. The next step is then to decide how to best remedy or manage the identified problems. You can reiterate at this step that the intervention will inform the participants of several strategies to choose from and that they can choose which strategies are most acceptable to them^{7,11}.
3. Implement the strategy. The third step is to implement the strategy. There are three main tasks in implementing any strategy: (1) goal setting, (2) action planning, and (3) coping planning.
 - a. Goal setting^{7,11,12}
 - i. Make the goal specific, difficult, measurable, but not impossible.
 - ii. Include a time frame of when to complete the goal.
 - iii. Goals can be set to target behaviours or outcomes. For example, a goal for losing weight can be either: "walk outside for 30 minutes, 3x/week" or "lose 2 lbs in 2 weeks".
 - iv. Writing goals down is good practice.
 - v. The number of goals set or the number of times the same goal is set is the choice of the participant.
 - vi. There should be a logical connection between the self-management goal and the problem(s) identified.
 - vii. Consider telling or teaming up with a family member, friend, or another participant. They can be used for emotional support or as a teammate to achieve the goal together. Research indicates that stating goals publicly actually improves the chances of success¹².
 - b. Action plans^{7,11}
 - i. Just as the name would indicate, an action plan is a specific plan for acting and engaging with a self-management strategy.
 - ii. Successful action planning starts with realistic expectations for achieving the set goal. Clearly detail a plan to achieve the set goal(s). For example, "I plan to walk with my partner

on Sunday at 10 a.m. for 30 minutes at the park.” This is called a *when-where-how* plan.

- iii. Set up prompts or reminders in a diary or phone.
- iv. If needed, learn how to perform specific behaviours, or undertake a training course. For example, a new or novice exerciser may need the help of a personal trainer to learn how to perform exercises correctly.

c. Coping plans^{7,11}

- i. Coping planning helps in overcoming barriers by anticipating them. These plans offer an alternative plan if the original action plan becomes unrealistic or does not work out.
- ii. To develop coping plans, the participant is to think of all the potential barriers that could prevent them from performing their action plan and come up with an alternative option. For example, “If I feel too tired or am in too much pain to exercise, I will do my physiotherapy exercises or gentle range of motion exercises instead.”

The final key message of this module is to inform and reassure the participants that finding strategies that work for them will take time and it is a trial-and-error process. [This recommendation is based on co-designer needs].

“I think that the one thing that is quite important is that self-management is going to take time and I think you need to get that across to people. This is not going to happen overnight. Your life is not going to change magically just because you do all this stuff in a week or two. This takes time. You will fall off the wagon and you will think ‘I can’t be bothered doing any of it’. It’s very difficult to get yourself into a routine or a system or a programme, and again that is psychological thing. It’s a psychological hurdle that you got to get over. This is going to take quite a bit of change.”-Iona

“It takes a long time for your mindset to change.”-Fraser

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INTRODUCTION TO THE MODULE

Module 2 aims to provide information to the participants regarding pain and flares. This module helps participants to develop a better understanding of their experience of pain and flares, and it presents non-pharmacological management strategies for each.

KEY MESSAGE RECOMMENDATIONS

Co-designers expressed that pain can be complicated to understand and that differentiating between different types of pain can be challenging. The first key message of this module is to educate the participants on what pain is and the different types of pain they may experience. [This recommendation is based on clinical guideline recommendations]. 

"I've had stills disease for almost 17 years, I'm only now coming to terms with the management of pain. (...) I've now accepted I'll always be in pain, and to not fight it constantly."-Fraser

"I was diagnosed with psoriatic arthritis but at the same time I was also diagnosed with fibromyalgia. So, over the years it has been difficult to distinguish between what pain. (...) It's taken me at least 20 years to work out how to deal with it and how to cope with it and to know the difference between the arthritis and fibromyalgia."-Isabelle

- Clinical guideline recommendations:
 - NICE guidelines recommend people living with IA receive education on pain and its management¹.
 - How pain is defined in scientific literature:
 - The International Association of the Study of Pain (IASP)² define pain as "an unpleasant sensory and emotional experience associated with, or resembling that association with, actual or potential tissue damage."

- Suggested talking points:
 - Explain the different pain mechanisms (e.g., inflammatory, mechanical, chronic persistent, and combination).
 - Provide information on the benefits of a non-pharmacological approaches to manage pain.
 - Advise that pain will fluctuate over time and that flare-ups should be expected.
 - Emphasis that pain can also have emotional and mental consequences. However, the management of these will be discussed in Module 5.

Following on from the discussion of pain, the next message focuses on flares. All the co-designers reported experiencing multiple flares throughout the disease course. [This recommendation is based on co-designer and clinical guideline recommendations].

"Flares start to become a part of life. (...) It's a natural thing for people to overdo it when they are feeling ok or sometimes you decide to overdo it because you want to do something, and you are willing to suffer the consequences."-Iona

- Clinical guideline recommendations:
 - NICE guidelines recommend people living with IA receive education on disease flares^{1,20}.
- Suggested talking points:
 - Explain what a flare is and the impact it can have on daily and work.
 - Introduce the concept of triggers and that triggers can be predictable and unpredictable. Common triggers reported by the co-designers:
 - *"I get flares with my arthritis when my Crohn's gets really bad. I also get flares when the weather gets really bad."- Maisie*
 - *"Every year without fail, when the weather turns, around October or November I have a flare. (...) Stress is also a trigger for me."-Craig*
 - *"If you start out the day warm and then you get cold, you can't get warm again."-Fraser*

- Overexertion was another common trigger mentioned by the co-designers.
- Reassure that flares are a normal part of the disease cycle
 - *"You're thinking, especially with a flare up, 'oh god is this the next stage'."-Fiona*
- Discuss when to seek medical attention and how to access care

The third key message of this module is educating the participants on how to treat and manage their pain. Many of the co-designers were particularly keen to learn about non-pharmacological interventions for managing pain. [This recommendation is based on co-designer needs, clinical guideline recommendations, and the scientific literature]. ㄱㄴ

"It doesn't really matter what you take in relation to pain relief. You're generally in pain anyway. (...) When I was first diagnosed, I thought drugs were the only thing that would help."-Fraser

Electrotherapy

- Guideline recommendations:
 - There are conflicting guideline recommendations on the use of electrotherapy. While NICE RA guidelines recommend the use of transcutaneous electrical nerve stimulators (TENS) for short-term pain relief⁵, NICE Chronic Pain guidelines specify you should not offer electrotherapy, such as TENS, ultrasound, and interferential therapy, to people living with IA as there is limited evidence to support their effectiveness³.
- What the evidence indicates about TENS:
 - An older systematic review exploring the effects of TENS on 78 people living with hand RA found that acupuncture-TENS reduced pain and improved strength, whereas conventional TENS had no clinical benefit. However, people living with IA using conventional TENS perceived a greater clinical benefit on change in disease compared to acupuncture TENS⁸.
 - *Note: This is believed to be the most recent systematic*

review exploring the use of TENS and IA.

- More evidence on the effects of TENS in IA is needed.
- Suggested talking points if you decide to recommend TENS to your participants:
 - Advice on the purpose of TENS and contraindications
 - Advice on safe and appropriate TENS techniques
 - Bring a TENS machine and demonstrate how to use
- Suggested talking points if you decide not to recommend electrotherapy:
 - Discuss the current evidence base and why you believe it is not appropriate to use electrotherapy

Thermotherapy

- The co-designers recommended the use of heat and cold therapy as a method for pain relief.
- What the evidence suggests:
 - In a 2002 systematic review of thermotherapy applications in RA, no significant effects of cold or heat applications on pain, joint swelling, range of motion (ROM), and grip strength were found⁹.
 - *Note: This is believed to be the most recent systematic review exploring thermotherapy and IA.*
 - Two systematic reviews found that whole-body cryotherapy can significantly reduce pain and disease activity in people living with RA^{10,11}. However, a recent RCT suggests these benefits are only short-term¹².
- Suggested talking points:
 - Advise on the benefits of heat and cold therapy
 - Advise on how to apply heat and cold therapy
 - Advise on the benefits of cryotherapy and signpost to local businesses

Complementary and alternative medicine

- Co-designers wanted more information regarding complementary therapies as they are "(...) *determined not to put anything more in my body that I didn't need to use.*"-Fiona
- Guideline recommendations:

- NICE RA guidelines recommend informing those who wish to try complementary therapies that some may provide short-term symptomatic benefit, however there is little or no evidence for their long-term efficacy⁵.
- NICE Chronic Pain guidelines recommend the use of acupuncture or dry needling³.
- Additional supporting evidence:
 - Acupuncture has a short-term effect on pain and can improve overall quality of life^{13,14}.
 - Although balneotherapy (mineral bath) studies have demonstrated benefits with regards to pain, general well-being, and the number of tender joints, there is insufficient evidence to support recommendations for its use¹⁵.
 - There is no evidence available for other complementary therapies, such as aromatherapy, art therapy, and music therapy, in IA.
- Suggested talking points:
 - Advise on the purpose and benefits of acupuncture.
 - Advise that complementary therapies should not be a replacement for any treatments provided by their HCPs.
 - If there are local acupuncture practitioners in the area, you can signpost the participants there.
 - Although there is no evidence for art and music therapy, co-designers have found these to be helpful to distract themselves from pain.

Orthotics and assistive devices

"You need time spent on how to use [assistive devices] and some people don't know what is available to you or how to use them."-Iona

- Guideline Recommendations:
 - EULAR guidelines recommend the use of orthopaedic shoes in RA⁴.
 - NICE RA guidelines recommend the use of functional insoles and therapeutic footwear for all people living with RA⁵.
 - NICE SpA guidelines recommend the use of physical aids⁶.

- SIGN guidelines recommend people living with RA receive education on assistive devices⁷.
- Additional supporting evidence:
- Orthotics/Splints:
 - A systematic review found that therapeutic shoes have benefits on pain and function in RA. Although, these results are based on a small sample size¹⁶.
 - A systematic review reported that working wrist splints had a significant reduction in pain and improvement in grip strength. However, there was no improvement on function and a negative impact on hand dexterity was reported¹⁷.
 - Resting hand splints have been shown to have beneficial effects on pain, grip, and pinch strength, and function¹⁸.
 - Assistive devices:
 - The most frequently used assistive devices include kitchen utensils (such as jar openers), broad handles for covers and doors, buttoning and zipping aids, and bathroom appliances¹⁹.
 - Evidence about the effectiveness and use of assistive devices in IA is limited.
- Suggested talking points:
 - Provide information on appropriate footwear and insoles.
 - Advise on the purpose and benefits of orthoses and assistive devices.
 - Bring in assistive devices and demonstrate how to use each of them.
 - Ask the participant group what gadgets they have found to be helpful.
 - Advise on where to access devices/equipment.

Exercise Therapy

- Exercise and physical activity were recommended for the management of pain by several guidelines³⁻⁷; however, this will be discussed in greater depth in Module 4.

The final key message recommends providing education on flare management. [This recommendation is based on co-designer and clinical guideline recommendations].

"I feel if I keep my core warm, it helps with my mobility. But the minute you get cold, that is when it kicks in."-Fiona

"You will do things your way or you will suffer the consequences."-Eilidh

"When I have a flare, I get my mom and sister to help me. I also give myself more time to get ready in the morning and kind of constantly topping up on pain killers or getting a hot water bottle."-Maisie

- Coproducer recommendations:
 - For most flares, co-designers recommend that simple pain self-management strategies and a few days rest are enough to treat a flare.
 - Other self-management strategies recommended by the co-designers were:
 - Keeping their core and affected joints warm were considered as effective strategies to many co-designers. In those with cervical arthritis, some recommended the use of a snood/buff to help keep their neck warm.
 - Finding new ways to perform activities of daily living.
 - Asking a loved one for help.
 - Allowing extra time to get places or performing activities of daily living.
- Clinical guideline recommendations:
 - NICE guidelines recommend people living with IA receive education on disease flares and its management¹.
- Suggested talking points:
 - Advise that pain self-management strategies can be helpful.
 - Advise on additional flare self-management strategies.
 - Advise to self-monitor triggers, symptoms, and reduce activity levels until the flare has resolved.

- Ask participants if they have found any self-management strategies to be helpful.

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MODULE THREE- FATIGUE & WORK

INTRODUCTION TO THE MODULE

The fatigue and work module informs the participants on fatigue and how thoughts, emotions, and behaviours interrelate in the context of fatigue. It provides participants with fatigue self-management strategies and sleep hygiene tips. Lastly, it discusses issues related to employment and managing treatment at work. The co-designers considered all key messages to be important in this module.

KEY MESSAGE RECOMMENDATIONS

The first key message of this module is to educate the participants on fatigue and its causes. [This recommendation is based on co-designer needs, clinical guideline recommendations, and the scientific literature]. 📋

"The two biggest things for me are the pain and fatigue. Whether I am in a flare or not, the fatigue is always there."-Craig

"It's not as simple as 'ok you've got a wedding on Saturday, if you stay in bed all day Friday, you will manage.' No. It depends on how I feel when I wake up on Saturday morning. I might manage or I might feel like death. (...) You have no idea how you are going to feel that day [Iona]... and even that day you will feel great when you wake up and within an hour of waking up you don't feel well or vice versa. [Isabella]"

"Fatigue can significantly contribute to loneliness. I often have to force myself to go out and meet someone even if it's only for an hour. I always feel better emotionally after it."-Fraser

- How the co-designers described their experience with fatigue:
 - Ambiguous
 - Has several physical, cognitive, emotional, and social consequences.
 - Contributed to their sense of loneliness

- Difficult to discuss with others and they typically avoided discussing it when in company
- Clinical guideline recommendations:
 - NICE guidelines for the management of IA recommends people living with IA receive education on fatigue¹.
- The research indicates:
 - A systematic interpretive analysis described fatigue as 'a vicious circle of an unpredictable symptom'. The analysis corroborates the co-designers' experience of fatigue, in that fatigue contributes to loneliness; is difficult to control; significantly impacts their ability to complete tasks; and makes planning events/occasions difficult².
 - A framework for fatigue in RA suggests that fatigue is moderated by several factors, including disease-related factors and patient cognitive factors³.
 - IA-related fatigue affects work productivity and absenteeism⁴.
 - There is a relationship between sleep disturbances and fatigue in RA⁵.
- Suggested talking points:
 - Inform on what fatigue is and its causes.
 - Advise that fatigue is a fluctuating symptom, and it can range in severity.
 - Provide information on how fatigue can affect their everyday life, including restriction to perform activities of daily living, work, home life, and social roles.
 - Validate and acknowledge their experience of fatigue and the impact that it can have on their lives.

The next message of the module teaches the participants about non-pharmacological interventions for the management of fatigue. [This recommendation is based on co-designer needs, clinical guideline recommendations, and the scientific literature]. 78

"Trying to plan doesn't always work. Doing nothing the day before an event can result in broken sleep and fatigue. Fatigue management is a balancing act not an exact science."-Fraser

"The thing that I would change, if I could tell myself now from what I have learnt and having gone through it, is to not push yourself to the extreme. Maybe, just push yourself to a certain point and tell yourself 'that's manageable' and then next time maybe go a little bit more. Rather than go the full way and be like 'oh my god why have I done that and now I am in agony and now I am knackered and that was a really bad idea.' Like take it in stages, rather than just push yourself too hard too quick."-Maisie

"It's knowing when to push yourself and when to not push yourself."-Isabelle

- Clinical guideline recommendations:
 - SIGN guidelines recommend people living with RA and PsA receive joint protection education, including joint protection techniques, rest and sleep hygiene, energy conservation techniques, and exercise^{6,21}.
 - EULAR guidelines recommend advising people living with IA on how to manage sleep disturbances¹⁴.
- Supporting evidence:
 - Age does not affect choice of non-pharmacologic interventions for fatigue in people living with RA⁷.
 - Qualitative studies have reported that people living with RA find activity diaries to be helpful for managing fatigue⁸⁻¹⁰.
 - A large systematic review demonstrated the beneficial effects of physical activity and psychological interventions on the effect of fatigue¹¹. These interventions will be discussed in

more depth in Modules 4 and 5.

- Evidence evaluating the effectiveness of sleep interventions in IA is lacking.
- Common sleep complaints reported in people living with RA include trouble falling asleep, poor quality and disturbed sleep, waking up earlier than normal, and excessive daytime tiredness¹⁵.
- Suggested talking points:
 - Inform the participants on the purpose and benefits of energy management.
 - Provide information about the role of rest and sleep in IA.
 - Educate about the effects of sleep disturbance.
 - Advice on the importance of good sleeping hygiene and good sleep habits^{16,17}.
- General energy management recommendations^{12,13}:
 - Demonstrate proper body mechanics for common ADLs (e.g., lifting something from off the ground) to participants.
 - Do not use more energy than they perceive they have.
 - Do not 'push through' their symptoms.
 - Don't wait until symptoms become severe before resting or changing tasks.
 - Pace yourself by spreading physically demanding tasks throughout the day or the week by breaking down activities/tasks into smaller, more manageable chunks or allow more time to perform a task/activity. Alternating between activities that are more and less physically demanding can also be helpful.
 - Rest as needed. Don't wait until symptoms become severe before resting or changing tasks.
 - Ask for help from others. There may be times when the participant is not able to complete everything they wanted to do. If possible, they should ask a family member or friend to help. Delegating tasks can help them to spend more time on other tasks.
- Developing a plan for energy management:
 1. Begin by finding a sustainable level of activity.

2. Set realistic expectations and meaningful goals.
3. Determine energy facilitators and drainers. They can do this by recording the following:
 - Cognitive activity
 - Mobility and other physical activity
 - Ability to undertake ADLs
 - Psychological, emotional, and social demands (e.g., family, and romantic relationships)
 - Rest and relaxation
 - Both quality and duration
 - Plan for pre-emptive rest
 - Sleep quality and duration
 - Effect of environmental factors, including sensory stimulation
 - Anything else that is important to them
4. Establish a daily or weekly routine. Make a to-do list and goals for each day.
 - Arrange tasks and goals in order from most important to least important. Participants should try to complete the most important tasks at the time of day when they have the most energy. This could be morning for some and evenings for others.
 - Vary activities. If possible, balance boring tasks with more interesting ones and stressful tasks with more enjoyable ones.
 - Try not to do too much at once. Doing too much at one time can potentially trigger a flare. Taking breaks and breaking activities into smaller, more manageable chunks will be important.
 - Don't overcommit or let others pressure them. It is important that the participants communicate with others about what they are realistically able to commit themselves to. There may be times when others try to pressure us to do something we don't want to do or expect too much from us. The strategies provided in Module 5 will be helpful if the participant is having trouble saying no.
5. Review often and revise as needed.

The final message of this module educates the participants on work disability and self-management strategies they can use at work. [This recommendation is based on co-designer needs, clinical guideline recommendations, and the scientific literature]. 

"One thing you most certainly need help with is the financial benefits."-
Iona

"When I was getting diagnosed, I was questioned by my work, and it was very stressful. There was period of about 3 to 4 years that was bad."-
Craig

"My arthritis affects my ankle joints. When I was newly diagnosed, I was working at the hospital as an auxiliary nurse and there was a lot of walking around. Throughout the years, after trying to get the pain under control, (...) I decided I needed to reconsider what I was doing [for work]. I ended up retraining as a beauty therapist. That now means that I am self-employed, and I can choose how much I work in a day and how I schedule appointments. I have some sitting and I have some standing."-
Isabelle

- Clinical guideline recommendations:
 - EULAR guidelines recommend supporting people living with IA in maintaining their ability to work^{18,19}.
 - NICE guidelines for RA and SpA recommend providing advice about employment rights and ability to work^{25,26}.
 - SIGN guidelines for PsA recommend providing advice regarding work⁶.
- Supporting evidence:
 - Approximately one third of people living with IA stop working within 3 years of diagnosis. After 10 years, 50% stop working²⁰⁻²².
 - A national clinical audit estimated that nearly 30% of people living with RA in the UK occasionally or frequently needed time off²².
 - Qualitative evidence indicates that the most common challenge to those working includes, fatigue and energy loss, pain, stiffness, and functional

disability²³.

- Factors that promote work participation included prioritising energy for work, balancing work and home life, and constructive communication and support from managers, employers, and co-workers²⁴.
- Suggested talking points:
 - Acknowledge aspects of IA that can make work attendance and productivity more difficult.
 - Advise that employers and schools are required to make reasonable adjustments or adaptations to help them continue or return to work/education. This is the premise of the Equity Act of 2010.
 - Advise on ergonomic challenges and solutions.
 - Advise on the types of disability benefits that they may be eligible for.
 - Communication strategies will be discussed in depth in Module 5.
- Work self-management strategies:

"I have always allowed [my work] to have access to all my consultant letters and diagnosis."-Craig

- Find flexible approaches to work and school. Participants should consider discussing with their employer about adjustments, including remote work, online learning, a hybrid work model, and the use of assistive equipment.
- Pace and prioritise daily work activities. If possible, avoid scheduling things back-to-back and schedule time off.
- Establish boundaries. Set a time each day where they don't respond to phone calls, messages, or emails. Say no and don't overcommit.
- Pre-pack healthy lunches and dinners on the weekends. This is an easy way to still eat healthy and save energy during the week.
- Find a balance between work and home life. The goal is to make time for home, work, and time for themselves. Work and life balance doesn't mean that work and home are equally important; taking care of one doesn't mean not taking care of the other. It also isn't static and can change daily. Tips for achieving a balance:
 - Identify the problems that are causing the lack of balance and tracking how they spend their time.

- Make a list of how you spend your time each day by breaking the day down into hours.
- Make changes accordingly based on personal life and professional goals.
- Schedule time to sleep, exercise, and relax.

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INTRODUCTION TO THE MODULE

This module provides information on the risk of comorbidities and encourages the participants to engage with healthy lifestyle choices. Specifically, this module focuses on smoking cessation, reducing alcohol consumption, exercise, and eating a healthy balanced diet.

KEY MESSAGE RECOMMENDATIONS

The first key message of this module discusses the importance of a healthy lifestyle with the participants. [This recommendation is based on co- designer needs, clinical guideline recommendations, and the scientific literature].

- When discussing adapting to the condition, one participant said it's about "lifestyle adaptations".
- Clinical guideline recommendations:
 - EULAR guidelines for self-management of IA recommend the provision of lifestyle advice and quitting smoking¹.
 - SIGN guidelines for RA and PsA recommend explaining to people living with IA about the importance of lifestyle modification^{2,3}.
- Additional supporting evidence:
 - Being a smoker⁴, high body mass index⁴ (BMI), high systolic blood pressure⁵, and moderate to heavy alcohol consumption⁶ can increase RA disease activity and risk for cardiovascular disease (CVD).
 - Smoking cessation, exercise, and a healthy diet are needed to mitigate CVD effects^{4,7-9}.
 - A cohort study of 300 people living with RA found that being a smoker and high BMI can reduce the effectiveness of some medications⁹.
- Suggested talking points:
 - Advise on the benefits of living a healthy lifestyle.
 - Discuss that lifestyle modifications complement medical treatments.

- Inform that medications can influence weight.
 - Advise on the importance of routine lipid testing and blood pressure monitoring.
 - Discuss the effect that the following lifestyle factors can have on their risk for developing comorbidities:
 - Smoking
 - Blood pressure
 - Weight management
 - Alcohol intake, including restrictions with some medications
 - Signpost to local smoking cessation programmes.
- Self-management strategies:
 - Encourage self-monitoring by checking their weight weekly, physical activity levels, and drink and food intake.
 - The NHS have developed free apps¹⁰ that help to manage weight, quit smoking, get active, and drink less.
 - Reduce the amount of screen and TV time. You can recommend having TV-free days or setting a 2-hour time limit for watching TV¹¹.

The next key message is to discuss the importance of exercise and exercise guidelines. [This recommendation is based on co-designer needs, clinical guideline recommendations, and the scientific literature]. 📖

"I think it would be good to know what a good limit to exercise would be. (...) How much exercise is good and how much exercise are too much? What is appropriate for someone with arthritis?"-Maisie

- Clinical guideline recommendations:
 - EULAR recommends the promotion of physical active and exercise¹.
 - NICE guidelines for RA and SpA recommend improving general fitness through regular exercise as well as learning exercises for joint protection^{12,13}.
 - SIGN guidelines for RA and PsA promote regular exercise^{2,3}.
 - The UK Department of Health¹⁴ and American College of Sports

Medicine¹⁵ exercise guidelines recommend that individuals with IA participate in:

- Aerobic exercise
 - Intensity: moderate-to-vigorous; 55-90% of their heart rate maximum
 - Duration: (Pick one)
 - ≥150 minutes in continuous bouts of ≥10 minutes per week
 - 75 minutes of vigorous physical activity weekly
 - Combination of the two
 - Frequency: 3-5 days/week
- Resistance exercise
 - Intensity: 60-80% of 1 maximum repetition
 - Duration: 8-12 repetitions, 2-4 sets
 - Frequency: 2-3 days/week
- Do flexibility and balance exercises everyday
- Other recommendations:
 - Low or non-impact activities such as walking, swimming, cycling, yoga, Pilates, and Tai Chi during periods of increased disease activity.
 - Have a longer warm-up and cool-down period (about 15 minutes for each).
 - Divide exercise session into shorter bouts throughout the day.
 - Goal setting focuses on increasing time rather than distance.
- Additional supporting evidence:
 - A variety of physical activity and exercise interventions can have short-term benefits in IA¹⁶.
 - Several systematic reviews suggest that aerobic exercise and strength training have small- to moderate-effects on pain¹⁷, fatigue¹⁸⁻²⁰, quality of life¹⁷, and function^{17, 21,22,29} in IA.
 - Two systematic reviews reported that hydrotherapy is beneficial over no exercise, but there was no significant benefit of

hydrotherapy over land-based exercise^{23,24}.

- Two older, high-quality systematic reviews exploring the effectiveness of Tai Chi found limited effect on disease activity and symptoms^{25,26}.
- Low-intensity exercise interventions have demonstrated beneficial effects in pain and functional status when compared against high intensity programmes. High intensity programmes were found to exacerbate the inflammatory process; thereby increasing the risk of further joint damage²⁷.
- A meta-analysis of five RCTs reported yoga resulted in significant improvements in function²⁸.
- Suggested talking points:
 - Advise on the importance and benefits of exercise.
 - Inform participants on the guidelines for exercise prescription.
 - Advise it can take a long time to meet these guidelines.
 - Focusing on their goals and action plans can help to diminish overwhelming feelings.
 - Discuss the different forms of exercise, including endurance, strength, flexibility, and balance.
 - Advise on how to measure intensity, such as the talk test, perceived exertion, or heart rate.
 - Co-designers recommend that a physiotherapist demonstrate non-condition specific range of motion and posture exercises.
 - Co-designers recommend signposting participants to local gyms (indoor and outdoor) and recreational centres that host chair-based exercise classes or other classes that are appropriate for individuals living with IA.
- Self-management strategies for increasing physical activity and overcoming barriers to exercise:
 1. Establish physical activity baseline at a level that does not worsen symptoms.
 2. Set an exercise goal.
 3. Make an action and coping plan.
 - a. Choose exercises or physical activities that are enjoyable to do.

- b. Choose a time and place that best fits their diary.
 - c. Start slow.
- 4. Track their progress by keeping a record.
- 5. Revise their exercise programme by making flexible adjustments to help them gradually improve their physical abilities while staying within their energy limits. They can change their exercises every 3 to 4 weeks to keep things new and help to prevent boredom.
- 6. Be prepared for setbacks. Symptoms, getting sick, changing routines, bad weather, and even not being in the mood to exercise can all be barriers to exercise. Advise them to practice self-compassion when this happens and to pick up where they left off when they are ready.
 - a. *Remember: It's not about how many times they fall off the horse; the only thing that matters is that they keep getting back on.* This rule applies for all the new self-management strategies they try to implement into their lives.
- 7. Reward themselves for their hard work.

The final key message is educating the participants on how to eat a healthy diet. [This recommendation is based on co-designer needs, clinical guideline recommendations, and the scientific literature]. 📖

"I don't think that diet, to me, has been touched on by my consultant or anyone else."-Craig

"What are the [dietary] myths?"-Fraser "Does diet affect medication?"-Louise

"I would like to know about supplements and where to get them."-Maisie

- Clinical guideline recommendations:
 - SIGN guidelines for RA and EULAR guidelines for the self-management of IA recommend providing guidance on a healthy balanced diet^{1,2}.
 - NICE RA guidelines recommend informing those who wish to experiment with their diet that there is no strong evidence that

their arthritis will benefit. However, they could be encouraged to follow the principles of a Mediterranean diet¹².

- Additional supporting evidence:
 - A systematic review evaluating eight RCTs with a total of 366 RA participants explored the effectiveness of different diets on pain and function, including vegetarian, Mediterranean, and elimination diets. The review concluded was unable to determine efficacy due to the poor methodological quality of the included studies³⁰.
 - Another high-quality systematic review could also not support the effectiveness of herbal treatment, vitamin D, omega-3 fatty acid supplementation, and a Mediterranean diet¹⁹.
- Suggested talking points:
 - Advise that there is a lot of ambiguous information and myths on the best diet for IA.
 - Inform the participants that 'natural' or 'organic' doesn't mean free
- from side effects.
 - Provide information about what constitutes a healthy diet using the NHS healthy eating guidelines.
 - Encourage the participants to speak to an HCP if they would like advice about achieving a healthy weight for them, weight loss/gain programmes, or where specialised dietary advice is needed.
- General tips for eating³¹:
 1. Eat at three meals during the day. Skipping meals can leave people feeling hungrier later, and they can end up eating more than they needed to satisfy their appetite.
 2. Eat slowly. Meals should take no less than 15-20 minutes to finish. The brain needs time to catch up to the stomach. Putting the fork down or drinking water between bites can help.
 3. Drink plenty of water. Sometimes people think they are hungry when they are thirsty.
 4. Eat a wide variety of colourful fruit and veg.
 5. Don't eat while watching TV. Evidence suggests that eating while
 6. being distracted by the TV can cause us to eat more.
 7. Eat breakfast. Those who eat breakfast tend to have lower weight or gain less weight.

8. Limit 'fast' and 'takeaway' foods and drinks. These tend to have more calories.
9. Encourage those with nausea to keep up adequate fluid intake and advise them to try to eat regularly, taking small amounts often. Not eating or drinking may increase their nausea.

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MODULE FIVE- EMOTIONAL WELL-BEING AND COMMUNICATION

INTRODUCTION TO THE MODULE

The final module begins by discussing common emotional issues seen in IA and providing psychosocial self-management strategies. Next, participants are taught how to navigate through difficult conversations with their family, friends, and employers. The module concludes by informing the participants on the importance of shared decision-making, and their role in making decisions about their care plan.

KEY MESSAGE RECOMMENDATIONS

The first key message of this module is to introduce the participants to emotional issues commonly experienced, and the impact IA can have on relationships. [This recommendation is based on co-designer needs, clinical guideline recommendations, and the scientific literature].

"I think I would like to see the mental aspects addressed as well."-Craig

"People will take a look at you and think 'oh you can't be that bad' but they don't see the inside or the damage that has happened. So, you kind of feel that you are stuck. You are trying to live your life as best as you can and try to move forward. You want to be normal, but then you get penalised by other people's viewpoints because they see you moving or shopping or whatever, and they think 'oh she can't be that bad', but they don't know that you have two fake knees and a fake shoulder and on these really big drugs."-Eilidh

"I was 27 when I first started suffering with [rheumatoid arthritis] so not particularly old. Within nine-months of getting married, my body no longer worked. My poor sod of a husband had this young, care-free, happy girl that he married and within nine-months it was someone entirely different living in the house."-Louise

"I have huge guilt for my two kids. (...) 'We can't do this because mum can't manage. We can't do that because mums not able.'"-Iona

"Two relationships have broken down. Because when I am not well, I can't do this, or I can't do that."-Isabelle

- Clinical guideline recommendations:
 - SIGN guidelines for PsA recommend discussing self-esteem, body image, depression, and anxiety¹.
 - NICE guidelines recommend people living with chronic conditions receive information about depression and general anxiety disorder (GAD)^{2,3}.
- Additional supporting evidence:
 - People living with IA report the effect that their condition can have on their mental well-being. They frequently describe their condition can lead to frustration, isolation and loneliness, strained relationships, fear of the future, anxiety, and depression^{4,5}.
 - The risk of developing depression is doubled in people living with IA compared to the general population⁶.
 - Depression is the most common mental health disorder in people living with IA^{6,7}.
 - Physical symptoms, such as pain, fatigue, and early morning stiffness, can increase depression⁸.
- Suggested talking points:
 - Advise on common the following psychosocial issues associated with IA:
 - Stress
 - Stigma
 - Anger
 - Guilt
 - Self-esteem
 - Body image
- Provide information on signs and symptoms of anxiety and depression

The next key message educates the participants on psychosocial self-management strategies and when they should seek help from an HCP.



"Who to speak to about [mental health] because it's not something you always want to speak to your immediate family about."-Iona

- Clinical guideline recommendations:
 - EULAR guidelines suggest that better emotional well-being leads to better self-management⁹.
 - NICE RA guidelines recommend offering advice on relaxation, stress management, and cognitive coping skills (e.g., positive thinking and coping with negative thoughts)¹⁰.
 - NICE guidelines for depression and GAD recommend providing information about the range of treatments available^{2,3}.
- Additional supporting evidence:
 - A high-quality umbrella review found that psychosocial interventions have positive effects on pain, fatigue, and disability¹¹.
 - A systematic review of reviews found that psychological interventions (i.e., cognitive behavioural therapy (CBT), supportive counselling, psychotherapy, self-regulatory techniques, mindfulness, and disclosure therapy) had beneficial effects on disability, pain, fatigue, anxiety, and depression in people living with IA. Improvements in coping, self-efficacy, and engagement with physical activity were also seen¹².
 - CBT has been shown to be more effective than no therapy at all in those living with RA and who have depression. However, CBT is no more effective than any other psychological therapy^{12,13}.
 - Efficacy of psychological interventions for people living with IA is lacking.
- Suggested talking points:
 - Advise on stress management and relaxation techniques, such as distraction, mindfulness and meditation, breathing exercises, body scanning, and imagery.
 - Advise on cognitive coping skills, such as positive self-talk and emotional

disclosure journaling.

- Recommend trying low-intensity psychological interventions, such as individual non-facilitated self-help, individual guided self-help CBT, computerised CBT, and psychoeducation groups. If these interventions don't work, encourage the participants to speak to an HCP about being referred to a psychologist.
- General mental health self-management strategies:
 1. Practice self-compassion. Self-compassion is the act of being kind, sympathetic, and understanding to ourselves when we feel that we have failed or are suffering. IA will inevitably come with challenges and can make life more difficult.
 2. Find time to relax. The purpose of relaxation is to calm emotions and reduce tension in the body. Relaxation means something different for everyone. Everyone has their own ways they like to relax. Some may like to go for a walk, while others may like to play with their pet or take a long bath. It doesn't matter what their preference for relaxing is, but there are general guidelines for where and how often they practice relaxation.
 - a. Pick a quiet place and time. Find a spot where they won't be distracted for 15 to 30 minutes.
 - b. Try to relax at least 2 to 4 times per week. However, once a day is ideal.
 3. Spend more time socialising and enjoying hobbies. Spending time with people we love and doing things we enjoy helps to distract from stress and negative emotions.
 4. Spend time in nature and with animals. Being outside and playing with animals can improve our mood and well-being, reduce stress, and helps us to feel more relaxed.
 5. Live a healthy lifestyle. Staying active, getting enough sleep, and eating a balanced diet all help to reduce stress.
 6. Organise and prioritise time. Organising our time can help us feel more in control.

The third key message recommends providing education on common communication difficulties with family, friends, co-workers, and employers, and advise on how to overcome communication pitfalls. [This recommendation is based on co-designer needs]. 

"Understand that if we have to cancel plans or change plans, that its ok and we can do it another day."-Isabelle

"My wife has only known me with ankylosing spondylitis, and I have been very transparent with her. We tackle things together. (...) She picks me up when I am feeling sad. When I am having a flare-up and I can't pick my daughter up when she wants picked up and its heart breaking, it's my wife's support that I have to rely on."-Craig

"It's about knowing that someone will be on that end of the phone if you need help; like a call away. It's about trusting them to be there when you need them to be."-Maisie

"I need patience from my family when things are not good."-Craig

- Suggested talking points:
 - Using the illustrations above, discuss how relationships with family, friends, and partners/spouses can be affected by IA.
 - Advise on how to navigate the following conversations:
 - Discussing their diagnosis with someone new
 - Talking to children about their condition
 - Needing adjustments at work
 - Discussing sexual difficulties with a partner
 - Advise on how to effectively communicate needs and express feelings with family and friends.

The final key message of this module recommends advising participants on the shared decision-making process during their appointments. [This recommendation is based on co-designer needs and clinical guideline recommendations].

- Clinical guideline recommendations:
 - NICE guidelines recommend improving patient-HCP partnership and collaboration¹⁴.
- Suggested talking points:
 - Inform the participants that they will work in partnership with their HCPs to develop tangible and realistic healthcare goals.
 - Discuss the importance of shared-decision making, and their role in making a decision about their treatment.
 - Provide information on what they should be prepared to discuss with their HCPs, including:
 - What are their options for treatment?
 - Possible benefits and risks?
 - How can a decision be made together?
 - What would happen if they did nothing?
 - When deciding on a treatment, encourage the participants to think about what matters to them; what they hope will happen as a result of the discussion; and what questions they have.

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APPENDIX I- SIGNPOSTING RESOURCES PATIENT ORGANISATIONS

Organisation	Website.	Social Media
<i>Arthritis Action</i>	https://www.arthritisaction.org.uk	Facebook, Instagram, Twitter, YouTube
<i>Crohn's & Colitis UK</i>	https://crohnsandcolitis.org.uk	Facebook, Instagram, Twitter, YouTube
<i>National Axial Spondyloarthritis Society (NASS)</i>	https://www.papaa.org	Facebook, Twitter, YouTube
<i>National Rheumatoid Arthritis Society (NRAS)</i>	https://nras.org.uk	Facebook, Twitter, YouTube
<i>Psoriasis and Psoriatic Arthritis Alliance (PAPAA)</i>	https://www.psoriasis-association.org.uk	Facebook, Twitter
<i>Versus Arthritis</i>	https://www.versusarthritis.org	Facebook, Instagram, Twitter, YouTube

PAIN

<i>Action on Pain</i>	http://www.action-on-pain.co.uk/you-and-chronic-pain/medication/	Twitter
<i>British Pain Society</i>	https://www.britishpainsociety.org	Facebook, Twitter,
<i>Health Talk</i>	https://healthtalk.org/chronic-pain/nhs-pain-management-programmes	N/A
<i>My Live Well with Pain</i>	https://my.livewellwithpain.co.uk/	Facebook
<i>NHSinform</i>	https://www.nhsinform.scot/illnesses-and-conditions/mental-health/mental-health-self-help-guides/chronic-pain-self-help-guide	N/A
<i>Pain Association Scotland</i>	https://painassociation.co.uk/videos	Facebook, Instagram, Twitter, YouTube
<i>Pain Concern</i>	https://painconcern.org.uk	Facebook, Twitter, YouTube
<i>Pain Toolkit</i>	https://www.paintoolkit.org	Facebook, YouTube
<i>Pain UK</i>	https://painuk.org/blog/category/blog/	Facebook, Twitter
<i>Physiotherapy Pain Association</i>	https://ppa.csp.org.uk/content/links-people-living-pain	Facebook, Twitter

SLEEP HYGIENE

<i>Sleep Foundation (Sleep is the Foundation)</i>	https://www.sleepfoundation.org	Facebook, Instagram, Twitter, YouTube
<i>British Snoring & Sleep Apnoea Association</i>	https://britishsnoring.co.uk	Facebook, Instagram, YouTube
<i>The Sleep Charity</i>	https://thesleepcharity.org.uk	Facebook, Instagram, Twitter, YouTube
<i>Bed Advice UK</i>	https://bedadvice.co.uk	Facebook, Instagram, Twitter
<i>NHSinform</i>	https://www.nhsinform.scot/illnesses-and-conditions/mental-health/mental-health-self-help-guides/sleep-problems-and-insomnia-self-help-guide	N/A

***Sleepio is a free digital sleep intervention app for those with sleeping disorders. Sleepio is endorsed by NHSGrampian.**

EXERCISE

<i>British Heart Foundation</i>	https://www.bhf.org.uk/information-support/heart-matters-magazine/activity/chair-based-exercises	N/A
<i>NHS Pilates for Arthritis</i>	https://www.nhs.uk/conditions/nhs-fitness-studio/arthritis-pilates-exercise-video/	N/A
<i>We are undefeatable</i>	https://weareundefeatable.co.uk	Facebook, YouTube, Instagram, Twitter
<i>NHS Livewell-Yoga</i>	https://www.nhs.uk/Livewell/fitness/Documents/seated-yoga-workout.jpg	N/A
<i>NHS Livewell-Strength and Flexibility</i>	https://www.nhs.uk/live-well/exercise/strength-and-flexibility-exercises/sitting-exercises/	N/A
<i>Versus Arthritis</i>	https://www.versusarthritis.org/about-arthritis/exercising-with-arthritis/ https://www.youtube.com/c/VersusArthritis	YouTube

DIET*

<i>Versus Arthritis</i>	https://www.versusarthritis.org/about-arthritis/managing-symptoms/diet/	N/A
<i>Scottish Government</i>	https://www.foodstandards.gov.scot/consumers/health-eating/nutrition	Twitter, Facebook, Instagram, LinkedIn, YouTube
<i>NHS Inform</i>	https://www.nhsinform.scot/healthy-living/food-and-nutrition	N/A
<i>Age UK</i>	https://www.ageuk.org.uk/information-advice/health-wellbeing/healthy-eating/healthy-eating-guide/	N/A
<i>NHS Livewell</i>	https://www.nhs.uk/live-well/eat-well/	N/A
<i>British Nutrition Foundation</i>	https://www.nutrition.org.uk/healthy-sustainable-diets/healthy-and-sustainable-diets/a-healthy-balanced-diet/?level=Consumer	Twitter, LinkedIn, YouTube
<i>British Heart Foundation</i>	https://www.bhf.org.uk/informationsupport/support/healthy-living/healthy-eating/healthy-eating-toolkit/eatwell-plate	N/A
<i>Healthy Weight Grampian</i>	https://www.healthyweightgrampian.scot.nhs.uk	Facebook, Twitter

***THE NHS HAVE FREE APPS THAT HELP TO MANAGE WEIGHT, QUIT SMOKING, GET ACTIVE AND DRINK LESS.**

Available from: <https://www.nhs.uk/better-health/quit-smoking/>

EMOTIONAL WELL-BEING

<i>NHS Inform</i>	https://www.nhsinform.scot/healthy-living/mental-wellbeing/stress/breathing-and-relaxation-exercises-for-stress	N/A
<i>Silvercloud</i>	https://www.nhsgrampian.org/covid-19/covid-19-public-information/subpages/mental-health-support/access-additional-self-help-resources/	N/A
<i>Clear Your Head</i>	https://clearyourhead.scot	N/A
<i>Living Life to the Full</i>	https://lltff.com	Facebook, Twitter
<i>Breathing Space</i>	https://breathingspace.scot	N/A
<i>Penumbra</i>	https://www.penumbra.org.uk	Facebook, Instagram, Twitter, YouTube, LinkedIn
<i>Support in Mind Scotland</i>	https://www.supportinmindscotland.org.uk	Facebook, Instagram, Twitter, YouTube
<i>Samaritans*</i>	https://www.samaritans.org *has a free self-help app	Facebook, Instagram, Twitter, YouTube, LinkedIn
<i>Scottish Association for Mental Health</i>	https://www.samh.org.uk	Facebook, Instagram, Twitter, YouTube

COMMUNICATION

<i>Patients-Association</i>	https://www.patients-association.org.uk/Pages/Category/advice-and-information-leaflets	Twitter, Facebook, YouTube
<i>NHSGrampian</i>	https://www.nhsgrampian.org/your-health/realistic-medicine/information-for-patients-and-carers/	N/A
<i>National Rheumatoid Arthritis Society (NRAS)</i>	www.nras.com/relationships	N/A

WORK

<i>Citizens Advice</i>	www.citizensadvice.org.uk	Facebook, Twitter
<i>Law Centre Network</i>	www.lawcentres.org.uk	Facebook, Twitter
<i>Healthy Working Lives</i>	https://www.healthyworkinglives.scot/workplace-guidance/illness-absence/Pages/employees-with-health-conditions.aspx	Facebook, Twitter, LinkedIn
<i>Disability Rights UK</i>	www.disabilityrightsuk.org	Facebook, Instagram, Twitter, YouTube, LinkedIn
<i>Scottish Government Access to Work</i>	https://www.gov.uk/access-to-work	N/A
<i>Scottish Government- Disability Delivery Plan</i>	https://www.gov.scot/policies/disabled-people/job-support-disabled-people/	N/A