

Exploring the physical activity behaviours, lived experiences and preferences of teenage and young adults with cancer and beyond.

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Exploring the physical activity behaviours, lived experiences and preferences of teenage and young adults with cancer and beyond.

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ABSTRACT

Eilidh McLeod; Doctorate of Physiotherapy (DPT); Exploring the physical activity behaviours, lived experiences and preferences of teenage and young adults with cancer and beyond.

Physical activity (PA) is beneficial for both physical and mental health during and after cancer. However, there is a lack of research focusing on PA within the teenage and young adult (TYA) oncology population. This cohort have distinct physical and psychosocial needs which may affect their PA behaviours. The aim of this thesis was to explore the PA behaviours, lived experiences and preferences of TYA's with and after cancer. This thesis comprises a scoping review of existing literature related to PA information, interventions, barriers and facilitators within the TYA oncology population aged 16-25 and an explanatory-sequential mixed methods study, utilising an online survey and semi-structured interviews. Overall, the qualitative findings confirm and explain the quantitative findings. Results demonstrate TYA cancer patients and survivors are insufficiently active and do not meet PA guidelines. Both the physical and psychological impact of cancer and its subsequent treatment were found to negatively affect PA behaviours within this cohort. TYA's were interested in PA and rehabilitation following treatment however, they felt support offered from current services was too general and did not meet their individual needs. Findings highlighted a need for education regarding PA and cancer for both TYA's and their social networks as well as an unmet need for instrumental and informational support from a healthcare professional (HCP) across the cancer care continuum. Instead of general advice TYA's seek personalised support, tailored to themselves and their cancer delivered via a 1-2-1 conversation. TYA's were also found to prefer in-person over virtual support but felt favourably towards a hybrid model. This population were found to self-source PA support through the internet primarily using Google and the social-media platforms Instagram and YouTube. Although not an objective, this study also provides insight into the impact of COVID-19 on PA within the TYA oncology population. This research provides new knowledge and understanding about the PA behaviours, lived experiences and preferences of TYA cancer patients and survivors, emphasising the importance of personalisation and multidimensional social support. It highlights the need to evaluate the current PA support pathway within the Scottish TYA oncology services.

DISSEMINATION

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LIST OF ABBREVIATIONS

PA	Physical Activity
ADL	Activity of Daily Living
TYA	Teenage and Young Adult
TYACS	Teenage and Young Adult Cancer Survivor
AYA	Adolescent and Young Adult
AYACS	Adolescent and Young Adult Cancer Survivor
YASCC	Young Adult Survivors Childhood Cancer
AYASCC	Adolescent and Young Adult Survivor of Childhood Cancer
HCP	Healthcare Professional
AHP	Allied Health Professional
NHS	National Health Service
NHSGGC	National Health Service Greater Glasgow and Clyde
BWOSCC	Beatson West of Scotland Cancer Centre
MSN CYPC	Managed Service Network for Children and Young People with Cancer
WHO	World Health Organization
CNS	Clinical Nurse Specialist
MDT	Multidisciplinary Team
UK	United Kingdom
RGU	Robert Gordon University
SEM	Socioecological Model
TTM	Transtheoretical Model
HB	Health Behaviour
RCT	Randomised Controlled Trial

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CHAPTER1: INTRODUCTION

1.0 Thesis Overview

The following thesis explores the physical activity (PA) behaviours and lived experiences of teenagers and young adults (TYA) with cancer and beyond. This work was conducted as part of a professional doctorate in Physiotherapy and as such has been approached from both an academic and clinical lens.

This thesis begins with a general overview of the topic area in chapter one (defining physical activity, introducing cancer and the TYA population as well as behavioural change theory) before delving deeper into specific TYA oncology literature in the scoping review located in chapter two. The overarching research question of this thesis was then formulated from the research gaps identified in this extensive review. Then the methodological and philosophical underpinnings of this research are discussed and study methods outlined in chapter three, before the results are presented and discussed in chapters 4-7. Chapter eight illustrates the strengths and weaknesses of this thesis and lastly, chapter nine provides future research recommendations, discusses the implications of this research for clinical practice and summaries the study findings.

The following sections of chapter one will outline and define key terms and concepts related to PA, TYA with cancer (including incidence, UK services with a focus on Scottish services and treatment) and behaviour change to provide general context for this research. PA will then be discussed broadly across the oncology setting.

1.1 Physical Activity

1.1.1 Terminology

Frequently in literature and spoken language the terms “physical activity” and “exercise” are used interchangeably with one another. This, however, is a common misconception. Physical activity (PA) is an all-encompassing term containing many subgroups and domains. The World Health Organization (WHO) defines physical activity as “as any bodily movement produced by skeletal muscles that requires energy expenditure” (World Health Organization 2020). This includes all movement within the domains of an individual’s leisure-time, occupation, education, domestic life, as well as, movement undertaken to travel between places (World Health Organization 2020). Exercise, whereas is a subcategory of physical activity and has been defined as “planned, structured and purposeful

movement, carried out to improve or maintain components of physical fitness” (Caspersen, Powell and Christerson 1985). Generally, exercise is physical activity performed during leisure-time with the aim to improve health, performance or physical fitness (World Health Organization 2020).

The glossary below (table 1.0) contains physical activity subgroups, terminology and definitions, extracted from the World Health Organization (2020) guidelines on physical activity and sedentary behaviour, relevant to this thesis.

The WHO definition of physical activity has been used as the basis of this thesis, therefore, research relating to any sub-category of physical activity (outlined in table 1.0) has been considered in this work. Furthermore, activities of daily living (ADL), is a term used in healthcare to refer to an individual’s daily self-care activities, such as; washing, dressing, feeding one’s self (Mlinac and Feng, 2016), literature relating to this was also considered within this thesis.

Table 1.0 Glossary of Terms extracted from World Health Organization 2020 guidelines on physical activity and sedentary behaviour (pp. 8-9).

Term	Definition
Aerobic physical activity	"Activity in which the body's large muscles move in a rhythmic manner for a sustained period of time. Aerobic activity – also called endurance activity – improves cardiorespiratory fitness. Examples include walking, running, swimming, and bicycling".
Anaerobic physical activity	"Anaerobic physical activity consists of brief intense bursts of exercise, such as weightlifting and sprints, where oxygen demand surpasses oxygen supply".
Balance Training	"Static and dynamic exercises that are designed to improve an individual's ability to withstand challenges from postural sway or destabilizing stimuli caused by self-motion, the environment, or other objects".
Bone-strengthening activity	"Physical activity primarily designed to increase the strength of specific sites in bones that make up the skeletal system. Bone-strengthening activities produce an impact or tension force on the bones that promotes bone growth and strength. Running, jumping rope, and lifting weights are examples of bone-strengthening activities".
Cardiorespiratory fitness (endurance)	"A health-related component of physical fitness. The ability of the circulatory and respiratory systems to supply oxygen during sustained physical activity. Usually expressed as measured or estimated maximal oxygen uptake (VO ² max)".
Fitness	"A measure of the body's ability to function efficiently and effectively in work and leisure activities, and includes, for example, physical fitness and cardiorespiratory fitness".

Term	Definition
Flexibility	"A health- and performance-related component of physical fitness that is the range of motion possible at a joint. Flexibility is specific to each joint and depends on a number of specific variables including, but not limited to, the tightness of specific ligaments and tendons. Flexibility exercises enhance the ability of a joint to move through its full range of motion".
Functional exercises	"Exercises that can be embedded into everyday tasks to improve lower-body strength, balance, and motor performance. Examples include tandem and one-leg stands, squatting, chair stands, toe raises, and stepping over obstacles".
Household domain physical activity	"Physical activity undertaken in the home for domestic duties (such as cleaning, caring for children, gardening etc.)".
Leisure-domain physical activity	"Physical activity performed by an individual that is not required as an essential activity of daily living and is performed at the discretion of the individual. Such activities include sports participation, exercise conditioning or training, and recreational activities such as going for a walk, dancing, and gardening".
Muscle-strengthening activity	"Physical activity and exercise that increase skeletal muscle strength, power, endurance, and mass (e.g., strength training, resistance training, or muscular strength and endurance exercises)".
Occupation domain physical activity	"Physical activity undertaken during paid or voluntary work".
Physical inactivity	"An insufficient physical activity level to meet present physical activity recommendations."
Sedentary behaviour	"Any waking behaviour characterized by an energy expenditure of 1.5 METS or lower while sitting, reclining, or lying. Most desk-based office work, driving a car, and watching television are examples of sedentary behaviours; these can also apply to those unable to stand, such as

Term	Definition
	wheelchair users. The guidelines operationalize the definition of sedentary behaviour to include self-reported low movement sitting (leisure time, occupational, and total), television (TV viewing or screen time, and low levels of movement measured by devices that assess movement or posture)".
Sport	"Sport covers a range of activities performed within a set of rules and undertaken as part of leisure or competition. Sporting activities involve physical activity carried out by teams or individuals and may be supported by an institutional framework, such as a sporting agency."
Transport domain physical activity	"Physical activity performed for the purpose of getting to and from places, and refers to walking, cycling and wheeling (the use of non-motorized means of locomotion with wheels, such as scooters, rollerblades, manual wheelchair etc.)."

Physical activity can also be classified as either light, moderate or vigorous intensity, as determined by the metabolic equivalent (MET) of said activity (World Health Organization 2020). A MET of one equates to the energy cost of sitting at rest (Jetté, Sidney and Blumchen 1990) therefore the higher the intensity of the activity the more energy an individual expends performing said activity. Table 2.0, defines light, moderate and vigorous intensity activity and provides activity examples. Sedentary behaviour is defined as “any waking behaviour while in a sitting, reclining or lying posture with a low energy expenditure” (below 1.5 METs) (Tremblay et al. 2017). A systematic review and meta-analysis by Ekelund et al. (2019) demonstrated a non-linear dose-response between higher levels of total physical activity, of any intensity, and substantially reduced risk for premature mortality. Intensity classification and duration are the units used by the WHO to communicate weekly physical activity recommendations with the public (World Health Organization 2020).

Table 2.0 Physical activity intensity classification with activity examples (World Health Organization 2020 pp.8-9).

Classification	WHO (2020) Definition
Light-intensity physical activity	“Light-intensity physical activity is between 1.5 and 3 METs, i.e., activities with energy cost less than 3 times the energy expenditure at rest for that person. This can include slow walking, bathing, or other incidental activities that do not result in a substantial increase in heart rate or breathing rate”.
Moderate-intensity physical activity	“On an absolute scale, moderate-intensity refers to the physical activity that is performed between 3 and less than 6 times the intensity of rest. On a scale relative to an individual’s personal capacity, moderate-intensity physical activity is usually a 5 or 6 on a scale of 0–10”.
Vigorous-intensity physical activity	“On an absolute scale, vigorous-intensity refers to physical activity that is performed at 6.0 or more METS. On a scale relative to an individual’s personal capacity, vigorous-intensity physical activity is usually a 7 or 8 on a scale of 0–10.”

1.1.2 Physical activity guidelines

The WHO global action plan on physical activity 2018-2030 states that all countries should strive to have national physical activity guidelines (World Health Organization 2018). As a result of this plan, countries called for an update on the 2010 WHO guidelines on physical activity (Bull et al. 2020) leading to the generation of the WHO 2020 guidelines for physical activity and sedentary behaviour (World Health Organization 2020). Guidelines were generated based on the body of evidence regarding the health impact of different types, amounts and durations of physical activity as well as the impact of sedentary behaviours and its interrelationship with physical activity and health (World Health Organization 2020).

Table 3.0 is extracted from Bull et al. (2020) and is based upon WHO 2020 guidelines on physical activity and sedentary behaviour. The table illustrates that children and adolescents should engage in at least an average of 60min/day of moderate-to-vigorous intensity activity and adults should engage in at least 150–300 min of moderate-intensity aerobic physical activity, or at least 75–150min of vigorous-intensity aerobic physical activity, or an equivalent combination plus at least 2 days/week of muscle-strengthening activity (Bull et al. 2020).

It should be noted that there is no difference in the recommended duration or intensity of physical activity for adults with chronic conditions and those without, however, the guidance states that if an individual is unable to meet the above recommendations, “adults with chronic conditions should aim to engage in physical activity according to their abilities” (World Health Organization 2020). Inactive individuals are also recommended to gradually build up to guidance levels and some adults with chronic conditions are advised to consult with a medical professional prior to engaging in physical activity (Bull et al. 2020). As seen in table 3.0, the guidelines for children and the majority of the guidelines for adults have strong supporting evidence, with the exception of >300 minutes moderate-intensity aerobic PA and >150 minutes vigorous-intensity aerobic PA which is a conditional recommendation (Bull et al. 2020).

An individual is classed as “physically inactive” if they engage in activity levels below that of the current physical activity guidelines (Tudor-Locke and Myers 2001). In 2020, the WHO reported that globally 27.5% of adults and 81% of adolescents are physically inactive and that there has been little improvement to

these statistics over the last decade (World Health Organization 2020). There is however a significant geographic difference in physical activity levels as a result of inequity in access to opportunities to be active which further amplifies global health inequalities (World Health Organization 2020). It is estimated that 66% of adults in Scotland are physically active and 8.7% of deaths in Scotland are due to physical inactivity (Global Observatory for Physical Activity 2023). Not only are there geographic and economic inequality related to physical activity there is also a racial and gender inequality (Sohn et al. 2017). The WHO highlights that in most countries globally, woman are more likely to be inactive than men (World Health Organization 2020).

Advances in technology, a shift towards sedentary occupations and recreations and increasing use of personalised motorised transportation have all been identified as potential causal factors in rising global sedentary behaviours (World Health Organization 2020). However, this was summarised in 2020 and therefore does not take into account the full effects of the COVID-19 pandemic which resulted in many countries adopting lockdown restrictions (Onkyeaka et al. 2021). However, recently published literature suggests that COVID-19 and the associated lockdowns led to reduced PA levels and increased sedentary behaviour when compared to pre-pandemic levels (Wilke et al. 2022). In the UK COVID-19 restrictions included closure of public/ leisure facilities, closure of places of work, restricted movements with a 5-mile radius of home, limitations in social gatherings, limitations to leaving home for physical activity purposes (once daily) and a shift to working from home or blended working and occurred in various forms between March 2020-August 2021 (Institute For Government 2021; Scottish Parliament Information Centre 2023).

Table 3.0 Physical activity and sedentary behaviour guidelines based on age group (Bull et al. 2020).

Age group	Physical activity	Sedentary Behaviour
Children and adolescents (aged 5–17 years), including those living with disability	<p>In children and adolescents, physical activity confers benefits for the following health outcomes: physical fitness (cardiorespiratory and muscular fitness), cardiometabolic health (blood pressure, dyslipidaemia, glucose and insulin resistance), bone health, cognitive outcomes (academic performance, executive function) and mental health (reduced symptoms of depression) and reduced adiposity.</p> <p>It is recommended that:</p> <p>Children and adolescents should do at least an average of 60min/day of moderate-to-vigorous intensity, mostly aerobic, physical activity, across the week;</p> <p>Vigorous-intensity aerobic activities, as well as those that strengthen muscle and bone should be incorporated at least 3 days a week.</p> <p>Strong recommendation</p>	<p>In children and adolescents, higher amounts of sedentary behaviour are associated with detrimental effects on the following health outcomes: fitness and cardiometabolic health, adiposity, behavioural conduct/pro-social behaviour and sleep duration. It is recommended that:</p> <p>Children and adolescents should limit the amount of time spent being sedentary, particularly the amount of recreational screen time.</p> <p>Strong recommendation</p>
Adults (aged 18–64 years) including those with chronic conditions and those living with disability	<p>In adults, physical activity confers benefits for the following health outcomes: all-cause mortality, cardiovascular disease mortality, incident hypertension, incident type 2 diabetes, incident site-specific cancers, mental health (reduced symptoms of anxiety and depression), cognitive health and sleep; measures of adiposity may also improve.</p>	<p>In adults, higher amounts of sedentary behaviour are associated with detrimental effects on the following health outcomes: all-cause mortality, cardiovascular disease mortality and cancer mortality and</p>

Age group	Physical activity	Sedentary Behaviour
<p>Adults (aged 18–64 years) including those with chronic conditions and those living with disability continued...</p>	<p>It is recommended that:</p> <p>All adults should undertake regular physical activity;</p> <p>Adults should do at least 150–300 min of moderate-intensity aerobic physical activity, or at least 75–150min of vigorous-intensity aerobic physical activity, or an equivalent combination of moderate-intensity and vigorous-intensity activity throughout the week for substantial health benefits;</p> <p>Adults should also do muscle-strengthening activities at moderate or greater intensity that involve all major muscle groups on 2 or more days a week, as these provide additional health benefits.</p> <p>Strong recommendation</p> <p>Adults may increase moderate-intensity aerobic physical activity to >300min, or do >150min of vigorous-intensity aerobic physical activity, or an equivalent combination of moderate-intensity and vigorous-intensity activity throughout the week for additional health benefits (when not contraindicated for those with chronic conditions).</p> <p>Conditional recommendation</p>	<p>incidence of cardiovascular disease, type 2 diabetes and cancer.</p> <p>It is recommended that:</p> <p>Adults should limit the amount of time spent being sedentary. Replacing sedentary time with physical activity of any intensity (including light intensity) provides health benefits;</p> <p>To help reduce the detrimental effects of high levels of sedentary behaviour on health, adults should aim to do more than the recommended levels of moderate-to vigorous physical activity.</p> <p>Strong recommendation</p>

1.1.3 Benefits of Physical Activity

It has been well established that physical activity has many benefits for both physical and mental health within children, adolescents, adults and older adults (World Health Organization 2020).

In adults, physical activity been shown to be important at preventing non-communicable diseases (Anderson and Durstine 2019), there is strong evidence demonstrating that engaging in physical activity reduces risk of type-2 diabetes (Warburton, Nicol and Bredin 2006), coronary heart disease (Anderson et al. 2016), some cancers (Moore et al. 2016), hypertension (Warburton, Nicol and Bredin 2006) and obesity (Fogelholm 2010); as well as reduced cardiovascular disease and all-cause mortality (Ekelund et al. 2019). In children, regular physical activity has been linked to improved cardiovascular fitness (Silva et al. 2022), as well as reduced risk of obesity and diabetes (World Health Organization 2020). Furthermore, research into the effects of sedentary behaviours on health have demonstrated adverse impact on cardiovascular health, cancer risk, risk of musculoskeletal disorders, increased risk of all-cause mortality and metabolic disorders as well as negatively impacting mental health and cognitive functioning (Park et al. 2020)

Mental benefits of physical activity include: improved sleep and reduced risk of cognitive impairment such as Dementia/Alzheimer's (World Health Organization 2020), reduce social isolation (Robins et al. 2018) reduced symptoms of anxiety and depression (Rebar et al. 2015) and higher emotional and social quality of life (Gill et al. 2013; Pedersen and Saltin 2015). In children and young people, engagement in sport encourages prosocial behaviours during development (Li and Shoa 2022) and increases confidence and self-esteem (Eime et al. 2013).

1.2 Cancer

1.2.1 Definition

Cancer is a large group of related diseases, resulting from the uncontrolled division of damaged or abnormal cells. The disruption of normal cell division can occur at multiple stages within the process, and can occur almost anywhere in the human body, in any cell type. As a result, there are over two hundred different types of cancer and no individual cancer is the same (National Cancer Institute 2021).

In the UK it is estimated that 3 million people are currently living with cancer, with this figure expected to rise to 4 million by 2030 (Macmillan Cancer Support 2023).

Each year approximately 393,000 people in the UK are diagnosed with cancer, 33,160 of which are residents in Scotland (MacMillian Cancer Support 2023). This figure has increased by 19% over the last decade due to a growing and aging population as well as advances within diagnostic initiatives and public awareness (MacMillian cancer support 2023).

As the prevalence of cancer increases so does the economic burden, in 2010 the total annual estimated cost of cancer was approximately US\$1.6 trillion (World Health Organization 2018). In March 2016 the Scottish government launched "Beating Cancer: Ambition and Action" and committed to spend £100 million to improve the prevention, detection, diagnosis, treatment and aftercare of those affected by cancer (Scottish Government 2018). Not only are there direct financial costs but indirect costs such as loss of productivity, inability of the individual to work or attend education, as well as informal costs of care provided by family or friends, reduced quality of life and reduced social interaction are all associated with cancer (Lorgelly and Neri 2018). Cancer, therefore, provides both a large strain on healthcare resources and a large social burden on the individual and society.

1.2.2 Overview of TYA Cancer

Cancer can affect anyone, of any age, gender or ethnic background but groupings of common cancer diagnoses can be seen within paediatric, teenage and young adult (TYA) and older adult populations. This thesis shall focus specially on cancer in the TYA age group. TYA cancer care services and the challenges this population face is outlined below.

Within oncology literature there is variation between the terminology used to describe the teenage and young adult population; in the UK this population is referred to using the acronym "TYA" for teenage, young adult, whereas, in the USA, Canada and Australia the acronym "AYA" is used to describe this population referring to "adolescent and young adults". As this thesis has been conducted in the UK, the term TYA has been adopted throughout.

Not only are there international differences in the acronyms used to describe this population but there are also global inconsistencies in cancer literature and clinical pathways when defining the age range of this population (Janssen et al. 2021). The USA uses the age range 15-39-years (Janssen et al. 2021), Canada 15-29-years (Fernandez et al. 2011), the UK uses 13-24/15-24 (Fern and Whelan 2013),

Europe 15-39-years (Trama et al. 2023) and Australia 15-25-years (Janssen et al. 2021).

Another consideration of note within TYA oncology literature is that the term "TYA cancer survivors" is often used interchangeably to describe TYA aged survivors of childhood cancer as well as individuals diagnosed with cancer during adolescence or young adulthood (Pugh 2018). In this thesis care has been taken to exclude literature pertaining to TYA aged survivors of childhood cancer, where able, including information only relating to those diagnosed as a TYA.

Despite international variation between nomenclature and age ranges it is widely accepted that TYA patients are a distinct cohort from paediatric and older adult patients, with unique challenges and needs (Zebrack, Issacson and Piscione 2014; Janssen et al. 2021) which may influence their outcomes both during and after treatment (Close et al. 2019). Adolescence and young adulthood are a formative stage of any individual's life as it is a period of psychological and social development (Wood et al. 2018). It involves emotional, neurodevelopmental and social maturation, development of identity and values and increased independence from family constructs (Wood et al. 2018). Often young people begin employment or further education, enter romantic relationships and financial independence (Wood et al. 2018). A cancer diagnosis during this time period can result in a number of psychosocial challenges for TYA's. These include underdeveloped coping skills and abstract thinking, poor communication and relationship skills, lack of knowledge about their illness and treatment, competing obligations (school, job, family) and lack of psychosocial support (Jin, Griffith, Rosenhal 2021). These challenges pose unique issues of treatment adherence within the TYA cancer population (Zebrack Issacson and Piscione 2014). Furthermore, TYA patients are at a critical stage of their physiological development and often have tumours that are biologically and genomically distinct from their paediatric or adult counterparts (Close et al. 2019; Rod et al. 2023).

Although there is a general trend of increased cancer survival rates across cancer care, adolescent and young adult oncology patients have not shown the same improvement in survival as younger and older adult cohorts (Bleyer, Budd and Montello 2006; Close et al. 2019; Jin, Griffith and Rosenhal 2021). Adolescents and young people have been described as being on the "margins of medical care" (Goddard, Wolfson and Wolfson 2015). As a result of this population straddling

paediatric and adult health services, published data relating to health outcomes does not provide a clear picture of the health challenges this group face (Goddard, Wolfson and Wolfson 2015). Within oncology the TYA age group has historically been underrepresented in research (Bleyer, Budd and Montello 2006). This has been coined in literature as the “AYA gap” (Jin, Griffith and Rosenhal 2021).

TYA patients were too old for paediatric trials and too young for adult trials inclusion criteria (Fern et al. 2014). This lack of representation within clinical trials brings into question the generalisability of treatment protocols for TYA patients. However, in the UK, the National Cancer Institute Teenage and Young Adult Clinical Studies Group (NCRI TYA CSG) was established in 2005 to generate and promote research specifically for TYA’s with cancer (Fern and Whelan 2013). The NCRI TYA CSG has successfully lowered/removed the age eligibility criteria on adult clinical trials entering National Institute for Health Research (NIHR) meaning that more young people have been eligible to participate in trials, in an attempt to increase understanding of TYA interactions with various treatment options (Laurence 2018). Despite this, TYA patient continues to make-up a small percentage of participants within clinical trials (Bleyer, Tai and Siegel 2018). Additionally, TYA patients often experience delays to diagnosis due to insufficient awareness of cancer risk and symptoms among health care professionals (Janssen et al. 2021) and TYA patients themselves (Kyle, Forbat and Hubbard 2012).

1.2.3 TYA Incidence and Survival Rates

In the UK approximately 2,374 young people aged between 15-24 are diagnosed with cancer each year (Cancer Research UK 2023). In Scotland specifically, there are approximately 200 new cases of cancer per year in 16–25-year-olds, 51% of which are in females (Scottish Government 2021). Cancer incidence rates in TYAs are higher in those aged between 20-24 years compared to 15-19 years (Smith et al. 2016). The most common cancer types seen in the TYA population are carcinomas (22%), lymphomas (19%) and CNS tumours (14%) (Public Health Scotland 2023). Carcinomas mainly seen in this population include gastrointestinal (30%), thyroid (28%) and genitourinary (23%). Although cancer type does differ by gender with germ cell tumours, lymphomas, CNS tumours and carcinomas most common in males and carcinomas, lymphomas, melanomas and skin cancer and CNS tumours most common in females (Public Health Scotland 2023).

Although survival rates for TYA cancer have stayed relatively stable over the last decade (Public Health Scotland 2023), cancer remains the most common disease-related cause of death in the TYA population (Scottish Government 2021). One-year survival rate across the TYA population is 96.6% and five-year survival is 91.1%, although this does vary depending on cancer type (Public Health Scotland 2023).

As of December 2021, there were 1,529 young people, in Scotland, who had survived their cancer diagnosis, 651 of which were diagnosed as TYA's (Public Health Scotland 2023) and it is estimated that there are over 5000 survivors of childhood and TYA cancer living in Scotland since 1999 (Scottish Government 2021). Due to their survival rates and length of life post-treatment TYA cancer survivors are at an increased risk of secondary diagnosis and chronic conditions (Schwartz, Dirk de Heer and Bea 2017; Pugh 2018). Therefore, the ongoing care needs of this population must be considered (Scottish Government 2021).

1.2.4 TYA Cancer Services in the UK

The UK model of TYA cancer care is based upon collaboration between paediatric and adult cancer specialists within specific TYA cancer units. Upon its implementation this coordinated care of TYA cancer patients was considered internationally pioneering within cancer care (Vindrola-Padros et al. 2016). Within the UK, national guidance outlines the framework and mandates the quality of care that should be provided for every young person diagnosed with cancer (National Institute for Health and Clinical Excellence 2005).

UK policy advocates for age-appropriate care (Fern and Whelan 2013), with guidelines stating that young people should be offered the choice regarding where they receive their treatment (a principal treatment centre or a designated TYA hospital closer to home) and all TYA patients regardless of where they are treated should be discussed at national multidisciplinary team (MDT) meetings to ensure each young person receives the best care (NICE 2005).

In Scotland, the Managed Service Network for Children and Young People with Cancer (MSN CYPC) works in partnership with the 14 NHS boards, utilising national MDT working, to promote delivery of consistent and equitable care for children and young people with cancer across Scotland (Scottish Government 2021). TYA cancer specific services have been developed in adult cancer practice to meet the complex clinical, psychological, and social issues experienced by young cancer

patients (Scottish Government 2021). The most up to date Scottish Government cancer strategy for children and young people (developed in conjunction with NHS Scotland and MSN CYPC) was published in 2021 and outlines the status of current children and young people services and ongoing cancer strategy for 2021-2026 (Scottish Government 2021).

The provision of specialist age-appropriate TYA cancer services within adult cancer services, is delivered through the Scottish TYA cancer network model of care. This encompasses TYA cancer hubs established across five adult regional cancer centres and nominated geographical regions (NHS Grampian, GGC, Lothian, Tayside and Highlands). There are also two specialist teenage and young adult (TYA) cancer wards, located at the Beatson West of Scotland Cancer Centre (BWoSCC) in NHSGGC and Western General Hospital Edinburgh (Scottish Government 2021). The TYA ward at the BWoSCC provides specialist inpatient and outpatient care for 16-25-year-olds (Beatson West of Scotland Cancer Centre 2021), and was the primary recruitment base for this thesis. Due to this 16-25 has been selected as criteria to define this study population.

The Scottish TYA cancer hubs collaborate via weekly MDT meetings, to deliver personalised age-appropriate care and create more effective patient pathways. Each hub is supported by clinical leadership and a specialist workforce, knowledgeable of the biomedical and psychosocial issues specific to TYAs with cancer. Table 4.0 provides a brief summary of the Scottish TYA cancer specialist workforce adapted from the Scottish Government 2021-2026 cancer strategy, a full copy of the Table including post, funding body, base, hours and whole time equivalent (WTE), can be found in Appendix 1.

Table 4.0 Brief overview of the Scottish TYA Oncology Specialist Workforce in post (census March 2021) divided by clinical base adapted from the Scottish Government 2021-2026 Cancer Strategy (pg.80)

Base	Post
National Level	TYA National Lead Nurse, TYA National Clinical Lead, TYA National MDT Coordinator
NHS Highland	CNS, Social Worker, TYA Clinical Lead
NHS Tayside	CNS, Social Worker, Clinical Lead
NHS Grampian	CNS, Social Worker, Principal Clinical Psychologist, Clinical Lead
NHS Lothian	CNS (x2), Youth Support Coordinator, Social Worker, Clinical Lead
NHS GGC	Youth Support Coordinator, CNS (x2), Social Worker, Physiotherapist, Dietician

GGC= Greater Glasgow and Clyde; NHS= National Health Service; TYA= teenage and young adult; CNS= clinical nurse specialist

As can be seen in table 4.0, the workforce census demonstrated gaps regarding allied health professionals (AHP) across the TYA hubs as only one of the five hubs having a physiotherapist or dietician in post. The cancer strategy illustrates that this workforce gap indicates TYAs have a supportive care need in relation to health behaviours such as diet and exercise. Furthermore, the workforce census revealed that there is no dedicated provision of AHP aftercare support in any of the five TYA hubs in adult care (Scottish Government 2021). The current clinical landscape regarding PA support faces challenges due limited staff with relevant exercise prescription background. Pathways for after treatment care involves signposting and referral to community services which may not be equipped to deal with TYA cancer survivors and a small number may receive support from a designated TYA physiotherapist but location dependent (as seen in table 4.0) (Scottish Government 2021).

There were ten ambitions outlined in the Scottish Government 2021-2026 cancer strategy, two of which are relevant to this thesis. These were Ambition 3: "Incorporated supportive care services" and Ambition 5: "Continuing care when treatment completes" (Scottish Government 2021). The strategy aims to address

these by: suggesting improvements to the aftercare pathways to better support TYAs, generating a health behaviour educational resource for TYAs and creating a dedicated lead AHP position to implement AHP changes within TYA services (Scottish Government 2021).

1.2.5 Cancer Treatment

The type of treatment an individual receives is determined not only by the type, stage, grade and location of their disease but also by the patient's general health and their individual wishes (National Cancer Institute 2021). Treatments within TYA cancer varies from a single treatment type such as surgery, to an extended period of combined systemic treatments such as chemotherapy (Bleyer et al. 2007). Common treatment options utilised within TYA oncology include: surgery, chemotherapy, radiation therapy (or radiotherapy), immunotherapy, hormone therapy, stem cell and bone marrow transplants, targeted therapy and clinical trials (Bleyer et al. 2007).

In general cancer treatment is incredibly taxing on the body and can result in a multitude of treatment related side effects (Nass et al. 2015). There is a delicate balance within treatment between optimising treatment dose to maximise cure while minimising acute and chronic complications from treatment (Bukowinski et al. 2015). These may present acutely during treatment, shortly after treatment ceases or even months and years' post-treatment (Bukowinski et al. 2015). Many side-effects are temporary and improve or resolve once treatment is completed, however, some treatments may cause long-term damage, these are referred to as "late-effects" of treatment (Nass et al. 2015).

The list of possible side-effects from treatment(s) is extensive. Side-effects experienced by patients vary depending on treatment type (local vs systemic treatment), treatment intensity, treatment duration and the individual (Nass et al. 2015). It is out with the scope of this thesis to discuss all possible side effects or late-effects of treatment. However, common treatment side-effects and late-effects are outlined below as well as a discussion on the potential effect of these on patients/survivor's physical function.

Treatment-related toxicities (TRT) can occur as a direct result of anti-cancer therapies (Bukowinski et al. 2015). Common TRT's include nausea and vomiting, fatigue, pain, mucositis, diarrhoea, changes to executive functioning, myelosuppression and peripheral neuropathy (Zebrack et al. 2014; Bukowinski.,

et al. 2015). These TRTs can lead to side-effects and late-effects including: cancer-related fatigue (CRF) (Nowe et al. 2017), physical deconditioning (changes in cardiovascular fitness and muscular strength), changes in body composition (weight loss/gain) and psychological distress (Zebrack et al. 2014). If poorly managed, treatment side effects can lead to chronic fatigue, malnutrition and cachexia and deconditioning. This perpetuates a cycle of physical inactivity and deconditioning leading to reduced physical function and outcomes (Lucia, Earnest and Perez 2003; Munsie 2021).

Improvements in TYA cancer survival rates mean an increase in the number of individuals living with an increased risk of treatment-related long-term adverse effects (Bright et al. 2017; Woodward et al., 2011; Schwartz, Dirk de Heer and Bea 2017) and developing chronic comorbidities (Chao et al. 2020). There are both long-term health and psychosocial consequences of treatment (Nass et al. 2015; Woodward et al. 2011). Table 5.0, extracted from Nass et al. (2015), outlines common late-effects as a result of cancer. As can be seen, TYA survivors are at risk of developing cardiovascular, pulmonary, renal, endocrine and CNS complications (Nass et al. 2015). Table 5.0 also illustrates the many psychological issues that TYA survivors face including depression and anxiety and post-traumatic stress disorder (PTSD) as well as relationship problems, difficulties within employment and education and with problem solving (Nass et al. 2015).

Table 5.0 Potential late effects by system and exposure, adapted from Nass et al. (2015).

System	Exposures	Potential Late Effects
Cardiovascular	Radiation therapy Platinum's Anthracyclines	Myocardial infarction or stroke; congestive heart failure; valvular disease; hypertension
Pulmonary	Radiation therapy Bleomycin Carmustine/Lomustine	Restrictive lung disease; pulmonary fibrosis; reduced exercise tolerance
Renal/ Urological	Radiation therapy Platinum's Ifosfamide/ Cyclophosphamide	Renal insufficiency/ failure; Haemorrhagic cystitis
Endocrine	Radiation therapy Alkylating agents	Obesity; infertility and gonadal dysfunction; dyslipidaemia; diabetes
Central Nervous System	Radiation therapy High dose/ intrathecal antimetabolite chemotherapy	Learning disabilities; cognitive dysfunction
Psychosocial	Cancer	Affective disorders (anxiety, depression); post-traumatic stress disorder; sexual dysfunction; relationship problems; employment/ educational problems; affected adaption and problem-solving skills

Additionally, TYA cancer survivors have been reported to be at increased risk of osteoporosis and developing secondary malignancies (Woodward et al. 2011). Secondary cancers are commonly solid tumours which develop within the primary cancer radiation field (Nass et al. 2015). An increased mortality risk has been seen in TYA survivors of lymphoma (Catellino et al. 2011), testicular cancer (Beard et al. 2013), breast cancer (Hooning et al. 2006), soft tissue and bone sarcoma, leukaemia and brain tumours due to second primary cancers and cardiovascular disease (CVD) (Nass et al. 2015).

TYA cancer survivors are also at increased risk of developing multiple chronic conditions as a result of long-term toxic effects of cancer treatment (Pugh 2018). The risk for chronic health problems is elevated in TYA cancer survivors due to

treatment exposures potentiated by unhealthy lifestyle behaviours, comorbidities and underlying genetic factors (Nass et al. 2015). In comparison to the general population, TYA cancer survivors (aged 15-39) have a significantly increased risk of developing any cerebrovascular event (40%) (standardised hospitalisation ratio=1.4, 95% confidence interval [CI], 1.3–1.4), this risk was found to be higher for males than females and survivors of central nervous system (CNS) tumours, head and neck tumours and leukaemia (Bright et al. 2017).

Age at diagnosis is also a key risk factor in adolescent and young adult cancer survivors for subsequent cardiac and cerebrovascular mortality later in life (Pugh 2018). A study conducted by Henson and colleagues (2016) found TYA cancer survivors diagnosed between the ages of 15-19 had a significantly higher cardiac mortality risk compared to those diagnosed between ages of 35-39 years old; standardised mortality ratio (SMR): 4.2, 95% CI 3.4-5.2 and SMR 1.2, 95% CI 1.1-1.3 respectively, $p < 0.001$ (Henson et al. 2016).

Cancer-related fatigue (CRF) has been described as the 'most prevalent and distressing' of all symptoms experienced by TYA cancer survivors (Spathis et al. 2015). CRF often impacts significantly on an individual's cognitive and physical functioning, limiting their ability to concentrate at work or school as well as take part in usual social activities both during and after treatment (Spathis et al. 2015) and has been linked to poor psychosocial health (Nowe et al. 2017).

1.3 Cancer and Physical Activity

The following sections contain a more in-depth information regarding cancer and physical activity. As demonstrated above cancer treatment can significantly impact patients and survivor's physical function. The role of physical activity in cancer prevention and as an adjunct in cancer care will now be summarised.

1.3.1 Physical Activity in the Oncology Setting

Evidence supporting the integration of exercise as an adjunctive therapy in cancer care is now well established (Campbell et al. 2019). Multiple international bodies endorse exercise being embedded within cancer care as part of standard practice (Schmitz et al. 2021). In the UK, the NICE guidelines (2005) and Teenage and Young Adults with Cancer: Best Practice Statement (Chesman, Jeffery and Wright 2017) state that physiotherapists should be engaging both inpatients and outpatients in physical activity.

In 2018 the American College of Sports Medicine (ACSM) convened an International Multidisciplinary RoundTable on Exercise and Cancer with the aims to: summarise evidence regarding cancer prevention and survival post diagnosis; review efficacy of exercise to improve cancer related health outcomes (acute and long-term effects); update guidelines on physical activity and cancer based upon current evidence (Campbell et al. 2019). These are the most up to date guidelines on physical activity in cancer care therefore, results from this will be discussed below.

1.3.2 Physical Activity and Cancer Risk

Research suggests that physical activity (PA) may reduce an individual's risk of developing cancer as physical activity has been shown to reduce sex hormones and growth factors which can be linked to cancer (Winzer et al. 2011; Patel et al. 2019). In addition, PA can improve the function of the immune system and prevent obesity which has also been linked to increased risk of cancer (Patel et al. 2019).

A large systematic review by Moore et al. (2016) including 1.4 million adults, found that high compared to low leisure time physical activity was associated with a reduced risk of developing 13 different cancer types (oesophageal adenocarcinoma, liver, lung, kidney, gastric cardia, endometrial, myeloid leukaemia, myeloma, colon, head and neck, rectal, bladder and breast. Further support for a reduced risk of cancer from engaging in physical activity is demonstrated by McTiernan et al. (2019). Their 2019 systematic review and meta-analysis demonstrates strong evidence that physical activity reduced risks of bladder, breast, colon, endometrial, oesophageal adenocarcinoma, renal and gastric cancers and that engaging in high level physical activity also had a reduced risk of lung cancer compared to low level physical activity (McTiernan et al. 2019).

The ACSM roundtable concluded that there is strong evidence that physical activity lowers risk of; colon, breast, kidney, endometrium, bladder, stomach cancers and oesophageal adenocarcinoma, as well as moderate evidence for the prevention of lung cancer (Patel et al. 2019; Physical Activity Guidelines Advisory Committee 2018; Campbell et al. 2019). Reducing time spent sedentary may also lower risk of endometrial, colon and lung cancers (Patel et al. 2019).

Currently, information is limited with relation to physical activity and cancer risk by age as the majority of studies have been conducted in older adult populations (McTiernan et al. 2019). However, there is some evidence to suggest risk of colon

and breast cancer is increasing in younger age groups, who are less active than previous generations (PAGAC 2018). The 2018 Physical Activity Guidelines Advisory Committee Scientific Report (PAGAC), summarised that future research is required to test effect modification of age on the associations between cancer risk and physical activity.

1.3.3 Physical Activity and Cancer Mortality

The WHO supports physical activity to improve all-cause mortality, cancer-specific mortality, and risk of cancer recurrence or second primary cancer in adult cancer survivors (World Health Organization 2020).

It should be noted that the ACSM roundtable only found moderate levels of evidence that physical activity may reduce risk of dying from breast and colon cancer among those diagnosed with these malignancies (Campbell et al. 2019) and there was not sufficient evidence for any other cancer type.

A 2019 systematic review and meta-analysis of observational studies in breast cancer survivors conducted by Spei et al. found that compared to women in the lowest recreational physical activity level, women in the highest level had a lower risk of all-cause mortality, lower risk of death from breast cancer and a lower (non-significant) risk of recurrence (Spei et al. 2019).

1.3.4 Physical Activity and Acute- /Late-effects

Positive effects have also been demonstrated with regards to treatment acute and late-effects in cancer survivors. PA interventions have been shown to reduce body mass index (BMI) (Soares-Falcetta et al. 2018), improve cardiopulmonary functioning (Viamonte et al. 2023), and reduce fatigue both during and after active treatment (Husson et al. 2015; Mishra et al. 2012b; Mishra et al. 2012a). A 2018 study of physical activity in patients undergoing chemotherapy found it prevented strength loss and deconditioning usually associated with chemotherapy (Vollmers et al. 2018).

Figure 1.0 is an infographic output from the ACSM roundtable illustrating the physical activity guidelines for individuals with cancer and cancer survivors. The roundtable concluded that exercise was generally safe for individuals with cancer and cancer survivors and that every survivor should aim to maintain some level of physical activity (Campbell et al. 2019). Individuals with cancer and cancer survivors are recommended to avoid inactivity and aim to meet PA guidelines

(Campbell et al. 2019). As seen in figure 1.0 there is evidence suggesting physical activity (even in amounts lower than recommended) can improve treatment-related symptoms including CRF, depression, anxiety, sleep disturbances, physical function, health-related quality of life (HRQoL), bone health and lymphoedema (Campbell et al. 2019).

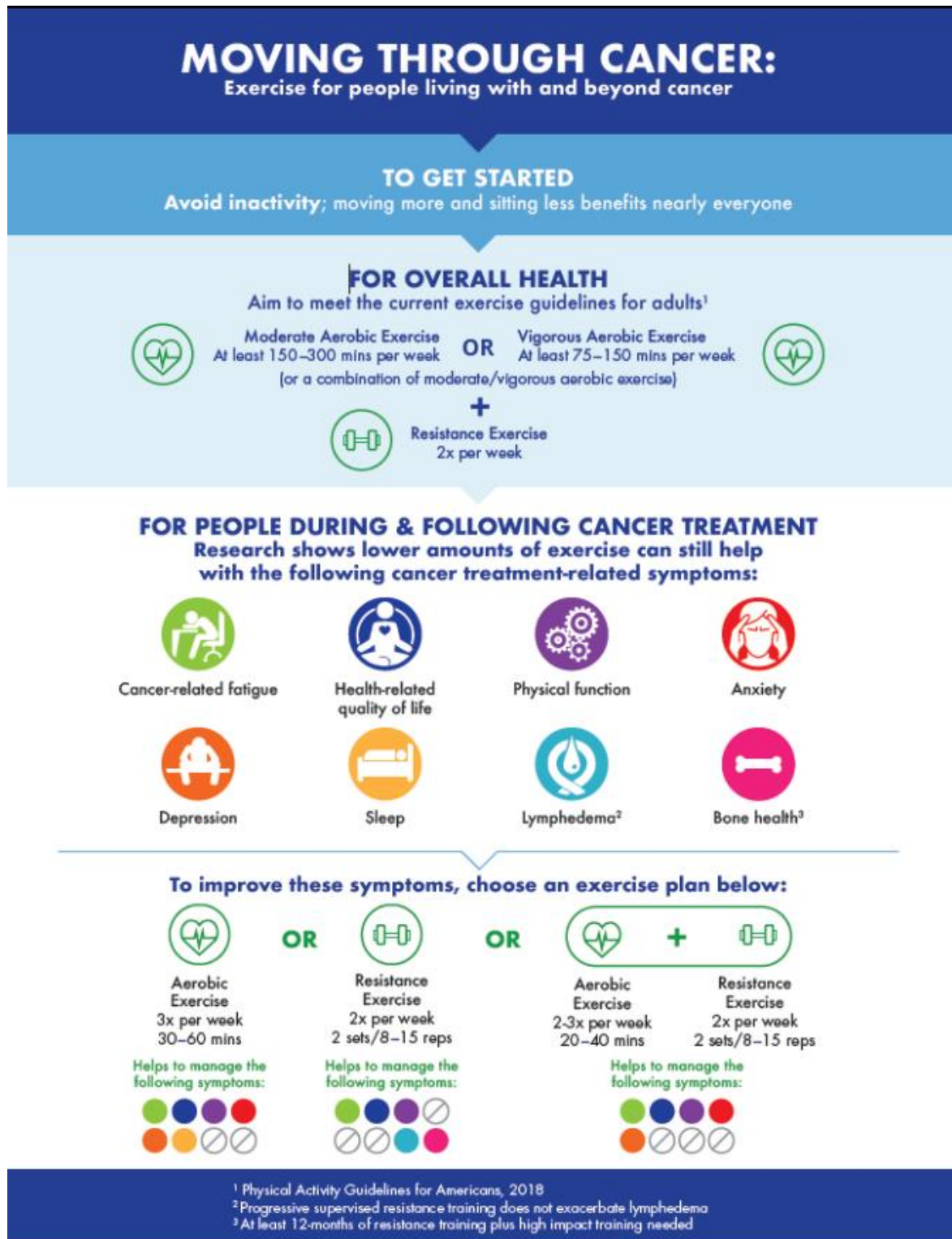


Figure 1.0 Consolidated infographic for the ACSM roundtable (2018) on exercise and cancer.

Figure 2.0 is another infographic developed from the ACSM roundtable (2018) containing information physical activity (activity type, intensity and duration) and health related outcomes in those with cancer (CRF, bone health and sleep). Health related outcomes are grouped based on strength of evidence, with strong evidence supporting physical activity to improve CRF, HRQoL, physical function, anxiety, depression and lymphedema and moderate evidence supporting improved bone health and sleep (Campbell et al. 2019). The ACSM roundtable found insufficient evidence to support physical activity improvement of cardiotoxicity, chemotherapy induced peripheral neuropathy, cognitive function, falls, nausea, pain, sexual function or treatment tolerance (Campbell et al. 2019). The following section shall synthesise the ACSM roundtable findings illustrated in figures 1.0 and 2.0.

Effects of Exercise on Health-Related Outcomes in Those with Cancer

What can exercise do?

- **Prevention of 7 common cancers***

Dose: 2018 Physical Activity Guidelines for Americans: 150-300 min/week moderate or 75-150 min/week vigorous aerobic exercise









- **Survival of 3 common cancers****

Dose: Exact dose of physical activity needed to reduce cancer-specific or all-cause mortality is not yet known; Overall more activity appears to lead to better risk reduction

*bladder, breast, colon, endometrial, esophageal, kidney and stomach cancers

**breast, colon and prostate cancers

Overall, avoid inactivity, and to improve general health, aim to achieve the current physical activity guidelines for health (150 min/week aerobic exercise and 2x/week strength training).

Outcome	Aerobic Only	Resistance Only	Combination (Aerobic + Resistance)
Strong Evidence	Dose	Dose	Dose
 Cancer-related fatigue	3x/week for 30 min per session of moderate intensity	2x/week of 2 sets of 12-15 reps for major muscle groups at moderate intensity	3x/week for 30 min per session of moderate aerobic exercise, plus 2x/week of resistance training 2 sets of 12-15 reps for major muscle groups at moderate intensity
 Health-related quality of life	2-3x/week for 30-60 min per session of moderate to vigorous	2x/week of 2 sets of 8-15 reps for major muscle groups at a moderate to vigorous intensity	2-3x/week for 20-30 min per session of moderate aerobic exercise plus 2x/week of resistance training 2 sets of 8-15 reps for major muscle groups at moderate to vigorous intensity
 Physical Function	3x/week for 30-60 min per session of moderate to vigorous	2-3x/week of 2 sets of 8-12 reps for major muscle groups at moderate to vigorous intensity	3x/week for 20-40 min per session of moderate to vigorous aerobic exercise, plus 2-3x/week of resistance training 2 sets of 8-12 reps for major muscle group at moderate to vigorous intensity
 Anxiety	3x/week for 30-60 min per session of moderate to vigorous	Insufficient evidence	2-3x/week for 20-40 min of moderate to vigorous aerobic exercise plus 2x/week of resistance training of 2 sets, 8-12 reps for major muscle groups at moderate to vigorous intensity
 Depression	3x/week for 30-60 min per session of moderate to vigorous	Insufficient evidence	2-3x/week for 20-40 min of moderate to vigorous aerobic exercise plus 2x/week of resistance training of 2 sets, 8-12 reps for major muscle groups at moderate to vigorous intensity
 Lymphedema	Insufficient evidence	2-3x/week of progressive, supervised program for major muscle groups does not exacerbate lymphedema	Insufficient evidence
Moderate Evidence			
 Bone health	Insufficient evidence	2-3x/week of moderate to vigorous resistance training plus high impact training (sufficient to generate ground reaction force of 3-4 times body weight) for at least 12 months	Insufficient evidence
 Sleep	3-4x/week for 30-40 min per session of moderate intensity	Insufficient evidence	Insufficient evidence

Citation: bit.ly/cancer_exercise_guidelines

Moderate intensity (40%-59% heart rate reserve or VO₂R) to vigorous intensity (60%-89% heart rate reserve or VO₂R) is recommended.



Figure 2.0 Infographic output from ACSM roundtable detailing effect of exercise on health-related outcomes in those with cancer.

Research has shown engaging in moderate- intensity aerobic training three times per week for at least 12-weeks can significantly reduce cancer-related fatigue both during and after treatment (Meneses-Echavez, González-Jiménez and Ramírez-Vélez 2015; van Vulpen et al. 2016). As seen in figure 2.0 moderate-intensity aerobic exercise plus resistance training sessions performed 2–3 times per week or twice weekly moderate intensity resistance training may also be effective at reducing CRF (Tomlinson et al. 2014; Cramp and Byron-Daniel 2012; Juvet et al. 2017).

Improvements in CRF have been found to be independent of supervision level and/or setting for training (Tomlinson et al. 2014; Keogh and MacLeod 2012). With regards to intensity, moderate to vigorous intensity exercise has the strongest effect on fatigue whereas the evidence for low intensity training currently suggests this would be unlikely to reduce fatigue (Meneses-Echavez, González-Jiménez and Ramírez-Vélez 2015, Juvet et al. 2017). Evidence suggests fatigue reductions are greater with exercise sessions longer than 30-minutes and programs longer than 12-weeks compared to shorter sessions and programs (Meneses-Echavez, González-Jiménez and Ramírez-Vélez 2015).

Improvements in HRQoL have been found to be greater in supervised training programs compared to unsupervised or home-based programs (Campbell et al. 2019). Figure 2.0 illustrates that combined moderate-intensity aerobic and resistance exercise performed 2–3 times per week, for at least 12-weeks, have been found to improve in HRQoL both during and after treatment (Lahart et al. 2018, Buffart et al. 2017, Sweegers et al. 2018). Findings from the ACSM roundtable suggest there is a greater benefit from engaging in combined aerobic plus resistance training programs, compared to only aerobic or resistance-based training programs (Sweegers et al. 2018).

Supervised exercise appears to be more effective to improve physical function compared to unsupervised or home-based interventions (Sweegers et al. 2018), although unsupervised programs may be effective in older cancer survivors (Swartz et al. 2017). Figure 2.0 illustrates moderate intensity aerobic training, resistance training or combined aerobic plus resistance training performed three times weekly for 8–12 weeks can significantly improve self-reported physical function in cancer patients and survivors (Buffart et al. 2017; Sweegers et al. 2018; Swartz et al. 2017).

Figure 2.0 illustrates that moderate intensity aerobic training three times per week for 12-weeks or twice weekly combined aerobic plus resistance training for 6–12 weeks can significantly reduce anxiety (Mishra et al. 2012a; Mishra et al. 2012b; Lahart et al. 2018) and depression (Brown et al. 2012; Craft et al. 2012) in cancer survivors during and after treatment. Improvements in anxiety and depressive symptoms are greater with supervised training programs compared to unsupervised or home-based programs (Campbell et al. 2019). High quality trials of aerobic exercise suggests that higher volumes of aerobic exercise (90-180 minutes/week) lead to better symptom reduction (Campbell et al. 2019). However, resistance training alone does not sufficiently reduce anxiety or depressive symptoms (Campbell et al. 2019).

Historically cancer patients and survivors were recommended to refrain from aerobic or resistance training to avoid onset or exacerbation of lymphoedema (Erickson et al. 2001; Petrek, Pressman and Smith 2000). The ACSM roundtable (2018) found that the evidence, which is limited to addressing upper extremity breast cancer-related lymphoedema, for this outcome is based on safety rather than lymphoedema prevention or improvement (Singh et al. 2016; Keilani et al. 2016; Nelson 2016; Campbell et al. 2019). Patients and survivors are recommended to engage in a supervised general progressive resistance training program focused on large muscle groups performed 2–3 times per week, with the principle of “start low, progress slow” (Ahmed, Thomas and Schmitz 2006; Courtney et al. 2007; Schmitz et al. 2009; Schmitz et al. 2010; Kilbreath et al. 2012). The roundtable concluded that there was insufficient evidence regarding the safety of other programs to make recommendations however, aerobic exercise may be safe for patients (Campbell et al. 2019; Lahart et al. 2018).

As seen in Figure, 2.0 limited recommendations can be made regarding exercise and bone health. Two systematic reviews in cancer survivors concluded that the evidence is inconsistent (Dalla, Daly and Fraser 2018; Fornusek and Kilbreath 2017), although RCTs with bone health as the primary outcome were largely consistent with the exercise recommendations made in the ACSM Position Stand regarding exercise and bone health (Kohrt et al. 2004). Aerobic training, particularly walking, does not appear to provide a sufficient stimulus to improve bone outcomes, which is consistent with RCTs in individuals without cancer (Campbell et al. 2019). However, evidence surrounding breast and prostate cancer patients in the post-adjuvant treatment setting, indicates a one-year supervised

program of combined moderate-vigorous intensity resistance plus high impact training (i.e., exercise that generates ground reaction forces above 3–4 times body weight) performed 2–3 days per week may be the most consistently effective modality to improve bone health (e.g., slow loss or slightly improve bone mineral density at the lumbar spine and hip) (Campbell et al. 2019). Currently, future research is required with regards to exercise and bone health (Campbell et al. 2019).

There is strong evidence that moderate to vigorous intensity aerobic training is associated with better overall sleep quality in the general population (PAGAC 2018) however evidence in the cancer population is mixed (Chiu et al. 2015; Mercier, Savard and Bernard 2017). A systematic review by Chiu et al. (2015) found a positive effect of walking on overall sleep quality yet another systematic review conducted in 2017, found no effect of exercise on sleep quality (Mercier, Savard and Bernard 2017). The ACSM roundtable concluded that there was moderate strength evidence for improved overall sleep quality for aerobic training (Rogers et al. 2009), walking (Chen et al. 2016; Roveda et al. 2017) and resistance training (Buffart et al. 2017) in cancer survivors. Figure 2.0 illustrates that moderate-intensity aerobic training, particularly walking, 3–4 times per week, for 30–40-minutes per session over 12-weeks is recommended to improve sleep in survivors (Campbell et al. 2019).

1.3.5 Physical Activity in Adolescent and Young Adult Oncology

Although the body of literature surrounding physical activity and cancer is growing the vast majority of this research has been conducted in adult cancer populations. As TYA's are diagnosed with different cancer types from older adults and have unique care needs it brings into question the generalisability of this evidence to a TYA population. When compared to the general population TYA cancer survivors are less likely to meet physical activity guidelines and they are less active and more sedentary than their siblings (Forsythe et al. 2013; Rabin and Politi 2010; Belanger et al. 2011a; Kimball et al. 2018).

Research into PA in the AYA population has reported that compared to paediatric and adults, the 18-39 cancer cohort remain underrepresented (Brunet, Wurz and Shallwani 2018) and there is a lack of clinical guidelines or recommendations for this population (Moraitis, Seven and Walker 2021).

A small review of the effects of PA on health and quality of life in adolescents (mean age= 14.0) reported PA to be safe and feasible. PA may also mitigate the reductions in bone mass and may be a viable strategy to improve fatigue, grip strength and HRQoL in adolescents however, high quality RCTs are required (Wurz and Brunet 2016). Furthermore, a 16-week community-based group PA program for adolescents (mean age= 16.2 +/- 1.6) was found to improve QoL, fatigue and self-reported PA. However, self-reported PA levels had declined at 3-month and 1-year follow-ups (Keats and Culos-Reed 2008).

The limited body of research into physical activity in TYA population suggests exercise programs to be feasible and safe for adolescent and young adult cohorts (Munsie et al. 2019; Moriatis, Seven and Walker 2021). However, the studies that have been conducted in this population often contain small sample sizes and lack robust methodologies (Munsie et al. 2019). Methodological challenges relate to how PA was operationalised, assessed and used in AYA research (Moraitis, Seven and Walker 2021). Furthermore, research suggests behavioural change interventions using online social media forums reportedly may promote PA in the 18-39 population and that targeted information/coaching is important in this population (Brunet, Wurz and Shallwani 2018).

1.3.6 Physical Activity Barriers and Motivators

Lack of time, being too busy and competing demands such as, work or family, have all been reported as physical activity barriers within AYA cancer studies (18–39-year-olds) (Rabin 2017; Kimball et al. 2017), adolescent cancer survivors (Wright et al. 2013) and within young adult childhood cancer survivors (YACCS) (Arroyave et al. 2008). Additionally, fatigue (Marchak et al. 2023; Adamovich et al. 2022; Arroyave et al. 2008; Wright 2015; Kimball et al. 2017), reduced strength (Marchak et al. 2023), pain (Wright 2015), illness or health issues (Wright 2015; Rabin 2017), physical limitations due to cancer treatment (Adamovich et al. 2022; Marchak et al. 2023) frustration with post-treatment body (Kimball et al. 2017), lack of motivation (Adamovich et al. 2022), boredom with exercise routines (Kimball et al. 2017) and not belonging to a gym (Arroyave et al. 2008) or lack of knowledge about AYA cancer specific resources (Kimball et al. 2017) have also been reported as barriers within AYA cancer survivors and YACCS.

Support from others (Kimball et al. 2017; Adamovich et al. 2022; Wright et al. 2013), social support from friends and self-monitoring (Valle et al. 2015) have

been reported as some of the biggest facilitators to physical activity in AYA cancer survivors and YACCS. The ability to track activity levels (Kimball et al. 2017), being male (Finnegan et al. 2007) and access to cancer specific resources (Adamovich et al. 2022; Kimball et al. 2017) have also been reported as facilitators of physical activity behaviours.

Finnegan et al. (2007) assessed correlates of physical activity behaviour in young adult survivors of childhood cancer (YASCC) from both an interaction model of client health behaviour (IMCHB) and transtheoretical model (TTM) perspective. Results of the study suggested that participants who were autonomously motivated and perceived fewer cons to being physical active were more likely to report being active than survivors who had low autonomous motivation and high perceived physical activity cons. Worries about the present and future were also seen to negatively impact on physical activity behaviours (Finnegan et al. 2007).

Poor physical activity engagement of TYA cancer survivors and patients despite the benefits outlined in sections 1.3.1-1.3.5 above highlights the need for TYA specific physical activity research. Chapter three of this thesis outlines a scoping review conducted to map the current literature surrounding physical activity and TYA cancer using the age range 16-25.

1.4 Behavioural Change Theories Relevant to this Thesis

1.4.1 Relevance to thesis

As this thesis will explore PA in relation to behaviours across the cancer journey as well as lived-experiences of PA including individual barriers, facilitators and support it is necessary to consider the theoretical underpinnings of behaviour and potential causal factors which influence PA engagement or behaviour change. Therefore, the following sections will provide an overview of relevant behaviour change theories and the practical application of these within PA research.

1.4.2 Behavioural Change Theories Overview

Within physical activity promotion, guidelines with broad statements encouraging people to achieve a certain amount of physical activity or simply telling them to "exercise more" has been found to be insufficient at eliciting behavioural change (Rhodes, McEwan and Rebar 2019). As a result, research into the internal and external factors that influence behaviour have been conducted and theoretical frameworks for understanding, explaining and intervening upon behaviours have been generated (Rhodes, McEwan and Rebar 2019).

There are multiple theoretical frameworks used within behaviour change research (Abraham and Michie 2008) and it is out with the scope of this research to discuss them all in depth. However, some of the most commonly used theories in physical activity research include the Social Cognitive Theory (SCT), the Transtheoretical Model (TTM), the Theory of Planned Behaviour (TPB), and the Self-Determination Theory (Buchan et al. 2012).

In the SCT, behaviour is determined by four factors; goals; outcome expectancies (physical, social and self-evaluative); self-efficacy (individuals' confidence in their ability to perform a behaviour) and socio-structural variables (factors which facilitate or inhibit behaviour) (Bandura 1997). Self-efficacy is the central construct within this model (Buchan et al. 2012). As seen in figure 3.0 it influences behaviour directly, through belief in one's ability to apply skills effectively in difficult situations, and indirectly through influence on goals, outcome expectations and barriers/facilitators (Bandura 2004; Stacey et al. 2015; Beauchamp, Crawford and Jackson 2019). Many physical activity interventions have applied the SCT by focusing on enhancing an individual's self-efficacy through goal setting, knowledge provision, self-monitoring of behaviour, behaviour modelling, behaviour prompting and positive reinforcement (Stacey et al. 2015).

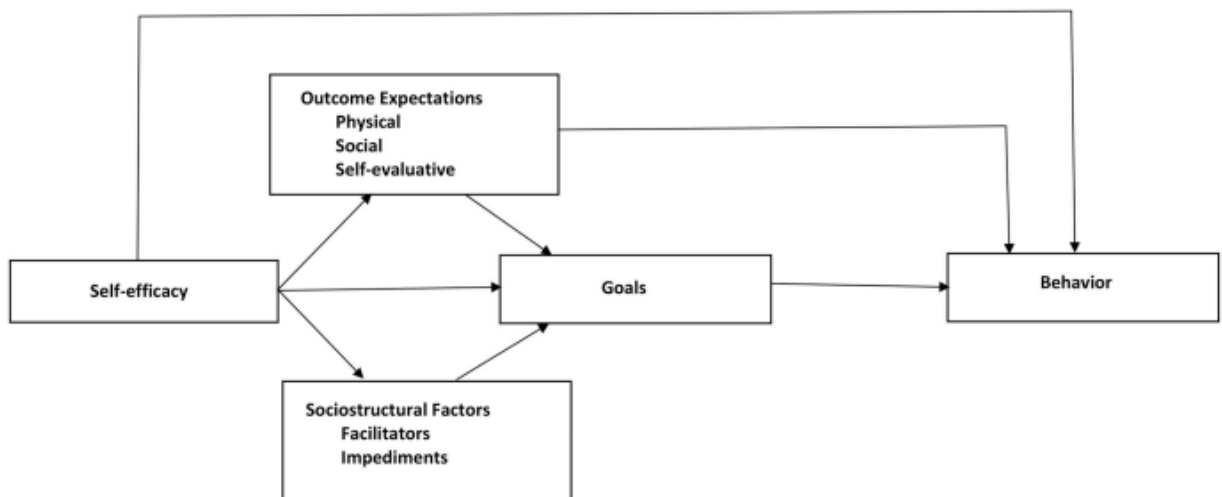


Figure 3.0 Illustration of the social cognitive theory (SCT) pathways (Bandura 2004) from Beauchamp, Crawford and Jackson (2019) "Social cognitive theory and physical activity: Mechanisms of behavior change, critique, and legacy" pp.111.

The TPB was developed from the theory of reasoned action, and aims to identify the influencing factors which shape an individual's behavioural intentions (Buchan

et al. 2012). There are three cognitive variables attached to behaviour intention within the TPB, these are: attitudes (negative and positive judgements based on a person's experiences), subjective norms and perceived behavioural control (extent to which an individual feels they have control over the desired behaviour when based with internal and external barriers) (Ajzen 1991). Although the TPB has been used to effectively predict physical activity behaviours, there are discrepancies in the literature regarding the strength of the behaviour-intention relationship (Downs and Hausenblas 2005). Additionally, a meta-analysis by Hagger, Chatzisarantis and Biddle (2002) found age to be a moderator of TPB with significantly weaker intention-behaviour relationship for PA in samples aged 25 and under. Further research is required into the moderating effects of subject characteristics within this framework (Buchan et al. 2012).

SDT focuses on the processes through which a person acquires motivation to initiate new health behaviours and maintain this over time (Buchan et al. 2012). There are three components within this theory: Autonomy (the feeling of choice and willingly endorsing one's behaviour); competency (experience of mastery and being effective in the behaviour) and relatedness (the need to feel connect and belonging to others within the behaviour). An individual needs to have an environment which promotes these three components in order to change and maintain their behaviour (Buchan et al. 2012).

The transtheoretical model (TTM), developed by Prochaska and DiClemente (1983), explains health behaviour change as a dynamic process whereby individuals pass through specific stages, characterised by patterns of psychosocial and behavioural changes (Buchan et al. 2012). Individuals are classified by their readiness to change into one of five stages: precontemplation (no intention of changing physical activity behaviour within the next 6 months); contemplation (serious consideration about changing physical activity behaviour but no physical behaviour change); preparation (strong intention to change physical activity behaviour with tentative or irregular behaviours taking place); action (recent initiation of regular physical activity behaviour); maintenance (the establishment of permanent behaviour for more than 6-months) (Ferron and Massa 2013; Hashemzadeh et al. 2019). This model is commonly displayed cyclically (as seen in figure 4.0) as individuals are likely to take several attempts at changing their behaviour prior to achieving the maintenance stage. Relapse is considered part of

the process as individuals learn from past regressions (Marcus and Simkin 1993; Buchan et al. 2012; Ferron and Massa 2013).

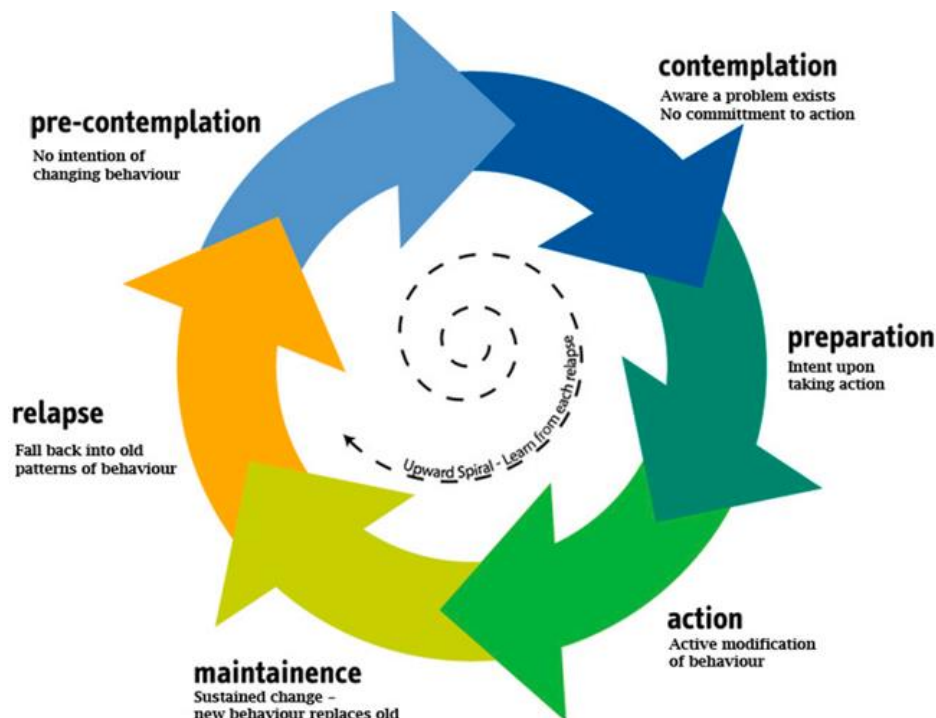


Figure 4.0 Visual representation of the transtheoretical model (TTM) based on Prochaska and DiClemente (1983).

These stages are referred to as an individual's 'stage of change'. Two influential factors which dictate an individual's stage of change are decisional balance and self-efficacy (Ferron and Massa 2013). Decisional balance refers to the perceived pros and cons (benefits and costs) related to engaging in a behaviour such as physical activity (Liu et al. 2018). Self-efficacy refers to an individual's confidence that they can engage in the positive behaviour and refrain from the negative behaviour (i.e., engage in physical activity and refrain from sedentary behaviour) (Liu et al. 2018).

The TTM states that in the initial stages of behavioural change (precontemplation, contemplation, preparation) the individual perceives the cons of carrying out the behaviour to outweigh the pros. However, as the individual moves through the stages (preparation, action and maintenance) and begins engaging in the behaviour the decisional balance reverses and the benefits are seen to outweigh the costs (Raihan and Cogburn 2023; Hashemzadeh et al. 2019). This change in decisional balance is related to self-efficacy as research has shown that an individual's self-efficacy increases with advancing stages (Liu et al. 2018).

These approaches have been popular in physical activity research because cognitive variables such as intention and self-efficacy represent reliable correlates of physical activity and have earned their utility in predicting physical activity behaviour (Rhodes, McEwan and Rebar 2019). A major benefit of these is that they are very efficient, usually involving questionnaire-based assessment at the individual level which is cost-effective and relatively simple (Rhodes, McEwan and Rebar 2019).

1.4.3 Practical Applications in Physical Activity Research

The use of theoretical frameworks has been shown to improve the effectiveness of behaviour change interventions (Bornstein and Davis 2014; Glanz and Bishop 2010; Noar, Benac and Harris 2007; Hashemzadeh et al. 2019) by facilitating researcher understanding of mediating factors and the reasons for intervention success or failure (Abraham and Michie 2008) and linking relevant causal factors to the appropriate change method (Bartholomew and Mullen 2011).

Gourlan et al. (2016) conducted a large meta-analysis (n=82) into the efficacy of theory-based RCT's to promote physical activity. The majority of the included interventions were based on a single theory (74%) however some contained multiple theories. The most commonly used single theory was the TTM (n=31) (Prochaska, Johnson and Lee 2009). The other behavioural change theories included in the review were the SCT (n=16) (Bandura 1997), TPB (n=8) (Ajzen, 1991), SDT (n=5) (Deci and Ryan, 2000) and the protection motivation theory (PMT; n=1) (Rogers 1983). Results demonstrated that theory-based interventions significantly impact the PA behaviour of participants. Moderation analyses revealed no efficacy difference between the theories (TTM, SCT, TPB and SDT), suggesting no clear benefit of one theory over another. This is in line with an earlier meta-analysis by Prestwich et al. (2013), which found no significant differences between the effect sizes of SCT-based interventions and TTM-based interventions at promoting physical activity and eating behaviours.

Gourlan et al. (2016) suggests that theoretical overlap may account for the absence of a differential effect between theories with self-efficacy a prime example of this. As outlined above this is the core construct within the SCT and is also present within the TTM, likely predicting trajectory of individuals through progression stages. Self-efficacy is also conceptually similar to the construct of 'perceived behavioural control' in the TPB and the need for competency in the SDT

(Gourlan et al. 2016). Due to this overlap, researchers have highlighted the importance of categorising and defining the specific constructs and/or behavioural change techniques utilised in interventions to allow intervention effectiveness to be related to the appropriate intervention component (Abraham and Michie 2008). Furthermore, if the content of an intervention is described in terms of discrete techniques and translated into clear practical procedures and materials it facilitates adoption and replication and increases replication fidelity in future studies (Abraham and Michie 2008).

However, these approaches have been criticised as being too simplistic, focusing on changing the behaviour of the individual and less on the environment (Buchan et al. 2012). Cognitive-behaviour modifications have been shown to be beneficial in the short-term, yet there is growing concern over short-lived effects of these interventions (Marcus et al. 2000; Conn et al. 2011). There is a large disconnect still between knowledge of physical activity benefits and physical activity prevalence in the population (Rhodes and de Bruijn 2013). This has been argued to be an over-reliance on the individual as the agent of change as opposed to considering the wider social, environment and political factors which influence behaviour (Rhodes, McEwan and Rebar 2019).

Within the past two decades other frameworks assessing PA behaviour from multiple levels of influence have gained traction (Buchan et al. 2012; Rhodes, McEwan and Rebar 2019). One of these is the Socioecological Model (SEM). The SEM, constructed by Bronfenbrenner (1979), proposes that behaviour is not only influenced by individual factors but also by broader social, physical, policy and environmental factors (Stokols 1992). It suggests five interrelated levels of behaviour determinants: intrapersonal (e.g., age, sex, cognitive characteristics), interpersonal (e.g., formal and informal social networks and social support systems), organisational (organisations or social institutions with rules e.g., clubs or school), community (e.g., built environment, community leaders, businesses transportation) and environment and/or policy level factors (local, national and global policies and laws) (Rhodes, McEwan and Rebar 2019). Terminology used to categorise these levels varies and has been adapted for physical activity behaviours. Figure 5.0 illustrates the SEM adapted for physical activity (Birtwistle et al. 2019). It should be noted that the SEM is entirely complementary with individual-level approaches (such as SCT or TTM) as it places individuals as actors within a broader system (Sniehotta et al. 2017).

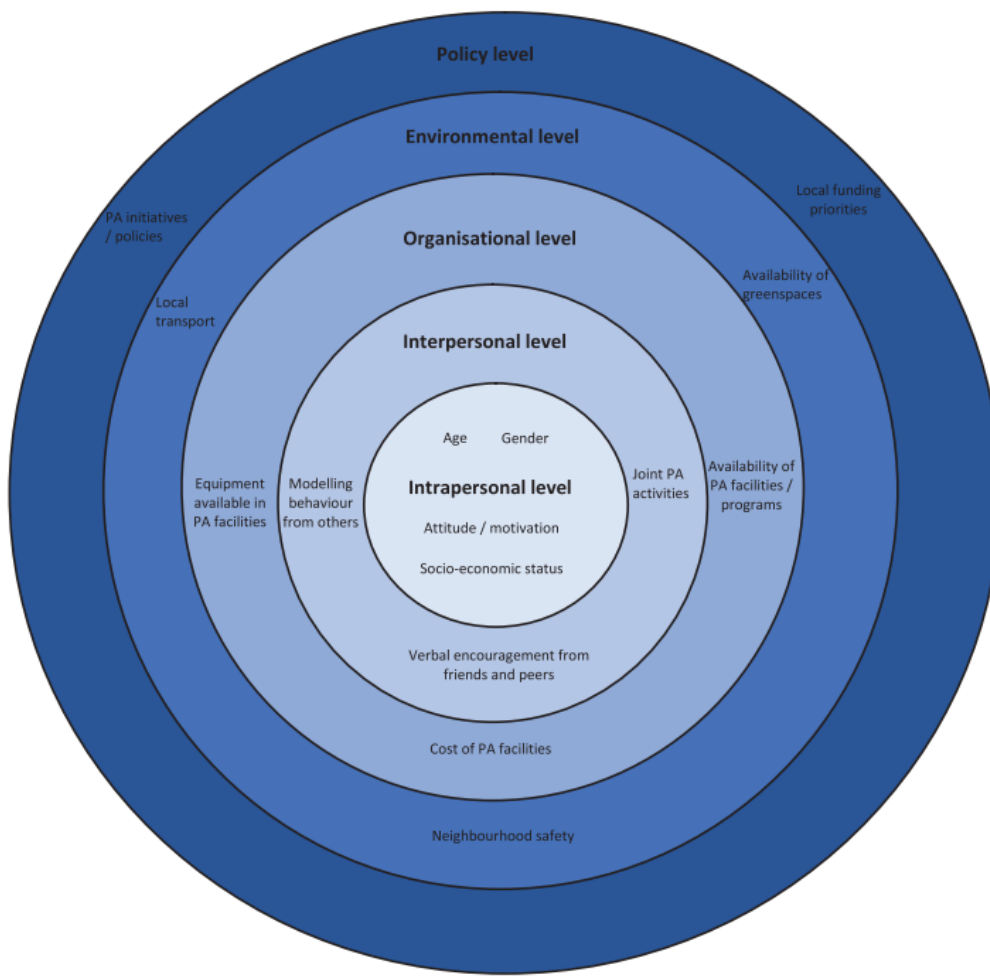


Figure 5.0 Physical activity adapted Socioecological model including adapted from Birtwistle et al. (2019).

Pugh et al. (2016) conducted a systematic review into health behaviour change interventions for TYA cancer survivors. Physical activity behaviour was investigated in eight of the thirteen (n=5 physical activity only and n=3 multiple behaviours including physical activity) papers included in the review. Of those eight papers however only one (Keats and Culos-Reed 2008) met the target population of this study, the remaining seven papers were AYA's (within the north American age bracket of 18-39) or young adult aged survivors of childhood cancers. There was a large combination of theoretical models and behavioural change techniques utilised within these studies; two adopted the SCT (Huang et al. 2014; Valle et al. 2013), two adopted the TPB (Belanger et al. 2014; Keats and Culos-Reed 2008), one the TTM (Li et al. 2013), one the theory of reasoned action (Berg et al. 2014), one the health belief model (Cox et al. 2005) and one did not use any underlying theory (Jarvela et al. 2012).

Due to the heterogeneity of samples this review was unable to investigate relationships between intervention efficacy and theoretical design (Pugh et al. 2016).

However, of the eight physical activity interventions four studies reported a significant change in physical activity behaviour. Valle et al. (2013) used the SCT to conduct a Facebook-based intervention which included goal setting, self-monitoring content and social support. At follow-up (3 months later) a significant improvement in moderate intensity physical activity, light physical activity and total physical activity was seen in the intervention group. Lie et al. (2013) utilised TTM to conduct an adventure-based training and health education program. The program intervention components included social support, goal setting and action planning (Pugh et al. 2016). At 9-month follow up there was a significant increase in self-reported physical activity and self-efficacy of the intervention group compared to the control (Pugh et al. 2016). Keats and Culos-Reed (2008) utilised the TPB and conducted a 16-week education and exercise intervention including goal setting, late effects and risk counselling and incentives. A significant increase in physical activity was seen between baseline and mid-intervention however this was not maintained at 3-month follow up. Finally, Jarvela et al. (2012) conducted a home-based exercise program with telephone counselling and included social support and goal setting. At the end of the intervention a significant increase in physical activity behaviours was observed.

As discussed above, there is a lack of conclusive evidence regarding the most effective theoretical framework to underpin physical activity interventions in TYA cancer patients and survivors. Both the TTM and the SEM of behaviour change were considered for this study in relation to participants physical activity behaviours and their underlying barriers and facilitators to engagement. This was to ensure a comprehensive assessment of the individual; social and environmental factors of PA behaviour were explored.

CHAPTER 2: SCOPING REVIEW

2.0 Chapter Outline

This chapter will present the literature surrounding PA in the TYA oncology setting to provide an in-depth synopsis of the area and justify the need for this doctoral thesis. The aim of this chapter is to map the evidence on physical activity in TYA cancer populations as this has not been reported previously. Firstly, the choice of literature review methodology will be discussed, and the scoping review approach adopted within this chapter justified. Following this, the inclusion criteria and methodological steps of this scoping review will be outlined and the findings discussed. Lastly, the overarching research question and objectives of this thesis informed by the findings of the scoping review will be outlined.

2.1 Scoping Review Justification

Evidence synthesis systematically gathers, summarises, and maps previous research on a specific topic (Snyder 2019), with the aim to add value to the literature base (Van Wee and Banister 2016). They can add value by synthesising empirical insights, methodologies or theoretical frameworks, identifying research gaps or real-world applications as well as providing guidance for future research (Van Wee and Banister 2016; Snyder 2019).

There are a number of ways in which the research base surrounding a topic area can be reviewed and synthesised (Snyder 2019). When deciding which review type to adopt considerations must be given to the research question(s) of the review, the volume of previous literature in the topic area and the depth of analysis intended (Snyder 2019).

Narrative, systematic, umbrella and scoping are all different types of evidence synthesis (Sutton et al. 2019). Narrative reviews can provide a broad overview of the topic area (Ferrari 2015) but are subject to bias as they can often lack transparency and may overtly advance a particular organisational or personal viewpoint (Sutton et al. 2019). As this evidence synthesis was conducted as part of a doctoral research programme a more robust type of review approach was selected to ensure methodological rigour.

Systematic reviews are the gold standard of literature reviews, as they are reliable and replicable (Munn et al. 2018), as they follow a robust methodology which is designed to minimise bias (Munn et al. 2018; Sutton et al. 2019). Characteristics of systematic reviews include clearly defined questions and selection criteria and

critical appraisal of research and findings (Synder 2019). However, this can only be undertaken if there is a sufficient number of studies to answer the research question(s) (Munn et al. 2018).

Umbrella reviews compile and compare systematic review findings on a specific research topic (Belbasis, Bellou and Loannidis 2022). As with systematic reviews this type of review requires an adequate number of pre-existing research to be conducted using a shared methodology to allow for comparison and analysis (Sutton et al. 2019; Belbasis, Bellou and Loannidis 2022).

Scoping reviews can be used to map concepts and theories underpinning a research area, and include a broad range of sources and types of evidence (Arksey and O'Malley 2005; Tricco et al. 2018a). Scoping reviews can also be used to identify knowledge gaps within the research base (Tricco et al. 2018b). Both scoping reviews and systematic reviews follow rigorous, transparent methods (Munn et al. 2018) however, scoping reviews are appropriate when the review is asking broad, typically descriptive questions about what has previously been researched in a topic area, whereas, systematic reviews are more appropriate when addressing focussed questions (Tricco et al. 2018a; Khalil et al. 2021).

As illustrated in chapter one, there is a growing body of research showing PA to be beneficial and safe for individuals with an active cancer diagnosis (Segal et al. 2017) as well as cancer survivors (Segal et al. 2017; McTiernan et al. 2019). However, historically this research has focused on paediatric or older adult populations (Munsie et al. 2019). Limited research has been conducted on the physical activity behaviours of young people, despite the NICE guidelines recommending this patient population be treated as a distinct group (NICE 2014). Therefore, the generalisability of the current evidence base for PA and cancer for a TYA population comes to question.

When deciding the most appropriate review type for this thesis a preliminary search (via CINHALL and MEDLINE using the terms "physical activity, "cancer" and "young adults") for systematic reviews and scoping reviews on this topic did reveal previously published literature reviews on PA within a TYA oncology population however, upon closer inspection these reviews did not comprise studies predominantly meeting the UK TYA age range.

Three scoping reviews (Brunet, Wurz and Shallwani 2018; Moraitis, Seven and Walker 2021; Caru et al. 2022) and two systematic reviews (Munsie et al. 2019;

Crowder, Buro and Stern 2021) on PA in the TYA oncology population were identified. Two of these scoping reviews (Brunet, Wurz and Shallwani 2018; Caru et al. 2022) only included two papers with a mean age meeting the UK TYA definition and a third scoping review conducted in 2021, focused on young adult cancer survivors aged between 18-39, included studies if 25% of their sample met their YA inclusion criteria meaning the samples of included studies again were not representative of UK TYA age range (Moraitis, Seven and Walker 2021). This was also the case with the 2021 systematic review conducted by Crowder, Buro and Stern which included studies with paediatric mean ages.

Lastly, a 2019 systematic review on the benefits of PA in young adults during and after cancer using an age range definition of 15-25 was identified. However, this review used the inclusion criteria of >50% of participants aged between 15-25 years old and only focused on PA interventions and not the wider area of PA in any context (Munsie et al. 2019).

Based on the above, it was deemed most appropriate to conduct a scoping review as there is still a need to map all the literature surrounding PA, 16-25 aged TYA population, as well as identify potential knowledge gaps.

The following sections outline the methodological process of this scoping review including: the research questions, inclusion criteria, types of considered sources, search strategy, data extraction process and analysis, review findings, discussion, and recommendations for future research and practice.

2.2 Research Questions

The research questions addressed by this review were:

1. What information has been reported about physical activity in young adults with cancer/ young adult cancer survivors?
2. What interventions for physical activity have been reported for young adults with cancer/young adult cancer survivors?
3. What are the components of physical activity interventions described in the literature for young adults with cancer/young adult cancer survivors?
4. What are the barriers and facilitators to physical activity in young adults with cancer/young adult cancer survivors?
5. What are the research gaps in physical activity research in young adults with cancer/young adult cancer survivors?

2.3 Inclusion Criteria

The inclusion criteria were defined for this scoping review using the “PCC” mnemonic, relating to the Participants, Concept of interest and the Context (Pollock et al. 2023).

2.3.1 Participants

Any individual diagnosed with any type of cancer when aged between 16-25 years old were included. Sources of evidence including cancer survivors up to the age of 35 were also included if participants mean age at diagnosis was between 16-25 years. Sources with ages out with this range were included if data relevant to the review population age range could be extracted. Sources of evidence including paediatric or older adult cancer patients were excluded.

2.3.2 Concept

The concept was physical activity within young adults with cancer and young adult cancer survivors. Physical activity is defined as: “any bodily movement produced by skeletal muscles that requires energy expenditure. Physical activity refers to all movement including during leisure time, for transport to get to and from places, or as part of a person’s work” (World Health Organization 2020). Sources of evidence including but not limited to physical activity, exercise, activities of daily living or physical activity in combination with behavioural interventions at any stage of the cancer continuum (diagnosis, during treatment, maintenance and after) were considered for inclusion.

2.3.3 Context

The context included any setting such as hospital inpatient or outpatient, gym, community or home setting. This review included any geographic location, culture, or gender as this was an initial mapping of the research in this specific population.

2.3.4 Types of Sources

This scoping review considered any study type to ensure a comprehensive map on the topic was produced. This included experimental and quasi-experimental study designs including randomised controlled trials (RCT), non-randomised controlled trials and before and after studies. In addition, analytical observational studies, and descriptive observational study designs. Qualitative studies, that focused on qualitative data including, but not limited to, designs such as phenomenology, grounded theory, ethnography and qualitative description, were also considered. In addition, systematic reviews that met the inclusion criteria were also included.

2.4 Methods

The scoping review was conducted in accordance with the JBI methodology for scoping reviews (Peters et al. 2020) which is the most up to date guidance for the conduct of scoping reviews. The open access protocol for this review, was registered on the Open Science Framework (OSF) (DOI 10.17605/OSF.IO/73P5B). This review has been reported in line with the Systematic Reviews and Meta-analyses extension for scoping review (Tricco et al. 2018b).

2.4.1 Search Strategy and Information Sources:

The search strategy aimed to identify both published and unpublished sources of evidence. Searches followed the JBI three-step search strategy (Peters et al. 2020). An initial exploratory search of MEDLINE and CINAHL was undertaken (using the keywords: exercise, physical activity, cancer and young adults) to identify articles on this topic. From this, the search strategy was developed in conjunction with the review team, NHS TYA oncology service provider (TYA physiotherapist) and an information specialist accessed via RGU library. Text words contained in the titles and abstracts of relevant articles, and index terms used to describe the articles were used to develop the full search strategies. The search strategy, including all identified keywords and index terms, was adapted for each included database and information source. Full search strategy by database can be found in Appendix 2. All search strategies were piloted and amended before the final searches were conducted to ensure specificity and sensitivity of the search. Lastly, reference lists of all included sources of evidence after full text screening were reviewed for additional studies.

The databases searched included MEDLINE, CINAHL, AMED, SPORTDiscus, SAGE Discipline Hub: Health and Nursing, PEDRo (all accessed through the EBSCOHost platform via the Robert Gordon University library) and EMBase (accessed through Ovid via NHS Scotland Knowledge Network). Unpublished literature was searched for via: Google Scholar, EThoS, National Institute of Health and Care Excellence (NICE) Evidence, Centers for Disease Control and Prevention (CDC), McMillian Cancer Research, Cancer Research UK, Teenage Cancer Trust, National Institute of Health (NIH) National Cancer Institute (NCI), Teen Cancer America, International Standard Randomised Controlled Trials Number Registry (ISRCTNR), Shine Cancer Support, Trekstock, Young Lives vs Cancer, Canteen, EU Clinical Trials Register (EU-CTR), ClinicalTrials.gov, Australian and New Zealand Clinical Trials Registry (ANZCTR).

Searches were conducted between 28th August- 2nd September 2021 and then updated between 1st-15th July 2022 to include further relevant information. Search parameters were limited by English language, as there are no financial resources to support translation costs, and studies published after January 2010, to ensure relevance of information to current practice. For Google Scholar searches were limited to 15 pages (150 results) or 5 consecutive pages without results.

2.4.2 Screening for Inclusion:

Following the searches, all identified citations were collated in ProQuest® RefWorks and duplicates removed. Sources were then imported to Covidence (v2477; Veritas Health Innovation, Melbourne, Australia) management software for two-level screening.

The review team comprised of five researchers: the doctoral student (EM) and four thesis supervisors (LA, JH, EH, DW). The large size of the review team was dictated by supervisors' workload capacity. Following piloting, title and abstracts were screened independently by the doctoral student researcher (EM) and a second reviewer (JH, LA). Good agreement (88%) was seen across reviewers, conflicts were identified by Covidence and resolved by a third reviewer (EM, LA). Full-text copies of all included sources following the title and abstract screening were then uploaded to Covidence. Full texts were again independently screened by two reviewers (EM, LA, DW, EH) with an agreement of 69%. Again, all conflicts were resolved by a third reviewer.

2.4.3 Data Extraction:

As per JBI methodological guidance, a bespoke data extraction tool was developed for this review in Microsoft Excel (Peters et al. 2020). The doctoral research student developed the extraction tool based off JBI methodological guidance and discussions with the supervisory team, who all had experience conducting reviews, regarding efficient data extraction methods, key demographic information, the review research questions and the type of information being extracted. This maximised efficiency during data extraction as the tool used was tailored towards the review questions.

Piloting and iterative development of the data extraction tool was conducted by the review team prior to commencing final extraction. Reviewers independently piloted the tool followed by team discussion and consistency agreement for

extraction via Microsoft teams. Amendments to the tool were made over 4 rounds of piloting by the review team prior to final data extraction commencing.

The following demographic information was extracted from the included primary studies: author(s), year of publication, country, study design/source type, aim/purpose, methodology, method, study setting, sample size, participant information (gender, age range/mean, other demographics), cancer information (diagnosis range/type, stage, age at diagnosis, treatment). Additionally, one author provided additional data following contact from the researchers.

Extracted data related to the review questions included: PA intervention (type and components), primary outcomes, secondary outcomes, analysis approach, barriers to PA, facilitators of PA, physical activity results, PA guidance/advice, qualitative PA results and author key findings. Physical activity intervention components were mapped against the Template for Intervention Description and Replication (TIDieR) checklist (Hoffman et al. 2014). This was included to identify the consistency of intervention component reporting across included intervention studies (Hoffman et al. 2014). The TIDieR tool has been widely used in health research and has been used in previous reviews of physical activity interventions (Howlett et al. 2019; Madden et al. 2020) including oncology populations (Grimmett 2019; Mbous, Patel and Kelly 2020; Cross, Howlett and Sheffield 2020).

All five researchers extracted data from the included studies (EM, LA, JH, EH, DW).

2.4.4 Data Analysis and Presentation

Search results, data screening and inclusion process is summarised in the flow diagram below (figure 6.0). This has been adapted from the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) statement (Page et al. 2021) to ensure transparency within this review. Characteristic data of included studies and study participant population is synthesised and described narratively. The five research questions outlined in section 2.2 are then answered with supporting figures and tables.

2.5 Results

2.5.1 Study Inclusion

As can be seen in the PRISMA flow diagram (figure 6.0) 1,675 records were identified from database screening and an additional 92 records were retrieved from grey literature searches (Google Scholar, ISRCTNR and ClinicalTrials.gov).

Following removal of duplicates, 1,080 records underwent title and abstract screening. Of these, 784 were deemed irrelevant and 296 records proceeded to full text screening. Following full-text screening a total of 44 studies met inclusion criteria and were therefore included in the review. As seen in figure 6.0 the main rationale for citation exclusion was wrong study population (n=161), however, duplication (n=33), wrong study concept (n=28), population not defined (n=24) or being unable to access the study (n=4) or extract data (n=5) were additional reasons for exclusion. A full list of excluded studies and exclusion rationale can be found in Appendix 3.

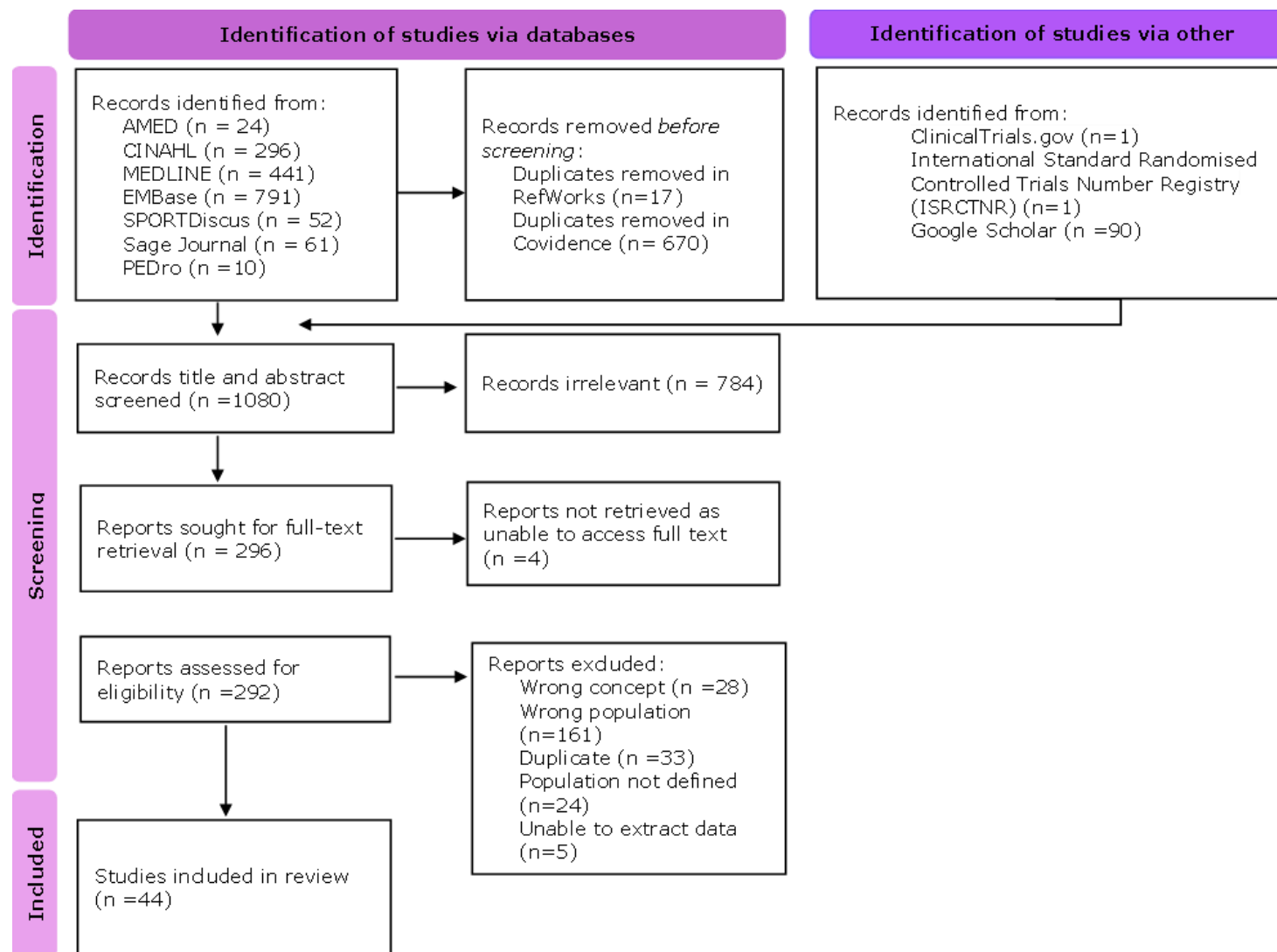


Figure 6.0 Adapted PRISMA flow diagram (Page et al. 2021) of search results and study inclusion process.

To support transparency and readability of the scoping review results, the included studies have been allocated a reference number (see table 6.0) which will be used to refer to the individual study in the rest of the results and discussion sections. This is a change from the Harvard referencing style adopted in the rest of the thesis to avoid large sections of references in the text. See appendix 4 for a full reference list of included studies.

Table 6.0 Included scoping review studies with corresponding reference number.

Reference Number	Author and year	Reference Number	Author and year
1	Atkinson et al. 2021	23	Mooney et al. 2017
2	Salchow et al. 2021	24	Wallis, Meredith and Stanley 2021
3	Munsie. 2021a	25	Smith et al. 2021
4	Munsie. 2021b	26	Hanghoj et al. 2021
5	Murnane et al. 2019	27	Kuntz et al. 2019
6	Yurkiewicz et al. 2018	28	Pugh et al. 2018
7	Smith et al. 2019	29	Devine et al. 2018
8	Diorio et al. 2018	30	McGrady et al. 2022
9	Murnane et al. 2021	31	Munsie 2021c
10	Murnane et al. 2015	32	Pitch et al. 2022
11	Pugh et al. 2017	33	Baker et al. 2021
12	Sawyer et al. 2017	34	Shaw et al. 2022
13	Deleemans et al. 2021	35	Roggenkamp et al. 2022
14	Spreafico et al. 2021	36	Arbit, Buck & Ladas 2014
15	Pugh et al. 2020	37	Atkinson & Osborn 2012
16	Rosipal et al. 2013	38	Mackland & Chesman 2019
17	Marec-Berard et al. 2021	39	Munsie, Collins & Plaster 2019
18	Bekkering et al. 2010	40	Salchow et al. 2017
19	Psihogios et al. 2020	41	Schwartz et al. 2016
20	Wu et al. 2019	42	Valle et al. 2021
21	Spathis et al. 2017	43	Salchow et al. 2020
22	Wu et al. 2015	44	Jong et al. 2022

2.5.2 Characteristics of Included Studies

As seen in Table 7.0 the 44 included studies consisted of a variety of study designs including: randomised controlled trials (RCT) n=4 ^(1,2,3,4), cohort studies (n=3)^(5,6,7), cross-sectional studies (n=5)^(8,9, 10, 11,12), comparison studies (n=3)^(13, 14, 15), pilot intervention (n=1)⁽¹⁶⁾, feasibility study (n=1) ⁽¹⁷⁾, mixed-methods (n=2) ^(18, 19), qualitative (n=8) ^(21, 22, 23, 24, 25, 26, 27, 28), secondary analysis (n=1)⁽²⁰⁾, narrative review (n=1)⁽²⁹⁾, retrospective audit (n=3)^(30,31,32), service evaluation (n=1) ⁽³³⁾, quality improvement initiative (n=1) ⁽³⁴⁾, abstracts/poster abstracts (n=7) ^(35, 36, 37, 38, 39, 40, 41), study protocols (n=3) ^(42, 43, 44).

Table 7.0 Characteristics of included studies.

Type of Study (n=44)		Country of Origin (n=44)	
Qualitative	n= 8 (18%)	USA	n= 15 (34%)
Abstract/ poster abstract	n= 7 (16%)	Australia	n= 12 (27%)
Cross-sectional studies	n= 5 (11%)	UK	n= 6 (14%)
Randomised controlled trials (RCT)	n= 4 (9%)	Germany	n= 3 (7%)
Retrospective audit	n= 3 (7%)	Canada	n= 2 (5%)
Study protocols	n= 3 (7%)	Italy	n= 1 (2%)
Cohort Studies	n= 3 (7%)	Netherlands	n= 1 (2%)
Comparison studies	n= 3 (7%)	France	n= 1 (2%)
Mixed-methods	n= 2 (5%)	Denmark	n= 1 (2%)
Pilot intervention	n= 1 (2%)	Sweden	n= 1 (2%)
Feasibility study	n= 1 (2%)	Taiwan	n= 1 (2%)
Secondary analysis	n= 1 (2%)	Sample Size (n=40)	
Narrative review	n= 1 (2%)	<10	n= 2 (5%)
Service evaluation	n= 1 (2%)	10-19	n= 3 (8%)
Quality improvement initiative	n= 1 (2%)	20-29	n= 2 (5%)
Year of publication (n=44)		30-39	n= 5 (13%)
2010-2011	n= 1 (2%)	40-49	n= 8 (20%)
2012-2013	n= 2 (5%)	50-59	n=4 (10%)
2014-2015	n= 3 (7%)	60-69	n= 2 (5%)
2016-2017	n= 6 (14%)	70-79	n= 1 (3%)
2018-2019	n=10 (23%)	80-89	n= 5 (13%)
2020-2021	n=18 (41%)	90-99	n= 3 (8%)
2022	n= 4 (9%)	100+	n= 5 (13%)
		Narrative review (no. of included studies)	n= 40

Most research originated from western countries (n=43, 98%) including North America = 17 (36, 29, 8, 27, 19, 41, 22, 6, 23, 42, 16, 30, 34, 25, 35, 13, 32); Europe= 14 (2, 40, 43, 14, 18, 17, 44, 38, 15, 28, 21, 11, 33) and Australia=12 (7, 3, 4, 31, 24, 1, 37, 9, 39, 10, 5, 12), with only one study originating from Asia (20). Only six (14%) of the 44 included studies were conducted in the UK (38, 15, 28, 21, 11, 33). The sample size of included studies (n=40) varied greatly, ranging from 4-355 participants. This could be due to the inclusion of a wide range of different study types in the review. The one narrative review included referenced 40 studies (29). Table 7.0 demonstrates that research interest

into PA within a TYA oncology population has increased in recent years with the majority (n=32, 73%) of included studies published in the last 5 years (2018-2022) (1, 2, 3, 4, 5, 6, 7, 8, 9, 13, 14, 15, 17, 19, 20, 24, 25, 26, 27, 28, 29, 30, 31, 32, 33, 34, 35, 38, 39, 42, 43, 44).

2.5.3 Characteristics of Included Study Participants

Excluding the three study protocols (42, 43, 44), as there was no published data for these, Table 8.0 illustrates the participant characteristics of the included studies (n=41).

The sample size of included studies (n=41) varied greatly, ranging from 4-355 participants representing 2,954 participants, 1,326 females, 1,112 males and 516 unknown genders. The race/ethnicity of study participants was poorly reported across included studies but for those that did (n=10) (8, 11, 15, 19, 23, 27, 30, 35, 36, 41), samples were homogeneous for White participants, with only one study reporting a majority of Hispanic participants (27).

Participants were predominantly young adults at time of study completion, with table 8.0 showing n=25 (61%) of included studies having a mean or median participant age within the young adult age group compared to n=7 (17%) in the adolescent group. Mean age of participants across included studies was 20.4 years at time of study completion. Age at time of cancer diagnosis was poorly reported across included studies with 61% of studies (n=25) not reporting participants diagnosis age, however, for those that did the mean age of participants was 18.5 years.

Furthermore, as seen in table 8.0.0 study samples were heterogenous across all stages of the cancer journey including: newly diagnosed patients, patients on-treatment, post-treatment and long-term cancer survivors. The most common cancer status of participants was those on-treatment and cancer survivors, (36.6% and 34% respectively). Table 8.0 also highlights that study participants were diagnosed with a variety of different cancer types, the most common of which was Lymphoma and Leukaemia. The type of cancer treatment participants received was again inconsistently reported across studies with 53.7% (n=22) not reporting treatment type. For those that did the most reported treatment types were chemotherapy (n=13 studies, 32%), radiotherapy (n=12 studies, 29%) and surgery (n=9 studies, 22%).

Table 8.0 Sample characteristics of included studies (n=41).

Cancer Type		Cancer Treatment	
Lymphoma	n= 29 (71%)	N/R	n= 22 (53.7%)
Leukaemia	n= 28 (68%)	Chemotherapy	n=13 (32%)
Other	n= 20 (49%)	Radiotherapy	n= 12 (29%)
Sarcoma	n= 19 (46%)	Surgery	n= 9 (22%)
Germ Cell	n= 17 (42%)	Bone marrow/Stem cell transplant	n= 5 (12%)
Central Nervous System (CNS)	n= 16 (39%)	Combined treatment	n= 4 (9.8%)
Solid tumours	n= 9 (22%)	Other	n= 4 (9.8%)
Haematological	n= 6 (15%)	Hormone therapy	n= 1 (2.4%)
N/R	n= 6 (15%)	Alternative therapy	n= 1 (2.4%)
Cancer status		N/A	n=1 (2.4%)
On-treatment	n= 15 (36.6%)	Mean/median age at Diagnosis	
Cancer survivors	n= 14 (34%)	N/R	n=25 (61%)
Post-treatment	n= 12 (29%)	Young adult	n=10 (24.4%)
Active diagnosis	n= 4 (9.8%)	Adolescent	n=6 (15%)
End of treatment	n= 4 (9.8%)	Mean/median age at time of study	
Newly diagnosed	n= 4 (9.8%)	Young adult	n=25 (61%)
N/R	n= 3 (7.3%)	Adolescent	n=7 (17%)
N/A	n= 1 (2.4%)	N/R	n=6 (15%)
		25+	n=3 (7.3%)

N/R= not reported; N/A= not applicable.

A full table of the individual study and participant characteristics, with corresponding reference number, for each included study can be found in Appendix 5.

2.5.4 What information has been reported?

Using an inductive coding approach, five core areas that PA studies in this population reported information on were identified: 1) Needs and concerns of TYA cancer patients and survivors 2) Impact of cancer on TYA related PA 3) Health behaviour (HB) information 3) Health behaviours (HB's) of TYA's 5) Interventions. Each topic area and the subsequent sub-themes are outlined below. Some included studies contained information relation to multiple topic areas.

2.5.4.1 Needs and Concerns of TYA Patients and Survivors

Studies that investigated the concerns and needs of TYA cancer patients and survivors (n=6) ^(12; 7; 27; 32; 38; 33) identified TYA needs and concerns from end-of-treatment clinics ^(38; 33), an AYA program at a cancer care centre ⁽³²⁾, online forums/AYACS community-based discussion boards ^(27; 25) and an Australian national survey of 15-25-year-olds with cancer ⁽¹²⁾.

Table 9.0 Identified needs & concerns of TYA patients and survivors.

	Needs and Concerns identified
Exercise/Physical concerns identified (N=3)	<p>Reduced exercise tolerance ^(25;32)</p> <p>Treatment related effects (pain, body composition changes, fatigue, avascular necrosis, musculoskeletal concerns) ⁽²⁵⁾</p> <p>Loss of strength ⁽²⁷⁾</p> <p>Unable to participate in preferred sports activity ⁽²⁷⁾</p>
PA needs identified (N=4)	<p>Daily PA encouragement during treatment ⁽²⁷⁾</p> <p>Need for PA advice regarding return to activity, keeping active and going to the gym post-treatment ⁽³³⁾</p> <p>Signposting to support services ⁽³³⁾</p> <p>Fatigue management and support regarding mobility issues ⁽³⁸⁾</p> <p>TYA specific support group ⁽³⁸⁾</p> <p>37% expressed need for exercise therapist ⁽¹²⁾</p>

TYA= teenage and young adult.

As seen in table 9.0. TYA concerns related to reduced exercise tolerance ^(25; 32), effects of treatment ⁽²⁵⁾, loss of strength ⁽²⁷⁾ and being unable to participate in preferred sports activities ⁽²⁷⁾. PA needs identified included: daily PA encouragement during treatment ⁽²⁷⁾; need for PA advice regarding return to activity, as well as advice about keeping active and going to the gym post-treatment ⁽³³⁾, signposting to support services ⁽³³⁾, fatigue management and support regarding mobility issues ⁽³⁸⁾, TYA specific support group ⁽³⁸⁾ and an exercise therapist ⁽¹²⁾.

2.5.4.2 Impact of Cancer on TYA Related PA

Another topic area identified were studies that investigated the impact of cancer on TYA related PA (n= 7) ^(22; 27; 24; 21; 18; 26; 9; 10). Studies evaluated lived experience

of cancer ^(24; 27), COVID-19 ⁽²⁶⁾, impact and management of fatigue ^(21; 9; 27; 24), Health related quality of life post treatment ^(18; 9; 10), mediating role of PA self-efficacy in symptom distress ⁽²²⁾.

As seen in the Table below, there were a number of reported impacts of cancer related to TYA PA. With regards to lived experiences, cancer led to activity challenges as a result of treatment ⁽²⁷⁾, reduced strength, deconditioning and affected ability to participate in preferred sports ⁽²⁷⁾, the effects of cancer were reported to linger physically, psychologically and cognitively ⁽²⁴⁾ and TYA's reported their perspectives regarding ADL's changed ⁽²⁷⁾. Furthermore, TYAs reported cancer led to a loss of connection/isolation from peers due to inability to participate ⁽²⁷⁾.

Fatigue was commonly reported by TYACS ⁽²¹⁾ and was worse in those more than 1-year post treatment ⁽²¹⁾. TYACS were found to have significantly higher fatigue levels than healthy peers ⁽⁹⁾, which impacted TYA's ability to attend school ⁽²⁷⁾, participate in ADLs or return to work ⁽²⁴⁾. Exercise was the most common management intervention recommended for fatigue, however this was regarded as unhelpful ⁽²¹⁾, although TYACS participating in an active fatigue treatment (such as exercise or physiotherapy) significantly more likely to recommend active treatment than rest focused treatment ⁽²¹⁾.

Table 10.0 shows that TYACS have poorer HRQoL compared to healthy peers ^(9; 18), however meeting PA guidelines was associated with higher QoL in TYA's at any stage on cancer continuum ⁽¹⁰⁾. TYACS who had undergone surgical treatment for bone cancer reported discontentment with physical limitations in sports, walking, daily living & cosmetic aspects of limb surgery ⁽¹⁸⁾.

Table 10.0 Impact of cancer on TYA related PA.

	Impact of cancer on TYA related PA
Lived experience (N = 2)	<p>Activity challenges due to cancer treatment ⁽²⁷⁾</p> <p>Changed perspectives related to ADL ⁽²⁷⁾</p> <p>Reduced strength, deconditioning, inability to participate in sports ⁽²⁷⁾</p> <p>Regret about not maintaining PA ⁽²⁷⁾</p> <p>Loss of connection/isolation with others ⁽²⁷⁾</p> <p>Cancer lingers physically, psychologically and cognitively ⁽²⁴⁾</p> <p>Testing new boundaries through PA ⁽²⁴⁾</p>
Fatigue (N= 4)	<p>85% TYACS report cancer related fatigue ⁽²¹⁾</p> <p>Unable to attend school due to fatigue ⁽²⁷⁾</p> <p>Fatigue & energy levels impacted ADL & return to work ⁽²⁴⁰⁾</p> <p>Fatigue worse more than 1 year post treatment compared to less than one year ⁽²¹⁾</p> <p>Advice to exercise most common management intervention, but regarded as unhelpful ⁽²¹⁾</p> <p>TYACS participating in an active fatigue treatment (such as exercise or physiotherapy) significantly more likely to recommend active treatment than rest focused treatment ⁽²¹⁾</p> <p>TYACS levels of fatigue found to be significantly higher than healthy peers ⁽⁹⁾</p>
Quality of Life (N=3)	<p>Meeting recommended PA guidelines has been associated with high QoL in TYA's at any cancer stage ⁽¹⁰⁾</p> <p>Poorer HRQoL in relation to physical and mental functioning, general health and pain compared to healthy peers ^(18, 9)</p> <p>Discontentment with physical limitations in sports, walking, daily living & cosmetic aspects of limb surgery ⁽¹⁸⁾</p>

Impact of cancer on TYA related PA	
COVID-19 impact (N=1)	<p>Loneliness, anxiety, a lack of psychosocial support & reduced physical contact ⁽²⁶⁾</p> <p>Lack of peer-support from other cancer patients and survivors at the cancer centre ⁽²⁶⁾</p> <p>Compromised physical rehabilitation and access to physiotherapists or psychologists ⁽²⁶⁾</p> <p>Negative impact on mood as a result of being unable to exercise ⁽²⁶⁾</p> <p>COVID-19 isolation period gave some much-needed time off both mentally and physically following their illness ⁽²⁶⁾</p>
Mediating role of PA (N=1)	Physical activity self-efficacy partially mediated relationship between symptom distress and exercise involvement ⁽²²⁾

PA= physical activity; ADL= activity of daily living; QoL= quality of life; HRQoL= health related quality of life.

Furthermore, one study evaluated the impact of COVID-19. As can be seen in table 10.0 this impacted access to peer-support, compromised physical rehabilitation and access to physiotherapists or psychologists, negatively impacted mood as a result of being unable to exercise ⁽²⁶⁾. However, COVID-19 provided some TYAs with much-needed time off both mentally and physically following their illness ⁽²⁶⁾.

Lastly self-efficacy was found to partially mediated the relationship between symptom distress and exercise involvement in adolescents undergoing cancer treatment ⁽²²⁾.

2.5.4.3 Health Behaviour Information

Studies that investigated health behaviour information (n= 6) ^(10; 11; 23; 28; 35; 17) evaluated health behaviour information needs and information access/delivery preferences. Health behaviours investigated included: PA programming preferences and information needs ⁽¹⁰⁾, delivery preferences of supportive care resources for PA, diet, social/emotional support and connecting to other AYA's ⁽³⁵⁾, internet use for accessing diet and exercise information ⁽²³⁾, information delivery preferences regarding PA, nutrition, UV exposure, alcohol, tobacco, cancer screening and professional exposures ⁽¹⁷⁾, previous advice experiences and advice delivery preferences regarding diet, PA, alcohol consumption and smoking ⁽¹¹⁾, and lifestyle information and intervention preferences regarding diet, PA, smoking, alcohol consumption and sun safety ⁽²⁸⁾.

Four studies reported that participants expressed interest in receiving PA information ^(10; 11) or HB information ^(23; 28). One study reported a discrepancy between amount of TYA's wanting PA information (85%) and the amount who received information (55%) ⁽¹⁰⁾ and another reported TYA's were generally dissatisfied with the practical support and healthy lifestyle information they received as it was brief, vague and out of context and that HCP were not forthcoming with providing HB information ⁽²⁸⁾. Whereas, one study reported the majority of participants felt they received the correct amount of HB information ⁽¹¹⁾.

With regards to *information content*, three studies reported a want for TYA specific HB information and information tailored to the needs of the individual and their cancer diagnosis ^(23; 28; 11). One study reported content must be age appropriate and not designed for children or older adults ⁽²⁸⁾.

One study reported 68% of TYAS were also interested in an AYA PA program, of which 62% had a preference for a program after treatment, 69% preferred home exercise programs and 50% preferred a program at the local gyms ⁽¹⁰⁾. Another two studies reported TYA's would participate an individual HB counselling session from HCP's ^(28; 11).

Delivery preference: Two studies reported TYA participants predominantly received PA information from their medical physicians ^(10; 11). Two studies reported preference for receiving HB information from an HCP ^(23; 28). Whereas, another reported a strong preference for receiving PA information from an exercise physiologist, in a face-face setting ⁽¹⁰⁾.

Three studies reported that TYA's use the internet to access HB information including physical activity ^(23; 11; 28). One study reported that the common concerns of TYACS regarding online HB information were that: there was too much unorganised information available, information was not TYA specific and therefore did not meet unique needs of TYAs and TYACS had concerns about the trustworthiness of online HB sources ⁽²³⁾. Another study supported this reporting varied satisfaction with self-sourced information as participants felt there was not enough TYA specific information and practical support available and that they were frustrated having to sort through large volumes of information ⁽²⁸⁾.

One study reported telehealth (email, app, internet, DVD, telephone) delivery to be participants least favoured HB information delivery method ⁽¹⁰⁾. Another study, also found telephone to be the least favoured HB information delivery method alongside group counselling sessions ⁽¹¹⁾. However, two studies reported a strong preference for HB information to be available online or via a mobile app ^(11; 28) as these are accessible and appealing ⁽²⁸⁾ and another reported cancer patient preference for receiving PA information via email ⁽³⁵⁾, while another reported 88% declared they would like to receive HB information via numeric tools (email, text message, social media) ⁽¹⁷⁾.

With regards to written material two studies reported a preference for shorter chunks of text over longer materials ^(11; 28). One study reported that although the majority of participants (88%) found HB information booklet useful/satisfactory, 86% would have preferred to receive this information in a different format ⁽¹⁷⁾.

Furthermore, one study reported participants were not likely to seek HB information from friends, family, YouTube ⁽¹¹⁾. One study reported HB information

should be presented in multiple different formats, using lists/topic guides, colour, interactive features, visuals and infographics as well as have the ability to pin or like content⁽²⁸⁾.

With regards to the *timing of HB information*, two sources reported a lack of consensus between TYA's regarding the timing of HB information delivery as it is dependent on the individual^(11; 28). One reported preference for PA information during or post-treatment⁽³⁵⁾ and another reported TYA preference for a PA program after treatment⁽⁵⁾.

2.5.4.4 Health Behaviours (HB)

Studies that reported health behaviours^(36; 30; 13; 8; 9; 20; 19; 15; 10; 1; 14; 25; 5; 16; 17; 27; 28; 21; 3; 4; 34; 26; 24; 2; 22) evaluated TYA cancer patients/survivors HB's compared to age match healthy norms^(13; 9; 15; 16), HB adherence or status^(36; 9; 10; 15; 4; 5), as well as HB barriers and facilitators^(27; 10; 28; 19; 21; 14; 22; 30; 3; 4; 34; 25; 16; 26; 24; 2; 8; 22). In line with scoping review question 4, HB barriers and facilitators is discussed separately in section 2.5.4.5.

PA behaviour status and adherence: Table 11.0.0 shows the participant reported PA guideline adherence (percentage) across these sources. As can be seen, TYA cancer patients and survivors PA guideline adherence varied greatly across the included sources from 3-53%^(36; 9; 5; 10; 15; 31) but studies suggest TYA cancer patients and survivors are insufficiently active. However, two studies reported the majority participants, TYACS, intended to increase their PA behaviours^(15; 36) and one study reported 91.5% of participants engaged in some form of PA a week although the definition of PA was not clearly defined⁽¹³⁾.

Furthermore, one study reported TYACS engaged in PA 3.7 days/week for 47 minutes⁽²²⁾ and another assessing PA in hospitalised TYA's receiving treatment reported that patients on averaged engaged in exercise on 76% of admitted days for on average 36.5 minutes, with walking being the most popular PA type, however, patients time spent exercising decreased by 34% following treatment⁽¹⁶⁾. Two studies reported that 6-minute-walk-test (6MWT) scores of TYA patients on treatment were lower than healthy age matched norms^(16; 17) highlighting the negative affect of treatment on PA behaviours. In another one study CS reported significantly lower number of minutes spent being physically active during and post-treatment compared to before diagnosis⁽¹⁰⁾. In another study, the baseline VO² peak of TYA's who had recently completed treatment was found to be 40%

lower than age matched health norms and 30% lower than inactive age matched healthy norms ⁽¹⁾.

Three studies reported a cancer diagnosis negatively altered PA behaviours ^(14; 25;10) with one study reporting 78% of participants discontinued exercise and 20% reduced their exercise participation following diagnosis ⁽¹⁴⁾; in another study 59% of participants reported worse fitness post-diagnosis compared to pre-diagnosis ⁽¹⁰⁾ and a qualitative study found participants were unable to participate in previously enjoyable PA following their diagnosis due to reduced exercise tolerance ⁽²⁵⁾.

Comparison to norms: Three studies compared the PA behaviours of young adult cancer survivors (YACS) to age matched healthy norms ^(13; 9; 15); none of these studies found a significant difference in the PA behaviours of YACS and age matched healthy norms. Suggesting TYACS PA behaviour levels are similar to healthy peers. One of the three studies also assessed the PA behaviours of young adult cancer patients compared to age matched healthy norms or YACS and found cancer patients engaged in significantly less PA ⁽¹⁵⁾.

Table 11.0 Participant reported PA guideline adherence across health behaviour sources.

Reference	PA Guideline adherence (150 minutes+)
Arbit, Buck and Ladas 2014	13% reported meeting PA guidelines (55% intend to meet in the next 6-months)
Murnane et al. 2019	On-treatment 21% sedentary, 74% insufficiently active, 5% sufficiently active Post-treatment 41% sedentary, 56% insufficiently active, 3% sufficiently active
Murnane et al. 2021	31% AYACS's reported meeting PA guidelines, 69% not meeting PA guidelines
Murnane et al. 2015	70% participants reported meeting PA guidelines before diagnosis, 9.5% reported meeting PA guidelines during treatment 49% reported meeting PA guidelines and 51% reported not meeting guidelines after treatment.
Pugh et al. 2020a	30% cancer patients meeting PA guidelines, 52% cancer survivors meeting guidelines
Munsie 2021c	53% of cancer patients meeting PA guidelines of >90 minutes PA/week

PA= physical activity; >= greater than

2.5.4.5 PA Barriers and Facilitators

Of the 44 sources included within the scoping review nineteen reported barriers (27; 10; 28; 19; 21; 14; 22; 30; 3; 4; 34; 25; 16; 26; 24; 2; 8; 36; 15) and ten reported facilitators (28; 22; 24; 14 2021; 27; 16; 19; 34; 22; 8; 26) to TYA cancer patients and/or survivors' physical activity engagement, adherence or stage of change. Tables 12.0 and 13.0 outline the barriers and facilitators reported across the included sources.

Of the included sources six reported barriers of TYA cancer survivors (26; 28; 22; 24; 2; 15); nine reported barriers of TYA cancer patients (3 inpatients and 6 outpatients) (27; 21; 16; 14; 30; 3; 4; 34; 25); three reported barriers of both TYA cancer patients and survivors (8; 10; 36); one reported staff (physicians, nurses, nursing assistants, physical therapists, social workers, pharmacists, and child life specialists) perceptions of TYA cancer inpatients' physical activity barriers and facilitators (34) and one reports both AYA and AYA-caregiver dyad perceived barriers (19).

Across the nineteen sources 30 different physical activity barriers for TYA patients and survivors were reported. These included barriers related to TYA patients and survivors' physical and psychological states as well as support systems, community, and organisational barriers. Table 12.0 highlights that the most frequently reported physical activity barrier was fatigue, with ten of the nineteen papers (53%) reporting this (10; 19; 21; 14; 22; 30; 3; 4; 34; 24).

With consideration to the categories of the socioecological model of behaviour change (Birtwistle et al. 2019) intrapersonal barriers were most frequently reported. As seen in Table 12 these predominantly relate to the physical and psychological impact of cancer treatment and recovery. However, one study reported gender to be a PA barrier, with females more likely to decline inpatient physiotherapy input than males (34) and another found ethnicity to be a PA barrier, reporting that young adult patients and survivors who identified as Hispanic engaged in less routine activity than those who identified as non-Hispanic (8).

Physical barriers included: general effects of cancer treatment (27; 10; 28; 7; 25); fatigue (10; 19; 21; 14; 22; 30; 3; 4; 24; 34) ; pain (10; 19; 25; 34); nausea (19; 3; 4; 34); changes in functional ability/ physical disability (10; 28; 14; 25); not feeling well/ too ill (19; 16; 30; 15); reduced strength/weakness (27; 34; 2); reduced fitness/exercise tolerance (34; 25), inappropriate/unsafe medical status for exercise (30; 4; 27), engaged in other ADL/recreational activity (30) and time (19; 28; 14; 2).

Table 12.0 also demonstrates that the psychological barriers reported included: low motivation ^(19; 16; 30; 34), mood including: negative thoughts and feelings, depression, feeling upset, embarrassment, anger, frustration with their post-treatment compared to pre-treatment bodies ^(22; 34; 19), being self-conscious in public spaces such as gyms due to body image ^(28; 22) and not liking PA ⁽²⁾. Cancer survivors also reported reduced confidence and self-efficacy in being active and feeling different from other healthy young people ⁽²⁸⁾ as intrapersonal barriers to PA.

Interpersonal barriers include: low social support ^(26; 22; 36) and poor family functioning ⁽¹⁹⁾. As well as, discouragement from doctors, parents, other patients and sports coaches that exercise was contraindicated for cancer patients ⁽¹⁴⁾.

Organisational barriers include: Logistical complications/ scheduling conflicts/ being engaged in other medical activities ^(3; 4; 30), financial cost of PA ^(28; 22), IV/ central venous attachments ^(14; 34), lack of equipment ^(22; 34) and insufficient information ⁽²²⁾.

Environmental barriers included geographical barriers of distance from/travel to PA location ^(28; 2) and hospitalisation ^(27; 3; 4).

Lastly, COVID-19 was the only policy related barrier identified across the included sources ^(26; 4).

Table 12.0 displays TYA cancer patient and survivors' physical activity barriers grouped using the socioecological model of behaviour change. Within each SEM group barriers are arranged in descending order from the most frequently reported to the least across the 19 sources.

Table 12.0 PA barriers identified across the included sources with number of studies reporting and socioecological category.

Barrier and references	Socioecological Category
Fatigue (10; 19; 21; 14; 22; 30; 3; 4; 34; 24)	Intrapersonal
Effects of cancer treatment (27; 10; 28; 25)	Intrapersonal
Pain (10; 19; 25; 34)	Intrapersonal
Low motivation (19; 16; 30; 34)	Intrapersonal
Change in functional abilities/ physical disability (10; 28; 14; 25)	Intrapersonal
Nausea/ vomiting (19; 3; 4; 34)	Intrapersonal
Lack of time (19; 28; 14; 2)	Intrapersonal
Not feeling well/ too ill (19; 16; 30; 15)	Intrapersonal
Mood (negative thoughts/ feelings, depression, embarrassment, feeling upset/ frustration) (34; 22; 19)	Intrapersonal
Reduced strength/weakness (27; 34; 2)	Intrapersonal
Inappropriate/ unsafe medical status / treatment precautions (30; 4; 27)	Intrapersonal
Reduced fitness /exercise tolerance (34 25)	Intrapersonal
Reduced confidence and self-efficacy (28; 34)	Intrapersonal
Feeling different from other healthy young people (28)	Intrapersonal
Self-conscious due to body (28; 22)	Intrapersonal
Engaged in other recreational activities or ADL's (30)	Intrapersonal
Gender (34)	Intrapersonal
Ethnicity (8)	Intrapersonal
Not liking PA (2)	Intrapersonal
Low social support (26; 22; 36; 34)	Interpersonal
Discouraged by GP/parent/sports coach/other patients (14)	Interpersonal
Poor family functioning (14)	Interpersonal
Logistical complications/scheduling conflicts/ engaged in other medical procedure (3; 4; 30)	Organisational
IV or central venous attachments (14; 34)	Organisational
Financial (28; 22)	Organisational
Lack of equipment (22)	Organisational

Barrier and references	Socioecological Category
Insufficient information ⁽²²⁾	Organisational
Hospitalisation ^(27; 3; 4)	Environmental
Geographical (travel to PA location) ^(28; 2)	Environmental
COVID-19 ^(26; 4)	Policy

ADL= activity of daily living, PA= physical activity, GP= general practitioner.

Of the ten sources which included PA facilitators four reported physical activity facilitators of cancer survivors ^(28; 22; 24; 26), one reports both AYA and AYA-caregiver dyad perceived facilitators ⁽¹⁹⁾, and five reported facilitators of cancer patients (two inpatients and three outpatients) ^(14; 27; 16; 34; 22). Additionally, one source reported facilitators of health behaviour stage of change ^(8; 22).

Seventeen different physical activity facilitators were reported across the ten sources; these related to social support, cognitive facilitators, and environmental facilitators. Again, these were considered in relation to the socioecological model of behaviour change (Birtwistle et al. 2019), table 13.0 outlines each facilitator and corresponding socioecological group. More than half of the facilitators reported were intrapersonal facilitators (11/17) followed by interpersonal (4/17), organisational (2/17). The most commonly reported PA facilitator was social support with five of the included sources (50%) reporting this.

The facilitators related to social support included support systems and health professional support during treatment ⁽²⁷⁾, support from other patients on the ward during treatment ⁽¹⁶⁾, engagement with PA to social with other TYA peers ⁽¹⁴⁾ and connecting online with family during treatment ⁽¹⁶⁾. Social relationships with friends, family, other TYA cancer peers, was also reported to provide companionship and accountability to be active ⁽²²⁾. Community aspect of sport was also reported to be motivational ⁽²⁶⁾. Social support was also reported to facilitate PA confidence and self-efficacy ⁽²⁸⁾.

The most common intrapersonal facilitator was goal setting and progress monitoring ^(28; 19; 22). The remaining facilitators related to health beliefs (fear of consequences, benefits of activity, perceived control of health) ⁽²²⁾, self-efficacy ⁽²²⁾, distraction from cancer ⁽¹⁴⁾, the feeling of missing out while on treatment ⁽²⁴⁾, improve mood ⁽¹⁴⁾, keep fit and combat treatment side effects ⁽¹⁴⁾ and heal their relationship with their body ⁽¹⁴⁾.

Access to resources ⁽²²⁾ and incentive-based exercise ⁽³⁴⁾ were reported as organisational facilitators to PA.

Also, knowledge strategies ⁽²²⁾, social support from friends and self-efficacy ⁽⁸⁾ were found to be facilitators of PA stage of change.

Table 13.0 PA facilitators identified across the included sources with number of studies reporting and socioecological category.

Facilitator and References	Socioecological category
Goal setting and progress monitoring ^(28; 19; 22)	Intrapersonal
Cancer as a catalyst of behaviour change ⁽²⁸⁾	Intrapersonal
Perceived control over health ⁽²²⁾	Intrapersonal
Distraction from cancer ⁽¹⁴⁾	Intrapersonal
Fear of consequences ⁽²⁰⁾	Intrapersonal
Belief in and evidence of positive effects of behaviour change ⁽²²⁾	Intrapersonal
Self-efficacy ⁽²²⁾	Intrapersonal
Feeling of missing out during treatment ⁽²⁴⁾	Intrapersonal
To keep fit and combat treatment side effects ⁽¹⁴⁾	Intrapersonal
Heal relationship with body ⁽¹⁴⁾	Intrapersonal
Improve mood ⁽¹⁴⁾	Intrapersonal
Social support (including peers, family, friends) ^(16;27;28;22)	Interpersonal
Health professional support during treatment ⁽²⁷⁾	Interpersonal
Community aspect of sport ⁽²⁶⁾	Interpersonal
Ability to socialise with peers ⁽¹⁴⁾	Interpersonal
Access to resources (gym memberships, wellness programs, skill-building) ⁽²²⁾	Organisational
Incentive-based exercise ⁽³⁴⁾	Organisational

2.5.5 PA Interventions

The last topic area identified were studies relating to interventions (n=22) ^(14;2;42;3;4;5;6;7;16;17;14;2;44;3;34;1;39 40;41;38;33;29). Three of these were study protocols for RCT's ^(21; 2; 44), one was a narrative review of digital health interventions ⁽²⁹⁾ and the remaining eighteen were interventions ^(14;2;3;4;5;6;7;16;17;14;3;34;1;39;40;41;38;33).

The narrative review of digital health interventions included 40 studies and reported that despite a lack of efficacy studies on the topic, digital health interventions for the AYA oncology population are feasible and acceptable ⁽²⁹⁾. The review suggests that digital health interventions may overcome common AYA intervention barriers of geography, time constraints, competing commitments and small participant numbers ⁽²⁹⁾. Furthermore, the review stated that digital health interventions allow for intervention tailoring to AYA specific needs but also acknowledges that engagement with digital health interventions relies on individual motivation ⁽²⁹⁾.

In line with scoping review questions 2 and 3, the included interventions and their components will be discussed in more detail below.

2.5.5.1 Consistency of Intervention Reporting

The consistency of intervention reporting was accessed using the TIDieR tool. This allows researchers to see how well an intervention has been reported to allow for replication in future studies. The twelve components include: brief name (provide a name or phrase which describes the intervention) why (rationale for the intervention), what materials (information on what materials were used in the intervention and where to access them), what procedure (description of each procedure/step involved in the intervention), who provided (information on who provided and their background/training), how (describe the mode of delivery), where (description of intervention location), when and how much (description of intervention frequency, intensity/dose, duration, delivery time period), tailoring (if personalised or adapted description of what, why, when, how much), modifications (if modified description of what, why, when, how), how well planned (description of how intervention adherence/fidelity accessed and strategies to maintain/improve), how well actual (describe intervention adherence/fidelity compared to planned) (Hoffmann et al. 2014). Hoffman et al. (2014) state that detailed inclusion of all twelve TIDieR components is required for an intervention to be fully replicable and for intervention reporting to be considered high quality. Figure 7.0 illustrates the consistency of reporting of each TIDieR component across

the included completed interventions (n=18) and is colour coded using a traffic light system. Items were classified as fully reported (green) if all information was included in the article or attached documentation and future studies would be able to exactly replicate this. Items were classified as partially reported (yellow) if authors included information regarding the component however some information may have been missing or lacking depth to allow for exact replication in future studies. Items were classified as not reported (red) if the information could not be extracted from the source.

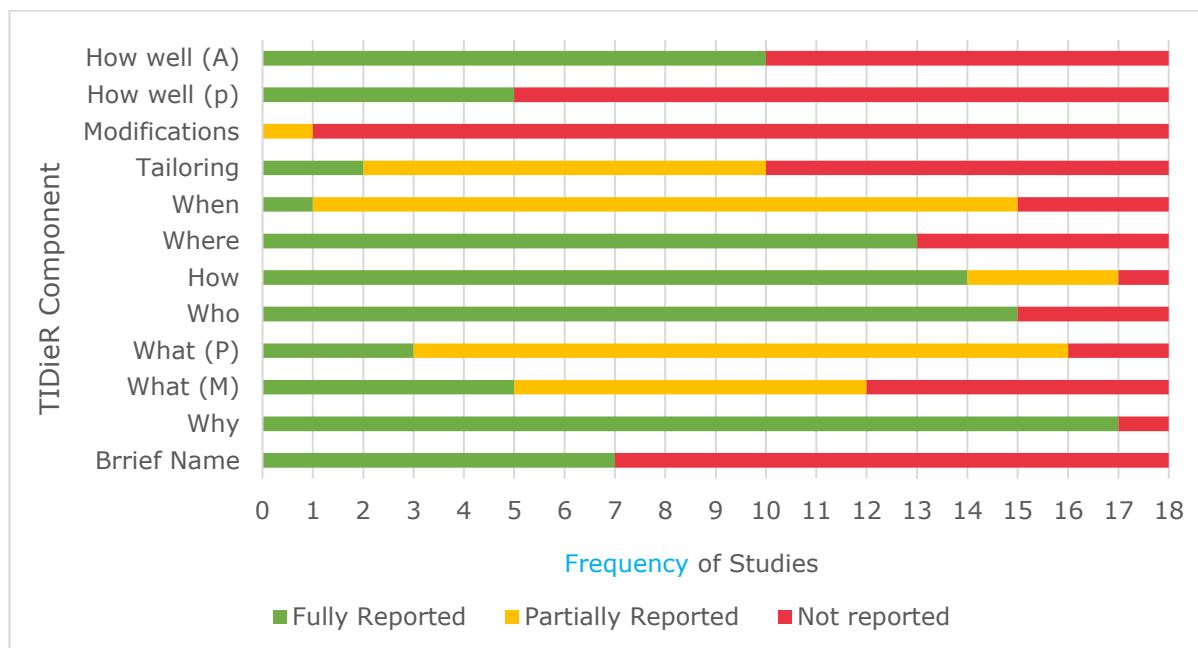


Figure 7.0 Consistency of reporting of each TIDieR component across completed interventions (n=18). (A)= actually; (P) =planned; (p)= procedure what (M)= materials.

As can be seen in figure 7.0, providing justification for why the intervention was being conducted (n=17), who provided the intervention (n=15), where they were provided (n=13), how well actually (n=10) and how they were provided (n=14) was fully reported in >50% of the studies. However, information regarding intervention tailoring (n=2), the intervention procedures (n=3), materials (n=5) and when and how it was conducted (n=1) was fully reported in less than 30% of the studies and information regarding modifications were not fully reported across any of the studies. The poor reporting of intervention materials, procedures, when and how intervention was conducted, tailoring and modifications suggests future studies may be unable to accurately replicate interventions.

Table 14.0 shows the consistency of reporting of TIDieR components for each intervention. This Table follows the same traffic light colour coding system as figure 7.0 and interventions are arranged in descending order from highest to lowest consistency of reporting. It should be noted that five of the included sources were intervention abstracts/poster abstracts ^(40; 39; 41; 38; 37) and as expected table 14.0 shows the with the exception of two studies ^(34; 6) consistency of reporting in abstracts was lower than in full papers.

Table 14.0 Consistency of reporting of TIDieR components for each intervention.

Author and Year	TIDieR Components											
	Brief Name	Why	What material	What procedure	Who provided	How	Where	When and how much	Tailoring	Modifications	How well planned	How well actual
Munsie. 2021a	Y	Y	Y	Y	Y	Y	Y	PR	PR	N	Y	Y
Atkinson et al. 2021	N	Y	Y	PR	Y	PR	Y	PR	Y	PR	Y	Y
Marec-Berard et al. 2021	Y	Y	PR	PR	Y	Y	Y	PR	PR	N	Y	Y
Rosipal et al. 2013	N	Y	Y	PR	Y	Y	Y	PR	PR	N	Y	Y
Smith et al. 2019	Y	Y	N	PR	Y	Y	Y	PR	PR	N	Y	Y
Munsie. 2021b	N	Y	PR	PR	Y	Y	Y	PR	PR	N	N	Y
Murnane et al. 2019	N	Y	Y	PR	Y	Y	Y	PR	Y	N	N	N
Munsie. 2021c	N	Y	PR	Y	Y	Y	N	Y	PR	N	N	Y
Baker et al. 2021	N	Y	PR	PR	Y	Y	PR	Y	N	N	N	Y
Salchow et al. 2021	Y	Y	N	Y	Y	Y	N	PR	N	N	N	Y
Spreafico et al. 2021	N	Y	PR	PR	Y	Y	Y	PR	PR	N	N	N
MacKland & Chesman 2019	N	Y	N	PR	Y	Y	Y	N	PR	N	N	N
Schwartz et al. 2016	Y	Y	Y	PR	N	Y	N	PR	N	N	N	N
Atkinson & Osborn 2012	N	Y	N	PR	Y	Y	Y	PR	N	N	N	N
Shaw et al. 2022	Y	Y	PR	PR	Y	PR	N	N	N	N	N	N
Yurkiewicz et al. 2018	N	Y	PR	N	Y	PR	Y	N	N	N	N	N
Munsie, Collins & Plaster 2019	N	Y	N	N	N	N	Y	PR	N	N	N	Y
Salchow et al. 2017	Y	N	N	PR	N	Y	N	PR	N	N	N	N

Y= fully reported; PR= partially reported; N= not reported.

2.5.5.2 Intervention Components

Three of the included studies were conducted as part of a PhD thesis ^(3; 4; 31) and two studies ^(40; 2) related to different phases of the same intervention development.

Interventions were conducted at various stages across the cancer care continuum, with five studies including TYA's undergoing treatment ^(3; 4; 17; 16; 31), four studies including TYA cancer survivors ^(2; 40; 39; 7), four included TYA's who had recently completed treatment ^(1; 41; 38; 33), two included TYAs on-treatment or who had recently completed treatment ^(37; 5), one included newly diagnosed TYA patients ⁽⁶⁾, one included hospitalised children and TYA's with cancer ⁽³⁴⁾ and one included children and adolescents with cancer ⁽¹⁴⁾.

There was a large variety of PA outcomes used across the interventions to assess cardiorespiratory fitness, physical function, strength, PA behaviour, PA engagement, flexibility and PA knowledge. These included: 6-minute-walk-test (6MWT) ^(17; 16; 34; 5; 7), International Physical Activity Questionnaire (IPAQ) ^(2; 40; 17), VO² peak ^(1; 3; 39), Godin-Shephard leisure-time physical activity questionnaire (GSLTPAQ) ⁽¹⁾, Global Physical Activity Questionnaire (GPAQ) ⁽³⁾; 1 repetition maximum (1RM) strength testing ^(3; 39), Timed up and go (TUG) ⁽¹⁶⁾, flexibility testing (sit and reach/back scratch) ⁽⁷⁾, dynamometry strength testing ^(3; 7; 5), sit to stand testing ^(3; 7; 5) 30 second maximum strength testing ^(3; 7; 5), Australian functional fitness norms ⁽³⁷⁾, Fullerton's functional assessment for older adults ⁽³⁷⁾, anecdotal reporting of intervention impact on PA ^(41; 6), PA knowledge scale ⁽⁴¹⁾, participant reported PA frequency, type, intensity and duration ⁽⁵⁾, number of days exercise undertaken and exercise duration whilst hospitalised ⁽¹⁶⁾, physiotherapy engagement ⁽³⁴⁾. PA was not measured in five of the eighteen interventions, two of which assessed the effect of PA on treatment-related toxicities ^(4; 31), one on fatigue and quality of life (HRQoL) ⁽¹⁴⁾ and two evaluated end-of-treatment clinics ^(38; 33).

Table 15.0 highlights the individual components of each intervention including: content, duration, intervention provider, mode of delivery and setting. As can be seen there was a large degree of variability across the components of the 17 interventions however, the most common intervention components were: interventions with a duration between 9-16 weeks (n=9), interventions delivered by an accredited exercise physiologist/ sports scientist (n=9), interventions with a delivery mode of in-person 1-2-1 (n=13) and interventions delivered in a hospital gym (n=7). The most common content components were supervised exercise (n=12) and interventions comprising of aerobic and resistance exercises (n=10).

Table 15.0 Components of the included interventions (n= 18) including content, duration, provider, delivery mode and setting.

Intervention Components	Completed Studies																	
	Atkinson et al. 2021	Salchow et al. 2021	Munsie ^a 2021	Munsie ^b 2021	Salchow et al. 2017	Schwartz et al. 2016	MacKland & Chesman 2019	Atkinson & Osborn 2012	Marec-Berard et al. 2021	Munsie, Collins & Plaster	Rosipal et al. 2013	Shaw et al. 2022	Baker et al. 2021	Murnane et al. 2019	Yurkiewicz et al. 2018	Smith et al. 2019	Spreatico et al. 2021	Munsie ^c 2021
Content																		
PA Counselling		X			X													
PA education/ advice		X				X	X		X				X				X	
Goal setting						X											X	
Holistic needs Ax													X					
Incentive-based PA												X						
Peer-support																	X	
Supervised Exercise	X		X	X				X	X	X	X	X		X		X	X	X
Unsupervised exercise									X		X	X		X				
Active Video Gaming											X							
Wearable activity monitor															X			
Sports*									X		X							
Motivational talk		X												X				
Personal exercise plan		X																
Signposting		X											X					
Exercise provision							X				X							
iPhone provision						X												
Activity log			X	X					X								X	
PA equipment referral							X											
Interactive texts						X												
TRT monitoring				X														X
Prevention Interview									X									

Intervention Components	Completed Studies																		
	Atkinson et al. 2021	Salchow et al. 2021	Munsie ^a 2021	Munsie ^b 2021	Salchow et al. 2017	Schwartz et al. 2016	Mackland & Chesman 2019	Atkinson & Osborn 2012	Marec-Berard et al. 2021	Munsie, Collins & Plaster	Rosipal et al. 2013	Shaw et al. 2022	Baker et al. 2021	Murnane et al. 2019	Yurkiewicz et al. 2018	Smith et al. 2019	Spreatico et al. 2021	Munsie ^c 2021	
Aerobic and resistance exercises	X		X	X				X	X	X	X			X			X	X	
Duration																			
Length of hospital stay									X			X							
Single session							X						X						
1-8 weeks											X			X		X	X		
9-16 weeks	X	X	X	X	X	X		X		X				X					
6 months-12 months															X				
Follow-up 6-12 months post intervention	X	X							X										
N/R																		X	
Provider																			
Research staff															X				
Healthcare professional							X				X	X	X			X			
Public Health professional									X										
Exercise physiologist/ Sports scientist	X	X	X	X				X						X		X	X	X	
Adapted-PA teacher									X										
N/R					X	X				X									
Mode of delivery																			
In-person 1-2-1	X	X	X	X			X		X		X	X	X	X	X		X	X	
In-person Group								X		X						X			
Telephone		X			X	X													
Self-led									X		X	X		X					
Setting																			
Hospital gym	X		X	X				X						X		X	X		
Telephone/mobile		X			X	X													
Outpatient clinic							X						X						
Community gym	X							X		X									
Inpatient									X		X	X							
Home									X					X	X				
Youth cancer unit																X			
N/R		X																X	

PA= physical activity; N/R= not reported; TRT=treatment-related toxicity *Sports included basketball, dance, yoga. Ax= assessment

As can be seen in table 15.0 the majority of the interventions consisted of short-term supervised exercise programs which combined aerobic and resistance exercises (1; 3; 4; 37; 39; 14; 7; 31). Although three studies took place in a group setting (37; 39; 7) all the exercise delivered in the interventions consisted of tailored, individual programs. None of the completed interventions assessed the effects of group programs.

Of the completed interventions that utilised psychological components: one included a peer-support component (7), one included incentivised exercise (34), two included goal-setting (7; 41), two included motivational talk (5; 2), two included PA counselling (2; 2) and six included a PA education/ advice component (2; 41; 38; 25; 17; 33).

2.5.5.3 Intervention Findings

Table 16.0 provides a summary of the main findings from the intervention studies included in the scoping review. The statistical significance of the intervention findings is indicated by a *p*-value, with a *p*-value of <0.05 showing weak evidence, <0.01 moderate evidence and <0.001 indicating strong evidence of a relationship (Johnson 2013). *P*-values are represented on the table by *p*= or an asterisk. As can be seen in table 16.0, findings regarding the effects of PA interventions on outcomes range from non-statistically significant to highly significant results.

Table 16.0 Summary of the main findings from each completed intervention.

Reference; Study design	Findings
Atkinson et al. 2021; RCT	A structure 10-week exercise program increased VO ² peak more rapidly in AYA intervention group however after 6-months results had plateaued and there was no difference to control group (<i>p</i> =0.61). There was no significant difference between intervention and control group total QOL scores and fatigue.
Salchow et al. 2021; RCT	A 12-week structured PA counselling-based intervention did not significantly impact vigorous-intensity PA behaviours in AYACS (<i>p</i> =0.541).
Munsie 2021 a; RCT	A structured 10-week exercise program significantly increased strength (1RM leg press**, chest press*, maximal push ups*) and global QoL** in the intervention group. Although no significant improvement in cardiorespiratory fitness and physical functioning between intervention and control groups, there was no significant decline observed over the 10-weeks. Regardless of group allocation, enrolment in the exercise study appeared to mitigate the treatment-related decline expected in AYA's undergoing treatment.
Marec-Berard et al. 2021; cohort study	Combined supervised and unsupervised home-based PA sessions found to be feasible and acceptable. Intervention led to significant improvement in participants level of PA***, physical functioning*** (6MWT), global QoL*** and a significant reduction in fatigue**and time spent sitting***. RCT required

Reference; Study design	Findings
Smith et al. 2019; cohort study	8-week Re-Activate program was found to be feasible and acceptable with a significant increase in HRQoL (physical***, psychosocial***, emotional*, school/work*), perceived occupational performance*** and satisfaction*** outcomes and physical functioning (6MWT***, Sit to stand***, strength*** and flexibility**). RCT required.
Murnane et al. 2019; cohort study	There was a positive effect of the individualised exercise intervention on physical performance of both TYA's on-treatment and post-treatment TYA's. Significant improvement in strength outcomes (sit-to-stand*, push-ups** and arm curls*) and the number of participants classified as sufficiently active post-intervention* for TYA's on-treatment. Significant improvement in strength outcomes*** (sit-to-stand, push-ups, arm curls, shoulder abduction, knee extension and dorsiflexion), function*** (6MWT) and the number of participants classified as sufficiently active post-intervention*** for post-treatment TYAs. RCT required
Rosipal et al. 2013; cohort study	No improvement in functional ability (6MWT $p=0.985$, timed up and go $p=0.375$) or QoL post-intervention. Results suggest that TYAs voluntarily exercise during admission, however their time spent exercising decreased following treatment administration. TYAs preferred standard exercise over active video gaming.
Salchow et al. 2017; RCT poster abstract	12-week intensified PA counselling significantly improved the intervention groups PA behaviour** and significantly reduced sitting time* compared to controls.
Atkinson and Osborn, 2012; poster abstract	10-week group exercise intervention significantly improved QoL***, fatigue*** and 11/13 function assessment measures.

Reference; Study design	Findings
Munsie, Collins and Plaster 2019; cohort poster abstract	<p>12-week intervention significantly improved participants strength** (chest press, leg press, row) and function** (sit-ups, sit to stand, push-ups).</p> <p>Significant improvement in subjective reporting of pain*, fatigue* and social*, emotional*, role* and physical* functioning variables of QoL.</p> <p>No change in cardiorespiratory fitness (VO² peak) over time.</p>
Munsie 2021b; RCT	<p>Results revealed a significant symptom burden for patients undergoing treatment. No statistically significant results ($p>0.05$) but exploratory longitudinal analysis revealed positive trends supporting the benefits of a 10-week exercise intervention at reducing severity of common treatment-related toxicities.</p> <p>Larger future study required</p>
Munsie 2021c; retrospective audit	<p>Treatment effects model demonstrated a 20% reduction for both combined total toxicity score and platelet count for the exercise group.</p>
Schwartz et al. 2016; RCT poster abstract	<p>Tailored health communication via text messages is feasible and has potential to increase health promoting behaviours and increase health knowledge (68% intervention group vs 58% control group) in AYA's who recently completed treatment.</p> <p>Larger RCT required</p>
Shaw et al. 2022; Quality Improvement initiative	<p>Following incentive-based exercise intervention participant refusal to participate in physiotherapy declined significantly* (24% refusal to 2% refusal). There was no change in physical function scores</p> <p>Staff perceptions of patient's motivation to stay active increased significantly.</p> <p>Future studies required</p>

Reference; Study design	Findings
Yurkiewicz et al. 2018; cohort study	Significant improvements*** across all dimensions of HRQoL in participants post-intervention. The majority of patients (85%) enjoyed using the digital technology to track their health, with the main use of the Fitbit being to track steps. The majority of patients did not wear their Fitbit whilst hospitalised Anecdotally 79% of participants reported increased PA behaviour post-intervention.
Spreafico et al. 2021; comparison study	Cancer diagnosis prompted all but one participant to stop previous exercise or sports even though continuation was not contraindicated. Following a 6-weeks exercise intervention, the GYM group had significantly better perceived emotional functioning*, and a trend toward a better social functioning compared to the No-GYM group.
Baker et al. 2021; Service evaluation	The pilot end-of-treatment clinic was successful and highly valued by TYA patients. Outcomes suggested that patients planned to make lifestyle changes as a result of attending the clinic, although actual behaviour change was not measured.
Mackland and Chesman, 2019; poster abstract	Pilot highlighted the need for an end of treatment clinic to address the significant physical and psychological needs of TYA's. Larger pilot required

QoL= quality of life; HRQoL= health related quality of life; TYA= teenage and young adult; AYA= adolescent and young adult; RCT= randomised controlled trial; 6MWT= 6-minute walk test; p = p -value; * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

The results of the intervention studies summarised in table 16.0 are outlined below. Supervised exercise was found to improve cardiorespiratory fitness ⁽¹⁾, improve strength ⁽³⁾, improve QoL ^(14; 3; 39; 25), reduce fatigue ^(14; 4), improve physical function ^(5; 25), reduced treatment-related toxicities ^(31; 4), improved occupational performance and satisfaction ⁽²⁵⁾ and was safe and tolerable during treatment ⁽³⁾. Although not all studies found supervised exercise improved QoL and fatigue ⁽¹⁾.

A combination of supervised and unsupervised exercise was found to improve levels of PA ^(17; 5), improve strength ^(5; 25) reduce fatigue ⁽¹⁷⁾, reduce time spent sitting ⁽¹⁷⁾ and reduce physiotherapy refusals ⁽³⁴⁾. One study also reported that a combined supervised and unsupervised exercise intervention improved participant QoL scores ⁽¹⁷⁾ whereas, another found no change in QoL ⁽¹⁶⁾. Additionally, two studies reported improved function ability as measured by 6MWT ^(17; 5) whereas another two studies reported no change in 6MWT scores post intervention ^(34; 16).

PA-counselling intervention results are contradictory with one study reporting no changes in vigorous-intensity PA behaviours of TYACS ⁽²⁾ and another reporting improved PA behaviours and reduced sitting time ⁽²⁾.

Three technology-based interventions were identified ^(41; 6; 16). A tailored health text message intervention was found to increase health knowledge and self-reported health behaviours ⁽⁴¹⁾. Standard exercise (walking and strengthening exercises) was preferred by TYA patients over active video gaming (AVG) ⁽¹⁶⁾. Furthermore, a Fitbit- and iPad-based intervention found improvements in all dimensions of HRQoL increased anecdotal PA behaviour ⁽⁶⁾.

End of treatment clinics were found to successful and valued by patients ⁽³³⁾ and be needed to meet the physical and psychological needs of TYAs following treatment ⁽³⁸⁾. Further robust research into end of treatment clinics is required as one of these sources was a small pilot study ⁽³⁸⁾ and another was a service evaluation ⁽³³⁾.

Lastly, incentive-based exercise was found to improve physiotherapy participation but not functional ability of TYA's with cancer ⁽³⁴⁾.

2.5.5.4 Components of Future Interventions

Table 17.0 illustrates the components of future interventions including content, duration, provider, delivery mode and setting as determined by study protocol.

Table 17.0 components of future interventions (n=3).

Intervention Components	Future studies		
	Valle et al. 2021	Salchow et al. 2020	Jong et al. 2022
Content			
Goal setting	X	X	
PA Education		X	
Wearable activity monitor	X	X	X
PA consultation's		X	
Mobile app	X		
Videochat sessions	X		
Social media peer support group	X		
Tailored feedback text-messages	X		
Behavioural lessons	X		
Signposting	X		
Wilderness program			X
Supervised group PA			X
Reflective practise			X
Duration			
3 months			X
12- months	X	X	
Follow-up period post intervention		X	X
Provider			
Healthcare professional		X	
Sport scientist		X	
Trained program facilitators			X
N/R	X		
Mode of delivery			
Telephone	X	X	
Online group	X		
In-person group			X
Setting			
Multi-centre		X	
Online	X		
Outdoors			X

N/R= not reported; PA= physical activity

As with the completed interventions there is variation in the individual components of the future interventions outlined in table 17.0. One protocol outlines an mHealth intervention which utilises BCT, goal-setting, social media-based peer-support, self-management ⁽⁴²⁾, one protocol ⁽²⁾ outlines a needs-based health behaviour change intervention which has been developed from previous interventions seen in table 17.0 ^(40; 2) and utilises goal setting and PA education and another outlines a group *wilderness-based* PA program ⁽⁴⁴⁾. It should be noted that the future interventions have a longer duration ^(21; 2) or follow-up assessment post-intervention ⁽⁴⁴⁾ to assess the longitudinal effects of the intervention and all interventions will utilise wearable technology as a PA measure ^(44, 42; 2).

2.5.6 Grey Literature

Table 18.0 illustrates the results from grey literature searching of charity prominent cancer websites. Although MOVE charity was not stated on the protocol this was identified through the Teenage Cancer Trust website. A full list of grey literature websites and search terms used on each can be found in Appendix 6.

As can be seen eight of the nine charity websites contained information or videos relating to cancer and physical activity or exercise (McMillian, CRUK, TCT, Shine, Trekstock, Young Lives vs Cancer, Canteen and MOVE). However, the volume of information available and the degree of tailoring towards TYA varied across websites. Neither McMillian or CRUK contained any information tailored towards the TYA population and Canteen only offered a small amount of general information stating remaining active was important.

Aside from written information about physical activity and cancer four websites (TCT, Shine, MOVE, Canteen) contained links to YouTube videos about physical activity and cancer or workout videos tailored for the oncology population.

Searches also revealed that two charity websites, Trekstock and MOVE, offer TYA or young adult specific exercise programs. Trekstock offer a structured 12-week exercise program (RENEW) aimed at young adults aged in their 20's and 30's when diagnosed with cancer. The RENEW program includes access to online support materials, a free gym membership and personal training from a Level 4 cancer rehab instructor. Literature searching revealed two research papers analysing the impact of the RENEW program however, these were not included in the review as the mean age of participants did not meet inclusion criteria (Pugh et al. 2020b, participant mean age=29; Below et al. 2021 participant mean age 33).

Furthermore, the charity MOVE offers a free online 8-week program for TYA's diagnosed between the ages 13-30. The MOVE program consists of access to zoom classes, weekly telephone calls and a tailored exercise plan generated by a Level 4 cancer rehab specialist. Literature search did not identify any research papers analysis the MOVE program so quality could not be access in this review. Lastly, the TCT website contained a signposting link to the MOVE exercise program and Young Lives vs Cancer contained a signposting link to the Trekstock RENEW program.

Table 18.0 Summary of the PA information available on prominent cancer charity websites.

Charity Websites	PA Content
McMillian Cancer Research	Website contained general information about physical activity/ exercise during and after cancer and information about the Move More service which includes exercise classes but there is no specific TYA information or services.
Cancer Research UK (CRUK)	Website contained general information about physical activity/ exercise during and after cancer.
Teenage Cancer Trust (TCT)	Website contained information about exercise and cancer including benefits of exercise during treatment, examples of exercises and a link referring to Trekstock Renew programme; yoga and cancer including benefits of yoga and link to a YouTube yoga class; 5-minute fitness for beginners including a YouTube video link and list of 5 exercises; 10-minute workouts at home including exercise examples/videos and link to MOVE 8-week program
Teen Cancer America	No information found on website
Shine Cancer Support	"Activity videos" collection of yoga and Pilates videos
Trekstock	Information on benefits of exercise during treatment, physical activity guidelines and Renew 12-week program (which includes access to online support materials, free gym membership and personal training support from level 4 cancer rehab instructor).

Charity Websites	PA Content
Young Lives Vs Cancer (formerly CLIC Sargent)	Website contains information about exercise and cancer as well as signposting links to the TCT and shine websites and the Trekstock RENEW program (for 20-years +).
Canteen	Website contained a small amount of general information and a short video stating exercise was important.
Move (not just TYA)	MOVE YOUR WAY containing links to YouTube sessions delivered by cancer rehab specialists, educational questions and answer videos about exercise and cancer, 5K your way initiative (not TYA specific) and 8-week free online program for people diagnosed with cancer between 13-30, providing a personalised exercise program from a level 4 cancer rehab specialists and weekly support phone calls plus access to zoom workouts.

2.6 Discussion

2.6.1 Discussion of Scoping Review Findings

Although there was variation seen in the reported PA behaviours of TYA cancer patients and survivors across included literature, this review demonstrates that TYA cancer patients and survivors are insufficiently active and the majority currently do not meet physical activity guidelines (Arbit, Buck and Ladas 2014; Murnane et al. 2021; Murnane et al. 2019; Murnane et al. 2015; Pugh et al. 2020a; Munsie 2021c). This has also been seen in adult cancer survivors. A recent systematic review and meta-analysis of health behaviour adherence in adult cancer survivors found that adult cancer survivors had poor PA adherence (45 studies), ranged from 12% to 78.4%, pooled estimate 43%; 95% CI, 39%, 46% (Tollosa et al. 2019).

Comparison between PA adherence in TYACS and age matched norms was not found to be statistically different, suggesting PA behaviours of TYACS are similar to healthy peers. It is established within health behaviour research that adolescence is characterised by declines in PA behaviours and that those who engage in low levels of PA are likely to remain insufficiently active in adulthood (Belanger et al. 2011b). However, this review found that studies did report a significant difference between the physical functioning of TYA cancer survivors and healthy age matched peers. This suggests that although TYACS and healthy peers may engage in similar activity levels TYACS are more deconditioned with worse physical functioning than their healthy peers.

Furthermore, cancer patients on-treatment were found to have significantly lower PA levels than healthy age matched peers or TYACS and Tya's reported reduced PA post-diagnosis compared to pre-diagnosis levels. This illustrates the negative affect cancer diagnosis and treatment have on PA levels.

Included sources also reported a number of barriers to PA in TYA's, the most common of which was fatigue followed by treatment related side effects, psychological barriers and environmental barriers. Previous research into AYA's age 18-39 and YASCC PA barriers supported a number of the TYA PA barriers outlined in section 2.5.4.5; time/competing demands (Rabin 2017; Kimball et al. 2017; Wright et al. 2013; Arroyave et al. 2008), fatigue (Marchak et al. 2023; Adamovich et al. 2022; Arroyave et al. 2008; Wright 2015; Kimball et al. 2017), reduced strength (Marchak et al. 2023), pain (Wright 2015), illness or health

issues (Wright 2015; Rabin 2017), physical limitations due to cancer treatment (Adamovich et al. 2022; Marchak et al. 2023) frustration with post-treatment body (Kimball et al. 2017) and lack of motivation (Adamovich et al. 2022) were all reported as barriers in AYACS and YASCC populations as well as TYAs.

As outlined in sections 2.5.4.2-2.5.4.3 TYA's have PA support needs during and after treatment. TYA's are concerned about the effect of treatment on their exercise tolerance and physical function. They also demonstrated a need for support regarding fatigue management. TYAs were found to be interested in receiving PA advice/information however, some TYAs were dissatisfied with the advice that they have previously received as this was too general and lacked context. Instead TYA's wish to receive advice tailored towards their unique needs and personalised to them and their situation including age, cancer diagnosis and treatment type. Previous research has shown that the wider AYAs cohort also want PA advice and support (Zebrack 2008; Belanger et al. 2012; Rabin et al. 2013). It has also demonstrated that the AYA oncology population feel that they are a distinct cohort with their own unique needs compared to adult cancer patients and survivors (Avutu et al. 2022).

With regards to delivery TYA's wanted PA information to be delivered from a reliable source and presented in multiple formats (online, face-face, written, app) which are engaging. A study into AYACS (aged 20-44) found AYACS in their 20's were more interested in PA information than AYACS in their 30's or 40's and were more likely to prefer receiving PA information via email or the internet (Belanger et al. 2012). AYACS have been reported to want to receive activity counselling from a fitness expert at a cancer centre and information via brochure (Belanger et al. 2012). Another study by Rabin et al. (2013), conducted interviews with AYACS (mean age=33.5 years) and found a need for convenient health behaviour interventions which provide social support but also account for AYACS busy lives and competing demands.

As shown in section 2.5.4.5 social support, access to resources, goal-setting and self-efficacy have been identified as PA facilitators in the TYA oncology population. Social support (Kimball et al. 2017; Adamovich et al. 2022; Wright et al. 2013; Valle et al. 2015) and access to cancer specific resources (Adamovich et al. 2022; Kimball et al. 2017) have been shown to facilitate PA behaviours in within AYA cancer survivors aged 18-39 and YACCS. This suggests some cross-over between

the PA barriers and facilitators of UK aged TYA cancer patients and survivors, AYA aged 18-39 and YASCC.

There was no consensus across included studies about the most appropriate time to receive PA advice and support with TYA's reporting that this is dependent on the individual. Teenage and young adulthood is a period of behavioural development and change where they learn behaviours which they adopt throughout adulthood (Belanger et al. 2011). Due to TYA cancer survivors increased risk of developing chronic health conditions and cancer reoccurrence within their lifetime (Nass et al. 2015) this is a pivotal time for engaging them in PA. Research suggests that cancer and its subsequent treatment may provide a teachable moment to instigate behavioural change (Pugh et al. 2017). Considering the negative impact of cancer diagnosis and treatment on PA behaviours outlined above, after treatment may be a key time for behavioural change. Delivery of PA support after treatment has been found to be preferred in AYACS (Belanger et al. 2012).

Although there is a limited amount of robust, RCT intervention studies in the TYA oncology population results suggest PA interventions are safe and acceptable during and after cancer treatment. This has been shown extensively within the adult cancer population (Campbell et al. 2019). Included interventions suggest PA can help reduce TRT, improve physical function, increase strength, improve QoL and reduce fatigue in TYA populations during and after treatment. The impact of PA interventions should be considered with caution however, as the interventions conducted were commonly short length, non-randomised studies with a small sample size. Four of the included interventions were service evaluations, audits or quality improvement initiatives (Mackland and Chesman 2019; Baker et al. 2021; Shaw et al. 2022; Munsie 2021c) and five of the included intervention sources were poster abstracts which have not been reported in full. Larger RCT's are required to continue research into PA interventions in TYA oncology populations. The section below discusses the research gaps and limitations identified in the scoping review in more detail.

2.6.2 Research Gaps and Limitations

Although this scoping review identified 44 sources relevant to PA and the TYA oncology population, there were also a number of limitations and research gaps identified. In line with review question five, the following section outlines these.

Firstly, the majority of interventions identified were short-term interventions which did not assess longitudinal impact. As it is well known that late effects from treatment persist well after treatment finishes (Woodward et al. 2011), it is important to not only understand the short-term impact of PA interventions but also assess how this effects outcomes long-term. Also, as physical inactivity is a modifiable behaviour associated with increased risk of cancer (Campbell et al. 2019), it is vital to understand not only if interventions alter behaviour but if this behaviour change is maintained throughout survivorship.

Also, there were methodological limitations to the included studies. As is common with TYA oncology literature included studies were mostly comprised of small sample sizes (Munsie et al. 2019). Additionally, included studies were predominantly comprised of white, western participants. Therefore, future research including larger, more diverse sample populations is required to ensure results are representative of the TYA cancer population as a whole. There was also a lack of robust randomised interventions identified and the majority of interventions require further large-scale or RCT research to test if results are replicable.

The use of the TIDieR checklist in this review highlighted inconsistencies in intervention reporting across TYA studies, because of this future research may be unable to accurately replicate interventions and thus directly compare results. This illustrates the need for future interventions to provide more in-depth reporting, particularly with regards to intervention procedure, materials, tailoring and modifications.

Future intervention research should also consider TYA PA facilitators. This review demonstrated that social support is reported to be a facilitator of PA behaviour however, the majority of TYA interventions have conducted in 1-2-1 setting, with only one study reporting that they included a peer-support element within the intervention. Therefore, there is a research gap surrounding the role of social support in PA interventions. Future research is need to investigate the impact this social support has on TYA PA behaviours and how social support can be generated within interventions to facilitate PA.

Treatment related side effects were found to be large barrier to PA engagement, although recent research began investigating the effects of exercise on TRT's in TYA cancer patients on-treatment (Munsie 2021), this review found no research

focused on the effects of different treatment types on PA engagement. This may be due in part to small sample sizes associated with TYA research however, multi-centre or international studies should be considered.

TYA intervention research has predominantly been conducted within a hospital setting, with limited research into community-based interventions and home-exercise programs and no research investigating the effect of a digital-intervention such as online exercise classes or hybrid model including in-person and online intervention delivery. These delivery modes warrant investigation as they may alleviate the PA barriers of lack of time and distance to travel (Devine et al. 2018). The, COVID-19 pandemic resulted in a number of healthcare services adopting an online model suggesting this is feasible (Tabaczynski et al. 2023).

As seen in section 2.5.5.2 intervention components, TYA PA interventions are most commonly delivered by accredited exercise physiologists. When considering implementing research into UK clinical practice, questions arise about how this relates to service delivery or pathways as UK TYA oncology settings do not have exercise physiologists in post (Scottish Government 2021). Future research into the delivery of PA interventions in the clinical setting, working with oncology HCP's, is required to determine who is best placed to deliver PA services.

With regards to PA behaviour research, PA has predominantly been addressed in non-intervention studies and included under the broader heading of health behaviours, with diet, alcohol consumption and smoking behaviours investigated alongside PA. Although this is common within health behaviour research, PA specific research should be conducted as there may be differences between behaviours with regards to physical activity information needs and preferences. Researchers should assess PA support needs of TYAs in more depth. Moreover, this research has mostly investigated PA behaviour via self-reported measures, which are susceptible to self-report bias (Fadnes, Taube and Tylleskar 2008). Future research therefore, should consider the use of accelerometry to more accurately measure PA behaviours (Sirard et al. 2013).

Another gap in the literature lies within investigating the psychological impact of physical activity. The main outcomes used to assess the psychological impact of PA are QoL and fatigue. Although these are important and allow for comparison with research conducted in older adult and paediatric oncology populations future research could investigate the effect of PA on TYAs wider mental health, such as,

outcomes that measure PA impact on: depression or anxiety, social functioning, self-concept and body image or cognitive functioning.

2.7 Conclusions

In conclusion the body of literature surrounding PA and the TYA oncology population remains limited both with regards to quantity and quality. There have been a number of intervention studies conducted which suggest positive effects of PA on health outcomes including strength, physical function, QoL, fatigue and PA behaviour however, the majority of these have been experimental designs with small sample sizes. Therefore, future research is required.

Furthermore, a number of studies have begun to outline TYA PA barriers and facilitators and support needs however, more research is required to explore the extent of impact of these barriers and facilitators and if there is any difference between cancer patients and survivors. Data surrounding PA preferences with regard to type, mode of delivery, setting and support is also limited and requires further research.

Findings of this scoping review provide evidence to support the need for further research into PA in the TYA oncology population within multiple contexts, including research investigating the PA behaviours, lived experiences of PA and PA preferences in TYAs with and after cancer. Further research into this is required to address gaps surrounding PA support within the TYA oncology population. This scoping review also demonstrated the relevance of both quantitative and qualitative methodologies for investigating this topic area providing support for the use of mixed methods approaches in future.

2.7.1 Thesis Research Question and Objectives

In its most simple form, research follows a cyclical process (figure 8.0) by which existing literature (conceptual and applied research) on a particular topic area informs research questions, through the identification of gaps within current literature (Maltby et al. 2010). Chapter 1 outlined the existing literature surrounding physical activity and cancer. This was then outlined in-depth in relation to the TYA oncology population in this scoping review chapter. As discussed in section 2.6 above a number of research gaps and limitations were identified. These informed the overarching research question and corresponding objectives of this thesis.

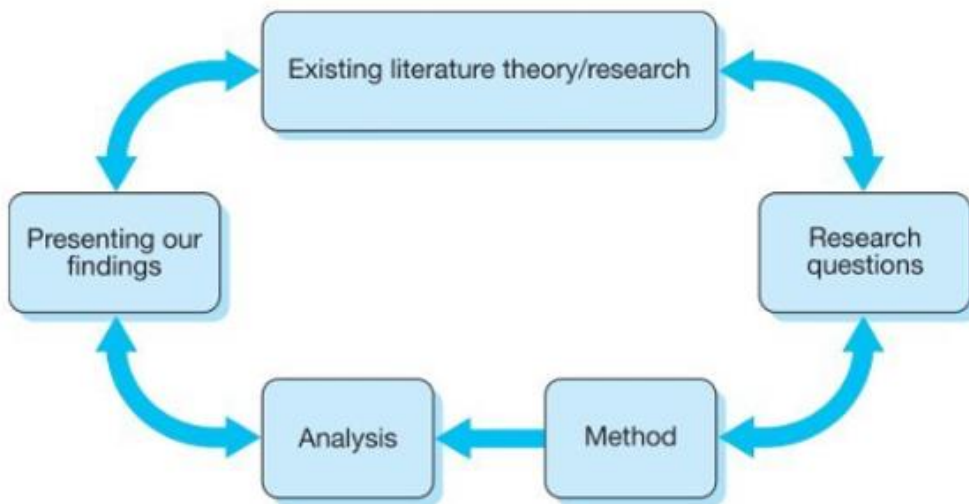


Figure 8.0 The research process cycle extracted from Maltby et al. (2010), pg.4.

The overarching research question was: What are the physical activity behaviours, lived experiences and preference of individuals diagnosed with cancer between the ages of 16-25, including those with an active diagnosis (on or off treatment), those in remission or those cancer free?

In fulfilment of this, the project objectives were as follows:

1. To identify self-reported physical activity levels of this population across the cancer continuum.
2. To explore the experiences this population has had with physical activity.
3. To identify the perceived barriers and facilitators to physical activity for this population. This includes exploring any potential group differences with regards to demographics, cancer type, treatment type on PA engagement.
4. To explore what individuals from this population feel is important to them, about physical activity.
5. To identify physical activity preferences in relation to type, setting, delivery method and support for this population.
6. To synthesise recommendations for physical activity in this group.

This overarching research question and the six research objectives aimed to add to the body of literature regarding TYA cancer patients and survivors' current PA behaviours. Engagement with PA across the cancer continuum, including the

physical and psychological impact of PA, were also explored through lived-experience. Furthermore, this thesis aimed to increase the knowledge base surrounding PA barriers and facilitators during and after cancer providing greater context as to why these barriers exist and how they can be overcome. Lastly the gap surrounding PA preferences and support needs was also addressed. It was out with the scope of this thesis to address the identified research gaps surrounding PA interventions.

As seen in figure 8.0, the next step in the research cycle is to devise a way (method) to investigate the research question(s) and then determine what has been discovered about the chosen topic area (analysis). This is then disseminated to the research community (written presentation and/or oral) to further inform the existing body of literature and in turn feed into new research questions (Maltby et al. 2010). The remaining chapters of this thesis will outline the method and analysis steps of this project and present the findings.

CHAPTER 3: METHODOLOGY

3.0 Chapter Outline

This chapter will begin by outlining the philosophical and methodological underpinnings of this thesis. Following this, an overview of quantitative, qualitative and mixed-method approaches to research and how they apply to this thesis will be discussed. Then study design, methods of data collection and analysis and ethical considerations will be explained. Finally, the impact of the COVID-19 pandemic on this project will be addressed.

3.1 Philosophy

Researchers must be aware of how their personal beliefs, values and experiences inevitably influence their research design, execution and interpretation (Holmes, 2020). Ritchie et al. (2013) argues that no research can remain completely 'neutral' or objective from the influence of the researcher. Therefore, engaging in reflexivity is highly important throughout the research process (Malterud, 2001).

Reflexivity is defined as "an act of self-reflection that considers how one's own opinions, values, and actions shape how data is generated, analysed and interpreted" (Jafar, 2018), and involves 'deconstructing' the impact the researcher has on the research process (Hill and Dao, 2021). It is a process which arose from qualitative research, however, its benefits within other approaches such as quantitative research is now being recognised (Jafar 2018). Although engaging in reflexivity does not fully eliminate researcher bias (there will always be some form of subjectivity), it does allow researchers to identify their areas of potential bias and account for them when planning, conducting and analysing research (Ritchie et al. 2013).

When reflectively considering research underpinnings, an important consideration is a researchers' world view (Creswell 2014) or philosophical paradigm (Saunders et al. 2015). An individual's worldview is their set of beliefs that guide their action (Creswell 2014). In relation to this we consider the ontological, epistemological, axiological and methodological components of a world view (Scotland 2012). Ontological assumptions are concerned with the nature of reality and the researcher's own perceptions of this; epistemological assumptions are concerned with knowledge and how it can be created, acquired and communicated (Scotland, 2012); axiological assumptions are concerned with the values of the researcher and how they influence the research (Creswell, 2014) and methodological

assumptions is the strategic plan and techniques applied to collect the research data (Scotland, 2012). Table 19.0 summarises the most common worldviews within health and social science research alongside their epistemological, ontological, axiological and methodological components (Creswell 2014).

Table 19.0 Four common worldviews in health and social science research.

Component	Worldview			
	Post-positivism	Constructivism	Transformative	Pragmatism
Ontology	Single reality; researcher rejects or accepts hypothesis	Multiple realities constructed through lived experiences – quotes illustrate different perspectives	Politic reality; negotiated with participants	Single and multiple realities; researchers test hypothesis and provide multiple perspectives
Epistemology	Objective; approximation of reality through research and statistics, minimal interaction with participants	Subjective evidence from participants enters the world of the researcher; researcher co-constructs reality with the participants	Multiple ways of knowing reality; collaboration	Practicality; researcher gathers data in the best way to answer the research question(s)
Axiology	researcher bias minimised and controlled	Biased; researchers are open about their biases and interpretations	Biases are negotiated with participants	Multiple stances; combining biased and unbiased stances
Methodology	Deductive; researchers utilise quantitative method(s); testing of theory	Inductive; utilises qualitative method(s); emergent theory	Emphasis on collaboration, participating politically and questioning of methods, highlighting concerns and issues	Combining; researchers utilise both quantitative and qualitative method(s) and integrate them

Pragmatists start with a research problem and aim to contribute practical solutions that inform future practice (Saunders et al. 2015) believing that multiple methods can be highly appropriate within a study to collect well-rounded and reliable data to advance research (Kelemen and Rumens 2008). Pragmatism, strives to

amalgamate accurate and rigorous knowledge with different contextualised experiences by considering theories, concepts and research findings in terms of the roles they play in thought and action (Saunders et al. 2015). As summarised in table 19.0, pragmatists believe in multiple realities, gathering knowledge via the most appropriate methods to answer the research question(s), typically adopting a mixed-method approach and combining biased and unbiased stances with the researcher playing a role in data collection and analysis (Creswell 2014).

As a researcher I am a doctoral student studying within the field of physiotherapy, with a background entrenched within the health and social sciences (BSc Biology and Psychology, MSc Sports Psychology). As my postgraduate studies continued and I underwent my clinical training in physiotherapy I found myself aligning with the pragmatic assumption that there is not one objective truth but multiple truths and perspectives. This has been derived from my first-hand experience that no two individuals' experiences within healthcare are the same despite having a similar diagnosis and being treated within the same clinical setting.

Initially, I approached this study from a post-positivistic perspective, with a preliminary research idea of conducting a physical activity intervention within a TYA oncology population. Post-positivism takes an objective approach to research, adopting a single reality and following careful methods of data collection to test a hypothesis (Creswell, 2014). Post-positivist research uses quantitative methodology, with the researcher remaining unbiased (Ryan, 2006).

As a newly qualified physiotherapist I was excited about the idea of combining my interest in research with my new clinical skills and developing (and potentially delivering) a physical activity intervention. However, this "somewhat idealistic" vision for my Doctoral thesis was quickly pushed aside after immersing myself in the TYA exercise oncology literature. It became evident that there was still a lack of information surrounding TYA cancer patients and/or survivors' current physical activity behaviours, experiences, and preferences.

I began asking myself questions about what influenced TYA cancer patients and/or survivors physical activity behaviours? What would these patients want and need from a physical activity intervention? When would be the best time to deliver this intervention? Who is the best person to support this? Does the adult literature translate over to this TYA group?

As a physiotherapist, two frameworks which underpin my approach to my clinical care also influence how I approach research. These are evidence-based practice (EBP) and patient-centred care (PCC). EBP is an integral part of healthcare, particularly within the NHS, and ensures patients receive the most appropriate and up to date care (Maltby et al. 2010). Within this framework clinicians make decisions about treatments based upon the current research-based evidence, clinical expertise and patient values and preferences (Akobeng 2005). Although critics argue that EBP encourages dehumanised, routine and decontextualised care (Leach 2006) there has been a shift towards greater involvement of the third branch of EBP, thinking about the patient and care more holistically, especially when considered in conjunction with PCC. PCC is defined as a “mutually beneficial partnerships between patients, their families and those delivering healthcare services which respect individual needs and values, and which demonstrates compassion, continuity, clear communication, and shared decision making. These have shaped my belief that it is not only incredibly important to consider the evidence-base but also the patient themselves. Gooberman-Hill (2012) states “an understanding of what patients want from healthcare is a cornerstone of patient-centred care”. I agree with this statement as I believe that patients should not just be involved with their care on an individual level but also within the broader healthcare system meaning that patient needs and preferences should be considered within healthcare service and intervention design.

Therefore, it was clear to me that exploratory “mapping” research was required to address this literature gap prior to undertaking a quantitative intervention-based study that would be susceptible to confirmation bias by potentially missing identifying all factors influencing participant behaviours and feelings (Johnson and Onwuegbuzi 2004). The current literature gap and my clinical stance that patient involvement within healthcare is vital to ensure services are meeting the needs of those who they care for helped me to finalise the overarching research question: what are the physical activity behaviours, lived experiences and preference of individuals diagnosed with cancer between the ages of 16-25?

This research question and my ontological assumption that multiple realities exist and should be considered in healthcare research resulted in a pragmatic approach being adopted to this research. Although table 19.0 highlights that a constructivist approach also adopts the ontological assumption of multiple realities and that knowledge is generated from subjective evidence (Creswell 2014), it was felt that

the exploratory nature of the research question addressing physical activity behaviours, lived-experiences, and preferences was most appropriately investigated using both quantitative and qualitative measures.

3.2 Methodology

3.2.1 Introduction

Historically, health research has been dominated by quantitative methodology and study designs (Tariq and Woodman 2013) however, there has been a dramatic increase in qualitative output (Curry and Nunez-Smith 2017) due to the increased focus on patient-centredness and the holistic perspective (Holloway and Galvin 2016). Acceptance of qualitative methodology led to growing interest in combining quantitative and qualitative methods in health research and thus an increase in mixed methods studies (Tariq and Woodman 2013). Mixed methods research is now recognised as the third methodological movement (Plano Clark and Ivankova 2016). Sections 3.3.2-4 of this chapter will provide an overview of each methodology.

3.2.2 Quantitative methodology

Quantitative methodologies, are deductive in origin (Antwi and Hamza 2015) and underpinned by a positivist (or post-positivist) stance which proposes that scientific truths or laws exist (Gerrish and Lathlean 2015). Quantitative research is usually referred to as empirical, as it focuses on turning information or data into numbers (Silverman 2013). Quantitative methodologies aim to describe the scope of phenomena, to generalise and compare across groups, and to test hypotheses (Curry and Nunez-Smith 2017).

Quantitative research includes experimental designs (using participant randomisation and control groups e.g., a randomised control trials), quasi-experimental designs (similar to experimental but lack participant randomisation and/or a control group) and observational designs (natural studies with no manipulation from researcher e.g., cohort studies, cross-sectional studies, case reports) (Mehrad and Zangeneh 2019).

Benefits of quantitative methodologies are that random sampling approaches allows for generalisations or inferences to larger populations (Curry and Nunez-Smith, 2017), and the use of validated research tools (Gerrish and Lathlean, 2015) and statistical approaches to data analysis account for the effects of potential

confounding factors that may systematically bias results (Curry and Nunez-Smith, 2017).

Quantitative methodologies are well-suited to test cause and effect relationships however, due to the use of close-ended questioning or research instruments they do not allow for an in-depth exploration of a research problem (Sukamolson 2007).

3.2.3 Qualitative Research

Qualitative methodologies allow for an in-depth exploration of behaviours, feelings and experiences; providing an insight into human perspectives and allowing researchers to make sense of attitudes and behaviours (Holloway and Galvin 2016). They are a means for exploring individuals, groups or organisations (Creswell, 2009). Qualitative methodologies are mostly inductive in nature, with data analysis typically working from the 'ground up', seeking to identify generalities or themes from that data, rather than test hypotheses (Gooberman-Hill 2012). Qualitative methodologies typically have constructivist or transformative underpinnings, which poses multiple realities exist (Creswell 2014).

There are multiple different approaches to qualitative research with researchers typically selecting their methods based upon the research question(s) under investigation (Gooberman-Hill 2012). Table 20.0 provides a brief description of common qualitative approaches (Bowling, 2014; Creswell 2014; Ntinda 2019; Doyle et al. 2020).

Table 20.0 Common Qualitative Approaches.

Qualitative Approach	Description
Narrative	Explores the experiences of individuals studied through stories
Ethnographic	Describing the shared patterns of behaviours of a group through long term observation and conversation in their natural setting
Case study	An in-depth understanding of a single unity or entity such as a person, process or organisation
Grounded Theory	A generalised abstract theory is produced from the constant comparison, in depth repeated interviewing, coding and analysis of layers of observational data
Phenomenological	Describing the common meaning of a concept or phenomenon through the lived experience of a group of people.
Descriptive	Describing the individual human experience in its unique context.

Interviews and focus groups are two common qualitative data collection methods (Creswell 2014). Interviews will be discussed in more depth later in this chapter.

As previously stated, qualitative methodologies allow for an in-depth exploration of a phenomenon however, this approach does not typically allow for random participant selection (Alssawi 2014) and the results of the research are susceptible to researcher bias (Creswell 2014), meaning that researcher reflexivity is critical as researchers much understand the role, they play in qualitative data collection and analysis.

3.2.4 Mixed methods

There are multiple different definitions of mixed methods research. Johnson, Onwuegbuzie and Turner (2007) developed the following definition from the systematic synthesis of nineteen previously published definitions: “a type of research in which a researcher or team of researchers combines elements of quantitative and qualitative research approaches (e.g., use of qualitative and

quantitative viewpoints, data collection, analysis, inference techniques) for the broad purposes of breadth and depth of understanding and corroboration” (p. 123). At its base level, integration or “mixing” of both quantitative and qualitative data collection and analysis is the key methodological component of mixed methods (Plano Clark and Ivankova 2016). This integration can take place within a single study or a series of studies (Creswell and Plano Clark 2011).

Mixed methods methodologies have typically pragmatic underpinnings whereby, hypotheses are tested and multiple perspective provided. Researchers’ base inquiry on the assumption that multiple types of data collection provide a better understanding of the research question(s) (Creswell 2014).

One of the main benefits of mixed methods methodology is that it allows for flexibility within study design (Creswell 2009). Although, critics of mixed methodology argue that the vast expanse of possible taxonomies adds confusion and a lack of consistency to the research area (Carr, 2009), those in favour of this methodology argue that mixed methods design capitalises on the respective strengths of both approaches with interactions between the two at multiple stages throughout the research (Curry and Nunez-Smith 2017). This allows for a better understanding of the research problem (Creswell and Plano-Clark 2011) as the core premise is that the use of complementary methods yields greater insight to a research question than quantitative or qualitative alone (Curry and Nunez-Smith 2017).

The three basic types of mixed methods design most used within health sciences research are convergent, sequential exploratory, and sequential explanatory (Creswell and Plano Clark 2011).

In a convergent (or concurrent) approach the quantitative and qualitative components are conducted simultaneously, with the results then integrated to form the overall results (Creswell and Plano Clark 2011).

In exploratory sequential design the qualitative component occurs first and informs the quantitative component (Creswell and Plano Clark 2011). An example of this could be interviewing a cohort to gauge the views of participants and then use this to build an instrument/ identify an appropriate instrument to further investigate the research problem quantitatively (Creswell 2014). Following these the qualitative and quantitative results are then integrated and presented (Creswell and Plano Clark 2011). The benefits to this approach are that it allows for greater

versatility in discovering novel ideas and allowing subdomains of ideas to be further explored or validated (Gogo and Musonda 2022).

In explanatory sequential design, the quantitative component is conducted first and used to inform the qualitative component (Creswell and Plano Clark 2011). The premise behind this is that the quantitative data provides a general understanding of the research problem and then the qualitative data explores this further (Ivankova, Creswell and Stick 2006). The benefits of this mixed methods design are that it is straightforward and allows for in-depth exploration of quantitative results particularly if unexpected quantitative results arise (Ivankova, Creswell and Stick 2006).

However, when compared to convergent approaches, sequential approaches are time consuming methods of collection and analysis (Ivankova, Creswell and Stick 2006; Fetters, Curry and Creswell 2013).

3.2.5 Methodology Conclusion

In conclusion, mixed method studies have become more popular within health care research (Tariq and Woodman 2013) and are now commonly used when researchers adapt a pragmatic worldview and feel a qualitative or quantitative methodology alone will not sufficiently answer the research question (Curry and Nunez-Smith 2017). A mixed methods methodology was adopted in this thesis.

3.3 Study design

An explanatory sequential mixed methods approach, utilising a cross-sectional survey and semi-structured interviews, was deemed to be the most rigorous study design to investigate the research question and objectives.

Due to the limited literature relating to PA in the TYA oncology population, as demonstrated in chapter two, the explanatory sequential design was selected. In using both a cross-sectional survey and interviews this research aimed to obtain an in depth understanding of cancer patients/survivors' physical activity behaviours, experiences and preferences with the interview phase aiming to provide deeper contextualisation than would be obtained using the survey only. Undertaking the quantitative research first, also allowed for the doctoral researcher to use the initial survey data to inform the interviews, which was felt to be beneficial given the doctoral researcher's novice status in conducting qualitative research.

Ivankova, Creswell and Stick (2006) highlight three methodological issues which must be considered when conducting explanatory sequential studies. These include the priority, implementation and integration of the quantitative and qualitative data (Creswell et al. 2003). Priority refers to the 'weight' given to the quantitative and qualitative data collection and analysis. This can either be spread equally between both data types or it can favour one data type over another (Creswell 2009). Typically, within an explanatory sequential study the quantitative data is given priority over the qualitative (Ivankova, Creswell and Stick 2006) however, within this study equal priority was given to both the quantitative and qualitative data as they were both considered vital for fully addressing the research objectives with neither collection method considered more important than the other. Implementation refers to the sequence of the data collection and analysis (Ivankova, Creswell and Stick 2006); in this case, quantitative followed by qualitative. Lastly, integration refers to the stage(s) at which the quantitative and qualitative data are integrated during the study. As expected in explanatory sequential designs full integration of the survey and interview results took place once all data collection and analysis had concluded (Creswell 2009).

3.4 Ethics

3.4.1 Ethical Approval

Firstly, ethical approval was sought from Robert Gordon University, School of Health Sciences Research Review Group (SHS SRRG) and approval was granted on 3rd July 2020 (Appendix 7). Subsequently, NHS approval was sought using the Integrated Research Application System (IRAS: 281795) in September 2020. The study was reviewed by the Proportionate Review Subcommittee of the North East –Newcastle and North Tyneside 2 Research Ethics Committee on the 1st October 2020 (REC reference: 20/NE/0235) (Appendix 8) and following minor clarification was approved on 28th October 2020. Permission to conduct the study locally was granted by NHS Greater Glasgow and Clyde Research and Innovation (R&I) (Project no. GN200N483) (Appendix 9) on 6th January 2021.

Following ethical approval gatekeeper approval was sought TCT Lead nurse TYA's with Cancer, TYA physiotherapist, TCT TYA's with Cancer Senior CNS and the TCT TYA's with Cancer CNS.

A non-substantial amendment application was submitted to IRAS for the addition of recruitment sites in NHS Lothian, NHS Tayside and NHS Grampian. This was

approved on 25th November 2021 and local NHS Research and Development (R&D) permission was sought for each of the additional sites. NHS Tayside R&D approval was granted on 27th September 2021 (Tayside Ref: 2021ON05) (Appendix 10) and NHS Grampian R&D approval was granted on 22nd October 2021 (Project No:2021HA006E) (Appendix 11). Unfortunately, it was not possible to obtain local R&D approval from NHS Lothian within the time constraints of this Doctoral study therefore, no recruitment took place within this site. Again, gatekeeper approval was sought from the TCT TYA's with Cancer Senior CNS in NHS Tayside and the TCT TYA's with Cancer CNS within NHS Grampian.

3.4.2 Informed consent, non-participation and withdrawal

All participants received a PIS about the study and were given the opportunity to ask the researcher any questions via email prior to deciding about participation. Informed consent was obtained for the survey, using a series of checkboxes and in the interviews via audio consent. Throughout the study participants were advised that they were free to decline to participate or that they could withdraw from the study at any time. Participants were informed that declining to participate or withdrawing from the study would not impact on their care.

3.4.3 Data protection and confidentiality

Participants were anonymised using a unique study number. Identifiable participant information was kept on a separate password-protected spreadsheet and used for linking to anonymised data via the study number. This spreadsheet was only accessible by the researchers directly involved in this study. All researchers were trained in Good Clinical Practice (GCP) and fully compliant with General Data Protection Regulations (GDPR), the Data Protection Act 2018 the NHS code of confidentiality.

3.4.4 Data Storage

All research data, with participant consent, was stored securely on a Microsoft Teams research drive project area on password protected computers within Robert Gordon University (RGU). Only members of the direct research team have access to data. All audio recordings were transferred to this secure site and then the recordings were deleted from the recording equipment. RGU is protected by an entry card system and can only be accessed by a member of staff. Anonymised data will be archived according to RGU guidelines and stored as research data for up to 10 years.

3.5 **Methods Overview**

As seen in figure 9.0 the study comprised three phases; Phase 1: a descriptive cross-sectional online survey, disseminated to eligible participants via a multi-method recruitment and distribution strategy; Phase 2: telephone or virtual “face-face” interviews recruited used the multi-method strategy; Phase 3 data synthesis and survey and interview data integration (Ivankova, Creswell and Stick 2006).



Figure 9.0 Methods overview adapted from Ivankova, Creswell and Stick 2006.

Participants had three options with regards to study involvement: 1) participate in the survey phase only, 2) participate in the interview phase only, 3) or participate in both the survey and interview phase of the study (Figure 10.0). Seventeen participants chose to partake in the survey only, one in the interview only and thirteen chose to take part in both the survey and the interview.

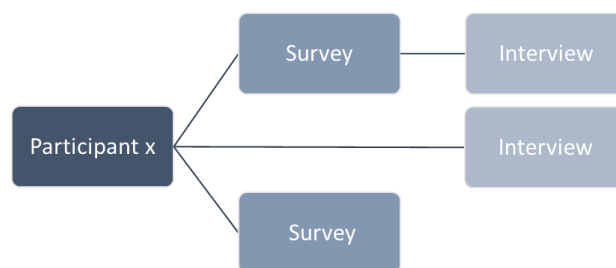


Figure 10.0 Visual representation of potential participant study involvement options.

3.6 **Inclusion Criteria**

As this study was exploratory in nature it was important to be inclusive with the study criteria to ensure as wide a representation as possible across the TYA cancer population. Participants were eligible to partake in the study if they had been:

- a) Diagnosed with any type of cancer between the age of 16-25 and were undergoing active or palliative treatment.

- b) Diagnosed with any type of cancer, in the last 10 years, when aged 16-25 but were now classified as in remission or cancer free.

Participants were excluded from participation if:

- a) They were diagnosed with cancer outside of the 16-25 age bracket.
- b) They were unable to fluently read or speak English as the survey was not translated into other languages and all interviews were conducted in English.
- c) They did not have internet access or digital technology (such as a smart phone or laptop/computer) or access to a telephone to complete the survey and/or the interview.

Due to the main study recruitment sites the majority of potential participants were expected to reside in Scotland however, the social media recruitment campaign and the targeting of prominent UK based TYA cancer charities meant that potential participants may have been located in the wider UK area or internationally.

Internet access was considered a minimal barrier to study involvement as 96% households in Scotland and the UK (Scottish Government 2023; Prescott, 2020) have access to the internet. Inpatients within NHS Scotland facilities have access to the internet via patient WIFI, which may occur a cost depending on location. The BWOSCC also has a patient tablet that can be accessed by those on the TCT unit.

3.7 Participant Recruitment

3.7.1 Recruitment Materials

Below is a list of the recruitment materials provided to the TYA physiotherapist and TYA CNS's who assisted with recruitment for the study.

- Participant information sheet (PIS) containing a summary of the study including; aims, rational, inclusion and exclusion criteria, any potential risk, data management and confidentiality information and researcher (Lead researcher and principal supervisor) contact information for further questions (Appendix 12).
- Recruitment poster (with information about the survey and interview phases) (Appendix 13)

- Online Survey link (which had PSI and Informed consent statements embedded within it)

3.7.2 Multi-method Recruitment Approach

The multi-method recruitment approach utilised in this study is described in the following section. A visual representation of steps a-h can be found in figure 11.0, followed by a more in-depth written description.

If any potential participants had questions or wished to discuss the project in more depth, they could contact the research team (lead researcher or principal supervisor) via email or telephone. Additionally, if any potential participants wished to participate in only the interview phase of the study, they were either provided with the lead researchers contact details to express their interest or clinicians obtained permission to pass their contact details along to the lead researcher.

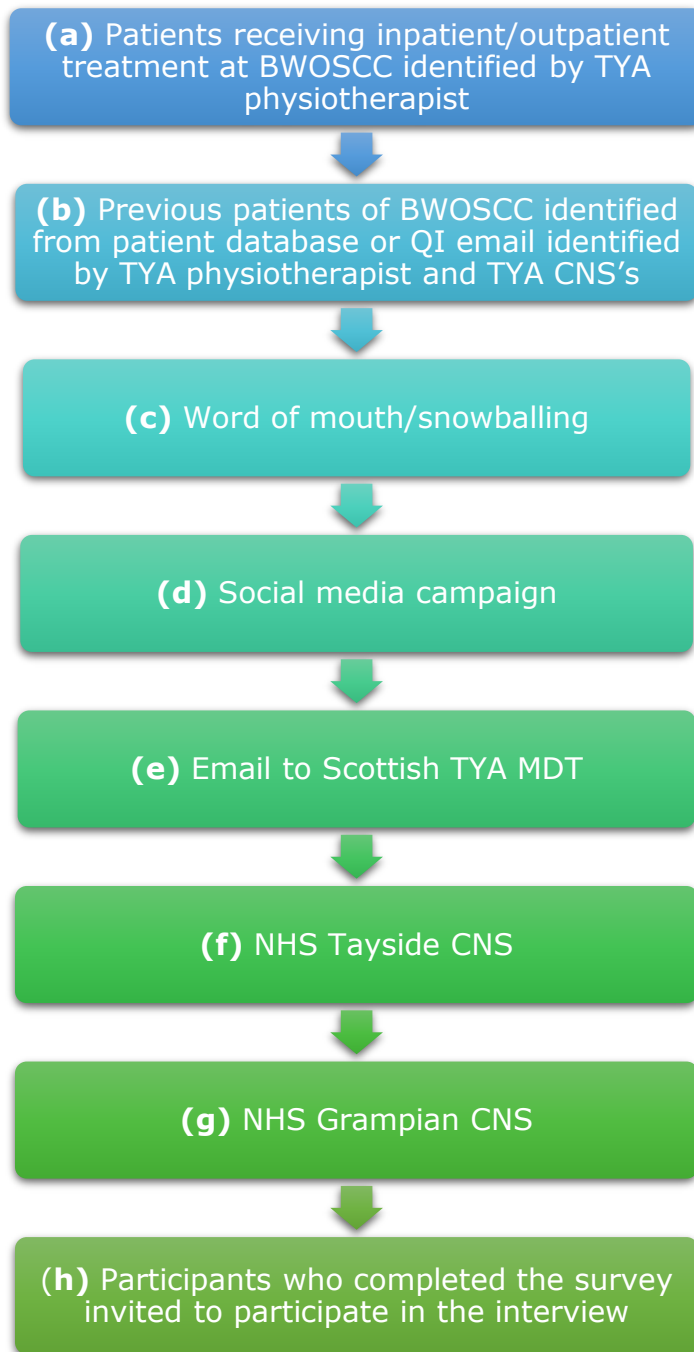


Figure 11.0 multi-method recruitment approach utilised in this thesis.

(a) Potential participants undergoing inpatient or outpatient treatment at the BWoSCC were approached by the TYA physiotherapist and informed of the study. If interested, the physiotherapist provided potential participants with the online recruitment pack. Coercion was minimised as the TYA physiotherapist only provided interested participants with the recruitment pack, they did not engage in further recruitment such as collecting consent or answering questions about the study.

(b) Individuals previously treated at the BWoSCC but were currently “off treatment” or were now cancer free were recruited to the study by the TYA physiotherapist or TYA clinical nurse specialists (CNS) via email, using the template provided and online recruitment pack attached to the email. Access to participant information was obtained from the BWoSCC patient database, which contained contact information of patients treated on the TYA ward at BWOSCC over the last 10 years, as well as patients on the clinicians’ caseloads and individuals who had recently received a BWoSCC TYA unit online quality improvement survey. As per the study protocol two reminder emails were sent at two-week intervals following the initial recruitment email (Nulty 2008), unless they specified that they had already completed the survey or did not wish to participate.

(c) word of mouth/snowball recruitment: participants informing other potential participants of the study and members of the public informing potential participants of the study. The researcher had planned to do a recruitment presentation to the TYA Youth Forum however, due to COVID-19 restrictions the forum was not meeting regularly so this was unable to be arranged.

(d) An online social media campaign (Appendix 14 example social media post):

- information about the study and the online survey link was shared via the research teams personal domains (such as Facebook, Twitter and Instagram), RGU Health Sciences and RGU physiotherapy Facebook and Twitter accounts, Managed Service Network Children and Young People with Cancer (MSN CYPC) social media accounts (Facebook and Twitter), NHS GG&C Physiotherapy Focus (online magazine). Researcher social media posts were updated regularly throughout data collection.

- Also, relevant cancer charities and “influencers” were contacted via social media pages regarding sharing study recruitment information with their followers. Charities which posted recruitment information on their sites included Teenage Cancer Trust (TCT) Scotland (Facebook), Maggie’s (Twitter), Jak’s Den (closed Facebook group), Cancer Lads (Twitter), Shine Cancer Support (closed Facebook group) and CLIC Sargent Scotland (now known as Young Lives v Cancer). A further external research support request was also sent to CLIC Sargent and Trekstock, however, one declined as they did not have capacity to promote external research at the time of the request and the other decided not to continue with communication.

(e) An information and recruitment email with online survey link was sent to the Scottish TYA multidisciplinary team, Scottish TYA nurse specialists and the two TCT activity coordinators (Glasgow and Edinburgh) via the Teenage Cancer Trust National Lead Nurse for Teenagers & Young People with Cancer in Scotland.

(f) The TYA CNS within NHS Tayside identified potential participants from their current or previous caseload. An initial email was then sent inquiring if the potential participant would be agreeable to hearing about a physical activity research study. Those who expressed interest were then sent the template recruitment email and recruitment pack. Again, two reminder emails were sent as per protocol (see strategy b. above)

(g) In NHS Grampian the TYA CNS posted the recruitment poster and a brief study description within a TYA oncology closed Facebook group (which was used for peer support and to post information about TCT events etc), group members expressed their interest by commenting on the post or contacting the TYA CNS directly. All interested potential participants then received a copy of the recruitment email and recruitment pack. One reminder email was sent to potential participants two weeks after the initial recruitment email. Due to data collection time constraints, potential participants only received one reminder recruitment email instead of two.

(h) At the end of the online survey all participants were invited to participate in the interview phase of the study. The lead researcher communicated with the potential interview participants via contact details provided by participants (email address or telephone number) at the end of the survey (Appendix 15 template interview recruitment email). As per the study protocol a reminder email was sent to the potential interview participants and/or a follow-up phone call was made. A mutually agreed time, date and interview modality (telephone or virtual "face-face" via Microsoft Teams) was then arranged.

3.7.3 COVID-19 Considerations

At the time of applying for ethical approval and data collection, various distancing measures were in place due to the ongoing COVID-19 pandemic. Much of the oncology population was considered in the "highest risk" category, meaning they were at greater risk of serious illness if they contracted the COVID-19 virus. As a result of this more extreme social distancing measures were placed on these individuals, with many on the "shielding list" due to their weakened immune response. Originally, it was planned that the interview phase would have the option

to be in-person however, in order to adhere to government health guidelines and ensure participant safety the study was designed to be “contact free”. The researcher did not have any in-person contact with participants and all recruitment was electronic (including the recruitment materials) with the exception of inpatient/outpatient clinic recruitment on the TYA ward at the BWoSCC. The risk of infection to potential participants during in-person recruitment was minimised as this was carried out by an NHS member of staff working on the TYA unit (TYA physiotherapist), who wore personal protective equipment (PPE) and was undertaking regular COVID-19 testing guidelines in line with NHS GG&C infection control and staff testing guidelines.

3.7.4 Sampling

In most research studies it is not feasible to collect data from all members of a given population, therefore, a sample is necessary (Ball 2019). This sample must be representative of the wider population to minimise sampling error (Sue and Ritter 2012).

Although preferred as it minimises the effect of bias, random sampling techniques are difficult to apply to online surveys (Ball 2019). However, one method is to identify a defined population of interest and invite all members of this group to complete the online survey (Ball 2019). This sampling technique was utilised in this study through the TYA cancer clinicians. As outlined above in section 3.7.2 eligible participants were invited to participate in the study via email, with email addresses sought from the TYA patient database at BWOSCC and TYA clinicians’ caseloads in NHS GG&C, Grampian and Tayside.

Another technique commonly used is convenience sampling of internet users. This technique allows potential participants to self-select into the sample (Sue and Ritter 2012) as responses are received from whoever sees the survey online and volunteers to participate (Ball 2019). This technique is less desirable than random sampling, as there is no way to compute sampling error or estimate how representative a sample is of the population as a whole (Ball 2019). Typically, individuals who volunteer to participate are interested in the survey topic and thus introduce a degree of bias into the results (Sue and Ritter 2012). This study also employed convenience sampling through the use of a social media campaign. Posting the survey link or tagging various TYA cancer charities in social media posts about the survey to increase its visibility to potential participants. Snowball sampling was also used during the social media campaign and word of mouth

aspects of the studies recruitment strategy. In this sampling technique members of the desired population recruit other members of said population to participate in the study (Sue and Ritter 2012).

To ensure the interviews were representative of the population (gender and age group) the research team aimed to undertake purposeful sampling of participants. Purposeful sampling ensures “information rich cases”, for the most effective use of limited resources (Patton, 2002) by selecting individuals that are knowledgeable or experienced in the phenomenon in question (Creswell and Plano Clark 2011) and willing to participate in the study (Palinkas et al. 2015). For this study purposeful sampling criteria aimed to recruit an even spread of interview participants who were cancer free and had an active diagnosis across both the adolescent and young adult age brackets (16-18 at diagnosis vs. 19-25 at diagnosis) and genders. This was to try and ensure that the experiences of both males and females, across both age ranges and all stages of the cancer journey were captured and adequate saturation of data achieved (Guest, Bunce and Johnson 2006).

However, low participant response rate meant that purposeful sampling was not feasible for interview participants. Instead, all participants who expressed an interest were interviewed regardless of gender, stage on the cancer care continuum or age at diagnosis.

3.8 Study Design Amendment

Recruitment and data collection for the quantitative phase of this study was originally scheduled to take place over a three-month period (February-April 2021). However, there was a significantly smaller number of patients than expected with contact information stored in the patient database at the BWOSCC and for those with information, the majority did not have an email address stored. As this study was unfunded and the university campus was closed due to the COVID-19 pandemic the study materials were unable to be disseminated via postal services. Following a low participant response rate, it was decided to extend the data collection period.

As mentioned previously within an explanatory sequential mixed method approach the quantitative data analysis informs the qualitative data collection phase (Creswell 2014). Although the decision to extend the quantitative data collection until the end of January 2022 deviated from the ‘true’ explanatory sequential study

design, initial survey responses (collected between February-April 2021) were still extracted and descriptively analysed by the researcher to inform the generation of the interview topic guide. Information gathered from the survey informed questions about the effects of cancer care on PA behaviours, barriers/facilitators, and PA support received during and after treatment. This coupled with previous literature was used to generate the final interview topic guide. A more detailed discussion of the interview guide generation and piloting can be found in section 3.10.4. As the quantitative data still informed the qualitative phase, this study employed a “modified explanatory sequential” mixed methods design following study amendment as not all quantitative data was collected prior to commencing the qualitative phase 2.

Furthermore, as the study was completely contact free it was decided to expand recruitment across additional NHS health boards with TYA cancer services across Scotland. The MSN CYPC & Teenage Cancer Trust Lead Nurse for TYA, facilitated discussions with relevant clinicians across the MSN CYPC network. Three health boards expressed interest in supporting the study, one expressed interest but was unable due to staffing issues and one declined but did not provide a reason. A request for a non-substantial NHS ethics amendment for additional study sites was approved (11th of June 2021). Subsequent local R&D approval was granted for NHS Tayside (27th September 2021, Ref: 2021ON05) and NHS Grampian (22nd October 2021, Project No: 2021HA006E) however local approval was not obtained within the time constraints of the study for NHS Lothian. An additional non-substantial NHS ethics amendment was obtained (25th November 2021) to extend data collection from November 2021-January 2022. Full ethics details are provided later in this chapter.

3.9 Phase 1: Cross-sectional survey

3.9.1 Survey Generation

Creation of the online survey followed the principles outlined in the survey research process flow diagram (figure 12.0) proposed by Sue and Ritter (2012).

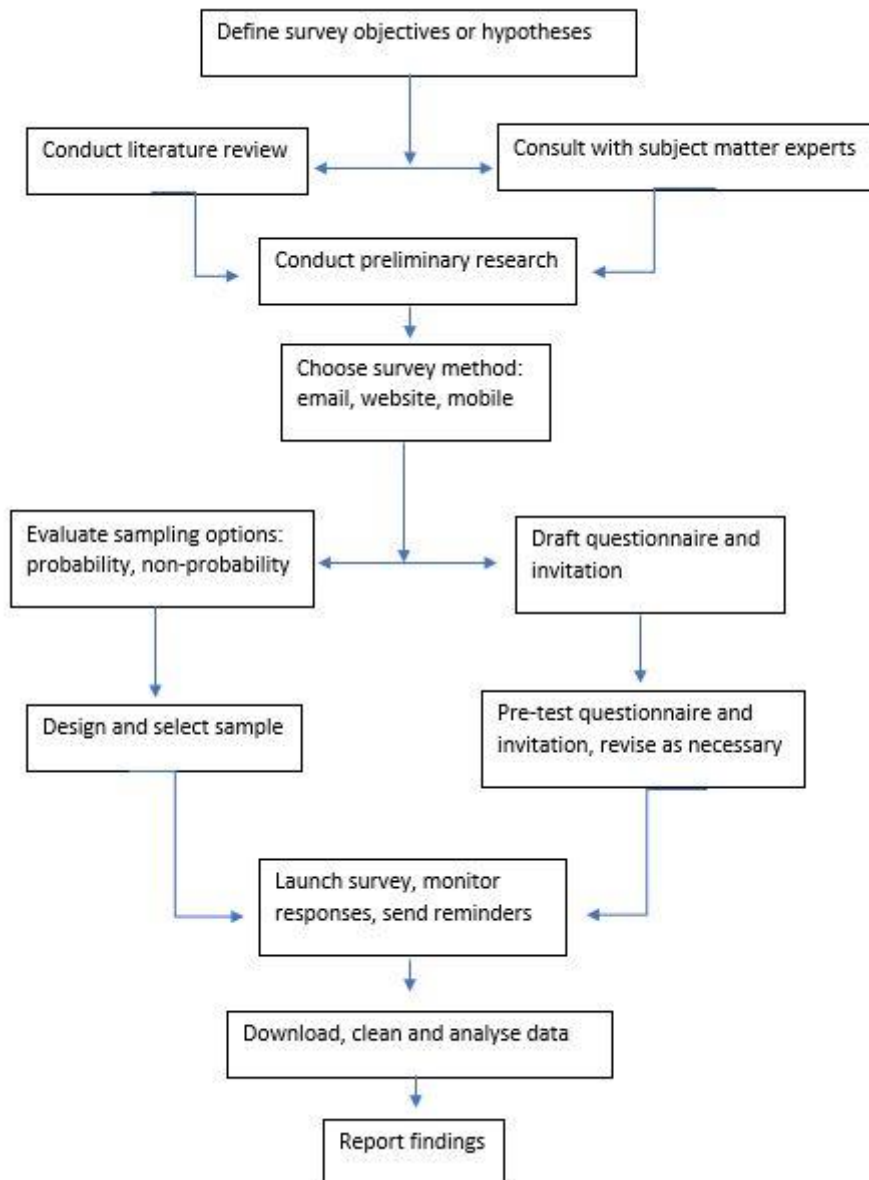


Figure 12.0 Survey research process flow diagram adapted from Sue and Ritter (2012) in *Conducting Online Surveys*.

Study objectives one to six, listed again below, were investigated within the survey. Literature review and consultation between TYA oncology experts and the research team took place prior to survey generation.

1. To identify self-reported physical activity levels of the TYA population (diagnosed aged 16-25) across the cancer continuum.
2. To explore the experiences the TYA oncology population has had with physical activity.

3. To identify the perceived barriers and facilitators to physical activity for the TYA oncology population.
4. To explore what individuals from the TYA oncology population feel is important to them, about physical activity.
5. To identify physical activity preferences in relation to type, setting, delivery method and support for the TYA oncology population.
6. To synthesis recommendations for physical activity in this group.

All study objectives except from objective four, which was only addressed in the interviews, were addressed by both the quantitative and qualitative data collection methods.

3.9.2 Online Survey Selection

Surveys are widely used to draw conclusions regarding behaviours and/or opinions of the general population or a subpopulation without having to study the population as a whole (Johnson, 2015). They are frequently used in healthcare to collect data on disease prevalence, behaviours, knowledge, attitudes, opinions and intentions (Saczynski, Mcmanus and Goldberg 2013) and are useful in the utilisation of preventive and curative health services as their results can assist health planners to establish health priorities (Dos Santos Silva 1999).

Surveys can either be cross-sectional, where measurement(s) are taken at a single point in time, or longitudinal, where measurement(s) are collected at least twice over a specified time period (Rindfleisch et al. 2008). Within cross-sectional studies participants are selected based on specified inclusion and exclusion criteria (Setia, 2016) and a "snapshot" of the subject under investigation is provided (Hofer, Silwinski, & Flaherty, 2002). Whereas, longitudinal studies are commonly used to detect changes over time (Rindfleisch et al. 2008). Cross-sectional methods in general do not allow for evaluation of causal associations, as they only provide information based on one point in time, however, they can identify prevalence trends, target large samples and identify characteristics of interest in the sample (Bowling 2014).

Survey methods are versatile, with multiple possible delivery methods including; pencil and paper, telephone or electronic/online surveys (Johnson, 2015). Table 21.0 summarises the main advantages and disadvantages of online surveys. The main advantages include being flexible, quick to conduct, cost effective, automated

and easy to use for both the researcher and participant, allows for data collection over a wide geographical spread and reduces social desirability bias by removing the research from participants. The main disadvantages include low participant response rate, internet reliance, risk of survey fraud or fatigue and increased risk of sampling bias with dissemination in online communities. Additionally in longitudinal studies missing data can be problematic.

Table 21.0 Summary of online survey advantages and disadvantages.

Advantage	Disadvantage
<p>Flexibility can be used with a variety of populations and investigate many different subject areas (Sue and Ritter 2012). Flexible use of structure, question type and design which can be more engaging to participants (Bernard 2011)</p>	<p>May increase risk of sample bias due to dissemination via virtual internet communities and social media (Alessi and Martin 2010) Some groups may not be represented due to lack of internet or technology proficiency (Bernard 2011). Not appropriate for illiterate populations (Bernard 2011)</p>
<p>Can be rapidly deployed to large number of potential participants using social media/email (Ball 2019)</p>	<p>Allow for a less in-depth exploration of phenomenon compared to qualitative research (Bernard 2011).</p>
<p>Cost effective (Ball 2019; Sue and Ritter 2012)</p>	<p>Low response rate (Nayak and Narayan 2019)</p>
<p>Automation Reduced risk of data entry errors (Callegro, Loza Manfreda and Vehovar 2015). Improved coding and data cleaning (Alessi and Martin 2010).</p>	<p>Although more commonly associated with longitudinal surveys missing data can be problematic (Ball 2019)</p>
<p>Ease of survey generation for the researcher by using online survey tools (Nayak and Narayan 2019). Ease for participants as they can complete the survey whenever is convenient from them and answer at their own pace (Callegaro, Loza Manfreda and Vehovar 2015).</p>	<p>Risk of survey fraud (participants submitting multiple responses or fraudulent information) Detecting survey fraud is difficult online (Bohannon 2016)</p>
<p>Can be used on large samples with wide geographic spread (Sue and Ritter 2012)</p>	<p>Online-Reliant on internet access (Sue and Ritter 2012).</p>
<p>May reduce social desirability bias as there is no researcher (Ball 2019).</p>	<p>Survey fatigue due to the large number of online surveys used in everyday life (Sue and Ritter 2012)</p>

Phase one of this study utilised a descriptive cross-sectional online survey. The survey was defined as descriptive as the data was not compared to a comparison group (Omair 2015).

There were four main reasons why an online survey was selected for this study. Firstly, the wide geographical spread of potential participants across Scotland meant that an online survey increased participant accessibility and reduced researcher burden. Secondly, online surveys are a contact-free method of data collection. This ensured the safety of potential participants, many of whom may have been immunocompromised due to treatment and adhered to COVID-19 social distancing and shielding measures and maximised the accessibility of the study to include those who were isolating. An online survey also offered flexibility with survey structure allowing easy integration of filter questions and a mix of open and closed questions (Bernard 2011). This was important as inclusion criteria included those with an active cancer diagnosis and those now cancer free. Questions regarding post-treatment physical activity or recovery would not be appropriate for participants newly diagnosed or going through treatment. Lastly, an online survey was selected as they are quick and cost effective. This was necessary as this DPT research was unfunded and had to be completed within limited time parameters.

As stated above an obvious disadvantage of online surveys is their reliance on internet access (Sue and Ritter 2012). This however, was deemed to be a small methodological barrier for participant recruitment due to the regular internet use in the majority of the TYA population. In a recent UK survey 99% of 16-44- year-olds reported internet use daily or almost every day (Prescott, 2020).

The next step outlined by Sue and Ritter (2012), is to identify the designated survey population or sampling field. This has been discussed previously in section 3.7.4.

3.9.3 Draft Survey and Invitation

The survey was generated using 'Online Surveys', an online service tool designed for academic research, education and public sector organisations (JISC 2019). This system was accessed via a Robert Gordon University (RGU) institution membership. 'Online surveys' was selected as it is General Data Protection Regulation (GDPR) compliant, user friendly and cost-effective as it was accessed via a university account.

Survey questions were designed with the study objectives in mind, using a combination of closed questions, Likert scale fixed choice responses and open-questions as appropriate. Survey questions were formulated based upon previous research, discussions with the supervisory team and the TYA physiotherapist. The TYA physiotherapist provided anecdotal information regarding TYA's experience of physical activity during the cancer journey. Where possible reliable and/or validated measures were used to collect data on behaviours. Section 3.9.9 discusses the survey piloting process used.

Figure 13.0 provides a brief overview of the survey structure. The first section of the survey was an introductory page which provided a survey overview and linked to the PIS for more in-depth information about study procedure and ethical considerations and approval. Before data collection could commence participants had to provide informed consent by checking a box(es) to indicate they were happy to participate in the survey. If they did not provide informed consent, they were unable to continue with data collection (Sue and Ritter 2012). Following this, participants were asked about their physical activity behaviours (current, pre-diagnosis and post-diagnosis), preferences, barriers and facilitators, as well as, the impact of covid-19 on physical activity and their social support network. Lastly, participants were asked to provide general demographic information (race, religion, age, gender, occupation) and cancer specific information (diagnosis, age at diagnosis, treatment(s) received, current stage e.g., on treatment, palliative, cancer free). The final page of the survey included a debrief statement, invitation to participate in the interview phase and links to TYA cancer support charities and physical activity guidelines. A copy of the full survey can be found in Appendix 16.

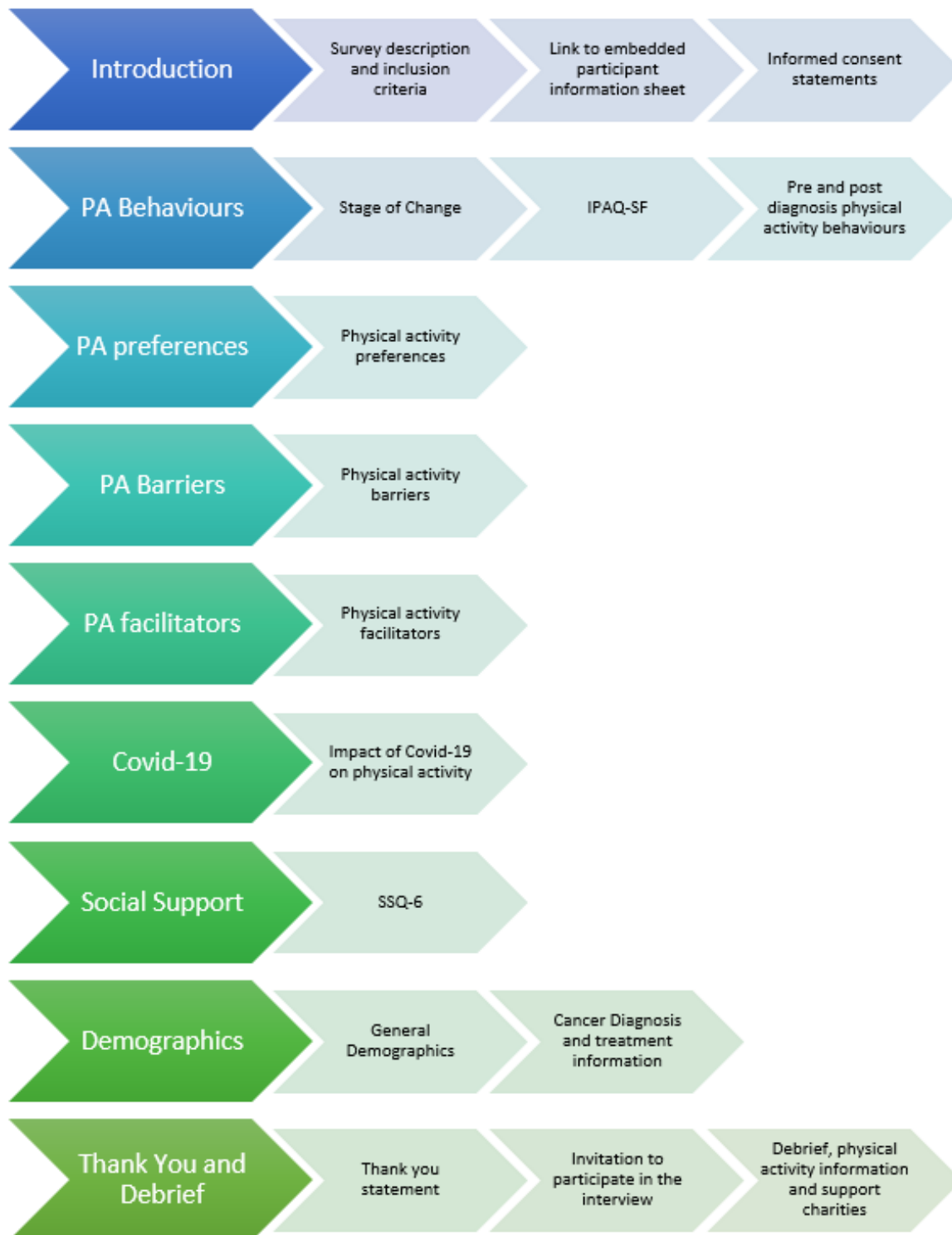


Figure 13.0 Brief overview of online survey structure.

Various methodological steps were embedded throughout the survey to reduce self-report bias. These included the use of valid and reliable questionnaires where possible, survey piloting and amending prior to distribution, researcher awareness of previously reported data within the topic area and minimalization of the effects of social desirability with an anonymity reminder at the beginning of the survey

(Fadnes, Taube and Tylleskar 2008; Sue and Ritter 2012). The chosen reliable and valid questionnaires for physical activity, stage of change and social support are discussed in more detail below as well as the justification for chosen barrier/facilitator and preferences questions.

3.9.4 Physical Activity Measure

There is currently no gold standard measure of physical activity (Lee et al. 2011; Misra et al. 2014) as all measures have reported limitations, although, accelerometers are increasing in popularity due to their objective measurements and small unobtrusive size (Lee et al. 2011). However, these are expensive and not practical to use with a large data sample (Lee et al. 2011). As this study aimed to recruit as many participants as possible, measuring physical activity using an accelerometer was not considered a viable option.

A self-report questionnaire was deemed to be the most appropriate option as they are relatively quick, cost effective and allow for the study of large populations (Kim, Park and Kang 2012). Three commonly used self-report measures in physical activity research are the Godin Leisure Time Exercise Questionnaire (GLTEQ) and the International Physical Activity Questionnaire long and short form (IPAQ-LF and IPAQ-SF respectively) (Healey et al. 2020; Keats and Culos-Reed 2008).

Although the IPAQ-LF has been demonstrated to be the most valid and reliable of all three measures in a systematic review (Mireille et al. 2010), it has been reported to be “too time consuming and boring” (Craig et al. 2003). Due to this it was decided that use of the IPAQ-LF would have likely decreased study participation. As this was just one element of the survey and would have greatly increased the time burden for study participants a shorter validated measure was considered more appropriate.

When deciding between the IPAQ-SF and GLTEQ, the GLTEQ has been validated within an oncology population (Keats et al. 1999), however, it does not account for occupational or educational PA (Keats and Culos-Reed 2008). Whereas, the IPAQ-SF enquires about the number of days, hours and minutes on which the participants performed vigorous physical activity, moderate physical activity (not inclusive of walking) and walking over the past seven days. Activity pattern can be obtained by treating these three activity categories individually and the total amount of physical activity performed in a week can be estimated by multiplying

each activity category by their estimated intensity in METs and then summing the values obtained for the three categories together (IPAQ Research Committee 2005). Total physical activity scores can then be categorised into three groups (low, moderate or highly active) as defined by the IPAQ core group as follows: Low-reporting no activity or little activity but not enough to meet the requirements of the other activity categories; Moderate-meeting any of the following three criteria: (a) performing vigorous-intensity activity on three or more days for a minimum of 20 minutes each day, (b) performing moderate intensity activity or walking on five or more days for a minimum of 30 minutes per day, or (c) performing any combination of walking, moderate intensity, or vigorous-intensity activities on five or more days and achieving at least 600 MET-minutes in a week; High-meeting either of the following two criteria: (a) performing vigorous-intensity activity on three or more days and achieving a minimum of 1500 MET-minutes in a week or (b) performing any combination of walking or moderate- or vigorous intensity activities in seven days of a week and accumulating at least 3000 MET-minutes per week (IPAQ Research Committee 2005).

The IPAQ-SF was developed solely for use among youths and middle-aged adults (Booth et al. 2003) and has been shown to be valid (moderate-vigorous PA and total PA for males $r= 0.27-0.31$, $p < 0.05$ and females $r=0.29-0.33$, $p < 0.01$) and agreeable (77.4%) with accelerometry in a young adult population (Mean age 22.9, 44.5% male) (Murphy et al. 2017). This tool is also the most commonly used PA self-report measure in TYA oncology PA interventions (Salchow et al. 2017; Salchow et al. 2021; Marec-Berard et al. 2021) and health behaviour research (Rabin and Politi 2010) as identified in the scoping review. The IPAQ-SF was selected to measure participants self-reported PA behaviours as this measure was developed for use within the target population and it is a quick and easy tool for participants to complete. Furthermore, it has been previously used within TYA oncology studies which may allow for comparison of results with previous literature relating to TYA cancer patients and survivors PA behaviours.

3.9.5 Stage of Change measure

As outlined in section 1.4 of chapter one, there are various models of behaviour change that have been applied within physical activity research. This study has opted to consider the individual in relation to the transtheoretical model (TTM) of behaviour change and assess participants stage of change (SOC). Although not utilised in a TYA setting Rogers et al. (2007) used this tool to measure exercise

SOC in adult breast cancer patients undergoing treatment. Within this study researchers compared SOC (dependent variable) with exercise barriers, expectations, preferences and values (independent variable). Due to the similarity in researcher objectives and the low participant burden for this measure it was selected to investigate participant SOC within this study.

Participants current physical activity stage of change (SOC) was measured using the standardised questionnaire designed and tested for validity and reliability by Marcus et al. (1992). This measure comprises of four dichotomous questions regarding physical activity behaviours and intentions. Participants responses are then classified into five stages: pre-contemplation (do not exercise regularly and do not intend to do so in the next 6 months), contemplation (do not exercise regularly but intend to do so in the next 6 months), preparation (exercising some but not regularly), action (regular exerciser for less than 6 months), and maintenance (regular exerciser for 6 months or more) (Marcus et al. 1996).

3.9.6 Barriers and Facilitators

There were three main factors which influenced the development of the potential barriers and facilitators questions; 1) discussion with TYA oncology physiotherapist 2) previous research into TYA cancer barriers and facilitators and 3) consideration of behavioural change theories.

Discussion with the TYA oncology physiotherapist provided anecdotal opinion around the barriers and facilitators of both TYA cancer patients undergoing treatment but also TYA cancer survivors post treatment. Discussion was also centred around physiotherapist perceived barriers which result from the hospital setting and current care pathway to provide comprehensive background information.

Previous research into the barriers and facilitators within a broader AYA (18-39 years) population or young adult survivors of childhood/paediatric cancer are outlined in section 1.3.6. Barriers and facilitators in TYA population are outlined in section 2.5.4.5. From the scoping review it was found that there is a large degree of heterogeneity in the previous research surrounding the barriers and facilitators of individuals diagnosed with cancer in the TYA age range and often barriers and facilitators are secondary outcomes of studies.

To identify potential barriers and facilitators participants were provided with a statement and asked to indicate their agreement using a five-point Likert scale

(strongly disagree, disagree, don't know, agree and strongly agree), as seen in figure 14.0 statements were generated based on the previous research and with consideration to the various levels within the SEM and constructs such as self-efficacy and decisional balance from the TMM of behaviour change. Table 22.0 illustrates the socioecological underpinning of each barrier and facilitator statement. The socioecological underpinning of each statement was allocated based upon discussion and consensus within the supervisory team. Reference was made during the discussion to the work of Birtwistle et al. (2019) which investigated the SEM in relation to PA. Thirty-six barrier and facilitator statements were selected for the survey. These were selected from a list of the most common barriers and facilitators identified in the scoping review and by the TYA physiotherapist, as well as previous research into PA behavioural change. Statements were limited to eighteen barrier and facilitator questions each to keep survey length to a minimum. However, to ensure no potential barriers or facilitators were missed participants were also asked to indicate any other factors which they felt prevented or help them to be active in a free-text box.

	Strongly Disagree	Disagree	Don't Know	Agree	Strongly Agree
I don't know how to be active.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Figure 14.0 Example of survey barrier statement and participant response options.

to ensure no potential barriers or facilitators were missed participants were also asked to indicate any other factors which they felt prevented or help them to be active in a free-text box.

Table 22.0 Survey barrier and facilitators statements and their corresponding socioecological model underpinning.

Facilitator statement	Socioecological classification	Barrier statement	Socioecological classification.
Being physically active helps me meet new people.	Interpersonal	I don't know how to be active	Intrapersonal
I want to improve my strength.	Intrapersonal	I don't have time to be active	Intrapersonal
I enjoy the social benefits of attending a sports club/fitness group.	Interpersonal	I don't want to get injured	Intrapersonal
My cancer diagnosis has motivated me to be more active.	Intrapersonal	I don't enjoy being active	Intrapersonal
I want to improve my mental health.	Intrapersonal	I am too tired to be active	Intrapersonal
I want to increase my independence.	Intrapersonal	Being active is not a priority for me	Intrapersonal
I want to improve my fatigue.	Intrapersonal	I am in too much pain when I exercise	Intrapersonal
Having access to a physical activity program makes me/would make me more active.	Organisational	I feel too weak to be active.	Intrapersonal
Being physically active helps me feel normal.	Intrapersonal	I don't have access to equipment or a facility where I can exercise.	Organisational
I want to maintain/improve my general health and fitness.	Intrapersonal	Bad weather stops me from being active	Environment

Facilitator statement	Socioecological classification	Barrier statement	Socioecological classification.
Having someone to exercise with helps me be active.	Interpersonal	I am too lazy	Intrapersonal
I know how to safely exercise.	Intrapersonal	It is too expensive to be active.	Organisational
If someone gave me information about how to safely exercise it would make me more active.	Interpersonal	I lack the motivation to keep myself active.	Intrapersonal
I enjoy being active.	Intrapersonal	I don't have anyone to exercise with.	Interpersonal
Being active before my cancer diagnosis has helped me remain active.	Intrapersonal	I can't be active outside my house due to COVID-19	Policy
Being active provides a distraction from cancer.	Intrapersonal	I have underlying health condition(s) other than cancer that makes exercising difficult.	Intrapersonal
Having encouragement and support from my family and/or friends helps me be active.	Interpersonal	I don't have transport to take me to where I can be active.	Environmental
I live close to facilities where I can be active.	Environmental	I worry about the way my body looks when I exercise.	Intrapersonal

There was a larger number of intrapersonal barrier questions within this study as previous literature identified in the scoping review (section 2.5.4.5) demonstrated that cancer patients and survivors experience more intrapersonal barriers to PA compared to interpersonal, organisational, environmental or policy barriers.

It is noted that this research could have also explored the strength of these barriers and facilitators and/or the frequency with which they impacted behaviour. However, as the aim of the research was only to identify potential barriers and facilitators and the overall length of the survey had to be considered, to account for participant burden, it was decided to only explore agreement with the barrier/facilitator statements.

3.9.7 Preferences

Physical activity preferences were measured using researcher developed questions. Questions were developed based upon previous research into: physical activity programme preferences of adult cancer survivors (Jones and Courneya 2002); physical activity programming preferences of adult breast cancer patients on treatment (Rogers et al. 2007); physical activity preferences of childhood cancer patients (Ross et al. 2018); intervention format and delivery preferences of AYA cancer survivors (mean age of participants 33.5 years) (Rabin et al. 2013); internet and social media preferences of AYA (mean age=30) related to their cancer information seeking behaviours and their preferences (Aggarwal et al 2020); physical activity preferences of adolescents (mean age 15) during and after cancer (Wright 2015). Furthermore, two TYA specific studies also informed the preference questions. Firstly, a 2018 qualitative study conducted by Pugh et al, investigating the lifestyle information and intervention preferences of TYA cancer survivors (mean participants age 22 years old) and secondly a quantitative study exploring the health behaviour information needs and preferences of TYA cancer survivors (mean age at diagnosis 16, mean age at study 20) (Pugh et al. 2017a). Although a large number of previous studies informed the development of these research questions no previous study investigated physical activity preferences only within the TYA population. Once preference questions were generated these were discussed with the TYA oncology physiotherapist at the BWOSCC to gain an insight into an anecdotal clinical perspective of TYA cancer patients and survivors physical activity preferences. Final questions (mixture of both open and closed questions) asked participants about preferred physical activity type, location, format, time of day and components of a physical activity program.

3.9.8 Social Support

Support from family, friends and others during a serious illness has been reported to be pivotal in patient's adapting to the illness as well as recovering from it (Keeling et al. 1996). Social support has been shown to be important factor in physical activity engagement (Laird et al. 2016; Wilson 2021) and is a key consideration in the SEM at the interpersonal level (Birtwistle et al. 2019). A separate social support measure was included in the survey to evaluate participants perceived social support and their satisfaction with this.

The Social Support Questionnaire (SSQ6) developed by Sarason et al. (1987) was used in order to assess if there was any correlation between perceived social support and self-reported physical activity levels. This measure was selected as it is quick to complete and has shown reliability in young adults ($\alpha=0.92$) (Tan, Barkus and Favelle 2021; Evangeli et al.. 2023). A quick measure was selected as minimising survey length was deemed to be important to maximise participant response rate.

The SSQ6 is based on two elements: the perception that a sufficient number of others is available to whom a person can turn to in times of need and the degree of satisfaction with the support available (Charles 2010). It is comprised of 6-paired questions, i.e., 12 in all. In each pair there is a 'contact question' and a 'satisfaction' question, e.g., 'Whom can you really count on to be dependable when you need help?' and its paired question: 'How satisfied?' (Questions 1 and 2). Each contact question refers to the actual number of individuals that can be counted on for help or support; while the satisfaction question refers to how the patient rates the quality of this/these contact/s. Contact questions had a possible range of zero contacts to a maximum of nine, i.e., 0 to 9 and it should be noted that any contact person listed could be used in any subsequent questions. The degree of satisfaction with social contacts was measured on a scale of 1 to 6: where 6 was very satisfied, 5-fairly satisfied, 4-a little satisfied, 3-a little dissatisfied, 2-fairly dissatisfied and 1-very dissatisfied. The responses of the six contact questions were added together to provide a total contact score (SSQN), this was repeated with the six satisfaction responses to provide a total satisfaction score (SSQS) (Charles 2010). This measure is quick to complete and has shown reliability in young adults ($\alpha=0.92$) (Tan, Barkus and Favelle 2021; Evangeli et al. 2023).

3.9.9 Survey Piloting

Prior to distribution a draft of the survey was reviewed by the TYA physiotherapist and the wider research team. Feedback was provided on how easy the questions were to understand, the appropriateness of question wording and if individuals felt there was anything missing from the barriers, facilitators, preferences and belief questions. Additional feedback was given regarding the survey length and how easy it was to use on various electronic devices (smartphone, tablet and computer). Following feedback relevant changes were made to the survey and a final pre-test was conducted by a 25-year-old male and 24-year-old female (with no cancer history) to ensure there were no technical issues with the finalised survey link and to gauge an accurate estimate of survey completion time by laypersons. Pilot responses were deleted prior to survey distribution.

3.9.10 Survey Data Analysis

Survey data was exported from 'Online Surveys' as an excel file and then processed/cleaned (Lindsay 2007). Data was explored descriptively with mean, median, standard deviation and percentages calculated. For physical activity data, the IPAQ scores were calculated in accordance with IPAQ research committee scoring protocol (2005). Participant SOC was calculated in accordance with algorithm outlined by Marcus et al. (1992). For participants with available data sets SSQ-6 scores were calculated in accordance with Sarason et al. (1987). The initial descriptive analysis collected informed the topic guide and questions asked in the semi-structured interviews

Inferential statistics were then conducted using IBM SPSS Statistics 28 to explore the relationship between participants SOC, cancer stage (active diagnosis vs cancer free) and IPAQ-SF category with self-reported barriers and facilitators to physical activity. As the data was not normally distributed, non-parametric correlation test Spearman's rho was conducted. Detailed demographic information (marital status, dependant status, age, gender, employment status, cancer treatment type) was collected for each participant as it was planned that the relationship between participant demographics would be explored in relation to physical activity behaviours as well as barriers and facilitators. However, due to the small sample size it was only possible to statistically analyse the relationship between SOC, cancer stage and IPAQ-SF category with barriers and facilitator statements.

3.10 Phase 2: Semi-structured Interviews

3.10.1 Introduction to Interviews

Interviews are the most commonly applied data collection method within qualitative research (Taylor 2005). They can be described as: structured (set questions); semi-structured (interview guide giving rise to more in-depth probing question); or unstructured (few, if any, set questions), (Bowling 2014; Gerrish and Lathlean 2015). Of these, semi-structured interviews are the most common method used in healthcare research (Gill et al. 2008) as they have been proven to be flexible and versatile (Kallio et al. 2016). The primary benefit of semi-structured interviews is that they allow the interview to remain focused while still giving the researcher autonomy to explore important themes or ideas which may emerge from the dialogue during the interview (Whiting 2008; Adeoye-Olatunde and Olenik 2021). This flexibility with questioning has been found to be successful at enabling reciprocity between the researcher and the interviewee (Kallio et al. 2016).

Semi-structured interviews, utilising a qualitative descriptive approach to explore participants unique lived-experiences of cancer and PA (Doyle et al. 2020), were selected for the second phase of the study. This approach is commonly used by junior qualitative researchers within health care research as it provides factual responses to how people feel about a particular space and reasons why people utilise or do not utilise services in said space (Colorafi and Evans 2016). It is also a flexible approach which is frequently used within mixed method studies where qualitative data can explain quantitative findings (Doyle et al 2020). Given the sequential explanatory design of this study and the overarching research question to explore TYA cancer patients and survivors' behaviours, lived-experiences and preferences, adopting a descriptive approach was deemed appropriate.

Arguably, unstructured interviews would provide a more in-depth exploration of themes than semi-structured (Bowling 2014) however, this method was deemed out with the researcher's experience level and thus not a viable data collection option for this study. The decision to conduct semi-structured interviews over structured interviews was made to allow for a deeper exploration of the research objectives and to enhance the survey data (Lindsay 2007; Adeoye-Olatunde and Olenik 2021). Semi-structured interviews allow the interviewer more freedom to explore unexpected topics or themes compared with structured interviews whilst also provide a topic guide and framework which aids the interview flow for the

novice researchers (Lindsay 2007). Given the exploratory nature of the research question and the experience level of the researcher, semi-structured interviews were deemed the most appropriate method of data collection.

3.10.2 Researcher Positionality

One important consideration when conducting interviews is the role of the researcher in the production of data (O'Reilly and Dogra 2017). Researchers shape and direct the interview, ultimately deciding what questions are asked, which in turn influences the responses that are received (O'Reilly and Dorga 2017). Again, engaging in research reflexivity is vital as the methodological perspective and worldview guiding the interview will have an impact on the questions asked and the nature of the relationship between the interviewer and interviewee (O'Reilly and Kiyimba 2015; Holmes 2020). Positionality relates to the position of the researcher as an 'insider,' member of the community being studied or lived experience of the topic in question, or an 'outsider,' someone who is separate from the community or topic in question (Merton 1972). This is also referred to as the emic-etic (insider-outsider) debate in which advantages and disadvantages to both stances have been argued (Holmes 2020). Insiders may gain better access to the participants being studied as they are viewed as "one of us" by the participants (Sanghera and Thapar-Björkert 2008) and may be able to ask more meaningful questions and gain more honest, open answers as well as producing more in-depth description as they understand the culture, do not experience "culture shock" and understand non-verbal cues and the colloquial language (Holmes 2020). Whereas an outsider may be able to ask provocative or "taboo"/ questions which an insider may not be due to culture. Outsiders may ask "dumb" questions and be provided with explanations/given information which may be not provided to an insider as it is deemed "obvious," and they may be more objective and avoid unknowing/inherent bias (Holmes 2020). Simply put the central questions of the debate are whether an individual from outside of a cultural group can understand the experiences of those within? And whether a researcher from inside a cultural group can detach themselves and observe a subject without bias (Holmes 2020). Holmes (2020) argues that rather than clear dichotomy between these two positions a researcher can inhabit multiple positions along the insider-outsider continuum and these positions can even be manipulated by the researcher (Herod 1999), meaning ongoing reflexivity throughout the research process is necessary.

Savin-Baden and Major (2013) state that when researchers are locating their positionality, they must consider themselves in relation to three things: the subject being investigated (e.g., personal positions that may influence the research), the research participants (e.g., how they view themselves and how others view them as well as acknowledging they may not be fully of this and that it requires in-depth thought and critical analysis) and the research context and process (Savin-Baden and Major 2013; Holmes 2020). Some aspects of a researcher positionality such as political or religious views and personal life history and experiences are more subjective, fluid, and contextual. Whereas other aspects are culturally fixed, including but not limited to their race, gender, or nationality. (Chiseri-Strater 1996). To ensure transparency within this thesis the following section reflects the researchers' positionality and potential biases. This reflexive process was informed by the (2020) article by Holmes discussing positionality for the novel researcher and the three considerations of Savin-Baden and Major (2013).

Being honest and open about ones' positionality and worldview allows for transparency within research as the reader has a clearer understanding of the researchers' potential biases meaning the reader can make a better-informed judgement about the research (Creswell 2014; Holmes 2020) Reflexivity in relation to the philosophical underpinning and development of this research has been discussed in section 3.1, however, it should be reiterated that the researcher had a pragmatic worldview when conducting the interviews.

Considering myself in relation to the subject being investigated it should be noted that I am biased in my opinion that physical activity is incredibly important not just for an individuals' physical health but also their mental health. This view is not only influenced by my professional opinion as a physiotherapist, but also by my opinion as an individual who has experienced the positive effects that engaging in regular physical activity can have on one's mood and self-esteem. My background in sports psychology and my experience working as a multi-sports coach with children, adolescents and young adults has shown me that behaviours, experiences, barriers, and motivators surrounding exercise are again unique to that individual. Acknowledging my strong belief about the benefits of PA was especially important during data analysis to minimise the effects of this on my interpretation of experiences.

Within physiotherapy there is a large health promotion role, discussing engagement with physical activity across a wide range of contexts. For example,

physical activity in relation to musculoskeletal injury rehabilitation, disease prevention (e.g., cardiovascular disease), strength or fitness maintenance within an aging population etc. With regards to physical activity in relation to an oncology population I have some clinical experience working with adult inpatients receiving a range of treatments including chemotherapy, radiotherapy, and surgery. This gives me a clinical "insider" perspective into the terminology used within the oncology setting, an idea as to potential side effects from various treatment types and some experience of delivering (or witnessing) physiotherapy advice regarding physical activity within an oncology inpatient setting.

Although there are some influencing factors which identify me as somewhat of an insider within an adult exercise oncology setting there is one major aspect which identifies me as an outsider. I am fortunate enough to say that I do not have lived experience of a cancer diagnosis. So, even though some participants may view me as an insider due to my clinical experience with physical activity and cancer, my lack of lived experience with cancer means I view myself as an outsider.

Furthermore, considering my demographics in relation to the participants being studied it is important to note that most participants who completed this study were white females, from the UK, in their mid-twenties. These are all characteristics which I share placing me as somewhat of an insider. Interestingly, due to the "contact free" nature of the research I wonder if these insider biases may have been reduced compared to what they would have been if I was involved in-person with participants as not all participants were made privy to this information depending on the interview method they selected (telephone vs Microsoft teams). None the less, during the virtual "face-face" interviews and social media campaign used within recruitment, these insider traits may have influenced participant attitudes towards me (the researcher) and vice versa. Furthermore, as a young adult I must acknowledge that I believe young adults to be a unique population with their own care needs and wants. My belief that the life experiences of young adults are vastly different to those in a paediatric or adult population and as such young adults should be classified separately within exercise oncology research may have biased this research.

Positionally, I view myself as an outsider with regards to lived experience of cancer however, I have insider perspective into the clinical workings of an oncology setting, have professional experience of physical activity and physical activity advice delivery and I share several characteristics with most of the participants. I

believe this means I bring both an insider and outsider perspective to this research.

The researchers' positionality as both an insider and outsider also remained throughout this phase, continually fluctuating based upon not just the researchers' perspective but also the interviewees and their perception of the researcher (as either an insider due to clinical background and/or demographic similarities or as an outsider of the TYA cancer community) (Holmes 2020).

3.10.3 Interview Setting

Interviews can be conducted in numerous ways including face-to face in-person, face-to-face videocall or via telephone (Adeoye-Olatunde and Olenik 2021). One main benefit of face-face interviews is that the researcher can make eye contact with interviewees and observe their non-verbal behaviours (e.g., facial expressions or body language) which can help with understanding of what is being said (Gerrish and Lathlean 2015; Adeoye-Olatunde and Olenik 2021). However, the drawback of face-to-face interviews is that it involves more participant burden (time and resources travelling). Telephone interviews on the other hand limit researcher's ability to detect non-verbal cues but are more cost-effective (less burden in time and resources travelling) (Gerrish and Lathlean 2015; Adeoye-Olatunde and Olenik 2021). Considering both this and the impact of COVID-19 outlined in section 3.7.3 participants within this study could select between a telephone or virtual face-to-face interview based on their personal preference. This allowed for the large geographic spread of potential participants and adhered to covid-19 social distancing guidelines.

3.10.4 Interview Guide and Piloting

As with quantitative research, rigorous data collection procedures influence quality and trustworthiness of research (Kallio et al. 2016). One technique to minimise bias is the use of interview guides. These can help with consistency and can be checked for subjective bias prior to use (Creswell 2014). Despite the popularity of semi-structured interviews there is a lack of consensus within the literature surrounding interview guide development (Kallio et al. 2016). Following a systematic methodological review Kallio et al. (2016) proposed an interrelated five-step framework for rigorous interview guide development. This five-step framework was followed during the interview guide design for this study to maintain trustworthiness. Step 1: identifying the prerequisites for using semi-structured interviews (i.e., the appropriateness of semi-structured interviews as

the data collection method for the research question) has been outlined above (section 3.10.1).

Step 2: retrieving and using previous knowledge (i.e., generating knowledge to inform interview questions. This can be done in numerous ways such as extensive literature review or consulting with experts) and Step 3: formulating the preliminary semi-structured interview guide, were both informed by previous literature into TYA cancer and physical activity and the preliminary results of the survey. Interview guides contain a list of predetermined questions (open, direct, verbal questions) and potential probing follow-up questions (verbal questions e.g., "can you tell me more about that?" and non-verbal gestures e.g., silence) which can be referred to throughout the interview (Whiting 2008; Adeoye-Olatunde and Olenik 2021). Probing questions should be neutral to avoid researcher bias or participants reporting what they think the researcher wants to hear (Harrell and Bradley 2009). Within the study a combination of predominantly descriptive and structural questions were used as the aim of the interviews was to explore in more depth the potential barriers and motivators to engagement with physical activity, physical activity preferences and participants experience with physical activity and cancer.

A draft interview guide was created and then in line with step 4 was pilot tested. Kallio et al. (2016) states this can be done using three different techniques: internal testing (testing within the research team), expert assessment (specialist(s) outside of the research team) and field testing (potential participants) (Kallio et al. 2016). Piloting was undertaken to reduce bias, check question content and avoid leading/double-barrelled questions (Whiting 2008). Internal testing within the research team took place first following question development. After this, six pilot interviews took place: three of these using the "expert assessment" technique (one clinical psychologist with interview research experience, one physiotherapist within the TYA oncology unit, one doctor with haematology experience) and three laypersons piloting (two young adults, male aged 25 and female aged 21 and one adult, female aged 35+). Feedback from piloting related to the wording of questions and how they were perceived, interviewer question delivery to ensure clarity and interview guide flow. Piloting highlighted that some questions felt repetitive so this allowed for the guide to be condensed. It also highlighted that the interviewer had a calm mannerism and engaged well with active listening due to their physiotherapy clinical background.

During semi-structured interviews it is important that interview guides are used flexibly (Robson 2011). The researchers must be aware of the risk of directing and steering the conversation around topics that they may have preconceived views about as this increases the risk of bias (Robson 2011). As such, an interview guide should not be read verbatim but instead used to provide a structure and focus to the natural flow of conversation (Robson 2011; Adeoye-Olatunde and Olenik 2021). Therefore, piloting of an interview guide is also important for researchers to practice and fully immerse themselves within the questions (Whiting 2008). Feedback was obtained from all pilot interviewees regarding question content and wording as well as the researcher mannerisms and interview style. Again, modifications were made to the interview guide based on this feedback. This then led to the final step in the framework: presenting the completed interview guide. It is important to present a clear, logical interview guide to ensure replicability of work by other researchers (Kallio et al. 2016). A copy of the interview topic guide can be found in Appendix 17.

3.10.5 Interview Procedure

As per the study protocol prior to commencing the interview, verbal informed consent was obtained and recorded from each participant. At the end of the interview participants were read a debrief statement and sign posted to relevant cancer charities for support should they wish it. They were also asked if they wished to receive a written summary of the study results via email. Any telephone interview participants who wished to receive a summary were asked to provide an email address for results correspondence. All interviews were audio-recorded using a password-controlled Dictaphone and transcribed verbatim by the researcher.

3.10.6 Interview Data Analysis

Following transcription of all interviews, the transcripts were analysed using thematic analysis (TA). Although TA is in a broad sense a method for identifying, analysing, and reporting themes in data it does not follow rigid theoretical frameworks but instead offers researchers analytic tools to make sense of data (Braun, Clarke and Weate 2016; Braun and Clarke 2021). TA therefore allows researchers great flexibility and is an accessible qualitative analysis technique. TA is a robust method for novice qualitative researchers, researchers wishing to conduct descriptive work, researchers working across disciplinary contexts and those wishing to produce research for public consumption (policy or practice orientated work) (Braun, Clarke and Weate 2016). Furthermore, TA is highly

accessible to novice qualitative researchers, providing a systematic entryway into coding and analysing data. TA is a flexible method which allows the researcher to analyse the data in multiple ways, assessing the entire data set or a phenomenon in-depth (Braun and Clarke 2012).

Undertaking TA involves a recursive, reflexive process (Braun, Clarke and Weate 2016). In 2006, Braun and Clarke outlined a six-phase model of TA (1. familiarising self with data, 2. generating initial codes, 3. searching for themes, 4. reviewing potential themes, 5. defining and naming themes, 6. producing the report) however, a common mistake researchers make when adopting this is to utilise this model in a linear fashion (Braun and Clarke 2021). In 2021, Braun and Clarke updated their definition as Reflexive Thematic Analysis (RTA) better encapsulates the reflective nature of this analysis type (Braun and Clarke 2021).

RTA requires researchers to make a series of active choices regarding how they engage with the data (Braun and Clarke 2019). RTA has big “Q” theoretical underpinnings with paradigmatic and epistemological assumptions such as qualitative paradigm, subjectivity, recursive coding, and continual reflection of the researcher (Trainor and Bundon 2021). Researcher reflection with regards to philosophical underpinning has been discussed previously in section 3.1 and researcher positionality has been discussed previously in section 3.10.2. Researcher reflection regarding the process of data familiarisation and the generation of initial codes and then themes is documented in section 6.2.

Furthermore, researchers can either adopt an inductive or deductive approach to analysis; inductive approaches are driven by what is in the data, they are usually experiential in orientation and essentialist in theoretical framework. Whereas, in deductive research the researcher brings to the data a series of concepts, ideas or topics that they base the data interpretation on. Deductive approaches are often critical in orientation and constructivist in theoretical framework (Braun and Clarke 2012). For this research project both an inductive and deductive approach has been taken.

3.11 Phase 3: Data Integration

The final phase involved data integration from both the quantitative and qualitative phases of the study (Ivankova, Creswell and Stick 2006). Results from the descriptive analysis were combined with the themes extracted from the interviews. These are compiled in the integration chapter seven. Results were combined to

fully answer research objectives 1-5 in fulfilment with research objective six. Findings from both phases were grouped in relation to each sub-question as is procedure with mixed-method sequential explanatory studies (Ivankova, Creswell and Stick 2006).

3.12 Summary of Methods

This chapter has discussed the philosophical and methodological underpinnings of this research. The chapter then presented and justified the study design and methods used to investigate the overarching research question and subsequent six research objectives.

CHAPTER 4: QUANTITATIVE: SURVEY RESULTS**4.0 Chapter Overview**

The following chapter illustrates the results of the qualitative survey. The first section outlines survey the survey distribution and response rate. Following this survey participants are demographics and cancer characteristics are presented. Survey responses are then displayed in relation to PA behaviours, PA preferences, barriers and facilitators and social support.

4.1 Survey Distribution*4.1.1 Clinicians*

Clinicians (CNS's and TYA physiotherapist) within NHS GGC contacted 107 individuals via email and verbally at clinics. TCT CNS for NHS Tayside identified 19 potential participants, 18 of which were happy to receive information via email about the study. NHS Grampian TCT CNS uploaded a recruitment post to a closed Facebook group with 33 TYA members, 28 individuals viewed the post and 8 wished to receive more information about the study via email. In total 159 potential participants were identified via clinicians.

4.1.2 Social Media and Charities

Recruitment posts were uploaded to the researchers personal Facebook and Twitter accounts. The twitter accounts for Maggie's cancer charity (@Maggie'scentres ten retweets), CancerLads (seven retweets) and the MSNCYPC (three retweets) each tweeted a recruitment post. A recruitment post was also released on the Facebook groups for Jak's Den and CLIC Sargent Scotland (now known as Young Lives V Cancer).

As seen in figure 15.0, the initial information and consent page (represented by p.1) of the survey was viewed 1666 times; this number includes all potential participants who received the online survey link during recruitment, clinicians working within TYA cancer services who may have been interested in the project as well as individuals who clicked on the survey link via the social media recruitment strategy. As recruitment was multi-faceted it is not possible to determine the exact number of eligible participants who viewed the survey and did not wish to participate however, it can be seen that a number of individuals began the survey and for unknown reasons did not complete it (n=40).

p.1	p.2	p.3	p.4	p.5	p.6	p.7	p.8	p.9	p.10
1666	12	13	3	3	3	5	1	0	30

Figure 15.0 Number of individuals who viewed/completed each page (p.) of the survey.

4.1.3 Survey Response Rate and Participant Inclusion and Exclusion Decisions

In total, 34 completed surveys were received however, four were subsequently excluded. One was excluded as it was a duplicate participant and the remaining three were excluded as participants did not meet inclusion criteria surrounding age at diagnosis; n=2 were paediatric diagnoses (younger than 16-years-old at diagnosis) and n=1 was an adult (older than 25-years-old) at time of diagnosis.

One participant, who was diagnosed within the inclusion criteria age bracket (16-25-years-old at time of diagnosis), received their diagnosis 14 years prior to survey completion. Although this did not meet the inclusion criteria of diagnosed within the last 10 years, the decision was made to include this data set. This stemmed from the overall low male response rates and the recruitment bias towards physically active individuals. As this data set was received from a male, within the correct diagnosis age range, who reported not engaging in regular physical activity it was decided that their responses should be considered and therefore included in the study results.

Due to the recruitment strategy adopted within this study it is not possible to calculate the "true" study response rate however, of the 'known' response rate calculated from the 159 clinician-identified potential participants was 18.9%.

4.2 Participants

4.2.1 Demographics

After data cleaning, 30 individuals participated in the online survey. The majority were female (n=24, 80%), with a mean age at survey completion of 24.2 years (range 16-32 years, SD +/- 3.4); and identified as White British (n=29, 96.7%). Fifteen participants (50%) reported they worked full-time, in a variety of careers. One participant reported having to reduce their hours at work following diagnosis and one participant was signed off work due to their diagnosis at the time of survey completion. Sixty percent (n=18) of participants were married/in a relationship

and 23.3% (n=7) reported having dependants. The majority of participants (80%) reported they were not religious but of those who were; 16.7% reported they were Christian and 3.3% reported they were Muslim. Full details of participant demographics, can be found in table 23.0.

Table 23.0 Survey characteristics including number of participant (n) and percentage (%).

Characteristic	n=30	(%)
Gender:		
Male	6	20
Female	24	80
Age (years):		
Mean	24.2 (SD +/-3.4)	
Range	16-32	
Ethnicity:		
White British	29	96.7%
Black/African/Caribbean	1	3.3%
Employment Status:		
Full time work as employee/self employed	15	50
Full time education/training	8	26.7
Part-time work as employee/self-employed	5	16.7
Not employed and not looking for work	3	10
Volunteer/unpaid work	3	10
Part-time education/training	1	3.3
Unemployed and seeking work	1	3.3
Marital status:		
Married/ In a relationship	18	60
Single	12	40
Dependant(s)		
Yes	7	23.3
No	23	76.7
Religion		
Not religious	24	80
Christian	5	16.7
Muslim	1	3.3

4.2.2 Participant Cancer Characteristics

Participants were diagnosed with a variety of cancer types, see table 24.0; the most common of which were Hodgkin's Lymphoma (n=8, 26.7%) and Thyroid cancer (n=7, 23.3%). Self-reported cancer status at the time of survey completion was as follows: 19 participants (63.3%) reported being cancer free, five participants (16.7%) were on active treatment, four (13.3%) reported not receiving active treatment at time of survey completion and two (6.7%) reported that they were on maintenance treatment. The mean age of participants at diagnosis was 20.9 years (SD +/-2.9; range 16-25), with a mean time since diagnosis of 40.3 months (SD=+/- 41.4; 3.4 years; range 4-176 months). There was no difference in mean age at diagnosis between males (20.6 years) and females (20.9 years), however, males on average had a greater time since diagnosis than females, 54.5 months (SD +/-62.3) and 36.7 months (SD +/-36.9) respectively. This difference was due to the inclusion of a male participant diagnosed >10 years ago. Due to the low response rate of male participants this data set was not immediately excluded. Analysis showed inclusion of this data set only increased participants overall mean time since diagnosis by 4.7months (35.6 months to 40.3 months). As this data set represented the male experience and did not greatly skew the average time since diagnosis the decision was made to include this participant. Recruitment of participants outside the target population is a limitation of snowball recruitment as the researcher does not have the same degree of control over recruitment material distribution as with convenience sampling.

Participants reported receiving a range of treatments, as seen in Table 24.0. The most common treatment type was chemotherapy (60%), followed by surgical intervention (50%). Fourteen participants reported that they received a single treatment type whereas, 16 reported receiving a combination of two or more treatment types. Two participants reported disruption to their treatment due to the COVID-19 pandemic (n=1 reported postponed chemotherapy and n=1 reported being unable to receive antibody treatment due to the risk from COVID being too high) and one participant reported participating in a UKALL clinical trial (combination of chemotherapy and steroids). Three participants reported long term medication use as a result of their cancer treatment, n=2 thyroxine and n=1 IV immunoglobulin.

For those who reported undergoing surgery: n=8 did not disclose the surgical procedure, n=2 reported undergoing a thyroidectomy and lymph node dissection, n=1 underwent an orchidectomy, n=1 reported having a partial thyroidectomy, n=1 reported having a lumpectomy and wide local excision, n=1 reported undergoing a retroperitoneal lymph node dissection and n=1 reported that they had a "tumour removal".

Of the 12 participants who received radiotherapy, n=5 had internal radiotherapy in the form of radioactive iodine, n=1 underwent proton beam therapy and n=1 reported receiving total body irradiation and n=6 did not disclose any specific information about the radiotherapy they received. Of those who reported receiving chemotherapy (n=18): n=5 did not disclose the drug type they received, n=7 reported receiving Doxorubicin Hydrochloride (Adriamycin), Bleomycin, Vinblastine Sulphate and Dacarbazine (ABVD); n=2 received Bleomycin, Etoposide and Platinum (BEP); n=2 received Bleomycin, Etoposide, Doxorubicin (Adriamycin), Cyclophosphamide, Vincristine (Oncovin), Procarbazine and Prednisolone (BEACOPP), n=1 received Doxorubicin, Bleomycin and Vincristine (ABV), n=1 received Capecitabine and Oxaliplatin (CapOx) and n=1 received Tafinlar and Mekinist. For those who reported undergoing immunotherapy, n=2 did not disclose the exact treatment they received but n=1 reported receiving Ipilimumab and Nivolumab and n=1 Blinatumomab.

Table 24.0 Participant cancer demographics including number of participants (n) and percentages (%).

	n=30	(%)
Cancer Diagnosis:		
Hodgkin's Lymphoma	8	26.7
Thyroid	7	23.3
Testicular	3	10
Ovarian	2	6.7
Sarcoma (Ewings; Osteosarcoma)	2	6.7
Melanoma	2	6.7
Non-Hodgkin's Lymphoma	2	6.7
Breast	1	3.3
Oral	1	3.3
Nasopharyngeal	1	3.3
Acute Lymphoblastic Leukaemia (ALL)	1	3.3
Self-reported cancer stage:		
Current Diagnosis:	11	36.7
- Active Treatment	5	16.7
- No active treatment	4	13.3
- Maintenance treatment	2	6.7
Cancer free	19	63.3
Age at diagnosis (years):		
Mean (SD)	20.9 (+/-2.9)	
Range	16-25	
Time since diagnosis (months)		
Mean	41.4	
Range	4-176	
Treatment:		
Chemotherapy	18	60
Surgery	15	50
Radiotherapy	12	40
Immunotherapy	4	13.3
Bone marrow transplant	2	6.7
High dose steroids	2	6.7
Stem Cell transplant	1	3.3
Clinical Trial	1	3.3

N= number of participants; SD= standard deviation

4.3 Survey Overview

The time taken by participants to complete the survey ranged from 13-98 minutes with an average completion time of 27 minutes (SD +/- 16.2 minutes). The first section of the survey included questions regarding participants' physical activity behaviours. This included participant TTM stage of change, self-reported current activity behaviours (IPAQ-SF) and self-reported pre- and post-diagnosis physical activity behaviours. The following sections will present these to illustrate participants physical activity behaviours before illustrating the impact of Covid-19. Participants self-reported social support network and network satisfaction will also be narrated. After this participant experiences (regarding physical activity information) and physical activity preferences (time of day, activity type, format, location, program content) will be presented. Lastly, physical activity barriers and facilitators and the impact of IPAQ category, cancer stage and SOC will be outlined.

4.4 Physical Activity Behaviours

4.4.1 Self-reported Current Physical Activity Behaviours and TTM SOC

At the time of survey completion 80% (n=24) of participants self-reported that they were currently physically active and 63% (n=19) self-reported that they engaged in regular physical activity however, only 40% (n=12) self-reported engaging in regular physical activity over the past 6-months.

Of the six participants that reported that they were not currently active two were on active treatment, three were not currently receiving treatment and one was cancer free. Of the eleven who reported they did not engage in regular PA six reported having a current cancer diagnosis (three active treatment, three no active treatment) and five reported that they were cancer free. Of the 18 who reported they had not been regularly active over the last 6-months ten reported they were cancer free, although two of them had completed their treatment less than 6 months ago, and eight had a current cancer diagnosis (five on active treatment, two not currently on-treatment and one on maintenance treatment). Eight out of the eleven participants who reported having a current cancer diagnosis were not regularly PA over the last six months. This suggests cancer diagnosis and treatment impacts PA behaviours however sample size was too small to assess for this.

The results from the stage of change questionnaire (Sarason et al1987) can be seen below in figure 16.0. None of the participants in this study were classified in

the pre-contemplation stage of the model. This suggests that all the participants were either physically active or intended to become physically active within the next 6-months (Raihan and Cogburn 2023). The six participants (20%) who reported they were not currently physically active were all in the contemplation stage of the behaviour change model and indicated they intended to change their behaviour change within the next 6-months. Five participants (17%) were in the preparation stage of the TTM meaning they were not regularly physically active; however, they were taking steps towards changing their physical activity behaviours and participating in some physical activity (Raihan and Cogburn 2023). Of the 19 participants who reported that they engaged in regular physical activity, 9 were in the action phase of the TTM (behaviour not yet sustained for six-months) and 10 were in the maintenance phase (behaviour sustained behaviour for at least 6-months). This however, does not align with the 40% (n=12) of participants who reported that they had been engaging in regular physical activity for the past six-months. Two participants (one in the contemplation stage and one in the preparation stage of the TTM) reported that they were not currently regularly physically active but that they had been regularly physically active over the past six-months. One of these participants had an active cancer diagnosis but was not receiving treatment at time of survey completion and the other participant was cancer free.

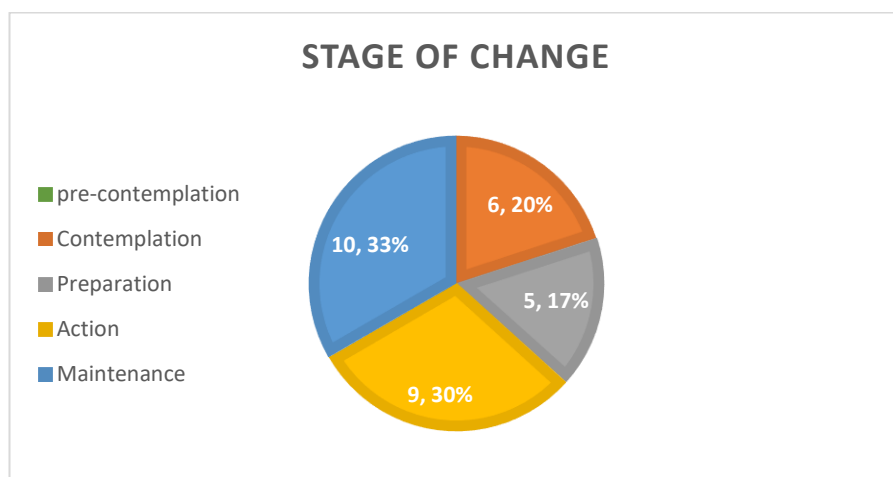


Figure 16.0 Pie chart indicating the number and percentage of participants at each stage of change within the TTM (n=30).

Furthermore, 87% (n=26) of participants reported that they intend to become more active within the next 6-months. This highlights that even though 33% of

participants are in the maintenance stage of the TTM some of these participants still wish to increase the amount of physical activity they regularly undertake.

4.4.2 International Physical Activity Questionnaire- Short Form (IPAQ-SF)

The following data pertains to participant IPAQ-SF responses. In line with the IPAQ-SF scoring protocol (IPAQ Research Committee 2005) four participants were excluded from the data set during data cleaning due to missing data. Both categorical and continuous scores were calculated for the remaining participants (n=26). Although excluded from IPAQ categorical and continuous scores, participant data was included in the number of days/per week participants engaged with each behaviour. In line with the truncation section of scoring protocol, one participant's data was capped at 180 minutes per day for moderate-intensity activity.

Figure 17.0 illustrates the number of days per week participants engaged in walking, vigorous-intensity and moderate-intensity activities based on IPAQ-SF responses (n=30). This highlights that walking was the behaviour that participants engaged in most regularly with 93% (n=28) reporting that they walked at least 1 day per week for 10 minutes or more and 47% (n=14) of participants reporting walking for at least 10 minutes or more 7 days a week. The average number of days participants (n=30) engaged in walking was 5 days +/- 2.3.

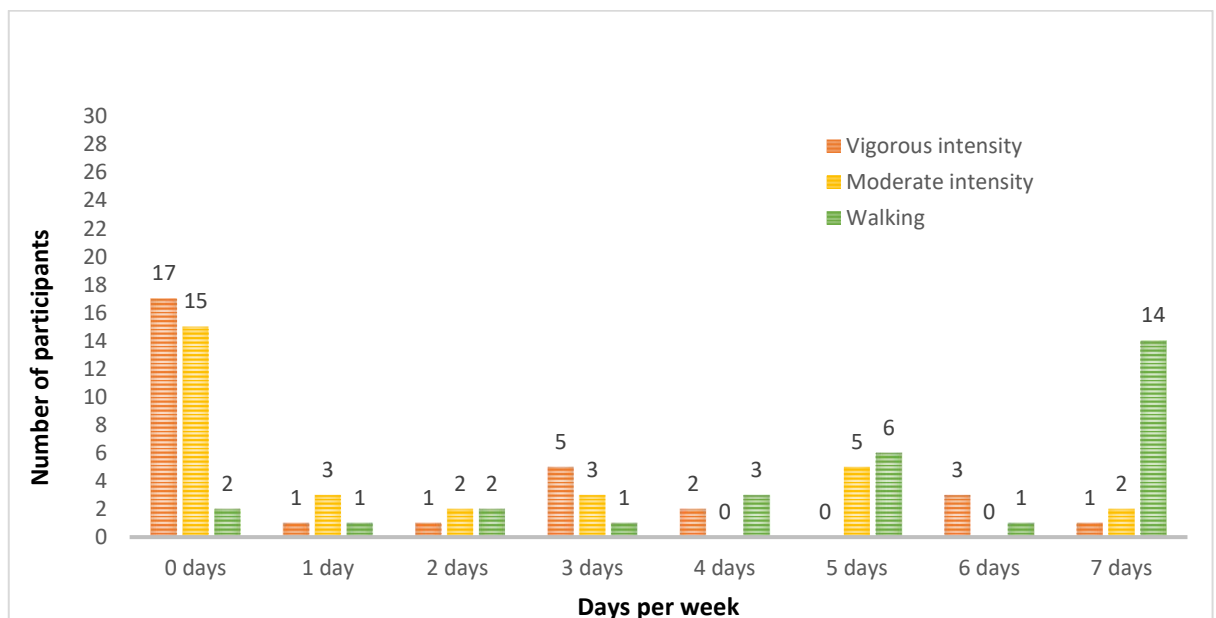


Figure 17.0 Number of days per week participants (n=30) engaged in IPAQ behaviours (vigorous intensity, moderate intensity and walking).

Figure 17.0 shows that moderate-intensity activity was the next most popular: 50% of participants (n=15) reported 0 days per week of engagement and 50% (n=15) of participants reported at least 1 day per week of moderate intensity activity. The average number of days participants (n=30) engaged in moderate-intensity activity was 1.8 days +/- 2.3. However, out of the 15 participants who engaged in moderate-intensity activity, the most common number of days per week was 5 days/week (n=5 33%) followed by 3 days and 1 day (n=3, 20%).

As seen in figure 17.0 vigorous-intensity activity was the least commonly performed physical activity behaviour by participants. The average number of days participants (n=30) engaged in vigorous-intensity activity was 1.6 days +/- 2.3. However, the majority of whom n=17 (57%) reported that they did not engage in any vigorous-intensity activity over the last 7-days. Of those who did engage in this behaviour (n=13) the most commonly reported weekly frequency was 3 days (n=5, 38.5%), followed by 6 days per week (n=3, 23%).

Table 25.0 shows the range, mean, standard deviation and median number of hours for participants reported weekday sitting, from IPAQ-SF responses. As can be seen participants spent an average of 8 hours a day sitting however there was a large degree of variation between participants as seen by the range, 1-24 hours, and standard deviation +/- 4.7 hours.

Table 25.0 Participants sitting behaviour, in hours, from IPAQ-SF responses including: range, mean, standard deviation and median.

Activity	No. of participants	Range (hours)	Mean (hours)	Standard Deviation	Median
Daily sitting	n=24	1-24	8	+/- 4.7	7

Of the six participants who did not provide a numerical sitting time one reported that they sat for "*most of the day*"; two reported that they did not know how long they spent sitting; one reported "*It depends on my mood some days I lie down all day other days I am motivated*"; one reported "*all day, I do college work, I go for naps every day, I also do crafts like embroidery*" and one reported "*Not sure but ALOT. Not got a lot of energy*". Four of the six participants had a current cancer diagnosis (three receiving active treatment) and two were cancer free, with a mean time since diagnosis of 7 months (range 4-14 months).

As previously stated, 26 participants provided sufficient data to calculate the IPAQ categorical and total continuous (MET-minute/week) scores. Six participants were classified in the low activity category, thirteen in the moderate activity category and seven in the high activity category. Table 26.0 below, illustrates the Total MET- minutes/week range, mean and standard deviation for each IPAQ-SF category. As expected, the mean MET- minutes/week increase sequentially from low to high, however due to the small sample size a large range and standard deviation can also be observed.

Table 26.0 Total MET-minutes/week for each IPAQ category, including range, mean, Standard Deviation (+/-) and number (No.) meeting PA guidelines (%).

IPAQ-SF Category	Total Continuous Score (Total MET- minutes/week)		
	Range	Mean (Standard Deviation)	No. meeting guidelines (%)
High (n=7)	2364-6426	4056.9 (+/-1437.6)	6 (86%)
Moderate (n=13)	628.5-2970	1434.4 (+/-691.8)	3 (10%)
Low (n=6)	0-576	347.7 (+/-212.2)	0

Using participants PA frequency, duration and intensity data collected in the IPAQ-SF, with WHO PA guidelines the number of participants meeting guidelines was calculated. It was possible to calculate PA guideline adherence for all 30 participants as the walking component of IPAQ-SF was the incomplete element which excluded the four participants in data cleaning. Two participants (6.7%) were completely sedentary and reportedly engaged in no PA, which correlated with their reported sitting behaviour ("all day, I do college work, I go for naps every day, I also do crafts like embroidery" and "24/7"). Seventeen participants (56.7%) engaged in PA however they did not meet the PA guidelines of ≥ 150 minutes moderate-intensity/ week or ≥ 75 minutes vigorous-intensity/week and eleven participants (36.6%) meet PA guidelines. It should be noted however that three of the participants who did not meet guidelines were just below the cut off.

Furthermore, table 26.0 illustrates none of the participants in the low IPAQ-SF category and only 10% of the moderate category met PA guidelines, whereas, almost all (86%) of the high category did. The three participants just below meeting activity guidelines were in the high (n=1) and moderate (n=2) categories.

Table 27.0 displays the range, mean, median and standard deviation for IPAQ continuous scores: vigorous-intensity, moderate-intensity and walking (MET minutes/week) of participants grouped by TTM stage of change. Table 27.0 also demonstrates participants corresponding IPAQ-SF category: low, moderate or high, (n= number of participants).

This table illustrates that as stage of change increases (contemplation to maintenance) so does participants physical activity behaviours. This can be seen in the range, mean and median of all 4 behaviours: vigorous-intensity scores, moderate-intensity scores, walking scores and total physical activity scores. The only exception to this can be seen in the continuous moderate-intensity scores of participants between the contemplation and preparation stages of the TTM. Participants in the preparation stage display lower moderate-intensity scores than those in the contemplation stage (range=0-180; mean=36 (SD +/-81); median=0 and range=0-180; mean=68 (SD +/-74); median=80 respectively). However, between the contemplation stage and the preparation stage participants can be seen to begin engaging in vigorous-intensity activity (range= 0-480; mean= 96 (SD +/-215); median= 0). Furthermore, an increase can be seen in walking scores (range= 0-396; mean=257 (SD +/-166); median=297 increased to range=149-2970; mean=987 (SD +/-1134); median=495) and total score (range= 0-576; mean 325 (SD +/-229); median=377 increases to range=495-2970; mean=1119 (SD +/-1042); median=675).

The trend between increasing stage of change and increasing physical activity behaviours can also be observed in the IPAQ-SF categorical score. All participants in the contemplation stage (n=5) are in the IPAQ-SF category "Low", this transitions to the one participant in the preparation group in the low category and the majority (n=4) in the "Moderate" activity category. Participants in the action stage are also predominantly in the moderate category (n=6) but one participant is in the "High" activity category. Again, this trend is seen when moving into the maintenance group with the majority in the "high" activity group (n=6).

Table 27.0 IPAQ-SF physical activity behaviours by TTM stage of change groupings.

Stage of Change	No. of participants (n)	IPAQ-SF Vigorous (MET mins/ week)	IPAQ-SF Moderate (MET mins/ week)	IPAQ-SF Walking (MET mins/ week)	IPAQ-SF Total (MET mins/ week)	IPAQ-SF category
Contemplation	n=5	0	range=0-180; mean=68 (SD +/- 74); median=80	range= 0-396; mean=257 (SD +/- 166); median=297	range= 0-576; mean 325 (SD +/-229); median=377	Low (n=5)
Preparation	n=5	range= 0-480; mean= 96 (SD +/- 215); median= 0	range=0-180; mean=36 (SD +/- 81); median=0	range=149-2970; mean=987 (SD +/- 1134); median=495	range=495-2970; mean=1119 (SD +/-1042); median=675	Low (n=1); Moderate (n=4)
Action	n=7	range=0-1920; mean= 377 (SD +/- 731); median= 0	range=0-360; mean=129 (SD +/- 164); median=0	range=693-2079; mean= 1322 (SD +/- 477); median= 1386	range= 990-3999; mean= 1828 (SD +/- 994); median= 1626	Moderate (n=6); High (n=1)
Maintenance	n=9	range= 0-3360; mean= 1333 (SD +/-1164); median= 1440	range=0-1680; mean= 444 (SD +/-612); median=160	range= 0-4158; mean= 1462 (SD +/- 1422); median= 1039	range= 1039.5-6426; mean= 3239 (SD +/- 1803); median= 2880	Moderate (n=3); High (n=6)

IPAQ-SF= international physical activity questionnaire short form; n= number of participants; SD= standard deviation.

4.4.3 Effects of Diagnosis on Physical Activity

When asked about pre-diagnosis physical activity levels, 86.7% (n=26) reported that they were physically active prior to their diagnosis. Participants reported that they participated in an average of 8.3 hours (SD +/- 9.4), median 5 hours (range 0.5-48 hours) of physical activity a week. If participants provided a range of durations, for example, 1-2 hours per week, the median, 1.5 hours, was used to calculate the average duration across participants. Twenty-five participants specified the type(s) of physical activity they participated in, and a full list of activities can be found in table 28.0, but the most common pre-diagnosis activity was going to the gym (n=9).

Post-diagnosis, 50% (n=15) reported that they engaged in physical activity, the most common of which was walking (n=5). The average time participants reported doing physical activity fell to 3.6 hours per week (SD +/- 2.5), median of 4 hours per week (range 10 minutes-8 hours). Additionally, 33.3% (n=5) of participants also reported that the activity they participated in post-diagnosis was gentle/low intensity and they self-report gradually building up their activity back up after their diagnosis.

"I managed what I could. After surgery I could only really walk for a few weeks, built back up slowly with cycling and swimming. Also did some more low intensity stuff like yoga/ Pilates" (Female, 26, no active treatment).

"Slowly re-entered the gym" (Male, 26, cancer free).

"I started doing home workouts and jogging in summer 2020 and have continued with this since then, straight after finishing treatment I did very little besides walking a fair bit but no strenuous exercise. I finished 2 years prior to starting exercising in 2020" (Female, 21, cancer free).

Table 28.0 Self-reported pre and post diagnosis physical activity types (n= participant number).

Pre-diagnosis activity	n=25	Post-diagnosis activity	n=15
Gym	9	Gym	4
Swimming	7	Swimming	2
Running	7	Running/Jogging	3
Dancing	5	Dancing	1
Weightlifting	4	Pilates	1
Cycling/Mountain Biking	4	Cycling/Mountain Biking	3
Gym Classes: Spin classes (n=2), circuits (n=1)	4	Home workout/ home workout class	4
Team sports (Football n=2, Volleyball n=1, Rugby n=1)	4	---	
Walking	3	Walking	5
Hiking/Fell walking	3	Hiking	1
Water sports: Kayaking (n=2) and Paddle- boarding (n=1)	3	---	
Rock climbing	2	Rock climbing	2
Yoga	2	Yoga	4
Gymnastics	1	---	
Tennis	1	Tennis	1
Boxing	1	---	
Roller Derby	1	Roller Derby	1
PA at work	1	---	

4.4.4 Impact of COVID-19 on Physical Activity

Participants were asked about the effect of the COVID-19 pandemic on their physical activity behaviour. The majority of participants, 80% (n=24), reported that Covid-19 did indeed have an impact on their physical activity behaviours. Participants were also asked if they had to adapt their physical activity behaviours due to COVID-19 and to explain the main impact COVID-19 had on their behaviours. Furthermore, when asked about physical activity adaptations as a result of the pandemic 63% (n=19) reported that they adapted their behaviours.

Content analysis on participant open-text responses regarding the effect and main impact of COVID-19 on physical activity and any subsequent behaviour adaptations was conducted. The main six points regarding COVID-19 have been extracted pragmatically. A full list of participants COVID-19 responses can be found in Appendix 18.

Participant responses to the questions regarding “the effect of covid-19 on physical activity” and “the main impact of covid-19 on physical activity” followed a similar pattern. COVID-19 affected participants physical activity behaviours in various ways with some participants reporting a positive impact and some reporting a negative impact.

Shielding/Social distancing, access to facilities, reduced physical activity, increased physical activity and no change to physical activity were the main themes reported by participants. shielding/social distancing negatively impacted physical activity as restricted what activity types participants could engage in, where participants could undertake activity and reduced participants social support as they could no longer be active with friends/colleagues.

Closure of activity facilities such as gyms and swimming pools negatively impacted participant activity behaviours as this limited the variety of activities participants could undertake, resulted in participants being unable to do they activities which they enjoy. Some participants who were on active treatment during lockdowns also reported that facility closure impacted their recovery.

Also, participants reported that shielding/social distancing and reduced access to facilities negatively affected their motivation to engage with physical activity.

Conversely, some participants reported that COVID-19 did not affect their physical activity behaviours and they managed to remain active during lockdown. Predominantly, these participants reported engagement with home/outdoor based activities which they continued with. Furthermore, a small number of participants reported that Covid-19 led to an increase in their physical activity behaviours as a result of increased time to engage and increased motivation. The main ways in which participants adapted their physical activity behaviours were to change the activity type in which they participated. This included stopping activities which they could no longer access and switching to home workouts or outdoor activities. The most commonly reported outdoor activity was walking. Participants also reported that if they were active outdoors this was limited to activities in their local area.

The participants who did not have to adapt their physical activity behaviour reported already undertaking activity at home or outdoors prior to the pandemic.

The main impacts reported are outlined below with supporting quotes.

- 1) **Reduced access to facilities:** The most commonly reported impact of the covid-19 pandemic on physical activity was reportedly reduced access to facilities (n=9) 30%. Participants reported Covid-19 caused closure of or restrictions to their regular facilities which impacted their behaviour.

"Access to regular places of activity" (Female, 25, active treatment).

"Gyms being closed has meant that I can't build my muscles back up" (Female, 24, cancer free).

"Mainly not being able to use the swimming pool, which is closed, and not being able to walk wherever I like. I live in a busy part of Glasgow, so it's not easy to find areas to walk where I won't be around other people. The route to parks I would usually walk to are along main roads, so I've not been able to go at all" (Female, 25, active treatment).

- 2) **Social distancing/ Shielding:** Participants (n=8) 27% also reported that covid-19 impacted their physical activity due to social distancing and shielding measures. These measures were reported to limit participants physical activity options and thus their behaviours.

"Shielding has limited the types of exercise I can do" (Female, 25, cancer free).

"Being put on the shielding list restricted the exercise I could do. So even on days where I was a little better, I still couldn't do much physically" (Male, 18, cancer free).

"Keeping socially distanced does distract me/knock off my focus when running" (Female, 30, cancer free).

- 3) **Mental impact:** A number of participants (23%, n=7) reported that the mental impact of the covid-19 pandemic/lockdown influenced their physical activity behaviours in various ways. Some participants report a negative impact on their motivation and the social side of being active. Whereas other participants reported that it had a positive impact on their motivation and that they used physical activity to reduce stress during the pandemic.

"Sometimes I feel so motivated to move and work out to do something but other times I feel completely drained and lazy. Major mood swings due to COVID have definitely had an impact" (Female, 24, cancer free).

"See it as a way to escape stresses" (Female, 29, cancer free).

"First lockdown I had zero motivation but this second lockdown something just clicked and I had the motivation to be more active" (Female, 24, cancer free).

- 4) **Reduced physical activity:** 13% of participants reported that the main impact of covid-19 was to reduce their physical activity behaviours. Also, one reported that they could not attend physiotherapy sessions at the hospital due to Covid-19.

"Less active which makes my body sore" (Female, 27, cancer free)

"I became less active as a result as I had to shield and could not walk as much as I would have liked" (Female, 26, cancer free).

"Can't attend physio sessions at the hospital" (Female, 24, cancer free)

- 5) **Physical activity increased:** Four participants (13%) reported the main impact of covid-19 was to increase their physical activity behaviours. Two of these participants reported that if they hadn't subsequently received their cancer diagnosis, they would have continued to increase these behaviours. One of these participants reported that during lockdowns their physical activity decreased however once restrictions eased, they increased their physical activity behaviours to help get them out of their house.

"During lockdowns, I had little to no activity but post I probably did more exercise than before due to a desire to get out the house more" (Male, 21, cancer free)

"I actually improved prior to cancer diagnosis as did more running, abs, home workouts then gym" (Female, 25, active treatment).

"I felt more active in the first lockdown, before diagnosis and if I wasn't for my diagnosis, I would have continued my physical activity" (Female, 16, no active treatment).

- 6) **No difference:** A small number of participants (7%) reported no difference to their physical activity behaviours.

"It's not made much difference" (Male, 27, maintenance treatment).

4.5 Physical Activity Preferences

The following sections outline participants physical activity preferences including activity type, location, format and time of day, as well as what content they would prefer in a physical activity program.

4.5.1 Preferred Physical Activities

Participants were asked their current physical activity preferences from a predetermined list; they were allowed to select all options which applied to them. If their preferred activity was not listed, they were instructed to select "other" and provide details in an open text box. An additional text box was used to gather further information from participants who selected "team sport" as a preference.

As seen below in Figure 18.0, walking was preferred by the majority of participants (n=27, 90%). Those who selected other (n=6) reported a preference for; yoga (n=2), fencing, weight lifting, kayaking, Pilates, rock climbing, tennis and home workouts using weights, exercise bands and kettlebells. Participants preferred team sports were rugby, netball and football. The gym (n=15, 50%) and housework (n=14, 47%) were the next more preferred activities, see figure 18.0.

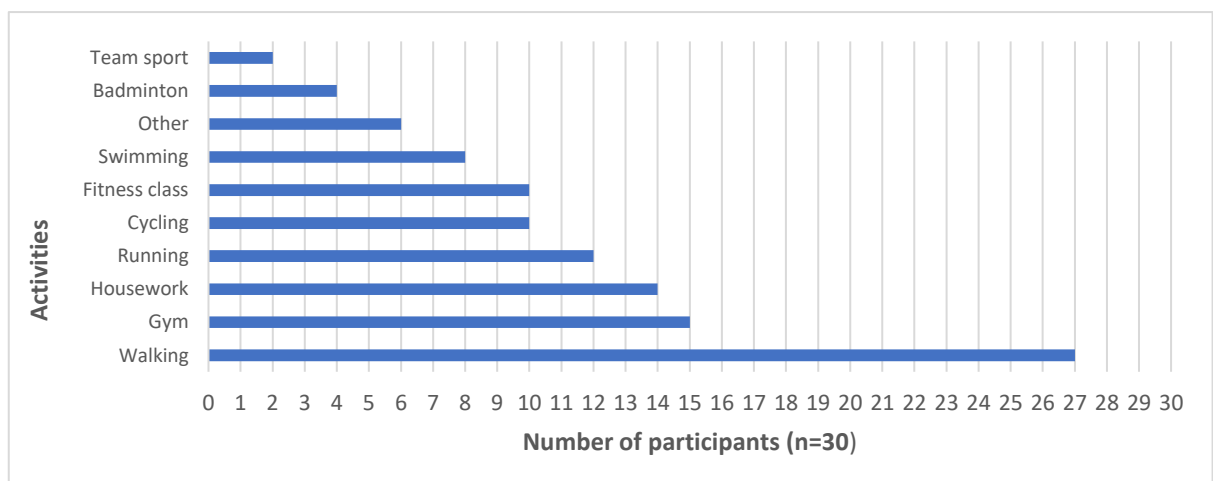


Figure 18.0 Participants self-reported physical activity preferences (n=30)

4.5.2 Preferred Location

Again, participants were asked to select their preference from a predetermined list. Participants were allowed to select all locations which they preferred. Figure 19.0 illustrates participant responses; as seen outdoors and home were the most

popular locations (n=25, 83% and n=24, 80% respectively). No participant selected hospital/doctors as a preferred location indicating that if there was the option to offer physical activity out with the hospital environment this may be preferred by TYA's.

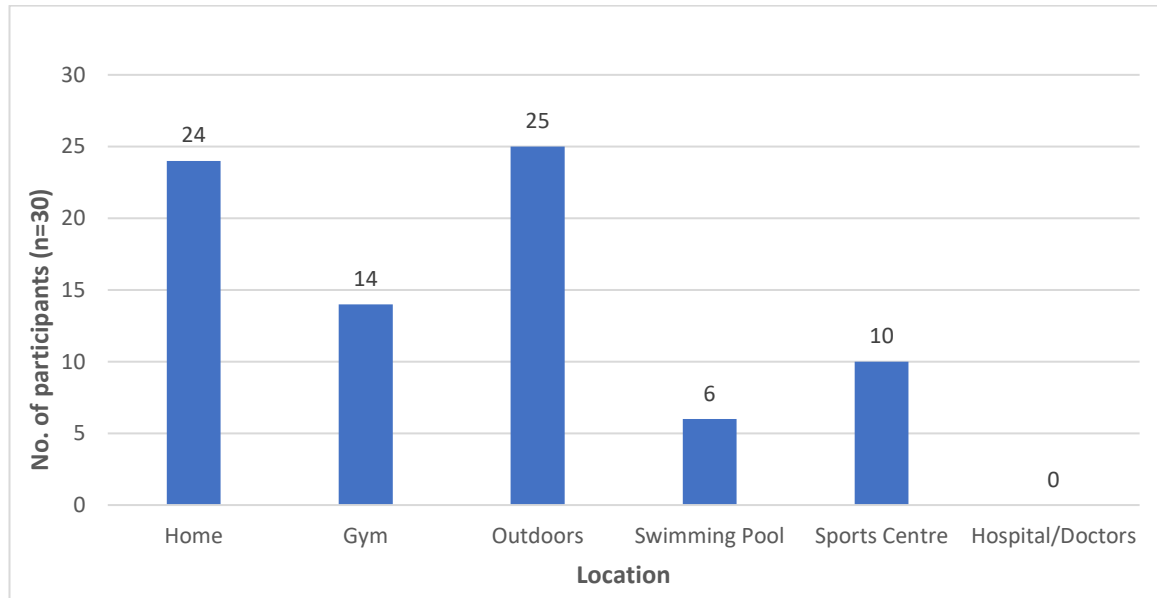


Figure 19.0 Participant self-reported location preference (n=30)

4.5.3 Preferred Format

Participants were asked about their physical activity format preferences as seen in figure 20.0 below. Participants were asked to select all options which applied to them and indicate any additional preferences not on the list by selecting "other" and providing information in an open text box. No participant selected the "other" option and the majority preferred doing physical activity alone (n=23, 77%) or with a friend (n=20, 67%).

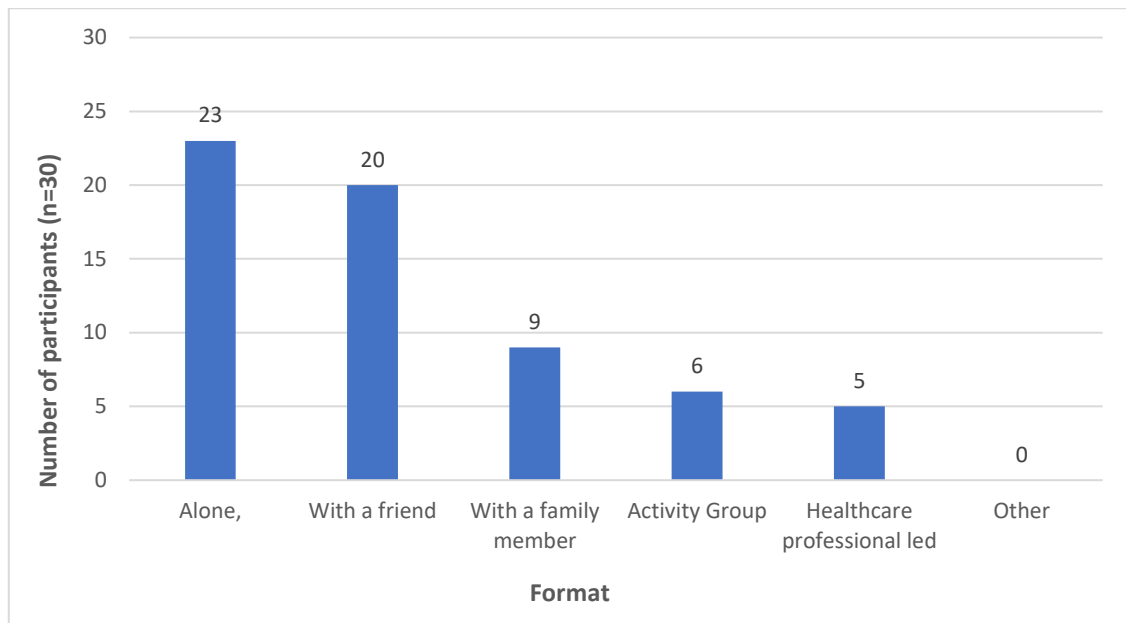


Figure 20.0 Participant physical activity format preferences (n=30).

4.5.4 Time of day

Participants self-reported preferred time of day for physical activity can be found in figure 21.0. As can be seen, there was no clear consensus from participants regarding preferred time of day however, the morning (n=14) was the most popular time indicated, followed by the evening (n=10) and then the afternoon (n=6). There was no difference between time preference across gender or self-reported cancer stage.

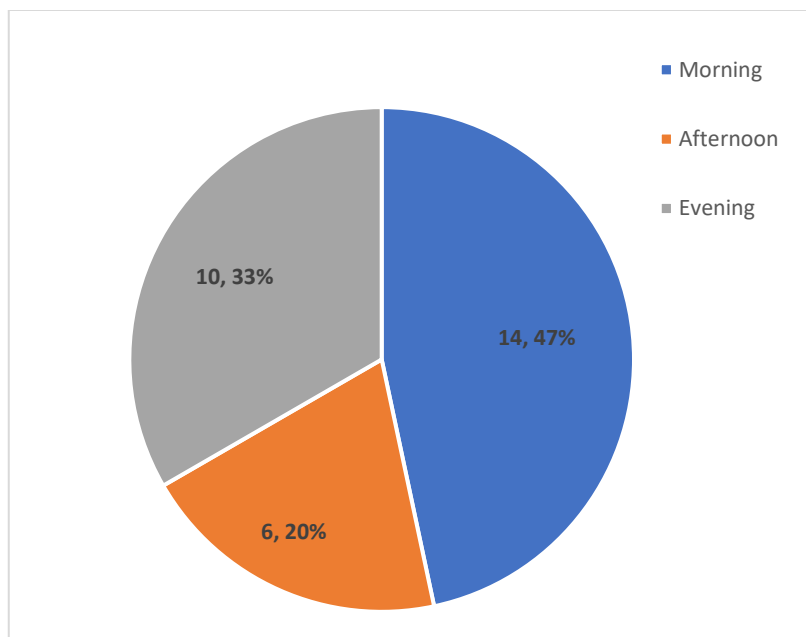


Figure 21.0 Pie chart indicating participants' preferred time of day for physical activity.

Participants were asked to explain their time preference in an open text box. Content analysis of responses was conducted and table 29.0 provides supporting quotes for each time preference. One explanation for time preference that appeared across all three time points was that participants energy levels were highest during their preferred time period. This indicates that fatigue plays an important role in physical activity engagement but also suggests that activity levels and fatigue are personal to the individual as there was no single time point where all participants reported highest energy levels.

In addition to energy levels the main reasons that arose from those who reported a preference for being active in the morning were: that it set them up for the day and they preferred getting it out of the way/more likely to do it. Energy levels were the main reason participants preferred activity in the afternoon however some participants also reported a preference for undertaking activity during daylight hours. Table 29.0 shows one of the main reasons behind participants preference for evening activity was that this fit better with their schedules (work and/or childcare).

Table 29.0 Supporting quotes for physical activity time preferences.

Morning	Afternoon	Evening
<p>Sets them up for the Day</p> <p><i>"I like to start the day off with exercise, it helps me wake up and feel productive for the rest of the day" (Female, 25, active treatment)</i></p> <p><i>"It helps to set me up for the day" (Female, 19, cancer free)</i></p> <p><i>"A reason to get up and start the day. Usually have more energy afterwards too" (female, 24, cancer free).</i></p> <p><i>"It's usually quieter and it's a nice way to start your day. Also, I'm bad for getting busy so doing exercise first thing means I'm more likely to do it" (Female, 26, cancer free).</i></p> <p><i>"Perfect start to the day" (Male, 25, cancer free).</i></p>	<p>Energy Levels</p> <p><i>"When I feel I have the most energy" (female, 27, cancer free).</i></p> <p><i>"I have the most energy and motivation" (female, 29, cancer free).</i></p> <p><i>"I feel most awake during the afternoon and have most of my free time then" (Female, 24, cancer free)</i></p>	<p>Work/Childcare Commitments</p> <p><i>"More quiet and suits better with work and kids" (Male, 24, No active treatment).</i></p> <p><i>"I work all day and am not a morning person" (female, 24, cancer free).</i></p> <p><i>"I have 2 children so want to get them all sorted before I have time myself and can have clearer head" (Female, 27, cancer free).</i></p> <p><i>"Once kids have gone to bed" (Male, 27, maintenance treatment).</i></p> <p><i>"It's most convenient and usually when I have the time, sometimes went through phases in the morning but it's harder when I'm needing to get out early to wake that bit earlier to get the workout in" (Female, 21, cancer free).</i></p>
<p>Prefer getting it out the way/more likely to do it.</p> <p><i>"Feel much better getting up and going rather than interrupt my day or going in the evening when I'm more likely to be tired" (Male, 21, cancer free).</i></p>	<p>Secondary: Daylight hours</p> <p><i>"I work during the day but like to go for a walk when it is still daylight". (Female, 26, cancer free).</i></p> <p><i>"Sunny" (Male, 32, cancer free).</i></p>	<p>Energy Levels</p> <p><i>"Due to work and energy levels being at the highest then" (Female, 22, no-active treatment).</i></p> <p><i>"I'm more awake and willing in the evenings" (female, 24, cancer free).</i></p>

Morning	Afternoon	Evening
<p>Energy Levels <i>"This is when I am fresh and have the most amount of energy in the day. However, I would chose days where I do not have any commitments like college as these things may not be able to get done"</i> (Female, 16, no active treatment)</p> <p><i>"I feel if I don't exercise in the morning, I can't be bothered to exercise at all as I become pretty fatigued by afternoon"</i> (female, 24, maintenance treatment).</p>	<p>Other: <i>"I feel nauseous in the morning and too tired at night. Due to lockdown I have nothing to do during the day so it's best. At home, my partner does home learning with his child so it means I don't interrupt them"</i> (female, 20 active treatment).</p>	<p>Other: <i>"Gyms are less busy in the evenings"</i> (female, 24, cancer free).</p> <p><i>"It's improves my mood and my health"</i> (female, 23, active treatment).</p>
<p>Secondary: Other commitments <i>"Depends on my day really, I fit it around my shift work depending on early / lates etc"</i> (female, 26, no active treatment).</p>		
<p>Secondary: Morning person <i>"I have always been a morning person, cancer hasn't changed that."</i> (Male, 18, cancer free).</p>		

4.5.5 Important Physical Activity Program Content

The majority of participants thought it was important to have a multi-faceted physical activity program with 90% (n=27) selecting multiple content options. As seen in figure 22.0 below, the most popular content preference was for physical activity advice (77%) but more than 50% also reported that it would be important to include tailored gym programs (57%), cancer specific group fitness classes (57%), subsidies on gym/fitness memberships (57%) and access to emotion support groups (53%). The participant who selected "other" reported it was important to include "tailored advice" that was "body and fitness level led".

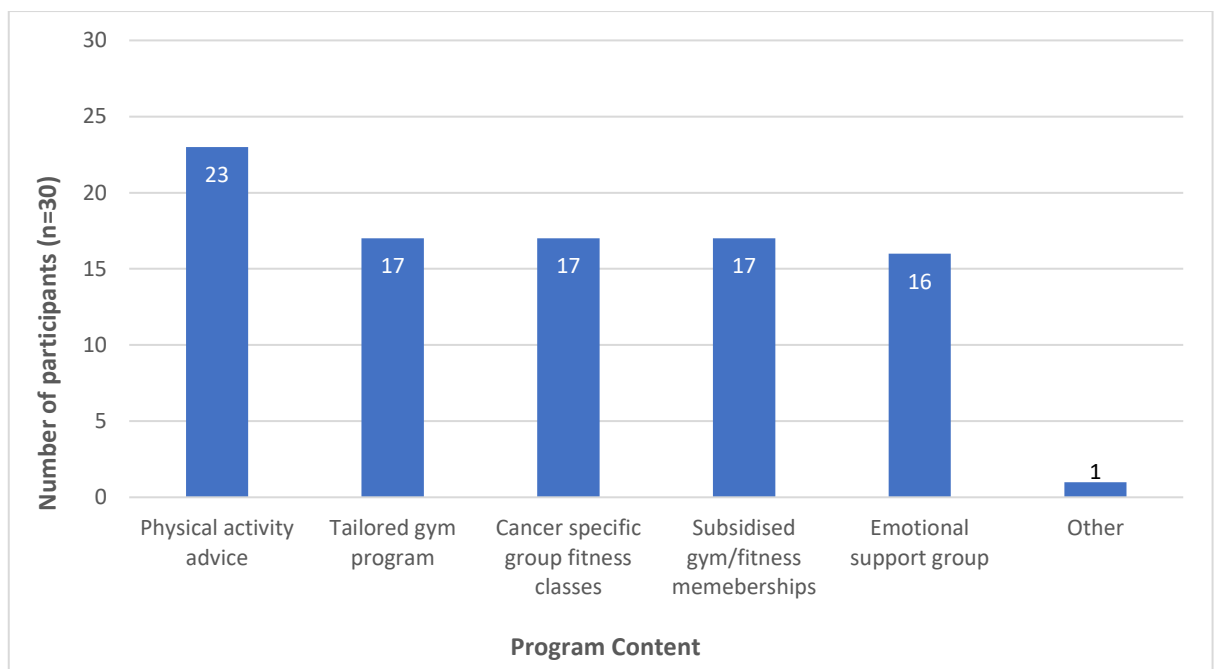


Figure 22.0 Preferred physical activity program content.

4.5.6 Physical Activity Information

When asked "Since your diagnosis, has a healthcare professional provided you with any information or advice about physical activity?", 57% (n=17) of participants reported they had not received any information. The remaining 43% (n=13) reported receiving a variety of information including; physiotherapy input/advice, exercises, advice to walk/keep active, sign posting to cancer charities for advice or exercise group(s), post-operative physical activity restrictions, see table 30.0.

Information was provided by physiotherapists (62%), the medical team (15%), TCT nurses/nurses (31%), charities (8%). As seen in table 30.0 physiotherapists were more likely to provide participants with exercises whereas, TCT nurses or

medial team were more likely to provide general advice to stay active and refer/sign post to alternative sources.

Table 30.0 also highlights that the most commonly reported time participants received PA information from healthcare professionals was after treatment (77%, n=10). However, one participant reported that they received information prior to treatment, two at diagnosis and five during treatment.

Table 30.0 Participant reported physical activity advice from a healthcare profession following cancer diagnosis (n=13).

Physical activity advice/ information received from healthcare professionals since diagnosis.	Healthcare professional who provided information	Time point it was provided at.
"Physio" (Female, 23, cancer free).	Physio	During and after treatment
"More physio advice, like light cardio and light stretching." (Female, 16, no active treatment).	My physiotherapist.	During (towards the end) and after treatment.
"Exercises to do at home, how long I should do exercises and at what level" (Female, 20, active treatment).	My physio	During treatment
"I have been treated by a physio therapist and the charity "move" who advised me on what exercises would be best for me to improve my physical activity levels". (Female, 19, cancer free).	Physiotherapist and "Move" Charity	After treatment
"Recommended exercises to gain strength again after losing a lot of weight/muscle. Recommended exercise classes online" (Female, 25, active treatment).	TYA physio	Upon hospital discharge and regular catch ups for a few months afterwards
"She gave me some exercise to do and advise me to walk and how to sit probably" (Female, 23, active treatment).	Specialist TYA Physiotherapist.	After treatment
"Mobility and strength exercises" (Female, 22, no active treatment).	Physiotherapist.	After surgery and treatment.
"To stay as active as possible throughout my treatment to stop muscle wastage and to stay as fit and healthy as possible." (Female, 24, cancer free).	Specialist nurse, consultant and the complimentary therapist	At diagnosis

Physical activity advice/ information received from healthcare professionals since diagnosis.	Healthcare professional who provided information	Time point it was provided at.
"A referral to CLAN for a service they provided during Covid to walk and chat". (Female, 26, cancer free).	TCT nurse.	After treatment.
"Information about a Maggie's class about getting into fitness again" (Female, 29, cancer free).	My TCT clinical support nurse	After treatment
"Written handouts, tips etc" (Male, 25, cancer free).	Nurses	Diagnosis, during and after treatment.
"I was advised to try and keep active during chemotherapy, and was given guidance before my surgery about what sorts of physical activity I could do in the 8 weeks afterwards (aim for a 5 min walk by week 3, 10 mins by week 4 etc)" (Female, 25, cancer free).	My medical team	Prior to treatment
"I've not had much but I was told once by a consultant to start weight training for my poor circulation and weakness" (Female, 21, cancer free).	Haematology consultant	This was at a check-up appointment over a year after completing treatment.

4.5.7 Independently Sourced PA information

Half of participants (n=15) reported they found information themselves, about being active. Table 31.0 shows where participants sourced this information from. There was a wide range of explanations reported as to why participants sourced physical activity information, this included: to increase strength/fitness (n=5, 33%); to help mental health (n=3, 20%); due to weight gained as a result of treatment (n=2, 13%); due to work related fitness requirements (n=1, 7%); to remain active (n=1, 7%); to get information from a source which specialises in cancer rehab (n=1, 7%); physical activity was a part of their identity (n=1, 7%); they had learned about the benefits and importance of physical activity at university on metabolism and bone density (n=1, 7%); found the information because of social media and charities (n=1,7%); came across information unintentionally when on a cancer charity website (n=1, 7%); did not understand why recovery was taking so long, worried the cancer had returned, looking for information about recovery (n=1, 7%); stressed and overthinking their condition.

Table 31.0 Participant sourced physical activity information locations including number of participants (n) and percentages (%).

Source	N=15	(%)
Internet	8	53.3
Cancer charities	4	26.7
Personal Trainer	2	13.3
Talking to friends/family	2	13.3
YouTube videos	1	6.7
Work (Royal Navy)	1	6.7
Consulting with GP	1	6.7
MSN Youth Advisory Forum	1	6.7

4.5.8 Information timing

There was no clear consensus amongst participants when asked about the best time to receive physical activity information in relation to their cancer. Table 32.0 illustrates the number that each time point was reported by participants. Of the 30 participants, 19 provided a time point and explanation of preference and 11 provided a timepoint with no explanation of preference.

Of the eleven participants without justification: n=3 reported the best time to receive physical activity information is "before, during and after", n=1 reported "earliest point realistically possible", n=1 reported "anytime if appropriate", n=3 reported "after treatment", n=1 reported "during treatment", n=1 reported "before treatment" and n=1 reported "at diagnosis or certainly before treatment".

Table 32.0 Physical activity information time preference.

Time point	N=30
Diagnosis	2
Before	13
During	16
After	17
"Earliest point possible"	1

Generally, participants acknowledged that diagnosis was not an appropriate time to receive physical activity information, as this was an overwhelming time and physical activity was not a priority at this time. Participants who felt that before treatment was the best time to receive information appeared to be seeking guidance or guidelines regarding physical activity and what to expect during treatment. Participants who indicated that during treatment would be a good time to discuss physical activity suggested that it would give individuals undergoing treatment reassurance and encourage recovery after treatment. However, as seen in table 33.0 participants also acknowledged that the individuals providing the PA information have to be mindful of the demands of treatment and provide realistic guidance.

After treatment was marginally the most popular time point for receiving physical activity information. Participants suggest that some individuals may not be ready for physical activity information during treatment, when your mind is preoccupied. So, after treatment when you can focus on recovery may be the most appropriate time point.

Furthermore, fourteen of the thirty participants reported that it would be good to receive information at multiple time points throughout the cancer journey (the most common of which was during and after treatment). As this allows for personalisation of information and helps set people up for recovery, see table 34.0.

Table 33.0 Participant explanation for time point preference

Diagnosis	Before Treatment	During Treatment	After Treatment
<p>Overwhelming <i>"I think at diagnosis it wouldn't be appropriate to go into detail about physical activity as all the information is overwhelming"</i> (female, 29, cancer free).</p> <p><i>"At diagnosis it may be too much information to take in"</i> (Female, 24, Cancer free).</p> <p><i>"At diagnosis seems too soon though as there's not much else you can think about"</i> (Female, 26, No active treatment).</p>	<p>Guidance <i>"Prior to surgery- I found it useful to know how active I could expect to be in the months following the op"</i> (Female, 25, cancer free).</p> <p><i>"I think before treatment would be beneficial. I was advised to keep walking during treatment but other information would have been helpful"</i> (Female, 26, cancer free).</p>	<p>Reassurance <i>"During treatment. To know it's normal if you don't have energy to do any exercise or motivation like you is usually would"</i> (Female, 25, active treatment).</p> <p><i>"During chemotherapy, my energy levels fluctuated a lot, which was something I discussed with the ward nurses"</i> (Female, 25, cancer free).</p>	<p>Capacity after treatment to think about activity <i>"I'd say after treatment, as your head is consumed with things and trying to get through the day. I think people should focus on getting their life back (especially in covid times) and exercise should be done for the fun, and to help with health, rather than competition or in competitive environments where it could be damaging to the individual's mental health"</i> (Female, 16, no active treatment).</p> <p><i>"Best timing to be focusing on going back to regular physical activities? Probably a couple months after your treatment ends (once you've received the all clear). While receiving treatment, you don't think about staying physically active, you are just trying to make it to the other end. Going back to regular activity can come later"</i> (Male, 18, cancer free).</p> <p><i>"After treatment as depending on the severity of the cancer, the mind is most likely to be focused on other things and after it has been treated it would be much easier to take in this information"</i> (male, 21, cancer free).</p>

Diagnosis	Before Treatment	During Treatment	After Treatment
	<p>Benefits of PA during <i>"Before starting treatment - at diagnosis it may be too much information to take in so before starting treatment it would be good to explain the benefits of staying as active as possible during the treatment"</i> (Female, 24, cancer free).</p> <p><i>"Before as you can keep your strength up during treatment, less muscle waste caused. Keep feeling both physically and mentally stable"</i> (Female, 27, cancer free).</p>	<p>Prepare for After treatment <i>"maybe mid-to-end treatment would be ideal for encouraging the next stage after treatment. Positive encouragement to get better"</i> (Female, 24, cancer free)</p>	

Table 34.0 Participant explanation for wanting to receive PA information at multiple timepoints through cancer care continuum.

	Multiple time points
Throughout cancer continuum	<p><i>"At all appropriate stages really. Different stages of treatment can bring different abilities in relation to physical activity. You're already being given so much information it's difficult to remember what's said to you about different stages. At diagnosis seems too soon though as there's not much else you can think about"</i> (Female, 26, no active treatment).</p> <p><i>"Before treatment starts- would be good to know how much physical activity is recommended during treatment, and how to gradually increase it back to the level it was before diagnosis once treatment is finished"</i> (Female, 25, Active diagnosis).</p>
During and after treatment	<p><i>"During treatment and after. During treatment as then they can see how our body reacts to treatment and what is best for us. After treatment to help us understand the state of our health and the 'new normal'. I struggled with physical health after being cleared of cancer and it took me going to the GP to get an idea of how careful I needed to be with my body. He compared my body to that of an 80year old when I was only 21, so I was putting too much pressure on my body without knowing it and this prolonged my recovery"</i> (Female, 30, cancer free).</p> <p><i>"During treatment and after treatment. If you only receive information about physical activity when you end your treatment you are tired after fighting so hard and can be emotional when weight/physical activity is brought up. But if you have time to prepare for this before you end treatment, I think it would be better"</i> (Female, 24, cancer free).</p>
Some advice during what more focused support after	<p><i>"I think gentle exercise recommendations during treatment would have been really helpful to keep me doing some form of movement, but support from finishing treatment would have been even more helpful as there was none given to me"</i> (Female, 21, cancer free).</p> <p><i>"I think probably when treatment is starting to wrap up. Or during treatment at a routine check-up? You've got enough to think about during treatment without adding extra. If you're going to be in treatment for a long time maybe a time when treatment is less intense"</i> (Female, 26, cancer free).</p>
Dependant on the individual	<p><i>"I think it depends on what kind of cancer you have and what treatment you're getting. In some situations, receiving such information would be good during treatment to give you something to do and keep motivated on, but then in some other circumstances after treatment if you aren't able to during treatment and it gives you something to work towards after treatment"</i> (Female, 24, cancer free).</p>

4.6 Barriers and Facilitators

The following sections will outline participant barriers and facilitators to physical activity. Considerations will be made to: the SEM and participants TTM stage of change, participant cancer stage (active diagnosis vs cancer free) and participants current physical activity behaviour (IPAQ-SF category: low, moderate, high).

4.6.1 Barriers

Participants were asked to indicate the extent to which they agreed with the pre-determined barrier and facilitator statements on a 5-point Likert scale (strongly disagree, disagree, don't know, agree and strongly agree). Figures 23.0 illustrates participant responses to each barrier statement.

As seen in figure 23.0, more than 50% of participants agree with four barrier statements. The statement with the highest agreement was "I don't want to get injured" with 22 participants (73%) agreeing, to some extent. This indicates that fear of injury may be a barrier to physical activity engagement within TYA cancer patients and survivors. Furthermore, 16 participants (60%) agreed, to some extent with the barrier statements "I am too tired to be active", "I lack the motivation to be active" and "bad weather stops me being active". Again, suggesting that these factors may negatively influence TYA cancer patients/survivors' physical activity behaviours. Three of these statements (fear of injury, motivation and fatigue) are categorised as intrapersonal factors within the SEM meaning that they influence the behaviour of the individual. The fourth potential barrier, bad weather, is categorised as "natural environment" within the SEM. Participants within this study demonstrated a preference for outdoor activity, as seen in figure 19.0. This preference may explain why bad weather is a main potential barrier to physical activity engagement.

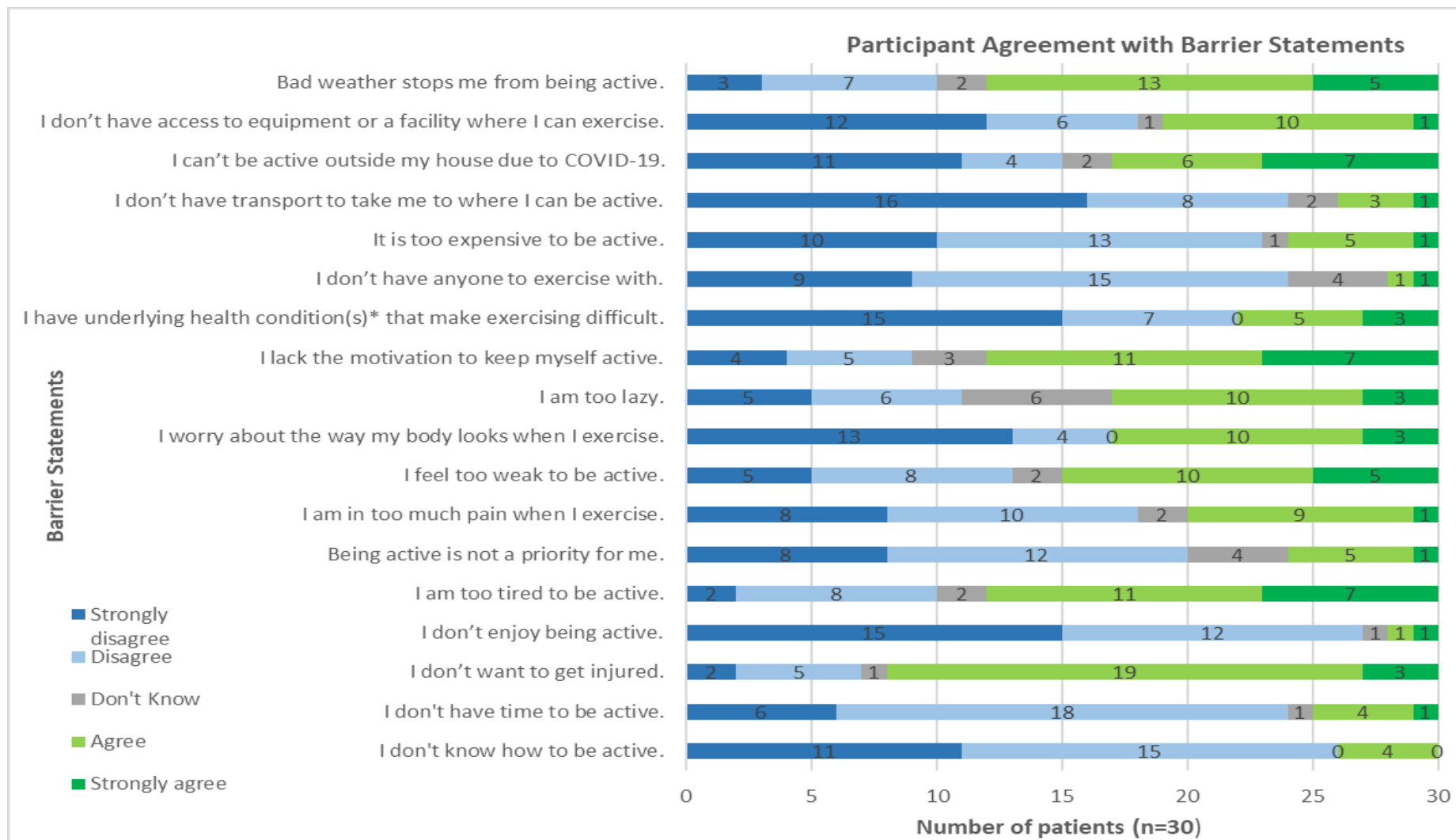


Figure 23.0 Participant (n=30) agreement with potential barrier statements based on the SEM of behaviour change. Underlying health conditions* = underlying health conditions that are not cancer.

Figure 23.0 also shows that the participants disagree with a large amount of the barrier statements. The most common of which was "I don't enjoy being active" with 90% (n=27) disagreeing, to some extent. Furthermore, 87% (n=26) and 80% (n=24) disagreed, to some extent, with the statements "I don't know how to be active" and "I don't have time to be active" respectively. This all indicates that the participants who participated within the survey may have been biased towards individuals who enjoy physical activity, possess a good knowledge of how to exercise and make time for exercise. A fact which is further supported as n= 20 (67%) of participants disagreed, to some extent with the statement "Being active is not a priority for me". This is also reflected within participants SOC classification, as demonstrated above none of the participants were in the pre-contemplation stage of the TTM.

Additional statements which the majority of participants disagree, to some extent, with are: 80% (n=24) "I don't have transport to take me to where I can be active" and "I don't have anyone to exercise with"; 77% (n=23) "it's too expensive to be active"; 73% "I have underlying health condition(s) other than cancer that make exercising difficult"; 60% (n=18) "I am in too much pain when I exercise" and "I don't have access to equipment or a facility where I can exercise" and 57% (n=17) "I worry about how my body looks when I exercise".

Fifteen participants (50%) disagree to some extent with the statement "I can't be active outside my house due to COVID-19". Participants who completed the survey between August 2021 and January 2022 when social distancing restrictions were no longer in place were more likely to strongly disagree with this statement. When those participants are excluded 57% of participants (n=23) agree, to some extent, with this statement suggesting that Covid-19 may have been barrier to physical activity engagement.

Participants were also given the opportunity to indicate any additional barriers which impacted their PA engagement. Fourteen participants provided additional physical activity barriers which included treatment related side effects including fatigue (n=7), other commitments (n=4), low motivation (n=4), Covid-19 restrictions (n=2), current injury (n=1), weight (n=1) and insecurity (n=1). Table 35.0 the supporting quotes for each barrier. Treatment related barriers, Low motivation/reduced willpower, insecurity, weight and current injury are all classified as intrapersonal barriers on the SEM. The other commitment barriers are classified as interpersonal and covid-19 restrictions are classified as policy barriers.

Table 35.0 Additional physical activity barriers reported by participants

Participant reported additional physical activity barriers
<p>Treatment*</p> <p>"I had knee femur and hip replacements so difficult to exercise" (female, 23, cancer free)</p> <p>"My cancer treatment has caused a condition called avascular necrosis which causes severe pain and limited/no mobility in my joints" (Female, 24, cancer free)</p> <p>"Thyroid cancer has made me very tired and not enough energy to have will power, all my energy gets taken up by looking after 2 children" (Female, 27, cancer free)</p> <p>"Back pain caused by treatment" (female, 24, cancer free)</p> <p>"Mainly tiredness, unmotivated with treatment. Also, I've had more moles removed so I'm not supposed to exercise for 6 weeks" (Female, 25, active treatment)</p> <p>"fatigue" (Female, 21, cancer free)</p>
<p>Other commitments</p> <p>"I have a 7-month-old son so it is hard to find time" (female, 24, cancer free).</p> <p>"My child" (female, 23, active treatment)</p> <p>"all my energy gets taken up by looking after 2 children" (Female, 27, cancer free).</p> <p>"Family commitments and work make it hard to find time" (male, 27, maintenance treatment)</p>
<p>Covid-19 restrictions</p> <p>"Lockdown as I can't go fencing and now need to stop as equipment is no longer aloud to be shared" (Female, 20, active treatment).</p> <p>"COVID has meant I can't go to spin classes, which is my favourite type of high-energy exercise, and I can't go swimming/to the gym since I've been shielding" (Female, 25, cancer free).</p>

Participant reported additional physical activity barriers

Low motivation/reduced will power

"Unmotivated with treatment" (Female, 25, active treatment).

"Unmotivated and lazy" (Male, 18, cancer free)

"not enough energy to have will power" (Female, 27, cancer free).

"Poor mental health (PTSD, trauma and other cancer related mental health issues have left me too unmotivated and 'lazy'" (Male, 18, cancer free).

Other

Insecurity (Female, 21, cancer free)

Current foot injury- fracture (Male, 24, no active treatment)

Weight (male, 32, cancer free)

effects of treatment* includes: avascular necrosis and pain, joint replacement, back pain, reduced mental health, post-surgical restrictions, low motivation while on treatment.

4.6.2 Facilitators

Figure 24.0 highlights that the majority of participants agreed with all but two of the facilitator statements. The facilitator statements can be grouped into statements about: health benefits, access to facilities, social aspects of physical activity, self-efficacy and other.

The statement group with the highest level of participant agreement was the health benefits statements. All participants agreed with the statement "I want to maintain/improve my general health and fitness" with 53% strongly agreeing with this. This was closely followed by "I want to improve my strength" with 97% agree to some extent and "I want to improve my fatigue", 90% of participants agreeing to some extent and 47% of participants strongly agreeing with this statement. 47% of participants also strongly agreed with the statement "I want to improve my mental health" (overall 87% of participants agreed to some extent with this statement).

Figure 24.0 shows that with regards to access to facilities 73% of participants agreed to some extent, that they live close to facilities where they can be active and 70% of participants agreed that having access to a physical activity program makes them or would make them more active.

Facilitator statements which related to social aspects of physical activity had mixed responses; 77% of participants agreed to some extent, that having someone to exercise with helps them be active and 70% agreed to some extent, that having encouragement/support from friends and family help them be active. Sixty percent of participants agree to some extent that they enjoy the social benefits of a sports club or fitness group however, only 47% of participants agreed that physical activity helped them meet new people.

The two facilitator statements which relate to participant self-efficacy were: "If someone gave me information about how to safely exercise it would make me more active" and "I know how to exercise safely". 77% of participants agreed to some extent, that they knew how to exercise safely and 63% of participants agreed to some extent that someone providing physical activity information would increase their physical activity levels. Only 53% of participants agreed with the statement "Being active before my cancer diagnosis has helped me remain active".

The remaining facilitator statements relate to intrapersonal motivators. Twenty-five (83%) participants agreed, to some extent, that being physically active helped

them feel normal and 63% of participants agreed that being active provided a distraction from cancer and that they wanted to increase their independence. However, only 43% agreed that having a cancer diagnosis motivated them to be more active. Furthermore, only three participants reported that they did not enjoy being active (90% agreed) suggesting this sample may be skewed towards physical active individuals and may not be representative of the TYA population as a whole.

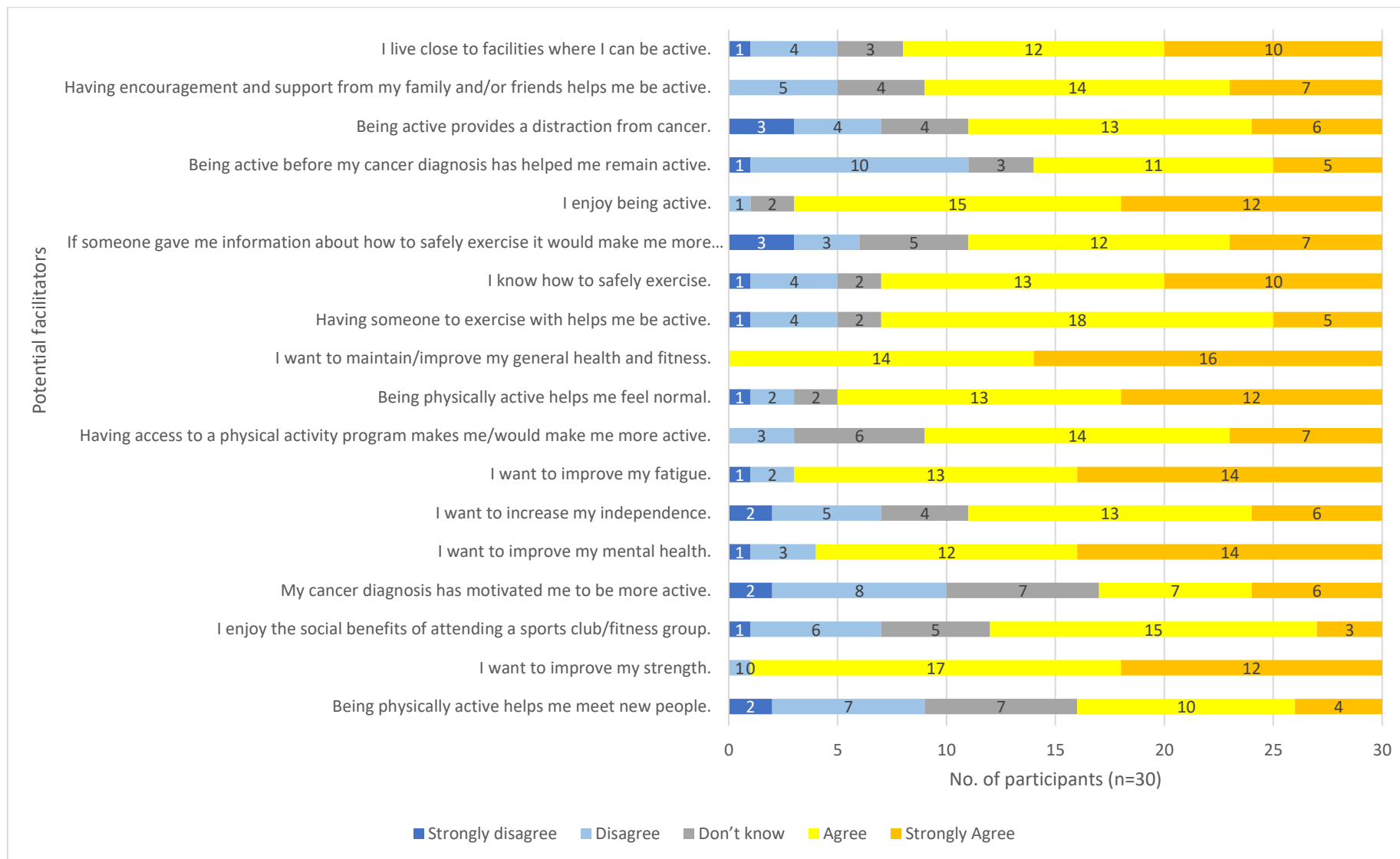


Figure 24.0 Participant (n=30) agreement with potential facilitator statements based on the SEM of behaviour change.

As with additional barriers participants were asked to provide any additional physical activity motivators. As seen in table 36.0 participants reported their additional motivators were motivation/mindset (n=3), good weather (n=2), children/family/future dreams (n=1), weight loss (n=1), having childcare (n=1), seeing physical improvements (n=1), encouragement from medical team (n=1), feeling less tired (n=1), getting back to pre-cancer levels (n=1), covid not being the concern (n=1).

Table 36.0 Additional physical activity facilitators reported by participants.

Please indicate any other things that you feel help you to be active:
The idea of losing weight and feeling less tired. (Female, 19, cancer)
Encouragement from my medical team (Female, 24, cancer free)
Good weather and childcare (Female, 30, cancer free)
Nice weather and covid not being a concern (Female, 26, cancer free)
My child and my family and my future dreams (Female, 23, active treatment)
Motivation (Male, 32, cancer free)
Getting myself back to where I was before cancer is a huge motivator for me. I want to be as fit and as healthy as I used to be (Male, 18, cancer free)
Motivation to maintain progress, physical improvements (Female, 21, cancer free)
Mindset (Male, 25, cancer free)

4.6.3 Effect of Stage of Change, IPAQ Category and Cancer Stage on Agreement with Barrier/Facilitator Statements

As stated in section 3.9.10, it was not possible to conduct all the initial planned inferential statistics in relation to barriers and facilitators due to the small sample size of the study. However, statical analysis was conducted to investigate the effect of cancer stage (current diagnosis vs cancer free), SOC and IPAQ category (low, moderate, high) on participant responses to the barrier and facilitator statements in order to explore potential group difference which may influence behaviour.

In line with the procedure adopted by Rodgers et al. (2007) statement responses were coded on a 3-point scale (1= disagree, 2= don't know, 3= agree) due to the small sample size with responses for strongly disagree and disagree combined to one group and responses strongly agree and agree combined another. Stage of change were coded on a 4-point scale (1= contemplation, 2= preparation, 3=

action, 4=maintenance) and IPAQ-SF category on a 3-point scale (1= low, 2= moderate, 3= high); Cancer stage on a 2-point scale (1= current diagnosis, 2= cancer free). As the data was not normally distributed a Spearman's rho correlation was conducted to assess the relationship between statement responses and participant characteristics (stage of change group, IPAQ group and cancer stage group). This was repeated for each barrier and facilitator statement. Full results for each statement can be found in Appendix 19. Table 37.0 below illustrates the significant relationships ($P < 0.05$). Although not statistically significant, due to the small sample size and exploratory nature of the research, correlation coefficient values of greater than or equal to 0.30 suggesting a 'medium' effect size (Cohen 1988; Gignac and Szodrai 2016) were also included in table 37.0.

With regards to stage of change, table 37.0 demonstrates that as participants stage of change increases (contemplation to maintenance) their agreement with the barrier statements in the table decreases. This is represented by the significant negative correlations seen in the table. The same can be seen for IPAQ-SF category. As participants IPAQ-SF category increases (low to high activity) participants agreement with the barrier statements in table 37.0 decreases. Again, this is represented by the negative correlation. Each statement in table 37.0 is discussed in more detail below.

Table 37.0 Spearman's rho correlation between stage of change, IPAQ category, cancer stage and agreement with barrier and facilitator statements.

Statement	Stage of change* (n=30)	IPAQ-SF category* (n=26)	Cancer stage* (n=30)
I am too tired to be active	Rho (30) = -0.429, $p=0.018$	Rho (26) = -0.368, $p=0.064$	----
I am in too much pain when I exercise	Rho (30) = -0.388, $p=0.034$	----	----
I feel too weak to be active	Rho (30) = -0.419, $p=0.021$	----	----
I am too lazy	Rho (30) = -0.490, $p=0.006$	Rho (26) = -0.429, $p=0.029$	----
I can't be active outside my house due to COVID-19	Rho (30) = -0.381, $p=0.038$	----	----
I have an underlying health condition(s) other than cancer which makes exercise difficult	----	----	Rho (30) = 0.339, $p=0.067$
I do not have access to equipment or a facility where I can be active	Rho (30) = -0.313, $p= 0.093$	----	----
I lack the motivation to be active	Rho (30) = -0.335, $p= 0.057$	----	----
Being active before my diagnosis helped me remain active	----	----	Rho (30) = -0.356, $p=0.047$
Being physically active helps me meet new people	----	----	Rho (30) = -0.332, $p= 0.082$

Stage of change= contemplation, preparation, action and maintenance; IPAQ-SF category= low, moderate, high; cancer stage= current diagnosis and cancer free; n= number of participants.

Figure 24.0 shows 50% agreed, to some extent, with the statement "I feel too weak to be active" whereas 43% of participants also disagreed with this statement. This suggests weakness may be a barrier for some individuals and not for others. This was further supported when the relationship between barrier statements and stage of change was evaluated. As seen in table 37.0 there is a significant negative relationship between participant stage of change and agreement with the statement "I feel too weak to be active" ($Rho(30) = -0.419, p=0.021$). This demonstrates that as participant stage of change increases the likelihood of agreeing with the barrier statement decreases. Therefore, suggesting that those in the early stages of change (contemplation and preparation) are more likely to agree that weakness is a physical activity barrier than those in the late stages of change (action and maintenance).

Figure 24.0 also illustrates there was no participant consensus with regards to the statement "I am too lazy" as 36.7% disagreeing to some extent, 20% don't know and 43.3% agreeing to some extent. Table 37.0 demonstrates a significant correlation between this barrier statement and two variables: participant stage of change and participant IPAQ category ($Rho(30) = -0.490, p=0.006$ and $Rho(26) = -0.429, p=0.029$ respectively). These are both negative relationships indicating that participants in an earlier stage of change or lower IPAQ category are more likely to agree with this barrier statement. This suggests that self-perceived laziness may be a greater potential barrier to physical activity to those in the earlier stages of change or low IPAQ category compared to those in a later stage of change or the high IPAQ category.

Table 37.0 also demonstrates significant relationships between participant stage of change and the barrier statements "I am too tired to be active", "I am in too much pain to be active" and "I can't be active outside my house due to COVID-19" ($Rho(30) = -0.429, p=0.018$, $Rho(30) = -0.388, p=0.034$ and $Rho(30) = -0.381, p=0.038$ respectively). Again, these are negative correlations suggesting that as stage of change increases agreement with the barrier statements decreases. This suggests that those in the early stages of change are more likely to agree that tiredness and pain are physical activity barriers than those in the late stage of change. Furthermore, those in the early stages of change were more likely to perceive COVID-19 as a larger barrier to being active outside their homes than those in the later stages of change.

Lastly, Table 36.0 shows a significant negative correlation between cancer stage (active diagnosis vs cancer free) and agreement with the facilitator statement "being active before my diagnosis helped me remain active" ($Rho(30) = -0.356, p=0.047$). This suggests that participants with an active diagnosis were more likely to agree that pre-diagnosis activity levels helped them to remain active compared to participants who were cancer free.

There were no other significant relationships between agreement with barrier/facilitator statement and participant stage of change, IPAQ category or cancer stage. However, although not statistically significant, due to the small sample size, correlation coefficients of greater than or equal to 0.30 suggesting a medium effect (Cohen 1988; Gignac and Szodrai 2016) were also included in Table 37.0. This infers a potential negative relationship between the barrier statement "I am too tired to be active" and IPAQ-SF category ($Rho(26) = -0.368, p=0.064$), suggesting those in the low IPAQ-SF category were more likely to agree with this statement than those in the high IPAQ category. Table 37.0 also demonstrates a potential negative relationship between the barrier statements "I lack the motivation to be active" and "I do not have access to equipment or a facility where I can be active" and stage of change ($Rho(30) = 0.335, p=0.057$ and $Rho(30) = -0.313, p=0.093$ respectively). This suggests that those in the earlier stages of change were more likely to agree with these statements than those in the later stages of change. Furthermore, a medium effect size was seen for the relationship between the barrier statement "I have an underlying health condition other than cancer that makes exercise difficult" and cancer status ($Rho(30) = 0.339, p=0.067$). As this was a positive correlation this suggests that those in the cancer free group were more likely to agree that they may have an underlying health condition that impacts them being active. However, participants were not asked to provide details of their health condition if they did agree to this statement, so it is not possible to determine if these health conditions were comorbidities due to treatment late-effects. Lastly, Table 37.0 illustrates that cancer status was potentially negatively correlated with the facilitator statement "being active helps me meet new people" ($Rho(30) = 0.332, p=0.082$), suggesting those with a current diagnosis were more likely to agree with this statement than those who were cancer free.

In summary overall, participants indicated fear of injury, fatigue, bad weather and low motivation to be their biggest potential barriers to physical activity. Participant

SOC negatively correlated with five potential barrier statements (too tired, too much pain, too weak, too lazy, can't be active out of my home due to covid-19) indicating that these may be barriers for TYA cancer patients/survivors in the early stages of physical activity behaviour change but not those in the later stages. Self-perceived laziness was also correlated to low IPAQ-SF category suggesting this may be a barrier for those engaging in low levels of physical activity but not those engaged with higher levels. Lastly, the most commonly reported additional barrier by participants was treatment side effects.

For facilitators participants agreed with all but two statements (my cancer diagnosis motivated me to be more active and being active helps me meet new people). The highest levels of agreement were seen in the facilitator statements relating to the health benefits of physical activity. This suggests the health benefits of physical activity may be a motivating factor in TYA cancer patients/survivors' physical activity engagement. Access to facilities and social support from friends/family was also seen to be a motivator to physical activity in participants.

4.7 Social Support (SSQ-6)

Seven participants incorrectly completed the SSQ-6 (Sarason et al. 1987) and therefore their data was excluded. Errors completing the SSQ-6 resulted from participants not listing each individual within their support network but instead providing a blanket statement such as "my family". The following descriptive data has been calculated for the remaining 23 participants. In line with scoring protocol the maximum network score available is 9; participants had a mean network score of 3.65 (SD +/- 2.29; median 3.17), with a range of 1-9 people within their network (Sarason et al. 1987). The maximum satisfaction score was 6, participants had a mean satisfaction score of 5.57 (SD +/-1.06; range 1-6; median 6) (Sarason et al. 1987). Only two participants demonstrated a satisfaction score below 5.5 indicating high levels of satisfaction within participants regarding their social support network.

5.0 CHAPTER 5: QUANTITATIVE DISCUSSION

5.0 Chapter Overview

The following chapter discusses the survey findings in relation to previous oncology literature. Comparisons are made with UK aged TYA populations where possible however some literature pertaining to the broader AYA oncology cohort has been included.

5.1 Recruitment

As outlined in Chapter three: methodology sections 3.7-3.8 participant survey response rates (RR) were lower than initially predicted by the research team. This could have been due to a number of factors; firstly, the BWoSCC patient database contained a smaller number of patient's contact details than anticipated meaning that initially the survey was distributed to a smaller number of potential participants. Secondly, the COVID-19 pandemic meant that there was an influx of online research projects, many of which were online surveys (Hlatshwako et al. 2021). This influx in online surveys and the increase of online working (for both students in education and many employees in non-essential roles) as dictated by the government COVID-19 strategy, may have led to survey fatigue, a phenomenon which negatively impacts survey RR (De Koning et al. 2021).

As outlined in chapter three section 3.8, appropriate measures were taken to increase participant RR. Study amendments included extending the survey data collection period to maximise the number of potential participants as well as the addition of two further recruitment sites in NHS Tayside and NHS Grampian. An additional factor which may have impacted the survey RR was the length of the survey itself. Previous research into survey response rates have found that survey length negatively affects response rate (Wu, Zhao and Fils-Aime 2022). From survey piloting and creation, it was estimated that the survey should take participants 20-minutes to complete however, results showed completion time ranged from 13-98 minutes with an average completion time of 27-minutes. Due to this wide range of time, some potential participants may have dropped out of the survey before completing it.

As can be seen in figure 15.0, a number of individuals began the survey but did not complete this. Due to the multi-faceted recruitment strategy and the use of an online social media campaign it is not clear whether these individuals were eligible participants who dropped out for an unknown reason before survey completion or

if they were clinicians or laymen interested in seeing the survey content. Within the survey development measures were taken to reduce the time burden on participants as much as possible however, the exploratory nature of this research and broad research objectives meant that numerous measures and questions had to be included. Response rate of previous surveys in adolescent and young adult oncology population have varied with Murnane et al. (2015), reporting a RR of 52% whereas, other studies have reported RRs of 29% (Belanger et al. 2011a) and 15% (Rabin and Politi, 2010). The 'known' RR of 18.9% within this study although low is therefore in line with previous TYA literature. One method of increasing online survey response rate is the use of incentives for completion including entry into a prize draw of cash or a prize of value to participants (Sammut, Griscti and Norman 2021). As this project was unfunded this was not feasible for this study however, given the low RR seen in other AYA studies future research utilising surveys within TYA populations should consider this as a method to increase RR and thus the representativeness and effectiveness of the data collected.

5.2 Participant Demographics

As seen in section 4.2.1 the majority of survey participants were White British, females, who were diagnosed with cancer as a young adult and were now cancer free. Historically within healthcare research individuals from ethnic minorities are underrepresented (Giuliano et al. 2000) and females have been shown to be more likely to participate in online surveys compared to males (Curtin et al, 2000). Smith (2008) suggests that females are more likely to participate in online surveys due to the nature of their cyberspace use. Females use the internet more connectively than males typically using it for communication and information sharing whereas males use the internet more separately, engaging in information seeking and therefore are less likely to participate in online research (Smith 2008).

As illustrated in the scoping review, section 2.5.3, participants in this study are in keeping with the participant characteristics of previously published research into PA and the TYA oncology population which, are homogenous towards White participants and studies with more young adult participants than adolescent participants. Although, it should be noted that the majority of TYA cancer patients are diagnosed between the ages of 20-24 years old (Smith et al. 2016). The participants were representative of TYA oncology population with regards to their cancer diagnosis as participants had an array of common TYA cancers including:

lymphoma (Hodgkins and non-Hodgkins), carcinomas (thyroid, oral, nasopharyngeal, breast), germ cell (testicular and ovarian), sarcomas, melanomas and leukaemia (Public Health Scotland 2023). Although this is representative of the TYA cancer population as a whole the small sample size of the study meant that it was not possible to assess for differences between groups based on cancer type or status, gender or age.

5.3 PA Behaviours

5.3.1 Current PA Behaviours

Both the TTM SOC and IPAQ-SF were used to measure TYA cancer patients and survivors' current PA status. The IPAQ-SF allowed for measurement of TYA's PA frequency, duration and intensity, however, due to the small sample size it was not possible to assess for between group differences with regards to gender, age, cancer status or cancer diagnosis, as was initially planned.

As seen in survey results section 4.4.1, the majority (63%) of participants self-reported engaging in regular PA, indicating this cohort classified themselves as active. Also 40% of participants self-reported engaging in regularly PA over the last 6 months, however, based on the results from the TTM SOC only 33% of participants were classified as physically active over the last 6 months. This highlights that the data may have been affected by self-report bias. Self-report bias is a common limitation associated self-report measures as participants have been found to both overestimate (Ogonowska-Slodownik et al. 2021) and underestimate their physical activity behaviours (Quinlan et al. 2021).

Doubly labelled water (DLW) method is the gold standard for measuring energy expenditure in PA research but this is infrequently used in literature due to cost, high subject burden and the fact it is time-intensive for the researcher and participant (Sylvia et al. 2014). Devices such as; accelerometers (allow for measurement of energy expenditure and PA patterns), HR monitors (physiological measure of PA and energy expenditure), pedometers (measures number of steps) or arm bands (motion and heat-related sensors to measure energy expenditure), are all alternative methods to DLW or self-report measures which can be employed to measure PA behaviours objectively (Sylvia et al. 2014; Healey et al. 2020). Accelerometers have become increasingly popular as a method to measure physical activity yet they are high cost and difficult to use in large samples due to personnel requirements associated with set-up and behaviour monitoring

compared with surveys (Sirard et al. 2013). Pedometers are cost effective and easy to use however, they only consider activity on a horizontal plane (Sylvia et al. 2014). There are limitations associated with all commonly used PA data collection methods therefore, some researchers have suggested using a combination of subjective and objective measures may provide a more accurate PA assessment (Sylvia et al. 2014).

None of the participants who participated in the survey were classified in the pre-contemplation stage of the TTM. This means that all participants were thinking about changing their PA behaviours (Raihan and Cogburn 2023). This may suggest a recruitment bias within the study, towards individuals who were physically active or considering becoming more physically active meaning the sample may not be representative of the TYA oncology population as a whole. On reflection the use of physical activity within the title of this study and within recruitment materials for this study may have contributed towards this bias of physically active individuals. Previous physical activity research has highlighted considerations need to be made when generalising study results due to recruitment bias of physically activity individuals within PA research (Harris et al. 2008).

Furthermore, the majority (87%) of study participants reported that they intended to become more physically active, suggesting TYA cancer patients and survivors are interested in increasing their PA behaviours. This supports previous research which found the majority of TYACS intended to increase their PA behaviours (Pugh et al. 2020a) and suggests that TYA cancer patients and survivors would be open to PA support. Cancer has been suggested to be a teachable moment for behaviour change in TYA's (Pugh et al. 2018). Typically, adolescence and young adulthood is a time of psychosocial development, where behaviours are learned and carried into adulthood (Wood et al. 2018), and following cancer TYACS report interest in PA change therefore while interest in PA information is high, behaviour change strategies should be capitalised upon (Pugh et al. 2018). Although this cohort are skewed towards physically active individuals, the results of this study suggest TYA cancer patients and survivors to be interested in PA behaviour change.

Again, due to the small sample size, IPAQ-SF results must be considered with caution however, the results show 50% of participants were classified in the moderate activity category, 27% in the high activity category and 23% in the low activity. This measure has been used previously to assess the effect of PA interventions (Salchow et al. 2017; Salchow et al. 2021; Marec-Berard et al. 2021)

however it was not possible to compare IPAQ results directly. The results of the IPAQ-SF show TYA cancer patients and survivors engage most commonly in walking with almost half of participants (47%) walking each day. Walking has been reported previously to be the most commonly performed activity in TYA cancer patients and survivors (Rosipal et al. 2013; Murnane et al. 2015) with one study reporting walking was the most common activity pre-diagnosis, during and after treatment in TYA's (Murnane et al. 2015).

When IPAQ-SF results were compared with SOC, a trend was found between increasing SOC (moving from contemplation to action) to increasing PA behaviour (MET-minute/week) of walking, moderate-intensity activity, vigorous-intensity activity and total continuous score. This is outlined visually in table 27.0 in section 4.4.2. This has been seen previously in on-treatment breast cancer patients' where later SOC was associated with higher levels of PA (Rogers et al. 2007). There was one discrepancy seen with this trend in the continuous moderate-intensity scores of participants between the contemplation and preparation stages of the TTM. Participants in the preparation stage displayed lower moderate-intensity scores than those in the contemplation stage, however when looking at this groups whole PA behaviours the decrease in moderate-intensity activity can be explained by the addition of vigorous-intensity activity and increased walking behaviours. Increasing stage of change and IPAQ category (low to high) is also observed. This phenomenon was also observed in a TTM based PA counselling intervention for TYACS (Salchow et al. 2021). The intervention group also exhibited a decrease in moderate levels of physical activity at the 12-week post-intervention assessment but an increase in vigorous level physical activity, suggesting that they occur concomitantly (Salchow et al. 2021).

Participants self-reported sedentary behaviour was also measured using the IPAQ-SF. Results showed that participants sitting time varied greatly (1-24 hours per weekday), with participants spending on average 8 hours (+/- 4.7) a day sitting. The IPAQ-SF does not take into account individuals' occupation so therefore no conclusions can be drawn around the impact of work or education on sitting time. In an evaluation of an exercise referral program in young adult cancer survivors (n=48; mean age =29) the sitting measure from the IPAQ and two items taken from the National Health and Nutrition Examination Survey (NHANES) were used to assess computer and television viewing as proxy measures of sedentary behaviour (Pugh et al. 2020b). Results found TYACS engaged in sedentary

behaviours an average of 13.3 +/- 4.6 hours a day. Although not directly comparable this suggest that the sample of this study may engage in less sedentary behaviour.

As with this study, previous research into TYA PA behaviours has also taken self-reported PA frequency, duration and intensity and compared that to PA guidelines (Murnane et al. 2015; Murnane et al. 2019; Murnane et al. 2021; Pugh et al. 2020a). As seen in the scoping review section 2.5.4.4 previous literature has found many TYA cancer patients and survivors to be insufficiently active and do not meet PA guidelines (Arbit, Buck and Ladas 2014; Murnane et al. 2015; Murnane et al. 2019; Murnane et al. 2021; Pugh et al. 2020a; Munsie 2021c). Based on data collected from the IPAQ-SF (frequency and duration) this study found that only 36.6% of TYA cancer patients and survivors were meeting WHO PA guidelines (World Health Organization 2020). This percentage is in keeping with the previously discussed scoping review literature (located in table 11.0 in section 2.5.4.4) as the number of cancer patients and/or survivors meeting PA guidelines ranges from 5-53% (Arbit, Buck and Ladas 2014; Murnane et al. 2015; Murnane et al. 2019; Murnane et al. 2021; Pugh et al. 2020a; Munsie 2021c). Comparison of self-reported PA to guidelines highlights the need for TYA PA support to increase PA levels in this population. However, the methods used to calculate guideline adherence in the literature thus far is subject to self-report bias (Fadnes, Taube and Tylleskar 2008; Sylvia et al. 2014). Future research needs to consider data collection methods for PA to ensure literature accurately represents TYA PA behaviours.

Furthermore, the Scottish Household Survey, 2021, found 74% of 16–24-year-olds reported meeting moderate-intensity PA guidelines of 150 minutes a week, with no differences seen between males and females. For muscle strengthening recommendations 49% of 16-24-year-olds reported meeting guidelines however there was a difference seen between males and females with males more likely to report meeting guidelines than females (Birtwistle et al. 2022). This suggests that in comparison to age matched population norms TYA patients and survivors are less active. The fact that most patients reported that they were currently active (80%) and a further 63% stated they were regularly active yet, half of the participants were classified as moderately active from IPAQ-SF and only 36.6% are meeting PA guidelines suggests that TYA cancer patients and survivors may not be aware of what PA guidelines are and how to meet them. Coupled with

walking being the most performed activity across this cohort, there may be a need for PA education regarding PA intensity and health benefits. However, it was not possible to assess for the effect of cancer stage (on- vs off-treatment vs cancer free) within this study and in the barrier and facilitator questions most participants indicated that they knew how to exercise therefore, future research should consider TYA cancer patients and survivors PA knowledge.

5.3.2 Effect of Diagnosis

In line with previous research which has found cancer diagnosis and treatment to negatively impact TYA cancer patients and survivors PA behaviours (Spreafico et al. 2021; Smith et al. 2021; Murnane et al. 2015) this study found a 37% decrease in self-reported PA pre- (87%) and post-diagnosis (50%). Not only did participants report engaging in less PA they also reported participating in shorter activity durations post-diagnosis. Content analysis of the type of activities participants performed pre- and post-diagnosis revealed the gym (36%), running (28%) and swimming (28%) to be the most common activities whereas, walking (33%) was the most common post-diagnosis. Open-text answers supported the reduction in activity intensity with participants reporting they engaged with gentle activities and had to gradually reintroduce PA post-treatment. This has been seen previously in a study on TYACS exercise habits which found that while PA significantly decreased during treatment, TYACS PA levels did increase post-treatment however, time spent being active remained significantly lower than pre-diagnosis (Murnane et al. 2015).

Another difference between pre- and post-diagnosis PA was that no participant reported engaging in home-workouts pre-diagnosis however 28% reported that they did post-diagnosis. Previous literature has shown being self-conscious in public exercise spaces about their post-treatment body to be a PA barrier in TYACS (Pugh et al. 2018). Also "insecurity" was reported as an additional PA barrier by one participant of this study.

Results of the open-ended question about PA barriers also found that the effects of treatment negatively impacted participants PA behaviours. This supports previous literature (Kuntz et al. 2019; Murnane et al. 2015; Pugh et al. 2018; Smith et al. 2021) which found effects of treatment to be a PA barrier in TYA's with and after cancer.

5.3.3 COVID-19

The COVID-19 pandemic was an unprecedented time which negatively impacted global PA behaviours as a result of the COVID-19 social restrictions and lockdowns (Hailey et al. 2022; Tison et al. 2020; To et al. 2021; Stockwell et al. 2021). The majority (80%) of participants reported COVID-19 impacted their PA behaviours. Four out of the six participants who reported that COVID-19 did not affect their PA behaviours completed the surveys between August 2021 and January 2022. In Scotland COVID-19 social distancing restrictions were eased and facilities re-opened at the beginning of August 2021 (Scottish Parliament Information Centre 2023)

COVID-19 was reported by participants to have both a positive and negative impact on PA. Negative impacts included: closure of facilities, impacted recovery, reduced PA engagement, reduced motivation and reduced social support due to shielding /social distancing measures. Whereas, positive impacts included increased PA due to increased time to engage in activity and increased motivation to be active. The majority of participants reported they had to adapt their PA behaviour which included altering the type of PA they engaged in and switching to home or outdoor workouts from facility-based.

The research examining the effect of COVID-19 on TYA cancer patients and survivors is limited however a small number of sources are available (Hanghoj et al. 2021; Sundell and Soanes 2020; Yan et al. 2023). Both a positive and negative impact was also seen in TYA populations in a Swedish study which assessed impact of COVID-19 lockdown (Hanghoj et al. 2021). TYACS also reported the positive impact of COVID-19 was giving them time and space to recover physically and mentally (Hanghoj et al. 2021). Previous TYA literature has reported time and competing commitments as a PA barrier (Psihogios et al. 2020; Pugh et al. 2018; Spreafico et al. 2021; Salchow 2021) to TYACS and patients. Time was not found to be a PA barrier in this study however, content analysis of open-text response revealed a small number of participants reported child and family commitments to be PA barrier. Furthermore, in line with this research Hanghoj and colleagues (2021) also reported a number of negative impacts of COVID-19 which included impacted rehabilitation and reduced access to social support. The TCT patient survey also revealed TYA participants poorly managed their physical health during the pandemic (Sundell and Soanes 2020). In adult services the impact of COVID-19 on an established Macmillian Move More cancer service in Northern Ireland

found that the percentage of participants who were not regularly active increased from 4% prior to COVID-19 restrictions to 21% during COVID-19 restrictions (Brown et al. 2021). However, an online cross-sectional survey investigating adolescent and young adult (aged 18-49, mean=30) experiences during the pandemic in Canada found only 33% decreased their PA levels whereas 53% maintained and 12% increased their PA levels suggesting the impact of COVID-19 on younger patients may have been less than older patients (Yan et al. 2023).

5.4 PA Preferences

The majority of participants indicated that their preferred type of activity was walking (90%) followed by the gym (50%) and housework (47%). As mentioned above, walking has been shown to be the preferred activity in other TYA cancer cohorts (Rosipal et al. 2013). Participants also indicated that their preferred activity location was outdoors (83%) and at home (80%). This may have been driven by participants preference for walking and to a lesser extend housework. Previous research into PA program preferences partially supports these findings as it reported TYACS preferred home-exercise programs and programs at local gyms (Murnane et al. 2015).

None of the participants indicated that the hospital was their preferred activity location yet, as seen in the scoping review the vast majority of TYA interventions take place in a hospital gym setting (Atkinson et al. 2021; Munsie 2021a; Munsie 2021b; Atkinson and Osborn 2012; Murnane et al. 2019; Smith et al. 2019; Spreafico et al. 2021). Another study investigating TYA PA program preferences also found a small number of TYACS (29%) wanted a PA program to be in their local cancer centre (Murnane et al. 2015). This illustrates that previous TYA interventions may not align with TYA preferences regarding location. Furthermore, none of the interventions took place outdoors, although a study protocol for a TYA wilderness-based intervention was identified (Jong et al. 2022), and only a small number of interventions included a home exercise component (Marec-Berard 2021; Murnane et al. 2019).

Participants preferred PA format was alone (77%) or with a friend (67%) with only a small number indicating a preference for group activity (20%). Unlike with intervention settings previous research has focussed on TYA interventions that take place in a 1-2-1 format (Atkinson et al. 2021; Salchow et al. 2021; Munsie 2021a; Munsie 2021b; Mackland and Chesman 2019; Marec-Berard et al. 2021;

Rosipal et al. 2013; Shaw et al. 2022; Baker et al. 2021; Murnane et al 2019; Yurkiewicz et al. 2021; Spreafico et al. 2021; Munsie 2021c).

There was no consensus between participants regarding a preferred time to engage with PA but open-ended question responses indicated that fatigue/ energy levels were a large driving force dictating PA time preferences. This was seen to vary across participants with some reporting they had more energy in the morning, some the afternoon and some the evening. Another influential factor on time preference was other commitments. This aligns with previous TYA research, which has found this cancer population to have additional burdens such as, work and dependents to care for, compared with paediatric or older adult cancer populations (Rabin 2017; Kimball et al. 2017).

Participants felt that it was important for PA programs to be multifaceted. Results of this survey also demonstrated that PA advice was the most selected PA program content. As illustrated in the scoping review TYA cancer patients and survivors want PA information (Murnane et al. 2015; Pugh et al. 2017a; Mooney et al. 2017; Pugh et al. 2018) a need which has also been seen in the broader AYACS population (Belanger et al. 2012).

However, the majority of participants in this study did not receive any PA advice or information during their cancer journey. This further illustrates the AHP workforce gap in the Scottish TYA service outlined in the Scottish Government 2021-2026 Cancer Strategy (Scottish Government 2021). For those who did, they most commonly received this information from a physiotherapist or a CNS. Previous research has reported that most commonly TYAs receive PA information from their physician (Murnane et al. 2015; Pugh et al. 2017a). The higher provision of advice from a physiotherapist in this study may be due to the primary recruitment location being the TYA unit in the BWoSCC NHS GGC. As demonstrated in the TYA workforce (Table 4.0 located in section 1.2.4) this is the only Scottish TYA hub with a physiotherapist in post and this may have skewed responses. Participants reported that the PA advice they received differed across the clinical professions providing advice, with physiotherapists providing more tangible support in the form of exercise provision alongside information and CNS and doctors providing general advice to stay active and signposting to resources. Another UK based TYA oncology study reported that TYACS were dissatisfied with the PA advice they received from medical staff as it was vague and lacked context and they instead wished for TYA specific information (Pugh et al. 2018). In general

health promotion research guidelines with broad statements about PA have been found to be insufficient at eliciting behavioural change (Rhodes, McEwan and Rebar 2019). This suggests that HCP's who are providing TYAs with information may need up-skilling to be able to offer more specific PA advice.

Half of the participants reported self-sourcing PA information, most commonly from the internet. Lack of information from HCP's has previously been reported to cause TYAs to self-source information from online resources (Pugh et al. 2018) however, the volume of information available online has been reported to be overwhelming and frustrating (Mooney et al. 2017; Pugh et al. 2018). Studies have reported TYA cancer patients and survivors prefer to receive healthy behaviour information in a variety of ways including: from HCP's (Pugh et al. 2018; Mooney et al. 2017), an exercise physiologist (Murnane et al. 2015), online or via a mobile app (Pugh et al. 2017a; Pugh et al. 2018), via email (Roggenkamp et al. 2022; Belanger et al. 2012) or numeric tools (email, text message, social media) (Marec-Berard et al. 2021). However, there is not always consensus across literature as one study reported telehealth (email, app, telephone) to be TYAs least preferred delivery method (Murnane et al. 2015). Furthermore, one study reported participants were not likely to seek health behaviour information from friends, family, YouTube (Pugh 2017). The survey results support this as two participants reported seeking advice from friends/family and one from YouTube.

Participants reasons for self-sourcing PA information were to improve their physical and mental health and due to body composition changes as a result of treatment. Other than lack of HCP provision, previous literature has not yet investigated the motivators behind TYA's self-sourcing PA information. There was no timing preference seen across participants with regards to receiving PA information however, diagnosis was generally felt to be an overwhelming time. A lack of timing preference has been reported in previous TYA studies with both during and after treatment seen as appropriate (Pugh et al. 2017a; Pugh et al. 2018; Murnane et al. 2015; Roggenkamp et al. 2022).

Furthermore, more than half the participants also felt it was important for a PA program to include tailored gym programs, TYA cancer specific group fitness classes, subsidies on gym/fitness memberships and access to emotion support groups. Previous research into PA program preferences has shown a preference for TYA specific PA programs (Wu et al. 2015; Murnane et al. 2015) which address unique TYA needs (Wu et al. 2015) and starts after treatment (Murnane et al.

2015). Two studies also indicated TYA's would participate an individual health behaviour counselling session from HCP's (Pugh et al. 2018; Pugh et al. 2017a). When considering this cohorts PA format preferences only 20% participants indicated that they preferred group-based activity yet, 57% of participants indicated that a TYA specific fitness class would be a valuable component of a PA program. This suggests that the TYA element of the group is more important and that this cohort are looking for peer support. Peer support has been shown to be incredibly valuable to TYAs with and after cancer as they often report that their friends do not fully understand what they are going through and cannot relate to their unique challenges (Pennant et al. 2019; Stark and Philips 2013). Results of the scoping review show financial costs associated with exercise (Pugh et al. 2018; Wu et al. 2015) and low motivation (Psihogios et al. 2020; Rosipal et al. 2013; McGrady et al. 2022; Shaw et al. 2022) and mood (Shaw et al. 2022; Wu et al. 2015; Psihogios et al. 2020) have all been established previously as TYA PA barriers and may explain participants preferences towards subsidies on gym/fitness memberships and access to emotion support groups as part of a PA program.

5.5 Barriers and Facilitators

With regards to the statistical analysis of barrier and facilitator statements caution must be applied to the results due to the small sample size as well as the volume of tests conducted. As there were thirty-six barrier and facilitator statements analysed against SOC, cancer stage and IPAQ-SF category there is a risk that significant results may occur due to chance, this is also known as type one error (Steiner 2015). The following discussion points and statistically significant results have been considered with this in mind and analysed in relation to the body of previously published TYA oncology and behavioural change literature.

Four potential PA barriers emerged from the survey, three of which were intrapersonal, being too tired, fear of injury and low motivation, and one was an environmental barrier, bad weather.

As demonstrated in the scoping review, the intrapersonal barrier of fatigue in this population is well established in previous literature (Murnane et al. 2015; Psihogios et al. 2020; Spathis et al. 2017; Spreafico et al. 2021; Wu et al. 2015; McGrady et al. 2022; Munsie 2021^a; Munsie et al. 2021^b; Shaw et al. 2022; Wallis, Meredith and Stanley 2021). Statistical analysis also revealed being too tired to be physically

active was negatively correlated with participants SOC, indicating that for TYA's in the higher stages of change, fatigue was less of a barrier compared to those in a lower SOC. Those in the higher SOC (action and maintenance) are engaging in PA regularly. Engaging in PA has been shown to improve fatigue in cancer patients and survivors (Meneses-Echavez, González-Jiménez and Ramírez-Vélez 2015; van Vulpen et al. 2016). This suggests that regular PA engagement may be positively impacting participant's fatigue. Furthermore, although not significant, statistical analysis suggested a negative relationship between tiredness and IPAQ-SF category as the correlation coefficient was >0.3 , suggesting a medium effect size (Cohen 1988; Gignac and Szodorai 2016). This further supports that fatigue may negatively impact PA behaviours, as those in the low IPAQ category were more likely to perceive fatigue to be a PA barrier than those in the high IPAQ category. Further research would be required to investigate this fully.

The second intrapersonal barrier fear of injury has not been previously found to be a PA barrier in the TYA oncology population but it has been reported as a PA barrier in adult breast cancer patients undergoing chemotherapy (Rogers et al. 2007). Due to the closed-question approach used to collect the majority of barrier information in the survey an explanation for why this was a potential barrier in this cohort was not provided. Moreover, section 4.4.3 highlighted no participant engaged in team sports (rugby, football, volleyball) post-diagnosis. Due to the physical nature of these sports and risk of contact involved with participation of these, fear of injury may have influenced TYA's engagement with this post-diagnosis. Safety concerns regarding being physically active following diagnosis was explored qualitatively within the interviews and is discussed in section 6.3.4.1.

As seen in the scoping review, the last intrapersonal barrier of low motivation has been commonly reported as a PA barrier in TYA cancer patients and survivors (Psihogios et al. 2020; Rosipal et al. 2013; McGrady et al. 2022; Shaw et al. 2022). As discussed in section 1.4.2 motivation is a key component in SDT of behaviour change (Deci and Ryan 2000), whereby an individual becomes increasingly more intrinsically motivated for behaviour change as they move through the behaviour change process (Ferron and Massa 2013). Progression from amotivation through external motivation to intrinsic motivation for physical activity has also been demonstrated to be significantly correlated with the TTM stages of change and physical performance in fitness tasks (Ferron and Massa 2013). Within oncology research this has been observed in YASCC where more autonomous levels of

motivation were associated with higher SOC and more PA (Finnegan et al. 2007). As can be seen from Table 37.0 statistical analysis revealed a potential negative correlation between SOC and the PA barrier of low motivation within this cohort. This may not have been significant due to the small size of this sample, but as the correlation coefficient effect size was >0.3 medium effect is suggested (Cohen 1988; Gignac and Szodorai 2016). This was also observed in a study investigating SOC and PA barriers in on-treatment breast cancer patients with a similar sample size ($n=23$) which found pre-contemplation SOC to be correlated to procrastination and lack of self-discipline (correlation coefficient >0.3) (Rogers et al. 2007).

As with fear of injury bad weather has not previously been reported as a PA barrier in TYA cancer patients or survivors. However, this is an example of an environmental barrier to PA when considering the SEM of behaviour change (Birtwistle et al. 2019). This environmental barrier may have been found due to the high number of participants within this cohort with a preference for outdoor activity. An additional reason why bad weather may not have been previously reported in TYA literature but appeared within this study may be due to the geographical location where study participants reside. As illustrated in the scoping review the majority of previously published TYA PA research was conducted in the USA and Australia however, the majority of participants in this study live in Scotland. Due to the different climate of this country the environmental barrier of weather appears to be more significant within this TYA cohort. The facilitator open-ended question also revealed good weather to be a PA facilitator for some of this cohort, highlighting the importance of PA preference when considered an individual's barriers and facilitators for behaviour change as well as the geographical area in which they live.

COVID-19 was seen as an additional policy barrier to PA engagement when excluding participants who completed the survey after UK social distancing measures were removed. This barrier related to being active out with participants homes. As illustrated earlier the majority of participants reported that COVID-19 impacted their PA behaviours and one of the main reasons for this was due to access to facilities. The additional social distancing measures placed upon cancer patients and survivors illustrates the influence that policy decisions have on behaviour as outlined in the SEM (Stokols, 1992; Birtwistle et al. 2019). Although there is very limited research into the impact of COVID-19 on TYA cancer patients and survivors PA behaviours two previous studies have also reported COVID-19 as

a barrier (Munsie 2021a; Hanghoj et al. 2021). A negative impact of COVID-19 on PA has also been found across a heterogeneous global cancer sample (Tabacynski et al. 2023). Also, statistical analysis revealed that this barrier was negatively associated with SOC. This suggests that being unable to be active out with their home was more of a barrier for those in the early stages of behaviour change. Within the TTM those in the earlier stages of behaviour change believe the cons of an activity outweigh the pros, whereas the opposite is the case for those in the later stages (Hashemzadeh et al. 2019). Engaging regularly in PA and the benefits of PA participation appears to have offset the barrier of being unable to exercise out with their home for those in the later stages of the TTM.

SOC was also negatively correlated with the potential PA barrier statements: too much pain, too weak, or too lazy. This indicates that pain, weakness and considering one's self lazy may have been barriers for TYA cancer patients/survivors in the early stages of physical activity behaviour change but not those in the later stages. Pain (Murnane et al. 2015; Psihogios et al. 2020; Smith et al. 2021; Shaw et al. 2022) and reduced strength/weakness (Kuntz et al. 2019; Shaw et al. 2022; Salchow et al. 2021) have both been reported previously as PA barriers in TYA cancer patients and survivors. Feeling weak has also been previously correlated to TTM stage of change in breast cancer patients during treatment (Rogers et al. 2007). Participant SOC was also found to be correlated to the PA barrier lack of equipment/ access to facilities with a correlation coefficient >0.3 , suggesting a medium effect (Cohen 1988; Gignac and Szodoria 2016). Lack of equipment has been found previously to be a PA barrier in the TYA (Wu et al. 2015) and as with weakness it has been found to be correlated with stage of change in on-treatment breast cancer patients (Rogers et al. 2007). Additionally, self-perceived laziness was correlated with being classified in the low IPAQ-SF category suggesting self-perceived laziness was more of a barrier for those who were less active than those who engaged in more weekly activity.

Self-efficacy (Pugh et al. 2018; Shaw et al. 2022), lack of enjoyment (Salchow et al. 2021) lack of time (Psihogios et al. 2020; Pugh et al. 2018; Spreafico et al. 2021; Salchow et al. 2021) and engagement in other ADL's/ recreational activities (McGrady et al. 2021) have all been found previously to be TYA PA barriers. However, participants of this study disagreed with statements regarding not having time to be active, not enjoying PA, not knowing how to be active and exercise not being a priority for them. This suggests that this TYA cancer cohort

have high self-efficacy and prioritise PA. Coupled with the aforementioned high self-reported pre-diagnosis activity levels and the lack of any participant being in the pre-contemplation SOC this may suggest that this sample is skewed towards physically active individuals.

Furthermore, reduced social support (Hanghoj et al. 2021; Wu et al. 2015; Arbit, Buck and Ladas. 2014), distance from/travel to PA location (Pugh et al. 2018; Salchow et al. 2021), financial cost of PA (Pugh et al. 2018; Wu et al. 2015) have all previously reported PA barriers in TYA cancer patients and survivors however, based the survey responses this study did not find access to transport, social support or financial costs associated with being active to be PA barriers within this cohort.

Lastly, the most commonly reported additional PA barrier by participants were treatment related side-effects including: avascular necrosis and pain, joint replacement, back pain, reduced mental health, post-surgical restrictions and low motivation while on treatment. Effect of treatment has been reported previously to be a PA barrier and negatively affects PA behaviour (Kuntz et al. 2019; Murnane et al. 2015; Pugh et al. 2018; Smith et al. 2021).

As seen in section 2.5.4.5 of the scoping review there is less literature surrounding PA facilitators of TYA cancer populations than there is PA barriers. Nonetheless, social support has been found to be one of the main facilitators of PA behaviour within the TYA cancer population (Rosipal et al. 2013; Kuntz et al. 2019; Pugh 2018; Wu 2015; Rosipal et al. 2013) as it provides motivation (Hanghoj et al. 2021), accountability and socialisation (Wu et al. 2015). Moreover, a lack of social support has been reported to be a common interpersonal PA barrier for TYA cancer patients and survivors (Hanghoj et al. 2021; Wu et al. 2015; Arbit, Buck and Ladas 2014; Shaw et al. 2022). Social support from a friend has also been found to be a facilitator of an individual's stage of change (Diori et al. 2018) and social support in general has been reported to facilitate TYACS self-efficacy and PA confidence (Pugh et al. 2018). In broader cancer research social support has been reported to be one of the biggest PA facilitators in AYACS and YASCC (Kimball et al. 2017; Adamovich et al. 2022; Wright et al. 2013). Results of the facilitator questions in this study suggest this cohort of TYA cancer patients and survivors strongly agreed having someone to exercise with and having encouragement from friends and family helps them be active. The majority of participants indicated they enjoyed the social benefits of sport and fitness groups however, only 47% agreed that PA

helped them meet new people. Statistical analysis revealed this facilitator statement to be negatively correlated to cancer status, suggesting that those with a current cancer diagnosis were more likely to agree with the statement than those who were cancer free. There was no additional data collected to provide context as to why they agreed or disagreed with the statement but it is known that TYA cancer patients seek peer support while on-treatment (Pennant et al. 2019). This finding may reflect this as those with a current diagnosis may have more of a desire to meet peers via social situations such as PA than those who were cancer free.

Participants had high levels of agreement with the majority of the survey facilitator statements, with the highest level of agreement seen in statements relating to the health benefits of PA. This was also supported in the open-text additional facilitators question where participants predominantly expressed that the physical and mental health benefits associated with PA were motivational. Results suggested improving health and fitness, reducing fatigue, improving strength and improving general mental health were all motivators of PA engagement within this population. This supports previous literature which has found keeping fit and combating treatment side effects and improving mood to facilitate TYA cancer cohorts' participation in PA (Spreafico et al. 2021).

The majority of participants also agreed that being active provided a distraction which has been seen previously to facilitate PA behaviour in TYA's with cancer (Spreafico et al. 2021). Two statements not previously seen in research but that participants agreed with was that being active helped them feel a sense of normalcy and that they wanted to increase their independence. Although not directly related a previous PA facilitator is that TYA's want control over their own health (Wu et al. 2015).

Participants agreed (77%) that they knew how to exercise safely which highlights this cohort believe they have good PA knowledge but 63% also agreed that if someone provided them with PA information about how to exercise safely this would make them more active. Education is an important component of behavioural change interventions for those in an earlier SOC and becomes less important as individuals progress through the cycle (Ferron and Massa 2013). The majority of participants also expressed that access to a PA program would make them more active. Access to resources (gym memberships, wellness programs, skill-building) has been shown to be another motivator of PA behaviour in TYACS

(Wu et al. 2015). Participants within this study agreed that they had access to facilities where they could be active locally to where they lived.

Participants did not agree with the facilitator statement "my cancer diagnosis motivated me to be more active" and "being active helps me meet new people". A 2018, UK based study by Pugh and colleagues interviewed TYACS and found cancer to be a catalyst of behaviour change however the results of this study contradict this. The reason for this difference may be because Pugh et al. (2018) investigated the impact of cancer on an array of health behaviours (diet, exercise, smoking, alcohol consumption and UV exposure) whereas this study looked at the impact of cancer diagnosis on PA only. Therefore, this suggests that a diagnosis of cancer does not motivate TYA's to be more active.

Only 53% of participants agreed with the statement "Being active before my cancer diagnosis has helped me remain active" however statistical analysis revealed a negative correlation with cancer status (active diagnosis vs cancer free) which suggests that cancer patients with an active diagnosis were more likely to agree with this statement than TYA's who were cancer free.

Upon reflection the use of predominantly closed-questions to evaluate barriers and facilitators within the survey means that limited information about why these factors influence behaviour can be derived from results. The use of open-questions for example, "please state your main physical activity barriers and provide reasoning for why these are barriers" may have provided more relevant contextual information. This would also have reduced the overall length of the survey which in turn may have increased RR. Future studies should consider this.

5.6 Social Support

As outlined above and in the scoping review social support facilitates PA behaviour within the TYA cancer population (Rosipal et al. 2013; Kuntz et al. 2019; Pugh et al. 2018; Wu et al. 2015; Rosipal et al. 2013). Section 4.7 illustrated that the measure used to assess the social support within this survey, the SSQ-6, was poorly completed by participants with results excluded for 23% of the sample. This may have been due to this measure appearing at the end of the survey which as previously stated was long, meaning participants were less engaged. For those that did complete the SSQ-6 results show participants predominantly receive support from family (parents, siblings, grandparents and aunts), partner/spouse or friends. TYA cancer patients were shown to have relatively small support

networks but that they were highly satisfied with them. This is supported by high participant agreement that they had someone to exercise with in the facilitator statements. Social support from family, friends, peers and medical staff has not only been shown to be an important facilitator of PA but it has also been shown to be important to help TYA cancer patients (mean age 18.9 years) to cope with cancer and its treatment (Pennant et al. 2019). Due to the poor completion of SSQ-6 this study may have been better to adopt a specific measure of participants PA related social support such as the social support for diet and exercise scale (Sallis et al. 1987). Nevertheless, the results suggest this cohort have access to PA support which they are content with.

CHAPTER 6: QUALITATIVE FINDINGS**6.0 Chapter Outline**

This chapter presents an integrated results and discussion of the interviews. This section has been integrated for ease of reading and to avoid repetition. First an overview of the interviews and participant demographic is provided. Following this and in keeping with the RTA approach, researcher reflexivity surrounding the data analysis process is discussed before the interview findings are presented. Each of the identified themes will be outlined and discussed in relation to previous literature. At the end of this chapter there will be a high-level summary of the qualitative findings.

6.1 Overview*6.1.1 Interviews*

Twenty individuals expressed interest in participating in the interview phase of the study. One individual contacted the researcher directly (see section 3.5) and expressed interest in participating the interview only, whereas, the remaining 19 individuals expressed interest in the interview following completion of phase 1, the online survey. Of these 20 individuals: one declined participation due to disease progression, one declined due to childcare time commitments, one provided incomplete contact information and three did not respond to researcher follow-up emails. Therefore, fourteen interviews took place over an eight-month period between June 2021 and January 2022. Research suggests twelve interviews are sufficient to provide adequate saturation of data (Guest, Bunce and Johnson 2006) however, it should be noted that the intended purposeful sampling of interview participants was not possible meaning an even spread between genders and adolescent and young adult age groups was not achieved. Interview duration ranged from 41 minutes to 105 minutes, with an average duration of 63 minutes.

6.1.2 Participant Demographics

Participant characteristics are outlined in table 38.0 and of the fourteen individuals who participated in the interview, 10 (71%) were female and 4 male (29%), with a mean age of 24.1 years (range 18-29). Participants were diagnosed with a range of cancer types including, Hodgkin's Lymphoma (n=4), Thyroid cancer (n=3), non-Hodgkin's lymphoma (n=2), Melanoma (n=2), Breast cancer (n=2) and Testicular cancer (n=2); the mean age of participants at diagnosis was 21.9 years (range 17-25).

Participants cancer stage at the time of interview was recorded; two participants were receiving active treatment, three were on maintenance treatment and nine were classed as cancer free. One of the participants on maintenance treatment one was receiving treatment for incurable cancer and the other two were receiving long-term hormone therapy. Two of the cancer survivors had finished their treatment within 6-months of the interview (one of which completed the survey whilst they were on-treatment) whilst the remaining seven finished their treatment >1 year prior to the interview. Furthermore, two participants discussed lengthy diagnosis periods.

Information regarding treatment type was gathered from the interview and, where applicable, from corresponding survey data. Participants reported receiving a variety of cancer treatments, the most common of which was surgery (n=9, 64.3%), followed by chemotherapy (n=6, 42.8%) and radiotherapy (n=6, 42.8%), hormone therapy (n=2, 14.3%), targeted drug therapy (n=1, 7.1%), and immunotherapy (n=1, 7.1%). One participant reported that their planned immunotherapy had been postponed due to the Covid-19 pandemic. Of the six participants who received radiotherapy, two received radioactive iodine. Disclosed surgeries included; orchiectomy, lumpectomy, wide local excision, thyroidectomy, Retroperitoneal lymph node dissection and inguinal lymph node dissection. Table 37.0 illustrates that eight participants received more than one treatment type whereas, six participants received a single treatment type. One participant also reported that they were involvement in a clinical trial but did not disclose further information about this.

Participants primarily reported receiving treatment within Scottish health boards however, two individuals reported receiving treatment within NHS England. Two participants reported having to travel for part of their treatment (one to a different health board and one to a larger mainland hospital) and one individual usually treated within Scotland reported that they were awaiting specialist testing and potential treatment at an NHS England facility.

Three individuals reported that they received their treatment on a TYA specific ward and seven reported they received treatment on an adult ward. The remaining four did not disclose the ward type where they received their treatment however, two of these participants reported that they had contact with a TCT nurse specialist. Furthermore, two of the participants treated on the adult wards also reported receiving TCT nurse specialist support. Of the seven participants treated

on an adult ward two participants expressed a desire to have been treated on a TYA ward rather than an adult ward whereas, one reported that they were glad to have been treated on an adult rather than TYA ward.

Table 38.0 Interview participant characteristics including gender, age at interview, age at diagnosis, diagnosis, treatment, cancer stage at time of interview and self-reported current physical activity (PA) behaviours.

Participant	Gender	Age at Interview	Age at diagnosis	Diagnosis	Treatment(s)	Cancer stage	Describes self as currently active and meeting PA guidelines
1	Female	24	24	Non-Hodgkin's lymphoma	Radiotherapy. Immunosuppressants postponed due to Covid-19	Incurable cancer (maintenance treatment)	Yes, but unsure if guidelines
2	Female	25	24	Superficial Spreading Melanoma	Surgery (mole and lymph node removal) and targeted cancer drugs (Tafinlar and Mekinist)	On treatment	Yes, but not meeting guidelines
3	Male	24	22	Hodgkin's Lymphoma	Chemotherapy (ABVD)	Cancer free	Yes, and meeting guidelines
4	Female	26	19	Thyroid cancer	2x surgery (thyroidectomy) and radioactive iodine	Cancer free	Yes, but not consistently meeting guidelines
5	Female	24	22	Thyroid cancer	2x surgery (thyroidectomy) and radioactive iodine	Cancer free (<1 year since	No

Participant	Gender	Age at Interview	Age at diagnosis	Diagnosis	Treatment(s)	Cancer stage	Describes self as currently active and meeting PA guidelines
						treatment completion)	
6	Female	29	23	Non-Hodgkin's lymphoma (primary mediastinal b-cell lymphoma)	Chemotherapy and radiotherapy. Participated in clinical trial.	Cancer free	Yes, and meeting guidelines
7	Female	26	24	Melanoma	2x surgery, HDU stay and Immunotherapy	On treatment	Yes, and most weeks meeting guidelines
8	Female	26	25	Breast Cancer (stage 1 grade 3, invasive ductal carcinoma)	2x Surgery (lumpectomy and wide local excision then further local excision and haematoma clear out), radiotherapy and hormone therapy	Maintenance treatment (hormone therapy)	Yes, and meeting guidelines
9	Female	26	25	Breast cancer (Stage 1 Grade	Surgery (lumpectomy); adjuvant chemotherapy and	Maintenance treatment	Getting back into activity but not yet

Participant	Gender	Age at Interview	Age at diagnosis	Diagnosis	Treatment(s)	Cancer stage	Describes self as currently active and meeting PA guidelines
				2, Ductal carcinoma)	radiotherapy; hormone therapy	(hormone therapy)	meeting guidelines
10	Male	18	17	Stage 2 testicular cancer	2x surgery (orchidectomy and Retroperitoneal lymph node dissection and inguinal lymph node dissection); chemotherapy (BEP)	Cancer free (<1 year since treatment completion)	Yes, and meeting guidelines
11	Female	21	17	Stage 4B Hodgkin lymphoma	Chemotherapy	Cancer free	Yes, meeting guidelines
12	Female	24	22	Papillary Thyroid Carcinoma	Surgery (thyroidectomy)	Cancer free	Yes, to an extent, not consistently meeting guidelines
13	Male	25	23	Hodgkin's lymphoma (Stage 2)	Chemotherapy (ABVD and BEACOPP)	Cancer free	Yes, and meeting guidelines

Participant	Gender	Age at Interview	Age at diagnosis	Diagnosis	Treatment(s)	Cancer stage	Describes self as currently active and meeting PA guidelines
14	Male	21	19	Testicular cancer	Surgery (orchidectomy)	Cancer free	Yes, and meeting guidelines

PA= physical activity; HDU= high dependency unit; ABVD= Doxorubicin (Adriamycin), Bleomycin, Vinblastine, Dacarbazine; BEACOPP= Bleomycin, Etoposide, Doxorubicin (Adriamycin), Cyclophosphamide, Vincristine (Oncovin), Procarbazine, Prednisolone; BEP= Bleomycin, Etoposide, Cisplatin; < = less than.

6.2 RTA process with reflection

Throughout this section I provide examples of my audit trail to show my data analysis process, demonstrate my active decisions and reflect on my thoughts and feelings.

The first phase of RTA is to familiarise yourself with the data (Braun and Clarke 2021). Following data collection, each interview was transcribed verbatim by myself, the researcher. I then familiarised myself with the data by reading each individual interview to fully immerse myself. Physical copies of the interviews were then printed off and I began making notes for myself in the margins actively engaging with the data (as seen in figure 25.0). Codes were then generated using labels and highlighting segments of raw data. This process was predominantly data-driven (inductive) but there was an element of theory-driven (deductive) coding due to pre-interview immersion in previous research as well as my physiotherapy and sports psychology background.

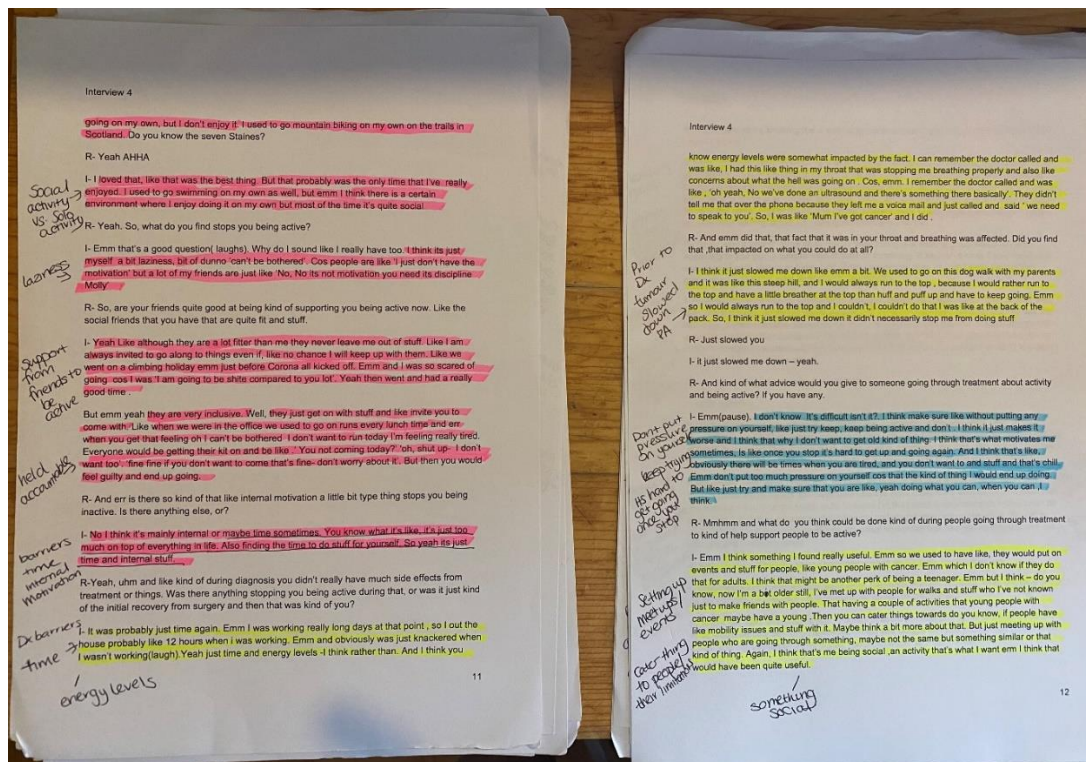


Figure 25.0 illustrates the initial coding process.

Once each individual interview had been initially coded all the individual codes were added to a word document. I found this document difficult to read and overwhelming due to the sheer volume of codes therefore, to manage this, I grouped the codes under a general subject heading (Appendix 20).

The next step in the process involved myself and my lead supervisor independently coding an interview. We then compared our two codes and discussed any differences; we also compared our codes to the initial coding sheet to ensure no codes were missing. As a novice qualitative researcher, I found this to be a reassuring step in the coding process as I was able to see similarities between my codes and my supervisors and could verbalise my thought processes.

After this I discussed my initial codes with my full supervisory team. This discussion focussed on both code and group descriptions. It became clear that there was a degree of overlap or repetition between the codes so, following this discussion I revisited the coding sheet condensing the overlap working back and forth between interviews. At this stage I also created a profile for each participant outlining basic demographic and cancer specific information including age, gender, age at diagnosis, diagnosis type, stage of cancer journey at time of interview. This provided me with greater insight into the data and allowed me to consider the role of external influencing factors on the data.

From these codes I then began to generate initial themes (see figure 26.0). I found the jump from codes to themes difficult as I was struggling to see the "big picture" instead focusing on the interviews at the individual level. One thing I found particularly helpful during this stage was to present my initial themes to my supervisory team in a short "elevator pitch." This gave me the opportunity to articulate my initial themes, theme description and the potential subthemes within them. As an individual I am a verbal learner therefore vocalising my thoughts to others was helpful for clarity, as well as highlighting areas of confusion or uncertainty.

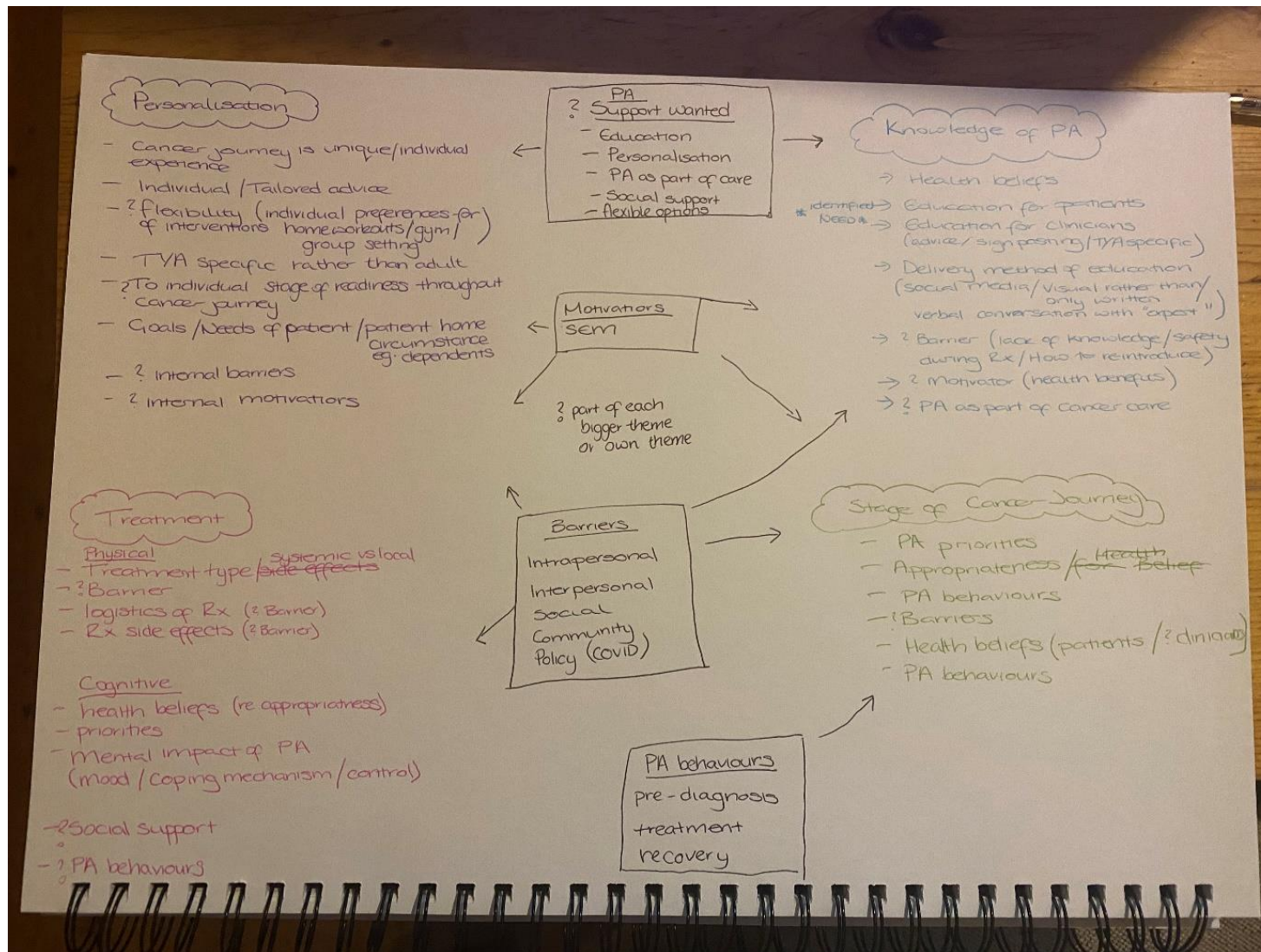


Figure 26.0 Initial themes and corresponding sub-themes.

It became clear that there was again a large degree of crossover between themes and that I lacked clarity regarding the theme descriptions. One major struggle I was having at this stage was considering themes in relation to TYA's cancer journey. Should this be hierarchical or should I consider themes across a timeline? Should journey stage be its own theme or should cancer stage be considered within all themes? Figure 27.0 shows timeline considerations and potential themes. Throughout this process I found verbally discussing themes and visually drawing them was incredibly helpful to create clarity within my own mind.

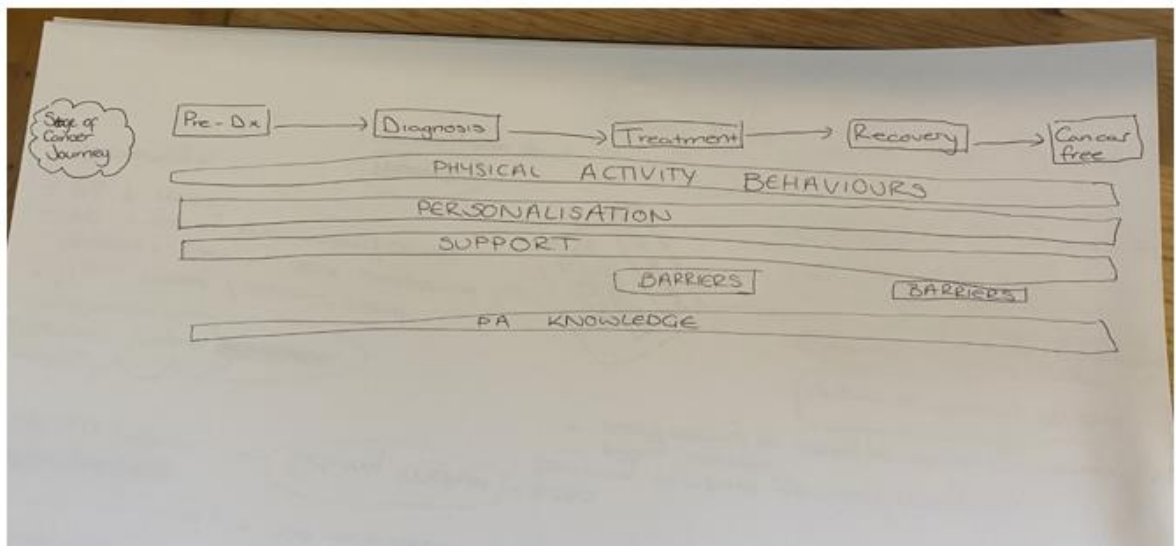
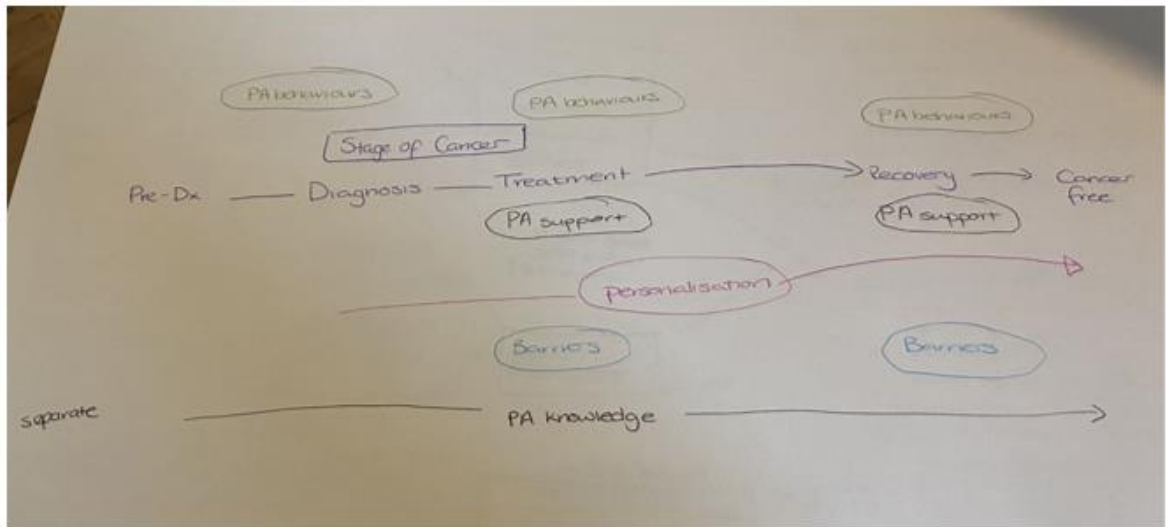


Figure 27.0 Potential timeline related themes.

Again, I revisited the interviews and the codes to see if this encapsulated the patterns seen in the data. One struggle I was having was to see the bigger picture where COVID-19 was concerned. COVID-19 is an unprecedented situation and did not apply to all participants or generally across all TYA cancer patients and

survivors' journeys. Therefore, I found myself asking should this be a separate theme? Where does it fit?

Figure 28.0 illustrates the next stage within the theme development. As can be seen six themes and the corresponding subthemes were outlined. I decided against themes along a timeline as every individual is different and although generally cancer stage can be grouped, patients' journeys are not linear. Following previous discussions and revision of codes, COVID-19 was identified as an independent theme; impact of cancer on PA behaviours was felt to be the only theme requiring consideration along the cancer journey timeline; personalisation and PA knowledge was considered under the broader theme of education and barriers and motivators were considered within themes.

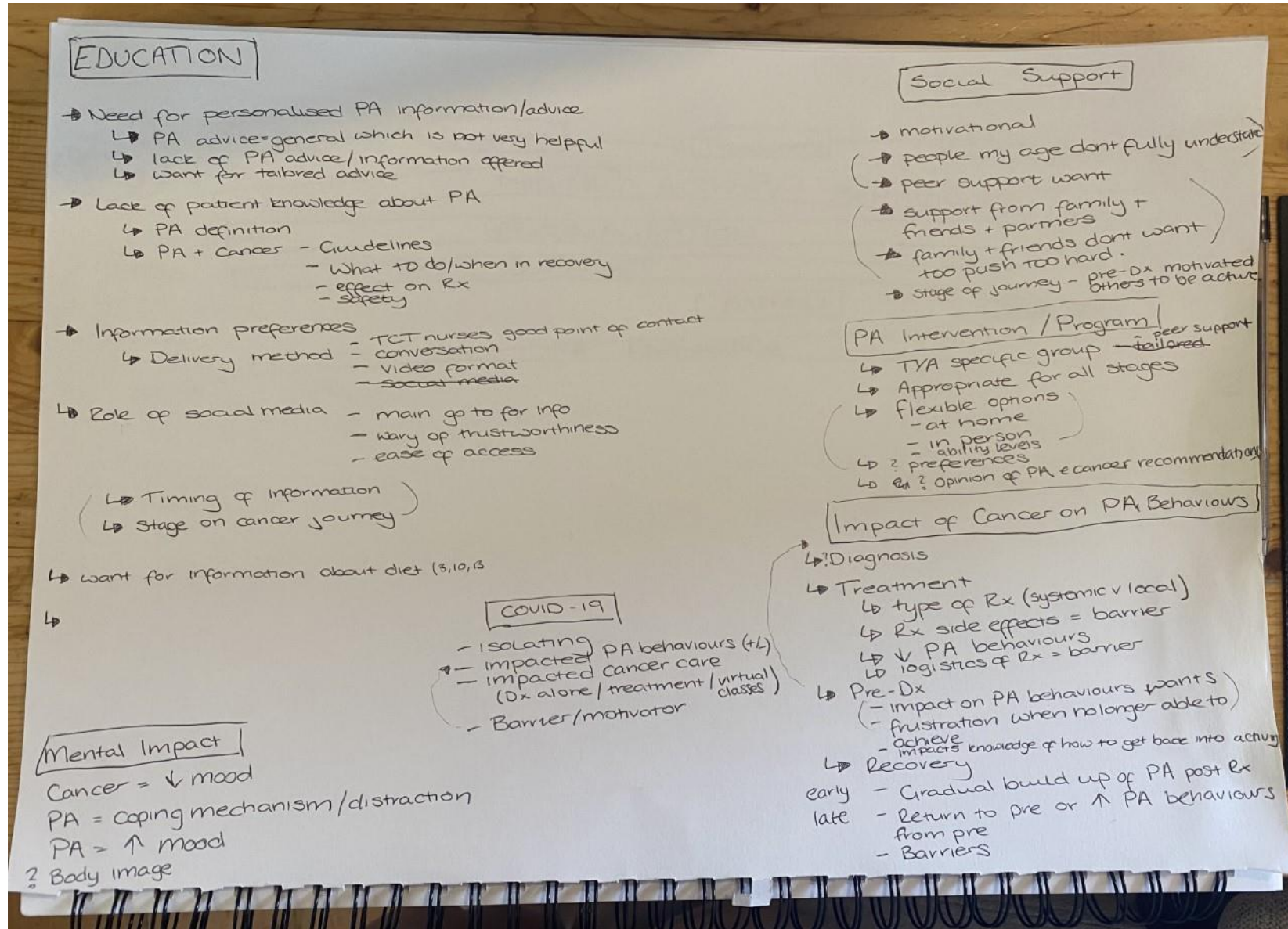


Figure 28.0 Development of six themes following supervisory discussion and revision of codes.

The next stage in this RTA process involved addressing each of the six themes individually and identifying appropriate supporting quotes. A flow diagram (figure 29.0) was created for each of the six themes going from theme title down to the individual code level. As a novice qualitative researcher these diagrams were useful for mapping out my thought process and for finalising the subthemes of each theme.

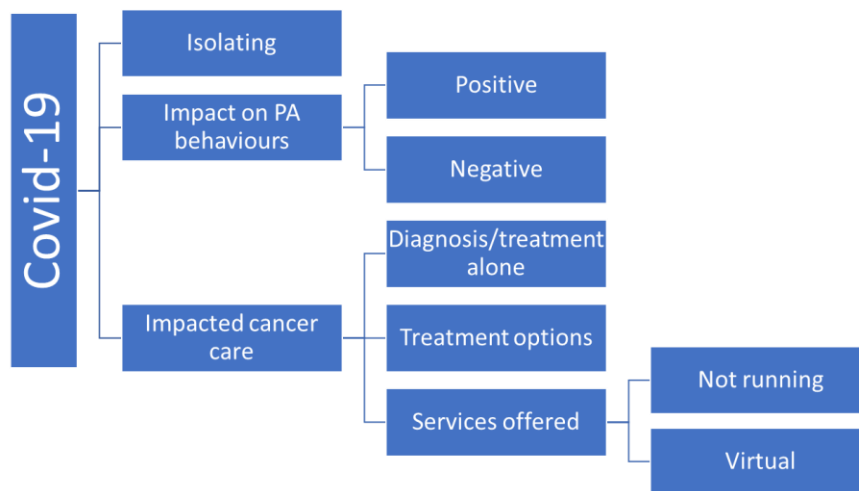


Figure 29.0 Example of thought process flow diagram for the theme of COVID-19.

Once I had mapped out my thought process for each theme I then returned to the interviews and grouped quotes relating to each theme. I began identifying the most appropriate quotes to encapsulate each theme which I found to be more time consuming than I had anticipated. Due to my inexperience, I felt a sense of pressure and at times I found myself second guessing my decisions when selecting supporting quotes.

Once I had begun identifying appropriate quotes for each theme it became clear that there was still a large degree of overlap. The development of my social support definition was key in my finalisation of themes. Originally, I had been defining social support in terms of emotional support from friends, family and peers. However, once I drew upon my previous knowledge and experience from my psychology background and considered social support as a multidimensional construct including not only emotional support but also the informational and instrumental support TYAs were receiving the theme definitions became much clearer. This led to the integration of the six themes (Social Support, Education, Mental Impact, Impact of Cancer on PA Behaviour, COVID-19 and PA Intervention/Program) into the final four interrelated themes (COVID-19, Social Support, Impact on Behaviours and TYA PA Opinions and Preferences). As

demonstrated through this reflective log I spent a long time fully immersing myself within the interview data fluctuating between the steps of “search for themes, reviewing potential themes and defining and naming themes” outlined by Barun and Clarke (2021). I found this to be a lot more challenging than I had expected however, I felt this process and engaging with reflection helped me grow in confidence as a qualitative researcher.

At the time of the interview, eight participants reported that they were currently employed full time, three were students (two of which also had part-time jobs), two were currently signed off work sick and one was unemployed. Also, two participants reported having dependants whom they were one of the primary care providers for during their treatment.

As highlighted in Table 38.0, twelve participants self-reported that they were currently physically active, one reported that they were getting back into activity and one reported that they were not physically active. However, only seven participants reported that they currently met physical activity guidelines of 150-minutes moderate-intensity or 75-minutes vigorous-intensity physical activity a week (World Health Organization 2020). One was unsure if they were meeting guidelines, three reported they were not consistently meeting guidelines and three reported they were not meeting guidelines.

6.3 Interview Findings

6.3.1 Theme Definitions

From RTA four large themes were identified within the data with regards to PA and TYA cancer (see figure 30.0). These were: COVID-19, Impact on Behaviours, Social Support and TYA PA opinions and preferences.

As seen in figure 30.0 the four themes are interrelated. COVID-19 is represented by a circle surrounding the other three themes to illustrate that this was an unprecedented circumstance which had an overarching contextual impact. A dotted line has been selected to highlight that COVID-19 was not constant but instead moved between various levels of lockdown and social distancing measures over the data collection period. Although it is not possible to definitively know, this Figure illustrates the researcher belief that without COVID-19 the other three themes remain relevant to the TYA population and PA.

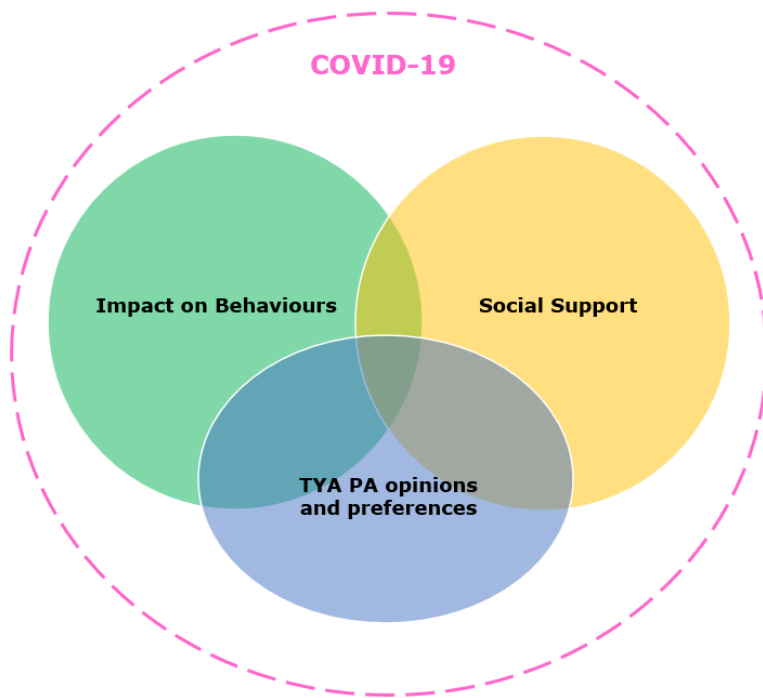


Figure 30.0 Four themes identified from RTA of interviews.

The theme of COVID-19 relates to the impact of the global SARS-CoV-2 virus pandemic which led to the introduction of UK national and local lockdowns and social distancing rules. It is comprised of three subthemes: isolation, impact on PA behaviours and altered PA support available. Impact on Behaviours is a large theme that relates to both the physical and psychological impact of cancer and PA on TYA patient and survivors. The theme TYA PA opinions and preferences encompasses TYA cancer patients and survivors' perceptions of PA and their preferences regarding various components of informational and instrumental PA interventions. For the purpose of this study, the term PA intervention will relate to actions or processes undertaken with the aim to influence PA behaviour. This has been adapted from the definition used in by Smith, Marrow and Ross (2015), "any activity undertaken with the objective of improving human health" regarding health-related interventions.

The theme of social support relates to all aspects of PA support TYA cancer patients and survivors receive across the cancer care continuum from their social network. Social support (SS) has been linked to health outcomes and is a multidimensional concept which has been conceptualised in multiple different ways (Wilson 2021). For the purpose of this study social support refers to the support an individual perceives is available and receives from their support network members (Gottlieb and Bergen 2010). Multiple distinct constructs or functions of social support are

reported in the literature but the main constructs relevant to this thesis are: emotional support, informational support, instrumental support, companionship support and validation support (Laird et al. 2016; Wilson 2021). Table 39.0 provides examples of social support function in relation to PA (Laird et al. 2016; Wilson 2021; Golaszewski and Bartholomew 2019).

Table 39.0 Examples of social support constructs in relation to physical activity.

SS Function	Example of PA support
Emotional	Encouragement to be active, providing praise for being active, watching individual perform PA.
Informational	Instruction or advice to be active, signposting to PA information, feedback on activities.
Instrumental	Tangible support to be active, financial assistance, provision of equipment, provision of exercise program, running of PA service, transportation to PA location.
Validation	Individuals seek out others for social comparison of behavioural norms and feelings. e.g., an individual with sore muscles after exercise seeking out others with sore muscles after exercise
Companionship	Sense of belonging and being part of a community, co-participation in an activity with an individual e.g., going for a walk or being part of a sports team.

6.3.2 COVID-19

The flow diagram (figure 31.0) below illustrates the theme COVID-19 and the three subthemes of isolation, impact on PA behaviours and altered PA support available. Descriptions and supporting quotes are provided and discussed against TYA cancer literature. As a result of the COVID-19 pandemic lockdown and social distancing measures were in place to varying degrees of severity between March 2020 and August 2021. However, cancer patients and some survivors were placed on a shielding list which involved more extensive social distancing compared to the general public for an extended period of time (Scottish Parliament Information Centre 2023). For some interview participants the COVID-19 pandemic was in effect when they were having treatment and for others it was post-treatment or

into their survivorship. Therefore, interviews captured the effect of the pandemic across multiple stages of the cancer care continuum.

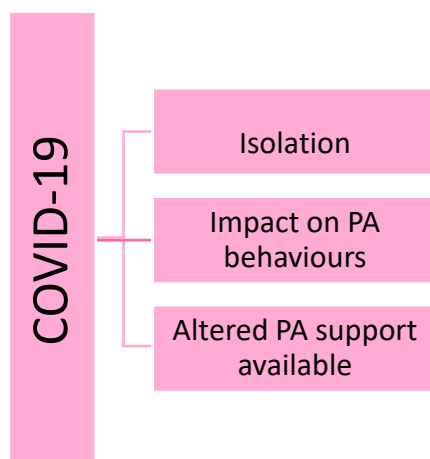


Figure 31.0 Diagram of the interview theme COVID-19.

6.3.2.1 Isolation

The main psychological impact of COVID-19 reported by participants was that they experienced isolation from the outside world and their support systems. These feelings were a direct result of being placed on the shielding list as well as national UK social distancing and travel restrictions implemented to reduce the spread of COVID-19. Participants reported that restrictions removed the social aspect of PA which in turn negatively impacted their PA behaviours and recovery.

"The constant feeling of wanting to get out and do things and keep active, because I feel like being closed in my house and not able to go out and socialise and do my fitness classes and stuff has had a major impact on me, how I am feeling and my mental wellbeing. Feeling isolated and stuff" (1)

"If COVID wasn't there and if I had a lot more people around me, like friends and family, I feel like it would be would have been a lot easier to maybe, get back in the swing of things health wise." (13)

"It was quite difficult because people wanted to be there, but also, they felt like they were a threat to me. So, they wanted to stay away physically but be there" (9)

A feeling of isolation as a result of cancer diagnosis has been established in cancer research (Adams et al. 2016). Interview participants felt that COVID-19 restrictions exacerbated the feeling of isolation which a cancer diagnosis itself poses.

"Cancers a lonely journey anyway and COVID just added this whole new dimension of isolation" (10)

Although research specifically assessing the TYA cancer experience during COVID-19 is limited an online survey into the impact of cancer and coronavirus on young people (n=118, ages: 19-24 (55%), 13-18 (29%) 25-30 (16%)) reported 81% had been asked to shield and of these 91% were affected by shielding and over half (53%) were managing poorly or very poorly to see friends and family (Sundell and Soanes 2020).

A qualitative study investigating the experiences of social isolation during the COVID-19 lockdown amongst Danish adolescent and young adult cancer patients and survivors (n=13, mean age 23.5 years) identified the theme "being alone"; with participants expressing they felt lonely experiencing cancer and recovery during lockdown and found it hard to see healthy peers socialise when they had to isolate (Hanghoj et al. 2021). The theme "need for giving and receiving support" was also identified. Participants reported a need for peer-support regarding cancer and COVID-19 however, they felt this was impacted by lockdown and distancing measures. Furthermore, these TYAs felt electronic communication methods with peers and support groups failed to replace human contact and in-person meetings (Hanghoj et al. 2021).

An online cross-sectional survey investigating adolescent and young adult (aged 18-49, mean age =30) experiences during the pandemic in Canada found most participants 54% (n=204) self-reported experiencing loneliness during the pandemic (Yan et al. 2023). Also, research investigating the health-related quality of life (HRQoL) of sarcoma patients treated during the first two months of the UK lockdown suggests experiences of loneliness during the pandemic may be associated with age, as adolescents and young adults (16-39 year) were significantly ($p=0.004$) more likely to experience loneliness than elderly adults aged (>65years), 33% compared to 15% (Younger et al. 2020). This was further supported in another cross-sectional survey investigating AYA cancer patients (aged 18-39) experiences of loneliness during the pandemic found younger AYA's (aged 18-25) and individuals currently on-treatment were significantly more likely to experience loneliness than older AYAs or those off-treatment (Howden et al. 2022).

6.3.2.2 Impact on PA Behaviours

Most participants reported changes to their PA behaviours as a result of the COVID-19 pandemic. Changes included the type of PA performed, including switching from exercise which was facility based (e.g., gym or leisure centre) to outdoor activities or homebased workouts. Participants reported that this was due to lockdown enforced facility closures.

"COVID has changed everything, like before COVID I would go climbing in the evenings and most evenings I would be doing some form of physical activity with other people. But yeah, at the moment its more just like the occasional run and yoga session, that kind of thing" (4)

Another impact was a change to the amount of PA participation. Some participants reported participating in less PA because of COVID-19 and others reported more. Those who reported that COVID-19 negatively impacted their PA behaviours attributed this to facility closures and reduced motivation to be active due to lockdown restrictions and social distancing measures. This is illustrated with the quotes in Table 40.0.

Table 40.0 Impact of COVID-19 on physical activity participation

Impact of COVID-19	Quote
Facility closures and demotivation	<p><i>"because cafes weren't open, it wasn't like I could be; OK, well I'll just walk there and get a wee coffee or something. I wasn't able to motivate myself in that way" (9).</i></p> <p><i>"my flat mate and I actually bought some equipment to do a little bit of exercise in our flat, but both quickly discovered we don't really have the same amount of motivation whilst stuck inside in our own flat than in the gym. So just not being in that right environment, I think demotivated both of us actually" (14).</i></p>
Lockdown and social distancing measures	<p><i>"you're already pretty sick and weak, and then you're feeling good and you want to go out but you're not even able to go out for exercise because of the really strict lockdown" (10)</i></p>

Impact of COVID-19	Quote
	<i>"I was sick to the back teeth of doing all the walking around my house. You know you get so sick of all the same routes all the time" (9)</i>

As well as reporting an impact on their exercise behaviours, participants also reported a reduction in their naturally occurring PA behaviours i.e., behaviours performed as activities of daily living such as going to the shops, due to being on the shielding list.

"there was slight, bits of, exercise and stuff like that but the majority of it was kind of restricted because, going to the shop was a no go, going out walking around the shops was also a no go so, it kind of restricted what we were doing and also meant if we were going somewhere, and there was too many cars parked outside, we would just go back in the car and go home" (3).

Conversely, those who reported a positive impact of COVID-19 on their PA behaviours stated that lockdown gave them more time to be active as it reduced external competing factors which usually took priority such as work, university or socialising with friends.

"lockdown gave me like the time to actually just make it a priority. so, I'd say like the lockdown was kind of the key to me actually getting properly into exercise and seeing results because I had full focus on it, it's like there wasn't really anything else that I could distract myself with; like work or uni stuff and even like friends you can go and meet them or anything" (11).

An additional positive on PA behaviours were some participants reported increased motivation to be active and access leisure facilities once lockdown restrictions were lifted as they were unable to do this for so long.

"I think it was just an- ok now I'm able to get out and do things actually I just got into a really good habit of it" (14).

Previous research into the impact of COVID-19 on PA behaviours has shown mixed results. One survey into the TYA population demonstrated that participants poorly managed their physical health during COVID-19 (Sundell and Soanes 2020). With other studies reporting lockdown impacting patient recovery, mood, socialisation,

motivation, and reducing PA behaviours (Hanghoi et al. 2021, Brown et al. 2021). Another survey exploring the impact of COVID-19 on an established McMillian Move More cancer service in Northern Ireland found that the percentage of participants who were not regularly active increased from 4% prior to COVID-19 restrictions to 21% during COVID-19 restrictions (Brown et al. 2021). But an online cross-sectional survey investigating adolescent and young adult (aged 18-49, mean=30) experiences during the pandemic in Canada found 33% of AYAs decreased their PA levels, 53% maintained them and 12% increased them (Yan et al. 2023). Also, some participants in the study investigating the experiences of Danish TYA cancer patients and survivors mentioned above reported lockdown gave them a rest which allowed them to recover physically and mentally (Hanghoj et al. 2021). The interview results support the mixed results found in previous literature and suggest that the effect of COVID-19 on PA behaviour varied depending on the individual and their unique situation.

6.3.2.3 Altered PA Support Available

Finally, participants felt COVID-19 impacted cancer care resulting in reduced availability of PA support services compared to non-COVID times. Two main changes reported were that services were either not running due to COVID-19 or they had moved to an online format, supporting quotes displayed in table 41.0.

Table 41.0 Impact of COVID-19 on support services.

Impact of COVID-19	Quote
Online services	<i>"my TCT nurse, *name*, he referred me to this kind of online fitness class that's cancer related. So, its people that have recently or are going through cancer but want to stay fit. It was just a little online zoom fitness class. If it wasn't during COVID they had an actual gym that you could go to" (10)</i>
Services not running	<i>"I was put in contact with the, young person's Cancer Network in my area, but again, I think because it was COVID they didn't do any meetups or anything like that. And they said they couldn't do anything online because of data protection issues" (8)</i> <i>[on TCT events] "COVID has been a massive hit on that, because they've not been able to do anything" (3)</i>

COVID-19 greatly affected the landscape of cancer care services (Greenwood and Swanton 2021; Tabaczynski et al. 2023). In the CRUK impact of COVID-19 survey (n=1868, aged 13-91 years, mean age=30), 64% patients reported that their care (as defined by “everything patients would expect as part of their care” including emotional well-being, mental health, physiotherapy etc.) had been impacted in at least one way as a result of COVID-19 (Cancer Research UK 2020). Just below half of the respondents (46%) in the TCT survey discussed above (Sundell and Soanes 2020) reported that they experienced changes to their treatment or support during the pandemic. Accessing a physiotherapist during the pandemic was reported to be more challenging than normal, with 69% of respondents reporting less than usual contact with physiotherapists (Sundell and Soanes 2020). Reduced access to physiotherapists due to staff redeployment has also been reported in AYA cancer patients (Hughes et al. 2022). This supports interview participants’ experiences of reduced PA support available during the pandemic.

As highlighted from the interviews, one method employed to continue the delivery of physical activity intervention to cancer patients and survivors during COVID-19 was the adoption of remote telehealth or virtual physical activity interventions (Tabaczynski et al. 2023). There is currently limited published data relating to physical activity interventions in oncology populations during the pandemic. However, a narrative review conducted by Gonzalo-Encabo et al. (2022) identified twelve published studies relating to exercise interventions in cancer populations during and beyond the COVID-19 pandemic. It should be noted that none of these studies related directly to TYA cancer patients as they were all conducted in adult populations (Gonzalo-Encabo et al. 2022). The review illustrated that virtually supervised group home-based activity, semi-supervised home-based activity and unsupervised self-directed home-based activity were all PA interventions utilised in oncology during the COVID-19 pandemic (Gonzalo-Encabo et al. 2022). Only one study measured participants perceptions of an online format compared to in-person (Gonzalo-Encabo et al. 2022). This study was a 3-month group-based walking or yoga intervention (n=78, mean age= 55 +/-9) which began in-person (3 weeks) and transitioned to virtual (7 weeks) (Gothe and Erlenbach 2022). The majority of participants preferred in-person to online sessions (60% vs 40%), the majority of participants (66%) reported no difference in the enjoyment of online vs in-person sessions and 20% felt the exercise intensity was easier during online sessions (Gothe and Erlenbach 2022). Furthermore, both an online exercise group

and home-based training-app have been found to be feasible and acceptable within the AYA oncology population (18-39, n=50, mean age=31.9 +/-4.9, 20% on-treatment at baseline) (Volland et al. 2023).

6.3.3 Impact on Behaviours

As outlined in section 6.3.1 the interview theme "impact on behaviours" comprises two large subthemes relating to physical and psychological impacts of cancer and PA. Figure 32.0 provides a visual representation of this theme and the third level subthemes which it is comprised of. Physical third level subthemes relate to participants behaviours across the cancer timeline moving from pre-diagnosis to recovery. Whereas the psychological third level subthemes relate to the impact of cancer on mood and body image and the impact of PA on mood and coping.

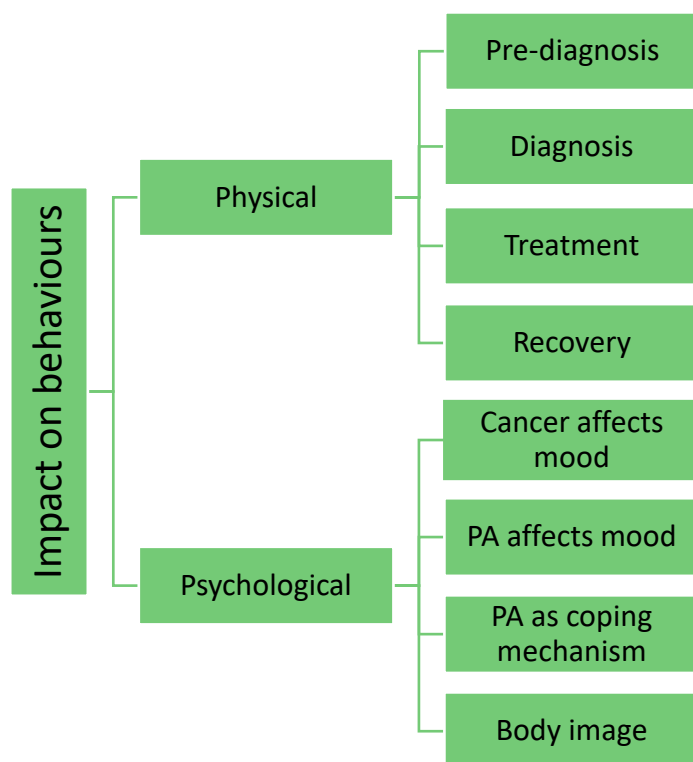


Figure 32.0 Impact on behaviour theme and subthemes.

6.3.3.1 Physical

The following section will discuss participants physical impacts of cancer and treatment at the various stages along the cancer care pathway. As noted earlier not all cancer journeys follow a linear timeline however for ease of data presentation, a linear timeline has been adopted here from pre-diagnosis to survivor.

Most of the interview participants reported that they were physically active prior to their cancer diagnosis. The type of activities reported varied across participants but included recreational, occupational, domestic and transport related PA. Due to the lower-than-expected response rate it was not possible to undertake purposeful sampling and have an equal representation of teenagers to young adults or individuals with a current diagnosis and those cancer free. As seen in the demographic section 85% of these participants class themselves as active and 50% report consistently meeting PA guidelines. Again, this suggests that this cohort may have been skewed towards physically active TYA and not representative of the whole TYA cancer population. During the planning of this study purposeful sampling consideration only related age and cancer status however, future thought should be given towards self-reported activity status, to ensure the experiences of those who do not class themselves as active are captured.

Participation in pre-diagnosis PA reportedly informed participants knowledge about how to return to activity following their cancer treatment as it gave them some degree of understanding about how to be active.

"I can imagine if it [physical activity] was something I'd never stepped into before it would be a big undertaking at this point, when you're so vulnerable and things are so much more difficult" (9)

"because I've always had that interest and likeness to doing a lot of running and sports and stuff, I felt like it was easier to kind of start things back up again. Whereas, if someone, well I don't know this, but I think it would be a lot harder for someone who previously wasn't into sports before and didn't really have that athletic ability. I think it would be harder to get the motivation to get going" (13)

A 5-year follow-up of BREX exercise intervention study in breast cancer survivors (n=446, aged 35-68 years) found higher pre-treatment leisure-time PA was significantly associated with higher long-term PA levels following adjuvant treatment ($p < .001$) (Kokkonen et al. 2022). Pre-diagnosis PA levels have also been seen as a predictor of long-term follow-up PA engagement in various other breast cancer trials (Courneya et al. 2009; Vallance et al. 2010; Schmidt et al. 2017). Although, this has not been investigated within the TYA population. The results of the interviews suggest that PA knowledge through pre-diagnosis engagement may facilitate or enable post-treatment PA.

In relation to PA, diagnosis was the least discussed stage of the cancer journey by participants. In part, this may be due to the interview questions themselves focusing more on pre-diagnosis, treatment and recovery PA behaviours. However, participants who did discuss PA at time of diagnosis illustrated that PA is not a priority at this time as there is too much going on and things move quickly from diagnosis to treatment. Cancer diagnosis itself has been seen previously to negatively impact PA behaviours within the TYA population with one study reporting that following diagnosis 98% of participants reported altered PA behaviours with 20% reduced their exercise participation and 78% discontinuing exercise altogether (Spreafico et al, 2021). TYA's feelings towards priorities at time of diagnosis must be respected however, past research into the behaviours of cancer patients out with the TYA population also show diagnosis to negatively impact PA levels. This highlights that in order to minimise the impact of cancer on PA behaviours it is vital to engage patients early within their cancer journey.

Some participants expressed that PA was important to them during treatment whereas, others again felt it was not a priority for them.

"keeping active was something that was really important to me throughout treatment" (8)

[physical activity] "It really wasn't on my radar until I finished treatment" (11)

This stage of the cancer journey was reported by most participants to negatively impact their PA behaviours.

"At the time I was getting my treatment I would have described myself as extremely unactive" (3)

As seen from the scoping review, this is in line with previous literature which has demonstrated TYA cancer patients are insufficiently active and do not meet PA guidelines (Murnane et al. 2019; Murnane et al. 2015; Pugh et al. 2020a and Munsie 2021c). One study of hospitalised patients found that post-haematological transplant adolescents engaged in 34% less PA than pre-treatment (Rosipal et al. 2013). Not only have TYA cancer patients been found to be inactive but studies have also found they have worse physical functioning (as indicated by six-minute-walk-test) than health age matched peers (Rosipal et al. 2013; Marec-Berard et al. 2021).

As has been found in previous TYA cancer cohorts (Rosipal et al., 2013; Murnane et al., 2015) walking was the most reported PA behaviour that the participants engaged with during treatment with many reporting that they would not have been able to go to the gym.

"So, I stopped doing any gym or like running, but I made sure I did like walks because I didn't want to completely stop doing things" (6).

Participants highlighted everyone responds to treatment differently so you cannot predict how an individual's PA would be affected however, treatment type received, treatment side-effects and the logistics of receiving treatment were all reported to influence PA behaviours.

Participants reported that each treatment type affected their PA behaviours differently.

"So, after the surgery in my head, I really, really wanted to do it; it was just my body restricting me whereas now [on immunotherapy] it kinda feels like it's my head that's restricting me because it's like the energy and motivation" (2)

Table 42.0 provides supporting quotes for the different treatment types and their effect on PA. Participants within this study reported radiotherapy had no impact or very little impact on their PA behaviours. With regards to surgery pain at surgical site and post-operative PA restrictions such as; avoidance of certain movements or movement patterns, reduced range of motion or lifting restrictions, were the most reported reasons for reduced PA behaviours. However, post-operative complications such as the need for additional surgery or prolonged hospitalisation or bed rest were also reported by participants to negatively influence their activity. Many participants reported that once they had recovered from their surgery and no longer had to follow post-op PA restrictions, their PA behaviours then increased/returned to normal.

Participants who had systemic treatments such as hormone therapy, chemotherapy or immunotherapy reported that treatment had a negative impact on their PA behaviours due to treatment side effects and motivation. One participant receiving hormonal therapy reported this lowered her PA motivation which in turn made her less active.

Table 42.0 Effect of different treatment type on physical activity behaviour with supporting quotes.

Treatment Type	Quote
Radiotherapy	<p><i>"the time I was in hospital was probably very sedentary, but I think afterwards. I think I was maybe quite tired, so...I maybe missed a couple of dog walks at that point... I don't remember it affecting me too badly (4)</i></p> <p><i>Comparatively to chemo the radiotherapy to me felt like a like a dawdle. I hate saying that because I don't want to belittle it but it was a kind of painless thing and they told me I'd be tired. I'm not sure if I was still kind of just so exhausted from the chemo but I don't know if I recognized it "(9)</i></p>
Surgery	<p><i>"the physical restrictions of having sort of stitches in and things like that and not being able to use the upper body...and obviously straight after surgeries as well the movement was quite restricted on one side" (8)</i></p> <p><i>"I don't think it really changed too much. Obviously when I had the surgery that was different. I think I had 3 weeks off work for recovery after my surgery. Certainly, the first week I don't think I moved out of bed. I can remember going to TK Max with my mum...and I was just so tired by the time we got home. I think because it's your neck I think anytime I was going to stand up straight it felt like my neck was going to burst open so, after surgery I don't think I was very active, but I think it probably didn't affect it too much" (4)</i></p> <p><i>"after I'd had surgery, I think I had about a month where I couldn't really, well probably longer than that, I couldn't really do any exercise at all. Obviously, I carried on doing things like walking and things like that, but sort of the more strenuous physical activity that I was used to, that obviously, all sort of stopped really quickly. So, it did impact it, but I always tried to stay as active as I could manage (8)</i></p> <p><i>"I couldn't really do much physically. I was really ill; my stomach was in excruciating pain so I couldn't even move sometimes...pretty much every time I stood up, I got a light head, I even collapsed a few times when I did try and go for a walk round the ward" (10)</i></p>
Hormone therapy	<p><i>"Well, my motivation is definitely lower. And I think where I was doing four to five sessions, a week before, I now may manage three, if I'm lucky four. So, I still do alright, I still do a sort of decent amount of physical activity. But I definitely do, a bit less" (8)</i></p>

Treatment Type	Quote
Immunotherapy	<i>"I was really struggling to eat and feeling sick all the time and I lost quite a bit of weight and I didn't have the strength really...and when I first got out of hospital and trying to go for a walk with my husband, I think I got to the second lamppost and had to turn back cause I didn't have the stamina for it at all...I struggled to build it back up" (7)</i>
Chemotherapy	<i>"feeling like unwell and nauseous and just weak really and tired". (6) "it just felt like one massive hangover. My head was all fuzzy like, you're really tired and fatigued (13) The two main side effects [of chemotherapy] that really affected my physical health was the nausea and the fatigue. Just the exhaustion. I was just chronically tired all the time. When I was at home I would go downstairs and make myself a cup of tea and go back up to bed and that was it. I was completely exhausted and wiped out. I would sleep for hours after doing menial kind of things. The nausea, pretty much if I got up and moved my head too much, I felt like I was going to be sick so I had to stay still. The nausea was a huge preventative of my physical health. And just the fatigue and being tired all the time didn't help with any motivation to get up and do anything" (10)</i>

One of the main barriers to PA engagement during treatment were treatment-related side-effects. Reported side-effects included fatigue, pain, nausea, body aches, muscle weakness, headache and dizziness. Not all participants experienced the same side-effects however, as has been seen previously with TYA literature (Murnane et al. 2015; Psihogios et al. 2020; Spathis et al. 2017; Spreafico et al. 2021; Wu et al. 2015; McGrady et al. 2022; Munsie 2021^a; Munsie et al. 2021^b; Shaw 2022; Wallis, Meredith and Stanley 2021) the interview participants most commonly reported side-effect was fatigue.

Findings of the scoping review concur with many of treatment-related PA barriers found in the interviews. As well as fatigue, general effects of cancer treatment (Kuntz et al. 2019; Murnane et al. 2015; Pugh et al. 2018; Smith et al. 2018; smith 2021); pain (Murnane et al. 2015; Psihogios et al. 2020; Smith et al. 2021; Shaw et al. 2022); nausea (Psihogios et al. 2020; Munsie 2021^a; Munsie 2021^b; Shaw et al. 2022); reduced motivation (Psihogios et al. 2020; Rosipal et al. 2013; McGrady et al. 2022; Shaw et al. 2022); changes in functional ability (Murnane et al. 2015; Pugh et al. 2018; Spreafico et al. 2021; Smith et al. 2021); feeling too ill (Psihogios et al. 2020; Rosipal et al. 2013; McGrady et al. 2022; Pugh et al. 2020a); weakness (Kuntz et al. 2019; Shaw et al. 2022; Salchow et al. 2021) and reduced exercise tolerance (Shaw et al. 2022; Smith et al. 2021) have all been reported to reduced TYA cancer patients PA behaviours. No previous research has evaluated the impact of different treatment types on self-reported PA behaviours in TYA oncology patients or survivors. The findings from the interviews suggest that although local treatment does impact on behaviours, the effects of this may be less severe when compared to systemic cancer treatments. However, as illustrated by participants no two patients' journey are the same.

Furthermore, during treatment participants reported that their energy levels fluctuated and with it their ability to be active. These fluctuations in energy levels were reported to be a barrier to PA as participants reported inconsistent PA engagement or having to pace themselves during the day and conserve energy for other tasks rather than PA.

"So, I think a lot of it while I was getting used to the medication I was on, no matter how much sleep I got, I would wake up tired. And I think I would often think to myself, right? If I go out and do something, like do physical activity I'm...not going to make it through the day without having a nap." (12)

[on barriers] "it's just energy, because sometimes I find if I go out a walk, I can be tired for the day, and I won't do anything else. So, it's just kind of trying to pick if I want to do it because I make a lot of music and stuff as well. So, I'm like, if I want to do that then I just won't do any exercise...It's just kind of picking and choosing" (2)

It is common for TYA's to receive multiple rounds of a treatment or multiple different types of treatment. Participants reported that the cumulative effects of treatment negatively impacted their PA behaviours which led to a cycle of deconditioning and reduced PA.

"I found initially I could do those things; I didn't take too much of a hit. I think midway through my chemo I just got worse and worse each cycle, the accumulative effect and by the end of chemo I was barely...I think I was walking from like my bed to the couch. I would try and walk, basically just walk around the block and I'd mostly have to go with someone in case I didn't feel well or felt a bit dizzy. During my radiotherapy I could be a bit more active but I was just really exhausted a lot of the time, so... I would mostly just walk" (9)

It is well understood in cancer care that management of treatment-related side-effects is vital to avoid worsening severity of symptoms such as chronic fatigue, malnutrition or cachexia (loss of skeletal muscle mass), which perpetuate the cycle of inactivity and deconditioning described above (Lucia, Earnest and Perez 2003).

Additionally, participants reported that the logistics of receiving treatment impacted PA behaviours. As seen in table 43.0 this included: the treatment delivery method such as spending a prolonged period attached to an intravenous (IV) drip or having a PICC line inserted and being unable to participate in certain activities such as swimming or heavy lifting; the time it takes to receive treatment as well as travel time to and from hospital/clinics and attending regular appointments e.g., attending the hospital on ten consecutive days for a cycle of radiotherapy.

Table 43.0 Logistics of treatment as a PA barrier.

Logistics of treatment	Quote
Delivery method	<p><i>"I had a Hickman line the whole way through my chemotherapy so there would be no way I could be doing anything like impact...but I don't think it would have been a good idea to be moving around because I wouldn't want to have dislodged it or anything, it had to be done under a procedure and I wouldn't want to repeat that" (6)</i></p> <p><i>"the PICC line came with its own kind of restrictions because I wasn't allowed to go into certain areas of work. I was restricted on what kind of heavy lifting I could do" (3)</i></p>
Time burden associated with treatment	<p><i>"the thing with the radio that was tiring was going up to the hospital every day. I lived in the South side of *city*, so going over to the *hospital*. It's difficult to say what was the treatment making me tired and what was just the physical having to go to hospital every day" (9)</i></p>

Furthermore, participants reported that receiving treatment as an inpatient impacted their PA behaviours as there is reduced opportunities to be active when limited to a hospital ward or room and they have less access to equipment to facilitate activity whilst an inpatient.

"I was confined to one room" (7)

"the time I was in hospital emm was probably very sedentary" (4)

Environmental barriers to PA which were found in the scoping review support the findings of the interviews with regards to logistic of receiving treatment. IV/ central venous attachments (Spreafico et al. 2021; Shaw et al. 2022), lack of equipment (Wu et al. 2015; Shaw 2022) and hospitalisation (Kuntz et al. 2019; Munsie 2021a; Munsie 2021b) were all demonstrated to be TYA activity barriers.

Within inpatient TYA cancer patients' logistical complications, scheduling conflicts or engaged in other medical procedures have been reported to barriers to PA engagement while hospitalised (Munsie 2021a; Munsie 2021b; McGrady et al. 2022), which coupled with these interview findings demonstrates how time-

consuming receiving cancer treatment is. Lack of time, being too busy and competing demands of work or family have also been reported within the wider AYA cancer population (18–39-year-olds) as PA barriers (Rabin 2017; Kimball et al. 2017).

Participants reported one motivating factor of trying to be active during treatment was that following activity their mood improved. This is discussed in the psychological impact section below.

Some participants found it frustrating during treatment and recovery when they were unable to maintain their pre-diagnosis activity levels. Frustration with post-treatment bodies has been previously reported in both TYACs (Wu et al. 2015) and AYACS (Kimball et al. 2017).

"It does annoy me that I can't go and do my workouts and stuff. So, I think that's probably why I'm I try to keep on top of like the house and stuff because then I feel like it's something does that make sense?" (2)

Of these participants not all of them found this frustration to be negative, with some reporting a motivational element to trying to return to pre-activity fitness levels.

"just thinking about who I was and how fit I was before cancer is a great motivator because I want to go back to that again. So even during treatment, when I was maybe ill or stuff I always try because I know one day, I should be back to that stage again. So, it's a good motivator for me. Kind of competing with your old self" (10)

There was a difference between the self-reported PA behaviours of participants less than one-year post-treatment and greater than one year post treatment. Participants more than 1-year post treatment reported that their PA behaviours had returned to their pre-diagnosis level or that they were now more active than they were pre-diagnosis.

"I've sort of got back to similar levels of activity as to what I was achieving before diagnosis" (8)

Whereas participants less than 1-year post-treatment reported that they were still less active compared to their pre-treatment activity levels, due to fatigue and deconditioning because of treatment.

"I am not as fit or strong as I used to be. I have lost a lot of that; I am very weak and I get tired easily" (10).

Participants reported that when returning to PA post-treatment they started with walking and light-intensity activities before gradually increasing the activity intensity and duration, this can be seen in the quotes in table 44.0.

Table 44.0 Gradual return to activity quotes

Gradual return to activity quotes
<i>"just starting small and then on the days I'm feeling good just push my boundaries and stuff" (10)</i>
<i>"I'm making a purposeful effort to walk more" (9)</i>
<i>"just started back with everything that I kind of enjoyed before so a lot more walks, would take the kids down the beach and stuff like that. more just kind of light exercise...once I was kind of back at work, I was put on a restricted duty...that kind of helped as well. So, the gradual kind of build up with work, as well as doing the personal exercise in the house" (3)</i>
<i>[TYA physiotherapist] "she kind of put me onto doing yoga on YouTube and there's hundreds of different ones for different abilities so that was quite good. That's been fun. Also, the abilities it's like kind of get started and work up" (7)</i>

Many participants reported a process of *"trial and error"* (13) to progress their activity levels. As seen in table 45.0 some participants reporting pushing themselves too far or not knowing where to start with activity.

Table 45.0 Return to activity as a process of trial and error.

Process of trial and error	Quotes
Unsure where to start	<i>"I wasn't sure where to start and if I'm honest, I also don't drive, so I felt my options were quite limited because there's not really a gym within like walking distance of me" (9)</i>
Pushing too far	<p><i>"We did do a couple of exercise things my partner was interested in...HIT workouts or something...We done a couple of them...but that was way too much" (3).</i></p> <p><i>"I started just going out like, walk my dogs because it was really sunny. Kind of build up from there. I got my energy back, was feeling a lot healthier and like, making healthier decisions. It was very gradual. I was trying to push myself I'd probably say maybe too hard. Like cause I felt good and because of...sometimes I didn't feel like I had cancer just because of how good I would wake up. But then I would get like a slap in the face really and I'd realize that no, I can't go for a run just yet. Or I can't do 10 Press ups kind of thing. So, at that point, I did have to listen to my body... Yeah, it was just a gradual thing" (13)</i></p>

Previous research into the lived experience of TYACS has also reported this process of having to gradually increase PA post-treatment (Wallis, Meredith and Stanley 2021). TYACS were also found to use exercise as a way to test their new boundaries and physical capabilities (Wallis, Meredith and Stanley 2021).

As with during treatment, fatigue was reported as a PA barrier particularly in the earlier stages of recovery. Table 46.0 contains quotes which illustrate the impact of fatigue.

Table 46.0 Impact of fatigue on PA.

Impact of fatigue quotes
<i>"the first year was really, really hard, like, I tried a couple of home workouts, and it would wipe me out for days. Erm I was being told like, it's good to be active and I was like I'm literally too tired" (11)</i>
<i>"For a couple of months afterwards, while I was getting used to the medication [thyroxine] that I was on, I was getting quite tired...I would say I maybe didn't do things as much, I still went and did all the stuff, but maybe not as much as it did before. And I'm kind of just building that back up now" (12)</i>
<i>"all I wanted to do during treatment was to swim and I couldn't because well obviously infection risk and I had a PICC line in my arm. And then when I did finish and I tried to swim I found that it was very difficult to catch my breath because I still didn't have the energy" (9)</i>
<i>"most of the time, I don't have the energy to do anything" (5)</i>

Those who participated in charity led PA programs when returning to activity post-treatment reported positive experiences as this gave them structure and support to be active in a safe environment with other cancer survivors.

"After I finished my treatment, I did a like a block of kind of getting back into physical activity with Maggie Centre and there was uh a physio. I don't know if she was a physio or a personal trainer...I was the only young person there...was all older people, but even then it was good to just do things, she was just showing you what you could do at home to kind of build up your strength and things. It was a bit like mini circuits, and I think that was great for me post" (6)

This has also been seen in the wider UK AYACS and adult cancer populations. A qualitative investigation, using semi-structured interviews, into a charity led PA initiative (n=16, mean age=33 years, 87.5% female) RENEW (12-week, 1-2-1 individually tailored PA program for AYACSs in their 20's and 30's) found AYACS had positive experiences with the program and felt it improved their general physical functioning and wellbeing post-treatment (Below et al. 2021). A cross-sectional survey (n=60, 62% female, 68% > 60 years, 66% breast/prostate cancer, 68% on-treatment) was used to assess experiences of a community-based charity led exercise program "CU Fitter" (Catt et al. 2018). Results found a positive

impact on adult patients and survivors fitness/health and social support (Catt et al. 2018).

6.3.3.2 Psychological

The following section will discuss the psychological impacts of cancer and PA in relation to previous literature, with supporting interview quotes for each third-level subtheme included in-text or Tables.

As mentioned briefly with the COVID-19 theme participants reported that their cancer diagnosis and subsequent treatment negatively impacts on mood. Studies into the psychological impact of cancer with TYA and AYA populations have found a large psychological burden associated with diagnosis and treatment with many patients and survivors experiencing depression, anxiety, PTSD and impaired cognitive function (Wu et al. 2015; Shaw et al. 2022; Psihogios et al. 2020; Zebracks et al. 2014; Nass et al. 2015). In terms of PA, low mood was then reported to adversely affects PA behaviours as it decreased motivation to be active. Interviews supported findings of the scoping review which found mood (including anger, embarrassment, depression and frustration) to be reported as a PA barrier within TYA cancer cohorts (Shaw et al. 2022; Wu et al. 2015; Psihogios et al. 2020).

[PA barrier] *"when...my moods really low because I just feel frustrated and I just can't seem to get myself out of that mood to get motivated"* [to be active] (1)

"I can still have periods of feeling quite down and that can stop me being active cause my motivation just goes" (9)

Although low mood was reported to be a barrier to PA engagement, participants reported psychological benefits to engaging in PA. Many participants reported it improved their mood and that they felt better for having been active. Participants attributed this to different reasons including post exercise endorphins, being active again after not being able due to treatment and increased self-esteem as a result of functional progress. Participants also reported engagement with PA provided a sense of achievement and boosted their confidence. Engagement with PA was also reported to generally have a positive impact on participants' lives as a whole and motivated them to engage with healthy lifestyle behaviours. Table 47.0 contains supporting quotes which illustrate the psychological impact of PA engagement.

Within cancer research there have been significant positive benefits associated with PA engagement. Benefits have included reduced symptoms of anxiety (Mishra et al. 2012a; Mishra et al. 2012b; Lahart et al. 2018; Campbell et al. 2019) and depression (Brown et al. 2012; Craft et al. 2012; Campbell et al. 2019) as well as improve HRQOL (Lahart et al. 2018, Buffart et al. 2017, Sweegers et al. 2018). The scoping review illustrated that meeting PA guidelines was associated with higher quality of life (QoL) in TYACS (Murnane et al. 2015) and a number of intervention studies found engagement with various types of PA significantly improved TYA cancer patients and survivors QoL (Munsie 2021a; Marec-Berard et al. 2021; Smith et al. 2019; Atkinson and Osborn 2012; Munsie, Collins and Plaster 2019; Yurkiewicz et al. 2018; Spreafico et al. 2021).

Table 47.0 Psychological impact of PA engagement seen through interview quotes.

Psychological Impact	Quote
Increased mood	<p><i>"I think for mood it can be really useful. Just to kind move my body more, it feels good...particularly for me right now, because I couldn't really do much for so long (9)</i></p> <p><i>"I like the endorphins I get after; I always feel great after working out (2).</i></p> <p><i>get your strength back and like your muscle back and everything, just really helps your self-esteem when you've been through a lot (11)</i></p> <p><i>think if you can be physically active then. It helps promote, like natural hormones, endorphins and stuff. So, it's basically just like your own, your free therapy (13)</i></p>
Sense of achievement	<p><i>[being active following treatment] it was a complete confidence booster. It just made me feel hopeful. A surgery and chemotherapy that's like a big blow on your health so it was a good feeling (10)</i></p> <p><i>On days where I don't do anything, because maybe I'm in a little bit of pain, I get really frustrated and quite bored and I don't sleep at night, usually I'm quite restless. But yeah, on days where I go for a jog, or cycle or take the dog out for a long walk I always get a better night's sleep and I feel a sense of accomplishment and stuff (10)</i></p> <p><i>it's like a sense of achievement after you finish a workout. Like... I struggled quite a lot with my mental health post treatment. But I do find if I do a workout, it makes me feel better. And like, I guess less depressed or less anxious, and less stressed maybe (11)</i></p>
Positive impact on life as whole	<p><i>"for me when I exercise as well, I feel like everything else kinda flows better in my life. I know that's a weird thing to say but when I'm working out and exercising, healthy eating kind of comes along with that, and then I seem to do better in work and have more motivation other places as well" (2)</i></p>

Psychological Impact	Quote
	<p><i>I just find like the physical health benefits and mental health benefits have a real positive impact on my overall life (8)</i></p> <p><i>"I just, I feel like exercising is what helps me mentally and to try and keep myself out of my bed because if I wasn't out walks or going to the gym or doing something active, I would just lie in my bed and sleep" (1)</i></p>
Obligation to be active	<p><i>because it's so fresh in my memory about how difficult it is and what it's like when you can't use your body, it feels like quite a privilege to be able to move. Which is both good and bad. I can feel like that thing where you're like, "oh, I should be really grateful, I should be moving every day because I can and because some people can't", but also, that's a lot of pressure to put on yourself. But some days I do feel like "oh, I should really run a marathon" because I've you know, got my legs back (9)</i></p> <p><i>you feel that obligation. I think that's that kind of survivor's guilt thing as well. You're like, well, I survived my cancer and I can move again, so therefore I should (9).</i></p>

However, one participant noted that although being active felt good there was also a sense of pressure and obligation to be active which they related to survivors' guilt. Survivors' guilt is an established concept within cancer care with many individuals feeling mixed emotions of happiness, anxiety and guilt during recovery and transition to survivorship (Perez and Greenzang 2019; Lui et al. 2016).

Not only was PA reported to improve mood it was also reported to be a way for TYA's to cope with their cancer diagnosis.

"yeah, it seems to be my coping mechanism when I am feeling down is a walk or exercise" (1)

"for your wellbeing and stuff and helping you to cope with cancer as well, It's quite a good thing" (6)

Participants reported various reasons that PA helped them cope with their diagnosis and treatment including: PA providing a distraction from their situation; engaging in PA provides an element of control during a period of their life which was mostly out with their control and dictated by their cancer; engaging in PA during treatment and in recovery provides a sense of normalcy. Physical activity providing a distraction from cancer was reported in another TYA study as a motivation behind PA engagement (Spreafico et al. 2021) as was perceived control over health (Wu et al. 2015). Table 48.0 illustrates the impact of PA on coping with quotes to support distraction, control and normalcy. As can be seen the use of PA as a distraction from cancer, taking control back over their health and providing a sense of normality during an uncertain time may all be PA motivators within the TYA cancer population.

Table 48.0 The impact of physical activity on coping

Reason	Quote
Distraction	<p><i>"it gave me that sort of period where I wasn't focusing on the diagnosis or the cancer or the treatment. It was sort of that half an hour to an hour where I was just focusing on what I was doing at that time" (8)</i></p> <p><i>"if I was sitting in the house, I would have been in a much worse mental state than I was. So, probably from that aspect and also from the, take you away from the scenario you can forget about it for about half an hour an hour" (3)</i></p> <p><i>Keeping yourself disciplined, keeping yourself busy and distracted from what's going on. Yeah, it's really important (10)</i></p> <p><i>"I think it just takes your mind off of everything else. just being able to get out the house and like, clear my mind, get away from everyone and anything, it just helped me massively" (13)</i></p>
Element of control	<p><i>"I think it give something to focus on, something that you can do something about as opposed to another medical situation that's going on that you can't do anything to change" (7)</i></p> <p><i>"I was also really scared of what was going to happen to my body and I think I wanted to feel like I could do something positive to kind of help it when so much kind of horrible poison and stuff would be going through it (9) I was like "okay how can I take control of this process in any way and for me physical activity was up there". (9)</i></p> <p><i>"Like you're basically losing control of your health through cancer, but it kind of gives you a bit of self-empowerment, like you're trying to regain that control" (13)</i></p> <p><i>"it's just a good way to look after yourself. I think discipline is important to me. It's helped through my treatment doing basic stuff like taking the dog round the block" (10)</i></p>
Sense of normalcy	<p><i>"there was also that normality for me to get back that control" (7)</i></p> <p><i>"it was like I felt more in common with my peers, because I was able to do what they were doing, because I was hearing like, other people talking about going to the gym and do workouts, and it's like, oh, like, I want to do that. So, once I could, it was like, I didn't feel like the cancer girl anymore. It's like you're suddenly part of things a bit more" (11)</i></p> <p><i>"just sort of feel better about yourself again...some people they could be absolute knocked over for a while, so it's giving that metal benefit of knowing they are able to do things again and live that normal life like everybody else" (14)</i></p>

The last psychological impact identified within the interviews was the impact of cancer on body image and the effect of this on PA behaviour. Body image was reported by participants to play an influential role over PA considerations and behaviours. Changes in appearance were reported as both barriers and facilitators to PA engagement in this cohort.

"It sounds very vain but physical appearance. I just wanted to gain muscle back and I wanted to feel fitter because I hated getting so breathless when I was with friends and we were walking the same distance and stuff, so that kind of spurred me on" (11)

One of the main motivating factors of PA was weight change because of treatment, table 49.0 highlights this through quotes. Participants reported that this influenced their decision to become more active post-treatment in order to return to their pre-cancer body composition. BMI has been found previously to have a significant positive relationship with interest in weight loss programs ($p=0.001$) in AYACS aged 18-40 (Rabin and Politi 2010), suggesting body image may be a driver to behaviour change in this population.

Table 49.0 Weight change as a motivator for physical activity

Weight change as a motivator
<i>"I am not the happiest with my weight at the moment as well so that's been driving me to do it" (1)</i>
<i>"I'm used to being fit and healthy so if I see, it's probably not the right motivator, but if I see I'm gaining weight I'm like right I need to start walking more". (2)</i>
<i>"I basically started to notice my weight going up, because I think I'd lost a lot of like my muscle mass and stuff when I was ill because you're in there most of the time. So, I found managing my weight quite difficult afterwards, so that was panicking, me. And like, sort of motivating me to try exercise more and more" (11)</i>
<i>"I really didn't like the weight loss and the way how I looked, or anything like that. So, I think possibly building the muscles back did positively impact mental health" (7)</i>
<i>"I would sometimes look through photos on my phone, my videos, and I would see like old photos of me and like how I looked. Erm it would kind of give me a bit of motivation and it would kind of make me feel good because I was at a certain level of fitness....so then I would try and just like go out and do something" (13)</i>

Another factor surrounding body image and PA reported by participants was that once they began being active and started to see physical changes, such as weight loss or muscle gain, this motivated them further to continue and reach new activity goals.

"when I started to see like the physical effects, like starting to see more muscle tone and stuff like that. As soon that started happening, I was like, I want to keep this up. And that kind of spurs me on. I'm like, I want to maintain this, not start losing it. So, I always, I just always want to get in, in the day" (11).

"I think being able to see the progress of being there as well. I was quite slim built before and from going to the gym I managed to, generally my shape bulked up quite a bit, so just being able to see that progress" (14)

Conversely, as seen in table 50.0, changes in appearance such as; hair loss, skin redness and body composition changes (weight gain, weight loss, loss of muscle) were reported as PA barriers. Participants reported that they did not want to be physically active around others as they were self-conscious about the way they looked. This included being active in group settings (charity rehab classes), leisure facilities or outdoors in the community where they might encounter people they know. Being self-conscious in public spaces, including gyms, due to body image has been reported in other studies to negatively impact behaviour (Pugh et al. 2018; Wu et al. 2019). One method of overcoming this barrier reported by participants in this study was to be active alone in their own homes. This study's findings add strength to the literature regarding body image as an PA barrier within the TYA oncology population as well as introduces the idea that body image can also conversely be a facilitator to PA engagement within this population.

Table 50.0 Body image as a barrier to physical activity

Body image as a barrier
<i>"feeling self-conscious to go out and wear my gym stuff to be able to lose the weight"</i> (1)
<i>"There was a few times where I didn't want to go for a walk, because I didn't want people looking at me, because I was getting self-conscious. It's a small town so, everyone knows everyone. And I didn't want it to be like, "oh, there's *name*, cancer boy" (13)</i>
<i>"I think it was more you just want to feel good in yourself. Especially as a young person when people are getting all dressed up to go out and like, kind of, in the prime of their like physical-ness...it can be quite difficult. You kind of want to just look really good. I know it sounds dumb, but you can't do your hair and I didn't have eyelashes or eyebrows for a while, so the best way I could think to kind of feel good about myself in those situations is to try and like exercise and look good" (9)</i>
<i>I'd say like the embarrassment when you're not that like fit or not that confident in your appearance that definitely was factor (11)</i>

6.3.4 Social Support theme

Social support has been theorised to impact health by directly (e.g., tangible assistance or advice) or indirectly (mediating other variable such as self-efficacy) facilitating the adoption of health promoting behaviours (e.g., physical activity) (Scarapicchia et al. 2017). Therefore, social support is classified as a behaviour change technique (BCT) (Michie et al. 2013). With regards to social support and the TTM, social support is proposed to facilitate adherence and maintenance of regular PA i.e., the action and maintenance stages of change (Scarapicchia et al. 2017).

There is a vast body of literature indicating a positive relationship between social support and PA adherence and attendance within the exercise setting (Golaszewski and Bartholomew 2019). It has also been demonstrated within healthy adolescents (aged 10-19 48% 15-19 3%) (Mendonca et al. 2014) as well as AYA (mean age=28.8) (Brunet et al. 2014) and TYA oncology populations (Rosipal et al. 2013; Kuntz et al. 2019; Pugh 2018; Wu et al. 2015; Rosipal et al. 2013) to positively influence PA.

A recent systematic review on PA behaviour change within oncology populations reported social support to be frequently used in PA interventions in people living

with and after cancer (Sailsbury et al. 2023). However, the type of social support used within oncology interventions is rarely specified. The review found BCT's are often used in conjunction with one another so it was hard to determine the efficacy of individual techniques (Sailsbury et al. 2023). Despite this the review concluded interventions which included goal setting, social support and action planning led to long-term PA maintenance in oncology populations and recommended clinicians to consider these in their clinical practice (Sailsbury et al. 2023).

Although the research into the different functions of social support within an oncology population is limited, AYASCC have been found to have high emotional and financial dependence on their parents (Smits-Seemann et al. 2017). One study adopted a dyadic approach to explore parental support for PA in adolescent survivors of childhood cancer (mean age at time of study 17.4 years +/-3.2, 70% male, completed treatment <5 years prior) (Price et al. 2021). As with this study the researchers explored support in relation to the constructs informational, instrumental, emotional and companionship (Price et al. 2021). Parents were found to provide instrumental support (such as financing activities and transportation), informational support (such as PA instruction) and emotional support (encouragement) however these were not viewed as particularly influential over PA behaviour (Price et al. 2021). AYA's emphasised the importance of receiving companionship support from their parents for PA however, parents were not aware of this and felt their role was to provide instrumental, informational and emotional PA (Price et al. 2021). This illustrates that not only is it important to receive different types of social support but that the provider of that social support may be important.

This section will review the PA social support TYA's received during and after treatment, the support they perceived was available to them as well as the identified unmet PA social support needs of TYAs under four different social support constructs, seen in figure 33.0. As previously stated, validation support is the fifth construct of social support, but it was not identified as a subtheme from the interviews. However, it will be briefly discussed in relation to social media use. Figure 33.0 illustrates the four social support subthemes identified from the interviews. These constructs have been defined in relation to PA in Table 38.0 section 6.3.1.

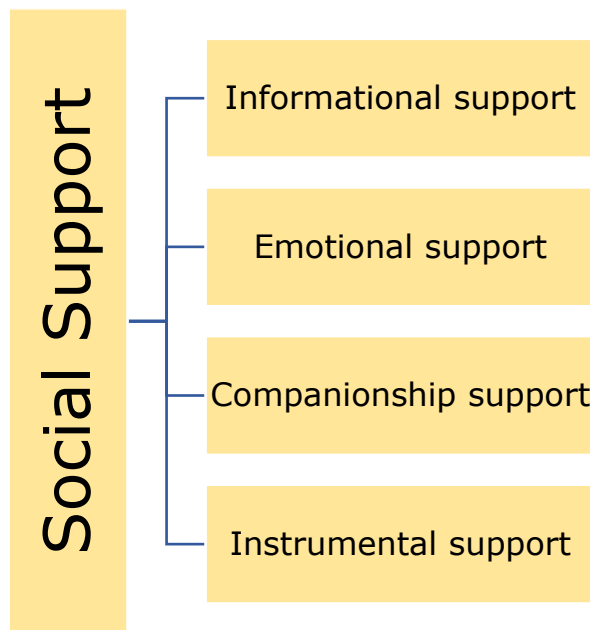


Figure 33.0 Social Support construct subthemes.

6.3.4.1 Informational support

Informational support was the most reported type of social support that TYA's received from healthcare professionals. Participants reported that they received general PA advice from medical staff (doctors and nurses) to try and remain active during treatment. Participants reported this informational support was provided in a variety of forms including conversations with healthcare professionals, post-surgical leaflets or signposting to online resources or charity run PA groups. Advice relating to post-surgical PA restrictions was the most reported type of informational support participants received.

"mainly from like the nurses... a lot of like simple helps and simple things that we could do that a lot of people that they'd spoke to when they're doing treatment had helped them. So, it was more kind of like, small wee exercises and wee hints and tips (3) [clarification on advice given] It was just kind of more lighter exercises like short walks.. Just to kind of keep you going. Err obviously nothing too strenuous. Look they weren't saying like go to the gym or stuff like that (3)

"they just said not to worry and it's really common and even though it's frustrating because of how I was before not to be too hard on yourself and listen to your body". It was to be expected that I wasn't gonna be nearly as fit or healthy as I was before". (10)

Participants felt that this generalised information was insufficient at meeting their needs as they expressed a lack of knowledge around PA and cancer, reporting that they did not know what they were able to do, or when they could do it. Some participants also reported safety concerns regarding being physically active while undergoing treatment and the effects that this may have on the efficacy of their treatment. This highlights a need for education surrounding the benefits and safety of PA for cancer patients as well as personalised, tailored advice with exercise examples and advice about appropriate PA intensity and duration. Supporting quotes which illustrate TYA cancer patients and survivors need for education regarding PA and cancer can be found below in table 51.0.

Table 51.0 Quotes illustrating TYA cancer patients and survivors need for education regarding PA and cancer.

Informational	Quote
Lack of knowledge	<p><i>"I just don't know what to do. Like if I was to go to the gym, I would not have a clue what to do because I've never been in the gym before" (12)</i></p> <p><i>"I don't know what to do. And I haven't tried to do anything about exercise, I feel maybe with my back pain, I don't know, maybe I will get worse. I will maybe get my back injured" (5)</i></p>
Safety concerns during treatment	<p><i>"it is scary to be active when you don't want to do more harm than good (9) I was afraid...the more I walked or whatever that I was pushing it too much (9)</i></p> <p><i>"there was a little bit of like I didn't want to cause any harm. So, I wanted to stay just keeping within like what I knew I definitely could do rather than pushing myself" [clarification of harm] worry about stuff [physical activity] affecting treatment in the wrong way or causing the drugs not to work or anything like that. It might sound silly but anything having a negative effect rather than a positive, I just didn't want to muck up" (6).</i></p>
Lack of Guidance	<p><i>"I was given the exercises to do like, sort of physio exercises to do to help improve the mobility and stuff like that after surgery. But there wasn't sort of beyond those sort of really basic physio exercises. There wasn't much guidance" (8)</i></p> <p><i>"Only like when I had surgery and the rules and stuff, just warning me how long it should take get to recover. But I don't think anyone's spoke to me about anything else" (2)</i></p> <p><i>"I was advised to stay sort of active and keep doing stuff, while as doing radiotherapy. But again, I was given very little guidance about like, what that really meant" (8)</i></p>

When asked what informational support would be beneficial for them participants reported that a conversation with someone regarding PA and cancer where they could ask questions and get tailored, personalised advice would be helpful. End-of-treatment TYA clinics which assess physical and psychological needs following treatment and provide advice, exercises and signposting to services to meet these needs has been found to be feasible and beneficial for TYACS in England (Baker et al. 2021; Mackland and Chesman 2019).

"I think it would have been beneficial, like, if I actually had like a personal trainer, or a health fitness advocate from the NHS, come and speak to me, like, tell me about maybe, like certain programs or regimes or like, what I might experience if I do exercise, what I might not experience. I think that would have just been like, a lot more reassuring and beneficial to me, instead of having to kind of do all the digging by myself. I think it would have just been a lot less stress and worry" (13)

As with previous research, participants showed a clear need for PA advice (Zebrack 2008; Belanger et al. 2012; Murnane et al. 2015; Pugh et al. 2017a; Mooney et al. 2017; Pugh et al. 2018). TYA's expressed a lack of knowledge about PA and cancer and safety concerns regarding exercise during treatment. This has been reported in previous literature as motivators for AYA's participating in PA interventions (Below et al. 2021). Furthermore, participants highlighted a potential need to provide informational support to their friends and family to foster PA encouragement as participants felt they were hesitant to encourage higher intensity activity due to safety concerns.

The most frequent type of SS TYA's received during their cancer journey was informational support in the form of general advice to keep active. This corroborates with previous research which found TYA cancer patients received general advice to maintain a healthy lifestyle as well as to remain active during and after their treatment to help with recovery and to manage cancer-related fatigue (Pugh et al. 2017a). In line with previous research, TYA's felt that this general advice was insufficient at meeting their needs (Pugh et al. 2018).

Information was predominantly provided to participants by medical staff (doctors and nurses), which supports existing literature suggesting physicians, nurses (Murnane et al. 2015; Pugh et al. 2017a; Pugh et al. 2017b) and family members (Murnane et al. 2015) all provide TYA's with PA information. As with the 2018 study by Pugh et al. where TYA's felt HCPs were not forthcoming with lifestyle

information, participants in this study felt they only received PA informational or instrumental support if they initiated the discussion or searched for it themselves.

"I very much felt that I led a lot of aspects of my support, including the physical, I was very proactive. My approach when I was first diagnosed was right, I'm going to go down every avenue of help I can, to find the ones that will suit me. But it did frustrate me that I had to seek out a lot of help" (9).

Research into UK HCP's perspectives of providing PA advice found discrepancies between HCP's reported knowledge of PA guidelines and provision of PA advice to TYA's; AHP's were found to have the highest self-reported knowledge of PA guidelines yet they were they least likely to enquire about PA behaviours or provide TYA's with PA advice (Pugh et al. 2017b). Furthermore, research suggests HCP's biggest barrier to advice provision was "not being the right person" (Pugh et al. 2017b) this suggests HCP's lack the knowledge and confidence to provide TYA's with PA advice. A recent study into TYA HCP's lifestyle advice provision concluded confidence to provide lifestyle advice could be improved by CPD on health promotion; improved access to TYA specific resources and referral pathways and cross MDT support (Pugh et al. 2022).

6.3.4.2 Emotional Support

Family, friends and partners provided the largest source of emotional support to participants regarding PA, by encouraging them to be active. Some friends, family members or partners were unaware of how much PA TYA's could participate in, so they were cautious of encouraging them to do too much. This caution has the potential to impact the emotional support TYA's received to be active and therefore, suggests that there may be a need to not only provide advice and education to TYA's but also their support networks.

Not all experiences of emotional support were positive however, one participant recounted a time where he was receiving encouragement to be active from nurses on an adult surgical ward but instead of being encouraging, he felt frustrated and demotivated as he felt like they did not understand his situation. Table 52.0 provides interview quotes to illustrate the different types of emotional support participants received.

Table 52.0 Quotes demonstrating PA emotional support received by TYA cancer patients and survivors from their social network.

Emotional Support	Quote
Encouragement	<p><i>"my boyfriend, he's quite active as well. And all my friends are very active so I do kind of have them as well. They'll text me and will ask if I want to go walks or anything like that. And my boyfriend's always asking if I want to go walks and stuff" (2).</i></p> <p><i>"during treatment. Yeah they were like 'We should go for a walk, and we should do this and that' again if I felt like it, but just trying to go for a short one even on the days I didn't feel like it and they kind of encouraged that" (6).</i></p>
Cautious	<p><i>"it's difficult because they don't know how to manage it as well. So, I think everyone, you know, everyone's a bit cautious, including you really, as a patient" (8)</i></p> <p><i>"I remember doing a lot of walking and stuff. I think people were not keen to meet me to do a lot more than that. I think they were just concerned about what implications could be things like that" (8)</i></p>
Demotivational	<p><i>"It was actually pretty frustrating. In Glasgow anyway they have these signs on all of the walls, all over the place....it was pretty much encouraging you to get up and get dressed and do things. And it's like...that's fair enough but with how I was I literally couldn't...But yeah, some of the nurses didn't really understand that. They just follow that, its hospital policy they just encourage everyone to get up as fast as possible so you can go back home...some of the nurses just sort of looked at me thought you know you're a healthy young lad, you should be able to do this, to get up and go for a walk and stuff...I ended up being really hard on myself because I was thinking; these nurses are saying I should be able to get up by myself and go for a walk and stuff and I can't" (10)</i></p>

As outlined in the psychological impacts section 6.3.3.2 cancer is a stressful time for young adults, participation in a general cancer support group has been shown to moderate the association between stress and physical activity behaviour in AYAs (mean age=28.8) (Brunet et al. 2014). This illustrates that emotional support is important for promotion of PA behaviours in young adults with cancer.

6.3.4.3 Companionship Support

This was found to be linked to emotional support with family, friends and partners again being the primary providers. As seen in table 39.0, section 6.3.1 within a PA context this often relates to engaging in activities with the individual (Wilson 2021). Participants reported that co-participation facilitates PA behaviour as it provides motivation and adds a social element to exercise. Participants also reported that making plans to be active with someone held them accountable and helped them push themselves. Table 53.0 provides supporting quotes for co-participation as a facilitator of PA behaviour in TYA cancer patients and survivors.

Table 53.0 Co-participation as facilitator of physical activity behaviour.

Companionship Support	Quote
Motivation	<i>"If I was home doing it with my mum would, it's kinda like you're motivating each other so I found that quite helpful."</i> (11)
Social Element	<i>"Just having good friends around. I feel like you need that accountability partner. You need someone to just push you on, out your comfort zone Yeah, it just helps having other people there who are like minded and looking out for you"</i> (13)
Accountability	<i>"because it's arranged or like, the social side of it will help, like with seeing friends and things like that. I guess as well not wanting to feel like you're letting people down by bailing last minute" (8)</i>
Push themselves	<i>"if you've got someone to push you a wee bit that's when I will go and do it" (2)</i>

A small number of participants also reported a change in PA support from friends, family or partners pre- and post-diagnosis. Where PA encouragement and co-participation invitations were offered more post-diagnosis than they had been pre-diagnosis from family or partners.

"it probably got a lot more frequent when I did get my diagnosis" (3)

Or there was a change in dynamic from participants being the one to provide PA encouragement to friends' pre-diagnosis to friends providing them with encouragement post-diagnosis.

"I was always the one that kinda encouraged others I would always be like, let's go to the gym, or let's go a run. So, I think, they've just switched the roles a bit and just turned it round so now it's them kind of texting me asking if I want to meet up" (2)

A systematic review into social support in healthy adolescents (80% of included studies medium-high quality on assessment) found positive associations between social support from parents, friends and family for physical activity (Mendonca et al. 2014). Family was found to most frequently provide encouragement and transportation support whereas, friends were more likely to provide encouragement and co-participation (Mendonca et al. 2014), The review also found those who received support from both parents, friends and family participated in higher PA levels (Mendonca et al. 2014).

On the other hand, although all the participants reported they had a support network around them some participants found that their friends did not fully understand what they were going through during treatment and into survivorship. Another component of companionship support is a sense of community or belonging experienced when individuals perceive they are part of a group (Wilson 2021). This lack of understanding about their cancer created a sense of isolation from their peers. Some participants also reported that they had less opportunity to receive support from their peers during treatment because of moving back in with their parents following their diagnosis. Table 54.0 outlines the complexities of peer companionship support through quotes.

Table 54.0 Complexities of peer-support

Complexities of peer support	Quotes
Friends did not fully understand	<p><i>"A lot them didn't understand. A lot of friends that I thought would, didn't...Some of them just stopped talking to me, because it was too awkward to speak to me and they didn't know what to speak about. I did lose some friends, they weren't as supportive as I thought they would have been" (10)</i></p> <p><i>"it's something [cancer] that is way more common in older folk and I think because of that it can be difficult. Most of my peers thankfully, haven't been through anything like this, whereas, maybe for older people like I don't know, you kind of have been through more life experiences and things. So, it can feel very isolating cause all of a sudden, you've kind of got this massive thing going on and none of your friends can relate to it. Like they kind of can to different aspects, but not really" (9)</i></p> <p><i>"I don't know if they really got it no" (11).</i></p>
Reduced opportunity for peer support	<p><i>"when I was finished treatment, I still lived with my parents for probably another year, so I didn't have many, my friends mostly stayed in like the cities and things. So again, you weren't meeting people to do like an activity or sport or anything like that" (6)</i></p>
Did not connect with older adult patients	<p><i>"I just brought the average age in the waiting room down by about 30 years, every time was in the hospital" (8).</i></p> <p><i>"on the chemo ward I was on the average age was probably like...it felt like it was 70 when I looked around so even though I might have been just out with that age bracket it felt like I had more in common with people in that age bracket" (9).</i></p> <p><i>"I was treated in the adult bit even though I was 17. So, you're surrounded by like, grannies, and grandads, because they're the ones who get cancer more so you end up feeling, like, a lot more like an outsider" (11)</i></p> <p><i>"I think it's just that you're at different stage of life" (9)</i></p>

Complexities of peer support	Quotes
Wanted to be treated with adults	<i>"So, I was part of the Teenage Cancer Trust kind of section. I had a Teenage Cancer Trust nurse specialist but because I was 23, I was still put in with all the adults and stuff. Which I felt was good, because I felt like an adult, obviously, I was 23 I didn't feel like I should have been treated differently" (13).</i>

As seen in table 54.0 some TYA's who were treated within adult wards or services felt that they did not connect with other cancer patients. Although they were peers in the sense, they also had cancer many TYAs felt that as they were much younger than them and at a different stage of life, they did not have a shared identity. This again, led to a sense of isolation and need for peer support from other young people. However, not all TYA's felt they should be treated separately from adults as they classed themselves as an adult.

A need for peer support from members of the TYA cancer community has been shown in past research into healthy lifestyle behaviours (Pugh et al. 2018). Young people were found to want support from other young people of a similar age and position to them. Many looked to identify with other TYA cancer survivors and described wanting to know more about their lifestyles and what was "normal" for them (Pugh et al. 2018). This suggests young people may not only want companionship support from other TYAs but may also be looking for validation support through social comparison (Golaszewski and Bartholomew 2019).

6.3.4.4 Instrumental Support

Participants expressed a need for more tangible support with many reporting that they did not receive this throughout their cancer journey.

"I had no physio whatsoever and I think it would have been really useful". (8)

[on accessing a charity exercise class] "They didn't say much about it. It was us, going to see it and thinking that would be good" (6).

Participants expressed that it's important to receive both informational and instrumental support as informational support alone may feel like all onus has been given to them to be responsible for their future health.

[on starting a new drug] "I was speaking to my nurse because I'm quite stressed about it and she said, "Oh well, this it'll actually only add like one or two percent benefit, the exercise you're doing like bone strengthening exercises that will have more benefit, which is obviously good to know and really good that she's telling me that, but for me I was really struggling after treatment with motivation and it felt like, oh, that's something that's been put on me and then I felt terrible, like I was going to up my chances of getting cancer again because I wasn't regularly doing bone strengthening exercises. So, I think it's a tough balance of saying to someone that this will really help you, but also recognizing they're in this

vulnerable period, where a lot of cancer patients struggle with anxiety and depression... I think it is good to suggest it but also providing like a means of doing it" (9)

Those who did receive instrumental support reported this positively impacted their PA behaviours and helped with their recovery. Table 55.0 illustrates participant quotes about the instrumental support they received. They reported receiving support from charity run exercise classes for adults with cancer (such as Macmillian and Maggie's classes) some of these were in-person and some were virtual due to the COVID-19 pandemic; one participant received a bicycle from a local charity; one was provided with Fitbit as part of a research study investigating daily step targets; or physiotherapy input (in-person and via telephone) which consisted of both instrumental support in the form of exercise programs and equipment provision and informational support in the form of PA advice and signposting to online resources. As can be seen from the list above cancer charities and physiotherapists were the predominant providers of instrumental support to TYAs.

Table 55.0 Instrumental support received during treatment and recovery.

Instrumental Support	Quote
Physiotherapy	<p><i>"she saw me at the *TYA unit* and gave me a couple days to settle on the ward and then she came to see me... I think she came in the first time...just with general exercises, and I think she kind of phoned throughout to see if I was ok". (7) [physiotherapy advice]" about being as active as I was able to basically but not tire yourself out, like she gave me a lot of specific erm exercises to target specific muscle groups I needed to build up again. She gave me lots of like online resources as well to go and have a look at, like I've done quite a bit of yoga (7)</i></p>
Online exercise (due to COVID-19)	<p><i>"I took part in some fitness classes online but to be honest I started when I was able to do a wee bit more, so I felt it was a wee bit too easy but understand that there were people there that it wasn't...as easy for" (7)</i></p> <p><i>"move more had a circuits class, once a week where it was just kind of online. It would be different things I guess like marching on the spot. It was designed for people with cancer so it wasn't too strenuous and you just did it in your house. But it was like a good level for pushing me without it being too much" (9)</i></p> <p><i>"my TCT nurse *name*, he referred me to this kind of online fitness class that's cancer related. So, its people that have recently or are going through cancer but want to stay fit... it was just basic stuff, just you know, 10 push-ups, 25 sit-ups, pretty beginner stuff. That seemed to help, it was a good way to gauge where I was physically... But that was the only piece of help I got" (10)</i></p>
In-person charity exercise classes	<p><i>"After I finished my treatment, I did a like a block of kind of getting back into physical activity with Maggie Centre and there was, uh a physio. I don't know if she was a physio or a personal trainer or a mix and I was the only young person there...it was all older people, but even then it was good to just do things, she was just showing you what you could do at home to kind of build up your strength and things. It was a bit like mini circuits, and I think that was great for me post" (6).</i></p>
Equipment provision from a local charity	<p><i>"a charity actually gifted me a bike whilst I was on treatment, so I sort of felt like I need to give this a go and it was like good for a bit but cycling is just never been something I've got like super into" (11)</i></p>

Instrumental Support	Quote
FitBit PA study	<i>"you got a basic Fitbit to record your steps. So that was straight after treatment, or just at the end, and that was really good because I had, I can't remember the exact number of steps, but you were to aim for this many and it was a really good motivating kind of thing to do and build strength back up" (6)</i>

Participants also discussed a number of instrumental support options that they were aware of but did not access. One participant was aware of a PA challenge run by a cancer charity through social media however they did not participate in this as they kept forgetting about it.

"it's a young cancer team. So, it's like Scotland vs Ireland vs England, so they are trying to get how many steps or wherever, if you do a yoga then that will go towards your team and stuff. I've not managed to do anything for it yet. Just because I do an exercise, I forget to tag them" (2)

Another two participants were aware of a walking group run through the TYA unit at their treatment facility but they did not utilise this as they felt the commute to the hospital from their house was too long and they didn't have the time.

"trying to find the time to be able to dedicate to go to Glasgow for an event or something. It was difficult to find the time for it. If I'd lived in Glasgow, I would have been able to find that time a lot easier, because it would have been just...a quick bus trip or something. While here it was a 45-minute drive" (3)

Some also reported that they were regularly invited to the TYA unit for events, but they did not participate in them as they again felt that they lived too far away and did not wish to travel or they felt that they were too old for them as they were TCT events. One participant with dependents also reported that he felt he was at a different stage of life from other young people who would be attending these. None of the participants reported these events were physical activity related.

"sometimes I feel like I'm a bit old for some of them, because obviously its younger people and I'm thinking "God I'm 25" (2).

[TCT] "They were quite active and always trying to implement things and inviting us to stuff. But I didn't really go to any of it again, purely for the fact of two kids and a job. Although, the majority of these things are, its more targeted to younger teenagers" (3)

Supporting the Scottish Government Strategy 2021-2026 ambitions three and five, which outline the need for more support incorporated into cancer services and aftercare (Scottish Government 2021) the interviews revealed that as with informational support many TYA's have an unmet need for or wanted more PA instrumental support.

Those that did engage with charity exercise classes and physiotherapy services reported mostly positive experiences with these. The individual components of each reported exercise class were not explored extensively within this study however, participants reported these followed a circuit format, with an instructor present and that these were for adult cancer patients and survivors meaning they were the youngest participants in attendance.

Previous research into PA interventions have demonstrated them to positively impact TYA cancer patients and survivors PA behaviours, physical function, QoL and fatigue (Atkinson et al. 2021; Munsie 2021a; Munsie 2021b; Atkinson and Osborn 2012; Munsie, Collin and Plaster 2019; Spreafico et al. 2021; Smith 2019; Munsie 2021c). The majority of these studies have investigated individualised 1-2-1 PA as there is a lack of research into group exercise for TYA cancer patients. However, a 12-week individualised supervised group exercise program for TYAs (aged 15-25) found significant improvements in strength, physical function, subjectively reported fatigue, pain and QoL, with qualitative feedback from program participants reporting extensive positive benefits of engagement (Munsie, Collins and Plaster 2019). Participation in group-based exercise has also positively impacted psychosocial functioning (Burke et al. 2017) and PA maintenance (Leach, Potter and Hidde 2019) within adult cancer patients and survivors.

TYA cancer only makes up a small percentage of global cancer cases, in the UK TYA cancer accounts for approximately 1% of yearly cases (Smith et al. 2016). As a result of this TYA patients are often spread geographically, making it difficult to run TYA specific group classes. Participants main reason for not engaging with a TYA walking group available at through their local TYA unit was that they lived too far and did not have the time to attend, both of which have been reported previously to be TYA PA barriers (Psihogios et al. 2020; Pugh et al. 2018; Spreafico et al. 2021; Salchow 2021). Additionally, some participants felt too old to attend TCT events which highlights young adults may be deterred from attending events based on their age.

6.3.4.5 Social Support Summary

As above, participants demonstrated a need for more personalised informational support tailored to their situation as opposed to generalised statements. Friends, family and partners provided TYA's with emotional support in the form of encouragement and companionship support through co-participation in activities however, there may be a need to provide informational support to TYA cancer

patients and survivors social networks in order to further increase their PA encouragement. The main form of instrumental support participants received were physiotherapy input or through participation in charity run PA classes. Those who received this instrumental support felt it was beneficial however, there was a want across participants for more instrumental support from HCP's. TYA cancer patients and survivors may also have a need for peer support as some reported that their healthy peers did not understand their situation and they did not connect with adult cancer patients as many of them are at a different stage of life. TYA appeared to be seeking peer support when describing PA needs.

6.3.5 TYA PA Opinions and Preferences

This theme is comprised of five subthemes outlined in figure 34.0 below. PA perceptions encompasses TYA patients and cancer survivors' perceptions of what PA is and their opinions of PA in relation to TYA cancer. Subthemes two and three (informational support and instrumental support) relates to TYA's with cancer and TYACS opinions and preferences regarding components of informational and instrumental PA interventions. The final subtheme includes TYA preferences regarding the timing of PA support within their cancer journey.

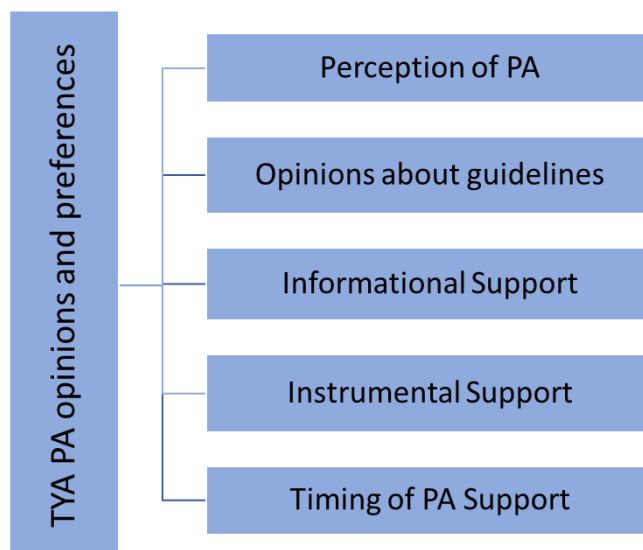


Figure 34.0 TYA PA opinions and preferences theme.

6.3.5.1 Perception of PA

When defining PA and what it meant to them participants predominantly described their everyday movements and generally keeping active. They provided examples of activities which mainly fell into the leisure-domain of PA, most commonly walking, sports and going to the gym. Some participants described PA as exercise and keeping fit and a small number of participants described their work and childcare as PA. Some participants also noted their description of PA has changed with the decreasing intensity of what they class as PA, see table 56.0.

Table 56.0 TYA cancer patients and survivors PA perceptions.

Defining PA and what it means	Quotes
Generally keeping active	<p><i>"to me, it doesn't really mean going to the gym three times a week and absolutely burning myself out. I think physical activity is just like taking my dog for a walk, going outside for a walk. I'm not really into like into really heavy physical activity. I'm quite a lazy person anyway but just going outside and generally being outdoors makes me quite happy. So, it doesn't really have to be anything mental" (12)</i></p> <p><i>"So physical activity is more just, I see it as keeping fit, getting moving" (1)</i></p> <p><i>"keeping active I would say, and sport and even just walking" (6)</i></p> <p><i>"Sort of anything from just going for walks to going to gym or sort of outdoor sports and things like that" (14).</i></p>
Occupation and Childcare	<p><i>"things like going on some walks, maybe going to the gym, obviously, manual labour that I have done on my work place. I have two kids as well so there's constant activity trying to chase them about" (3)</i></p>
Exercise	<p><i>"Kind of regular exercise" (7)</i></p> <p><i>"my sort of everyday movements so my like number of steps and things but also taking part in sports and activities. Sort of having an exercise regime is kind of how I would think about when someone says physical activity" (9)</i></p>
Change in definition	<p><i>"I think for a long time it would have meant doing exercise and going to the gym and stuff but probably, because I don't move around as much as I used to when I was younger, it means more just like not sitting at my desk all day erm, probably still like doing cardio exercise but also like yoga and going for walks and things like that" (4)</i></p> <p><i>"physical activity means to me like just working out. So, before I would never have classed a walk as physical activity but now, I do class a walk as it. So, yeah, I think it's like a workout, or go on a walk but like a long walk not just like a walk to the shop, like five minutes, you know or a run or something" (2).</i></p>

When discussing what they liked about PA or what the main benefits of PA were to them participants stressed the importance of PA not only for their physical health but also their mental health both in relation to general life and their cancer journey. One also noted that they enjoyed the social benefits of engaging in PA. This can be seen in table 57.0 through supporting quotes.

Table 57.0 Positives of physical activity (PA) with supporting quotes.

Positives of PA	Quotes
Physical and mental benefits	<p><i>I would say that it greatly helps your mental health. It helped me massively. I have seen it help a lot of people with their mental health massively. I think it just takes your mind off of everything else (13)</i></p> <p><i>obviously physical benefits as well. I feel like if you just sit about doing nothing or like, lie out and do nothing, you're not exactly helping yourself. I feel like if you continue to make conscious decisions of being physical... it does help your physical health, you notice the benefits as well (13)</i></p> <p><i>[on the gym] I like the endorphins I get after; I always feel great after working out. And then I like seeing my progress during it as well. I think it's quite easy to progress how much stronger you're getting. If you could do five more burpees than you did the week before I just like the progress feeling (2)</i></p>
Social benefits	<p><i>it's been like the main way I have made friends as an adult really, is through hobbies and sports and stuff so, I guess the social side of it as well (8)</i></p>

6.3.5.2 Opinions about PA Guidelines

The following section refers to the WHO PA guidelines outlined in section 1.1.2. Participants were asked about their awareness of the guidelines and their opinions on them. Most participants were unaware of what the PA guidelines were for adults in the UK. *"No, I don't know about this, it's the first time I have heard about it" (5).*

Of those who did express knowledge regarding the guidelines, participants were not aware of recommended PA intensity or duration and mostly underestimated these, although one participant overestimated guidelines.

"I've read it recently, but whether or not I remember it's a different thing, I think, is it like doing moderate intensity exercise like two or three times a week (9).

I should know. 60 minutes of vigorous activity" (11).

This illustrates a need for providing TYA's with specific PA advice about what constitutes PA and the different types of PA intensity; light, moderate and vigorous, and the associated health benefits of these.

Following this, the interviewer verbally stated the PA guidelines for all participants during the interview so they were aware of the exact guidelines for UK adults and individuals with cancer. When asked about the use of PA guidelines for cancer patients and survivors and their opinion regarding them being in line with general UK recommendations for adults TYA opinions were mixed, see table 58.0. A number of participants felt this to be overwhelming and unrealistic due to treatment side-effects.

"It just feels a bit like overwhelming...Like you know. It's hard isn't it because like that's the advice for a reason- being as active as possible, it's only going to be good. But it's just a lot, like it's a lot already when you are going through treatment and stuff like that to add on, like you should be doing this. I dunno" (4).

"it's good because it makes you want to try and still maintain that, but at the same time, when you're going through treatment, I don't think it's possible for everybody...it's kinda yeah, it's not like realistic sometimes" (2)

They were also felt to be potentially demotivational which in turn could negatively impact physical activity behaviours. *"I would be like I'm not doing that" (6)*

Instead, many participants felt that PA guidelines for individuals with cancer should be different from those of adults without cancer, due to treatment side effects, the fact that everyone responds differently to their treatment and that not achieving said recommendations may be detrimental to TYA's mental health.

Table 58.0 Participant reasoning for alternative guidelines

Reason for different guidelines	Quote
Treatment side-effects	<i>"I think it's a little bit unnecessary to calculate it by how many minutes of exercise for people with cancer because you know, you have good days and you have bad days...It depends on your energy levels, it depends on your fatigue, it depends on how you're feeling that day. It's a day-to-day basis. With people who are fit and healthy, they can plan it ahead. They know how they're going to be feeling in a week's time so, they can plan a fitness regime that week. For people with cancer, who are going to chemotherapy, they don't know how they're going to feel in the next hour. You could get worse or you can get better" (10)</i>
Response to treatment is individual	<i>everyone deals with the treatment differently. Some people will get treatment and they are literally floored for weeks so I don't think it should be that we are all the same (1)</i> <i>To me, thinking back, when I was on treatment that would have been impossible to meet. But obviously different people in different treatments can manage more like if you're on radiotherapy I don't think it knackers you as much. But it's so person specific (11)</i>
Negatively impact mental health	<i>I think it would actually do more damage than good. I think I know this sounds strange, but I would choose to protect mental health over physical health during treatment, which I know sounds strange. But of the two, I would probably prioritize that and I know they're so interlinked, but I would say that pushing that too much would have a negative mental health impact (9)</i>

Conversely, whilst acknowledging this would not be the case for all TYA's a smaller number of participants felt that these guidelines were appropriate and shouldn't be different. *"I'd guessed it wouldn't be any different. I didn't know that specifically. But I had sort of assumed there wouldn't be different guidelines"* (8)

Participants felt that having recommended activity intensities and durations gives you a goal to work towards and therefore could be used as a motivational tool during treatment and recovery.

"I think if someone had said, like, I recommend this amount of time, I think that would have been motivational. Like it would then give you a target to reach every week. And it felt like... like, obviously, from going from a working environment to then going home and doing nothing, it would then give you a purpose. I feel like that would have helped" (13)

As an alternative to weekly PA duration and intensity recommendations some participants felt reviewing PA based on the individual and providing tailored advice on how to adapt the guidelines to their situation to be more beneficial. It was also suggested that alongside the recommendations TYA's with and after cancer should be provided a caveat and should set their own PA targets with their medical team, supporting quotes are located in table 59.0.

Table 59.0 Participant provided alternatives to PA guidelines

Alternative	Quote
Case by case basis is more appropriate	<i>"maybe, if it was, like, staged, and it was kind of done case by case, obviously, I understand that's not necessarily possible as well. But in an ideal world...case by case would be a lot better"</i> (3)
Advice to adapt guidelines	<i>"maybe not like guidelines, but more sort of advice on how to adapt that to yourself and your situation"</i> (14)
Set own targets	<i>"I don't have an issue with like the recommendations being the recommendations, because if that's the recommendation...then that's fine. But I think, you know, if there's some sort of acknowledgment that people going through treatment will naturally find it more difficult to do that, then I don't think it should necessarily be changed. But equally, I don't think people should...there should be some sort of acknowledgement within whether it's with your team like your medical team...that that may not be a realistic achievement for you. And you could maybe set your own targets"</i> (8)

Some participants also highlighted the importance of the wording used when providing individuals with PA recommendations as this can impact how they are perceived.

"when you put it in minutes like that it can seem like a lot. But if we were to say to someone that is like half an hour a day, I think it is doable". (12)

"if someone looks [PA up] and it says something and they think, I can't do that, then it just stops them from trying. I find that it's almost like "run a marathon" and I'd be like I'm not going to attempt to run that whereas, if it was like try run a mile then I might be like, OK" (9)

6.3.5.3 Informational Support

The interviews revealed that TYA cancer patients and survivors sourced or would source PA information online using various online resources including Google, the social media platforms Instagram and YouTube and cancer charity websites. A small number of participants also reported that they would ask their friends for PA information.

"Instagram, YouTube, sometimes go on Google. I would just do a lot of research." (13)

"Google or YouTube, even just finding sort of appropriate social media pages and then also doing research maybe with Google into how trusted their sources are." (14)

"I have got quite active friends at work. So, anything like running, climbing, wild swimming related, probably [ask] that lot...I followed the couch to 5k. But I like a wealth of knowledge...so, I'd probably ask people." (4)

As seen in the scoping review this supports previous literature which has found TYA cancer patients and survivors use the internet to source information regarding health behaviours, including PA (Mooney et al. 2017; Pugh et al. 2017a; Pugh et al. 2018). However, one of these studies also reported very little participants (<15%) indicated they would use YouTube or their friends as sources of health behaviour information (Pugh et al. 2017a). The differing results with this thesis may be because Pugh et al. (2017a) examined preference for sourcing PA information in conjunction with multiple other behaviours: diet, alcohol consumption and smoking whereas this study assessed preference for PA

information only. AYACS (mean age= 30) have been found to seek significantly more information regarding exercise and fitness online compared to middle-aged cancer survivors (mean age=55), 32% compared to 2% respectively (Aggarwal et al. 2020) suggesting internet preference may be age related.

It should be noted that no participant volunteered that they sourced PA information via cancer charity websites, these were only discussed following interview prompting "did you ever use any of the cancer charity websites to source PA information?". Those who did, did not feel the information available on the websites was helpful, stating a preference for video format over written information. One previous study which investigated PA information preferences found that although a health behaviour information booklet was found by participants to be helpful the majority of participants would have preferred this information in a different format (Marec-Berard et al. 2021).

[charity websites] *"Yeah, I probably looked at them all, more than once...I'm not saying this in a bad way, but it was quite repetitive. I feel like just maybe to change it up a bit more, like some videos would have helped" (13).*

One of the main benefits participants associated with social media platforms was how easy and convenient they were to use as the algorithms recommended new accounts based on your search history and the accounts you follow. This meant that participants were constantly receiving new information and PA ideas.

"just the way social media algorithms work once you find one, they just start popping up everywhere...the way like algorithms work it's a bit more accessible, so it's something that's more tailored to me" (14)

"I would go with Instagram or YouTube because they have different varieties of influencers who could help you, they give you alternatives to the exercises and stuff so it's pretty good that way" (1).

Another positive reported about accessing PA information through social media was that information was available in a video format. This allows the viewer to see the correct technique for exercises or to follow along with an instructor rather than performing exercises alone. This suggests the video format provided both informational and instrumental support regarding exercise technique as well as companionship support by creating a sense of co-participation with the instructor in the video (Golaszewski and Bartholomew 2019; Wilson 2021).

"I never really thought too much of the websites and stuff. I think, like the exercise videos, it seemed quite convenient, because I have looked at websites, they kind of go like do this exercise and this one but a video, you're kind of doing it with the person. so, I just sort of preferred that" (11)

"It's a lot more beneficial to look at someone doing the technique rather than read some words describing it, so I like to see how it's done" (14)

Lastly, participants liked that the social media platform offered peer support from other cancer patients. It allowed them to connect through shared experience as they could see other patients or survivors' journeys and get advice from posts specific to their cancer or treatment type. As highlighted earlier participants wanted support from other TYA peers.

When I go on YouTube sometimes, I type "my experience after cancer" for what people do from their own experience (5)

[on Instagram] "I followed a few accounts of women, men, teenagers who had already been through it [cancer] and just kind of their experiences of what they went through" (13)

[Instagram] It was probably more the support network, but it led to the physical activity stuff. I think it was more the support network or trying to find like is there anyone else... similar to me that's gone through this and then normally the kind of accounts or people that had been through it, they mentioned other systems of support. So, I'd say that was like a good end to kind of finding out what was available (9)

Previous research with regards to social media use in relation to PA in the TYA oncology population is not available however, studies have revealed that social media can be used to generate peer-support within the AYA cancer community (Lazard et al. 2021; Lazard et al. 2023). One study (18-39, mean age 31 \pm 5.2) found AYACS used social media platforms to seek and share emotional support (88.9%), informational support (84.1%) and to make connections (81.3%) (Lazard et al. 2023). Within this study the three most commonly used social media platforms were Facebook (44.4%), YouTube (43.6%) and Instagram (43.4%) (Lazard et al. 2023). This is in keeping with the reported social media sites, Instagram and YouTube, used by participants of this study. Additionally, support for the findings of this thesis regarding social media use for informational support

can be found in a qualitative study into the use of social media again in AYA's (mean age 31, 56% completed treatment) by Lazard et al. (2021) which found AYA cancer survivors used social media for peer-support regarding their body post-treatment including diet and exercise advice as well as mental health support and navigating back into "normal life" post-treatment. As with the participants of this thesis the AYA cancer survivors within Lazard et al. (2021) acknowledged that advice gained from social media may not always be evidence based. Social media was also reported by the AYA cancer survivors to provide an alternative way to socialise which can help with cancer-related isolation and provide peer-support in those with an unmet need for this (Lazard et al. 2021). Considering the above previous literature into social media use in AYA oncology populations as well as the various social support constructs, the findings of the interviews suggest that engagement with other TYA cancer social media accounts may have provided the study cohort with both companionship support, due to the shared sense of identity and belonging within the TYA cancer community, and validation support as it provided social comparison in terms of PA behaviours and norms during and after treatment (Golaszewski and Bartholomew 2019).

However, not all participants used social media as a PA information source as they questioned the trustworthiness and reliability of the information available as individuals sharing the information may not be an expert in the field. Some TYA's also found the internet to be overwhelming.

"I don't trust social media. I take anything that's on social media with a pinch of salt. There's a lot of misinformation and very unreliable sources that are shared on social media. It doesn't mean it's true so I wouldn't trust social media" (10)

"I don't know but I feel like I try to avoid Googling things, it's always a bit overwhelming" (4)

Questioning the trustworthiness of information available online has previous been reported in a study that investigated TYACS use of the internet to source diet and exercise information (Mooney et al. 2017). TYA cancer cohorts have also previously suggested the volume of information available online can be overwhelming (Pugh et al. 2018; Mooney et al. 2017).

When asked about their preferred delivery method of PA support participants reported that it would be beneficial to have a designated PA conversation with an HCP or PA expert where they could discuss how to maintain or improve PA

throughout the cancer journey. Participants felt this would allow for advice to be tailored to their situation and provide answers to any PA questions they may have. Participants showed a preference towards a 1-2-1 setting for this conversation however, a small number of participants suggested a seminar or workshop format, used already by the TCT, may also be beneficial. Table 60.0 contains interview quotes which demonstrate TYA's PA information delivery preferences.

Previous research into PA program preferences in TYA's has reported a preference for PA information delivered via a 1-2-1 conversation with a fitness expert (Murnane et al. 2015) or from an HCP (Mooney et al. 2017). Also, studies have shown participants would be interested in attending 1-2-1 health behaviour counselling sessions after treatment (Pugh et al. 2018; Pugh et al. 2017). However, as seen in the scoping review other studies have shown a strong TYA preference for PA information to be received online or via a mobile app (Pugh et al. 2017; Pugh et al. 2018) or via numeric tools such as email (Roggenkamp et al. 2022; Marec-Berard et al. 2021) or text-message or social media (Marec-Berard et al. 2021).

Table 60.0 PA information delivery preference with supporting quotes

Delivery method	Quote
1-2-1 Conversation	<p><i>"You're given quite a lot of written information with cancer, with different things; like booklets of side effects and a booklet for hair loss and a booklet for you know. I personally found that it was kind of like when you read a self-help book and you think "OK, like I know what I need to do, but that doesn't actually help me do it". And for me that kind of personal I can phone this number and they're going to meet with me and discuss these things, and we're going to work through it together was a lot more helpful than just reading it passively" (9)</i></p> <p><i>I think it would have been more beneficial, like, if I actually had like, that personal trainer, or like the health fitness advocate from the NHS, come and speak to me, like, tell me about maybe; like certain programs or regimes or... what I might experience if I do exercise, what I might not experience. I think that would have just been a lot more reassuring and beneficial for me, instead of having to kind of, do all the digging myself. I think it would have just been a lot less stress and worry (13)</i></p> <p><i>"What would have helped me is probably in the last cycle of chemotherapy, I would have liked the physiotherapist or something to come in and just talk to me about things that they recommended me doing and stuff. That would have probably helped, I didn't get any of that. I just had to go on my own" (10)</i></p>
Seminar or Workshop	<p><i>the Teenage Cancer Trust, they done a session which was "look good, feel good". It was basically a lady who came on who was a make-up artist and she talked through all the different kinds of makeup for people who have cancer and ways to do your make-up and how to deal with hair loss and stuff. I feel like doing something like that, once a month or something. Getting someone in, it could be a personal trainer, a nutritionist, someone who specialises within sport and doing talks and not trying to recruit but like trying to reach out to people that do have cancer. These kinds of sessions it did help me... the "look good, feel good". I feel like that would be something that I would personally be interested in, speaking to someone who is within that industry and they could go through exercises but light exercises</i></p>

Delivery method	Quote
	<i>for people who might be affected by chemotherapy or whatever. I feel like something like that would be beneficial for us (1)</i>

Regarding the content of this conversation the interviews revealed TYA's want PA information on the benefits of physical activity and PA advice tailored towards to their cancer type and treatment. Participants also wanted information on how to initiate PA following treatment. Furthermore, some participants expressed an interest in receiving additional information and support regarding diet and healthy eating alongside PA information. Table 61.0 demonstrates these conversation content preferences and provides supporting quotes.

Table 61.0 PA conversation content preferences with supporting quotes

Conversation content	Quote
How to start PA	<i>"I think that can be the tricky part for a lot of people, is the finding where to start" (12)</i>
Person specific	<i>I think talking to a physio...just to see if there's anything that I could be doing, or should be doing... just more specific things to what treatment you're getting done and everything like that (6)</i>
Benefits of PA	<i>if they had someone to talk to face-to-face that provided the information on the benefits of being physically active during treatment. As opposed to maybe just telling them the risks, I feel like, if you were speaking to them in a positive tone and telling them the benefits and like in moderation. I feel like that would help and like being able to provide them groups and...workshops. I feel like that would help people so much (13)</i>
Diet	<i>I would probably say that there should really be a lot more stuff in terms of healthy eating (3) I feel like the nutrition side of things needs to be highlighted more (13)</i>

Following on from this, participants were asked about what advice they would give to other TYA's going through treatment and beyond. Most participants would encourage them to not put pressure on themselves but, if possible, to try and keep active throughout treatment even with small amounts of activity as this will make

them feel better mentally and to a less extent help them physically, this can be seen in Table 62.0.

Table 62.0 PA advice TYA's would give other TYA cancer patients during or after treatment.

PA advice
<i>"I would just say; take it as it comes. Don't force yourself. If you feel like you can do it, do it, but don't force yourself because if you force it, you'll feel a bit worse...So yeah, take it easy, and if you can, do it" (2)</i>
<i>"my advice would be a little bit often. So probably small sections of light exercise...just short walks, this that and the next thing" (3)</i>
<i>"It's always good to give it a go and do a wee bit of something and then you do feel better" (7)</i>
<i>[During treatment] "just try to do something even on the days that you feel bad". [After treatment] "Don't give in and take your time to build up your strength and you'll get there eventually" (6)</i>
<i>I would say to "carry on doing some sort of physical activity. Don't just close yourself off from it. Like, don't think that just because you're ill you can't do it". I would say that "it's going to help you more mentally than it will physically and it will put you in a better frame of mind throughout your treatment, you'll be more positive, you'll just feel so much better for it"(13)</i>

To summarise, participants mainly access PA information through the internet using social media or google. Participants showed a preference for receiving PA information in video format or through face-face conversations with HCP's or PA experts. Participants want to receive personalised advice about the benefits of PA and what they should be doing during treatment and recovery. Most participants felt that providing patients with the UK PA recommendations may be overwhelming, so it is important to come up with tailored PA goals.

6.3.5.4 Instrumental Support

During the interview participants were asked about their opinions on (and experiences of use if relevant) of different types of instrumental support delivery mechanisms. This included fitness apps, wearable device and PA groups (walking group and exercise group). For group-based support participants were also asked about their delivery mode (in-person, virtual, hybrid) preferences. The following section will discuss participants perceived pros and cons to each delivery mechanism and mode.

Some of the ways participants reported they supported themselves to be active during treatment and recovery was by using fitness programs such as couch to 5K, following workouts at home using YouTube videos or social media influencer apps and workouts or by getting themselves a personal trainer.

6.3.5.4.1 Fitness Apps

There are hundreds of thousands of apps available across Google Play Store and Apple Apps Store within the health and fitness category (Yan and Koenigstorfer 2021). Following the COVID-19 pandemic there has been a dramatic increase in the number of fitness apps available due to the stay-at-home measures adopted to control transmission (Angosto, Garcia-Fernandez and Grimaldi-Puyana 2023). A 2019 systematic review and meta-analysis of the effect smartphone apps on PA found modest evidence to support the effectiveness of smartphone apps at increasing PA in adults (Romeo et al. 2019). These apps are third party programs for smartphones or wearables that aid individuals with leading a healthy lifestyle, guiding sports learning and recording physical activity data (Eshet and Bouwman 2015). This definition of fitness app has been adopted to this thesis.

A number of participants already reported using a fitness apps for exercise and healthy meal ideas as well as training programs and instructor led exercise videos. As stated above, participants provided examples of the apps included the running app couch to 5K or apps associated to social media fitness influencers.

"I've actually got an app. I am saying this again but it's actually from a sport and exercise influencer from Instagram. Megan Grub her name is. I have her app and she puts up daily exercises and stuff and food ideas, healthy food options... I find it really good." (1)

When asked about a using a fitness-app-based exercise program participants had mixed feelings. Most participants felt this would be beneficial and something that

they would use during and after treatment. The positive aspects associated with a fitness app were: that they easy for young people to use as they are familiar with technology; it could be used to provide PA information and guidelines as well as exercises, it would allow others in their social network to be involved, it could help provide a starting point for activity and allows the individual to follow an instructor.

Participants highlighted that they would want a tailored PA program available on the app rather than only generic exercises or information. However, participants did report some concerns surrounding a fitness app as this relies on an individuals' internal motivation which can be affect by cancer and treatment. Low motivation has been seen as a barrier to physical activity participation in TYA cancer patients and survivors both in previous research (Psihogios et al. 2020; Rosipal et al. 2013; McGrady et al. 2022; Shaw et al. 2022) and within the survey sample of this study.

Some participants reported that they would benefit more from an in-person conversation compared to an app and one person reported they would benefit more from a PA group. Table 63.0 illustrates TYA's opinions on fitness apps through interview quotes.

Table 63.0 TYA opinions on fitness apps.

Opinions about Fitness Apps	Quotes
Beneficial	<i>definitely, I would have been interested in something like that (8)</i> <i>I definitely would have installed it and used it. I think that would have been helpful (10)</i>
Easy to use	<i>I think that would be [beneficial] especially for young people too, cause we are so used to using apps and stuff (11)</i>
Involve others	<i>that would have been quite good actually. That would have been quite interesting...specifically as well, because I could've gotten the kids involved (3)</i>
Internal motivation concerns	<i>For me more in-person or even if it's speaking with a coach over the phone or something. I've tried kind of, fitness app things before, but it feels too much on me to access things, so personally, I just end up like forgetting it's there. So, for me that doesn't work but maybe it works for other people (9)</i> <i>I would actually use that yeah. I guess the only thing with that is it is sometimes hard to get the motivation if you're in the house by yourself. But I think the days you do I would definitely use it (2)</i>
Help with starting point	<i>I think that would be quite good actually. I wouldn't really know what to do for... I don't want to say for how I want to be... like how much physical activity I want to do, for what I'm looking to get out of it and that kind of thing. I would not know where to start (12).</i> <i>I like try to go to the gym and stuff. It's quite scary so I always follow along a yoga video because I always don't really know what to do. And even with like running I would do the couch to 5k because I'm like I want a programme to follow (4)</i>
Want for tailoring	<i>if it was actually led by cancer professionals, they probably... have an app that could probably categorise... you could click on what cancer you have, where you are in your treatment, and how your fitness levels are and then based on those three things... you can make, like, a basic... to kind of follow. Just as a kind</i>

Opinions about Fitness Apps	Quotes
	<p><i>of guideline. Like, if you have stage three, abdominal cancer, and you're 65, and you're really, really tired, then, you know, maybe you could just advise, a walk round the block or something small. But if you have stage two testicular cancer, and you're 17, and you're fairly fit, you could make it personalised to what you put in (10).</i></p> <p><i>I think depending on how tailored it was...and maybe depends on the app a little bit as well (4)</i></p> <p><i>it would be good, to an extent, but it'd be quite generic. And everyone's needs are different (13)</i></p>
Negatives	<p><i>I tried an app before called "full body workout". I tried for 2-weeks and then stopped it and deleted it from my phone... the start days I was excited and then I said I don't want to do this anymore because as I told you I don't like to things by myself. So, I would prefer a group. (5)</i></p> <p><i>I just feel like it'd be more beneficial if it was face-to-face contact instead of through an app. But I still think it would help (13)</i></p>

6.3.5.4.2 Wearable devices

When asked about using a wearable device such as an activity tracker or pedometer some participants reported using smart watches to record their daily steps. Participants felt that this was an effective way to measure how much activity they were doing. One participant reported using an activity tracker and app to engage in physical activity with their social network during recovery which they found to be helpful:

"during my treatment myself and my partner bought, we all bought Fitbits. And...we were obviously challenging each other on the app and this that and the next thing, which was quite enjoyable" (3)

Table 64.0 illustrates TYA's opinions on wearable devices through interview quotes. Participants reported mixed opinions regarding the use of step targets as a mode of PA support. Some participants felt this could be beneficial to track their PA progress during recovery and having step goals may be motivational however, some felt that not achieving these goals would be demotivating or frustrating.

Table 64.0 TYA opinions on wearable devices

Wearable Device	Quote
Track progress	<p><i>"I feel like it would probably have been quite good when I was going through the recovery period after my surgery. Not necessarily a motivating factor but to just be like aware like that today you did 300 steps but I dunno and then the next day you did 500 steps, so you are like oh ok, I am moving a bit more than I was than yesterday- or something (4)</i></p> <p><i>I think it's a way of me measuring my activity. It kinda helps me keep tabs on things. I'm aware of what I was able to do before, I'm aware of what I did last week, what I did this week. And yeah, it's just a measuring tool basically" (9)</i></p>
Demotivational	<p><i>"So, I put it back on last week cause I thought I'm gonna start properly trying to do 20-minute HITs again but I've taken it back off now because I've been doing less than 5000 steps and I'm like "no", it's just annoys me [clarification of why] I think because I'm just so used to like smashing steps. I don't know. It's something so silly, but just it's something usually so easily done so the fact that I don't do it I'm just like I will put that away until I am" (2).</i></p> <p><i>"I think if there was sort of like step targets, and then I wasn't reaching them, because I'd had a bad day, I don't know, whether that would be counterproductive in terms of like, mental health and feeling like I wasn't doing enough" (8).</i></p>
Motivational	<p><i>"you got a basic Fitbit to record your steps... that was really good because I had I can't remember the exact number of steps, but you were to aim for this many and it was a really good motivating kind of thing to do and build, build strength back up" (6)</i></p>

6.3.5.4.3 Group-based Support

Many participants felt that group-based activities (walking group or exercise group) would be a valuable way to support PA. One of the main reasons participants were in favour of group-based activity was that it offers the opportunity to meet other people in a similar situation to themselves who understand what they are going through. For that reason, the majority of participants felt that they would prefer a TYA specific PA group over a general exercise group, however, some reported having a group specific cancer or your treatment e.g., post-surgical group would also be beneficial. Alongside gaining peer support, those in favour reported that being active in a group setting would be motivational as you all encourage each other. Furthermore, participants felt that a cancer specific activity class would be at the appropriate level for individuals during and after treatment. Table 66.0 outlines the main positives participants associated with group-based activities.

Not all participants were in favour of group-based support though, with some feeling like the group dynamic was intimidating, particularly if it was a general cancer class, and that they would prefer small classes or 1-2-1 support, as seen in table 65.0.

Table 65.0 Participant perceived group-based support cons.

	Quote
Intimidating	<i>"my TYA nurse... she did mention like Move and stuff, but again, it just felt...like the group dynamic really scared me and it was more like older people. It just didn't seem like something I wanted to try at the time. If I had more like 1-2-1 support, I think I would have got into that at an earlier stage, like when I get started exercising" (11).</i>
Prefer small groups	<i>"the more people the more I wouldn't be interested. I would prefer like a small group" (3).</i>
1-2-1 support instead	<i>I think having a point of contact would have been really good. Obviously, that's not the easiest depending on where you live and everything. But if there is like a physio or an exercise therapist or something that you met, maybe like once a week to walk you through stuff and then you can be sent away and given, like some sort of plan that you can work through (11).</i>

Table 66.0 The main positives participants associated with group-based activities.

Group-based Support	Quote
Motivating	<p><i>"it would be motivating and we would encourage each other" (5)</i></p> <p><i>"I like to be motivated, like see the way they shout at you and tell you to keep going and stuff, I like that. I feel that works for me because sometimes I can be lazy when I go to the gym. I am doing a gym exercise but really, I am being lazy and not really doing it to my full ability. So, I feel like the classes are good because there is someone there watching what you are doing" (1)</i></p>
Instructor led	<p><i>"I prefer gym classes because someone is there showing you what to do" (1)</i></p>
Appropriate level	<p><i>"I think an exercise class would be good. Just for everyone that's going through it, so it wouldn't be very intense and stuff like that. I think that would probably be good. And then I mean, not that anyone's feeling pressured, but like people wouldn't feel pressure to be like going and use all their energy at the class because everyone's in the same kind of position. So, if you're stopping and down in sitting for 15 minutes it's OK" (2)</i></p>
Social element	<p><i>"it's also like social as well. So even though you're working out you're getting a chat and I don't know if anyone's like me but I kind of laugh like to myself and I'm like "Oh God, I can't do that" (2)</i></p>
TYA specific	<p><i>"my ideal if I could find it but I don't think it exists, would be like an exercise class of like other young adults that have just been recovering from cancer" (9)</i></p>
Peer support	<p><i>"group sessions for people who are going through treatment at the time, I think that would be something that'd be nice, because everything would be modified to a level and it would also give you that chance to meet people who are going through treatment at the same time" (8).</i></p>

Group-based Support	Quote
Peer support continued	<i>"something like community walks and stuff. So, people that are going to treatment and stuff can come together and go for a little walk, so you're speaking to people who are also going through cancer. You can speak to them and you can make contact, even make friends. People who can actually relate to you and understand what you're going through. That would have helped, you know, cancer is a very lonely time for a lot of people. It was for me. Just in your head ...people who are going through cancer need people, we need support" (10)</i>

6.3.5.4.4 Preferred type of group-based Support

Participants did not show a preference between a walking group or an exercise group with positives associated to both. The perceived pros of a walking group were: fresh air and that was felt to be more accessible than an exercise groups as it caters to all different abilities and ages. Some participants were more interested in an exercise group rather than a walking group as they already engaged in regular walking in their everyday life. *I tend to go quite a bit of walking like myself and with my husband, so probably not as inclined to go to a walking group (7)*

Both exercise and walking groups reportedly allowed for socialisation with other cancer patients and survivors however, some participants felt that it was easier to socialise at a walking group compared with an exercise class. Participants also expressed interest in offering variety of exercise groups such as a yoga class or sports club to cater to different interests. Also, some participants expressed the want for tailoring within classes. This is illustrated through the quotes in table 67.0.

Table 67.0 Preferences between a walking group or exercise group.

Preferred Type	Quote
Variety	<p><i>pretty much anything basically, a walking group, a little climbing club or... something like mountain biking, I dunno cos that's not like a massively social activity, but maybe you could do something afterwards to like to check in with everyone... having people who are going through the same thing or similar and having different levels of activity that you can participate in (4)</i></p> <p><i>I think having different options, because obviously, different people have different interests... even just like go for a walk around the park, maybe like a yoga session (8)</i></p>
Walking group provides more opportunities for communication with others	<p><i>with exercise you are tired, extremely tired. Especially considering the circumstances, where on a walk, you might not necessarily be as tired, you've still got that time to communicate and form real friendships and stuff (3)</i></p> <p><i>but I think walking is like it's just quite good because you can talk and be active at the same time. Do you know if you go to a spin class you don't necessarily get the same like time to chat to people or like circuits (4)</i></p>
Walking is more accessible	<p><i>walk is probably the best thing. It's just more generic and everyone can walk, well most people can and it wouldn't be too difficult for most people (10)</i></p>
Personalised plan more beneficial	<p><i>I think having someone that's knowledgeable about exercising cancer who can help you with your specific situation and also create like a personalised plan for you (9)</i></p>

6.3.5.4.5 Comparison of in-person and virtual support

When asked about the delivery method of PA support many participants preferred in-person support compared with virtual support, however a number of benefits of virtual delivery were also discussed. Participants preferences for in-person was largely due to socialisation with other cancer patients as participants felt there was more opportunity to socialise at an in-person class rather than a virtual class. Participants also felt that in-person allowed for more support from professionals and was motivational. Table 68.0 provides examples of participant quotes to support an in-person delivery mode.

Table 68.0 Perceived benefits of in-person support

In-person	Quote
More support	<i>sometimes, like seeing a professional in-person, you get a little bit more support and things (11).</i>
Social	<i>think I'd be more motivated for an in-person one, purely for that social interaction (8)</i>
Motivational	<i>for me things being in-person and getting that in-person support is way more motivating (9)</i>

Table 69.0 illustrates TYA's perceived pros and cons of virtual classes or resources. One of the main positive of virtual resources is ease of this method as it allows individuals to be active at home, at a time that suits them. Virtual delivery was also reported to be inclusive, allowing individuals who would not normally be able to attend a PA class, due to isolation/hospitalisation or travel issues, the opportunity to participate.

Table 69.0 Perceived pros and cons of virtual support methods

Virtual	Quote
Reduced ability to socialise	<i>"There's no before meeting chat, there's no after meeting chat, it's here's the time of the meeting, do the meeting, and then end the meeting. It's very professional, very kind of, unemotional, it's very mechanical. In an actual in person meeting that doesn't happen...You can't get that online, its two completely different experiences". (10)</i>
Ease of own schedule	<i>"virtual is quite good for like, I dunno its less effort isn't it? You know you can just stick it on" (4)</i> <i>[pre-recorded virtual classes] "it's like 20-minute classes and you can do them at your own level which I have found has really helped me. And you can do them at any time and like any day so you can wake up in the morning not feeling active but later on in the day have a spout of energy you can go and do it then" (1)</i>
Inclusive	<i>"I think virtual thing would be good as well. 'cause then you could do it in your bedroom in the hospital. Or you could do it when you're at home. You don't need to travel to do it" (6).</i> <i>"I like that I can do it in my own home because sometimes it's just that getting from A to B puts me like "urg I can't be bothered now" (1)</i>

COVID-19 was discussed in relation to support delivery mode preference. Participants reported digital fatigue as a result of work/education being online, resulted in them being less motivated to engage with virtual PA resources. However, a small number of participants reported that they would not feel comfortable with in-person support due to the pandemic. Interviews of those preferring virtual due to COVID-19 took place earlier on in the pandemic. Table 70.0 highlights the impact of COVID-19 on TYA support delivery mode preferences.

Table 70.0 Impact of COVID-19 on PA support delivery mode preferences.

COVID-19 Impact	Quote
Preference for virtual	<i>[COVID-19] "I think just now that I'd be too uncomfortable into an in-person class" (7)</i>
Digital fatigue	<p><i>"for me in-person is a massive thing right now. I'm really demotivated with everything being online, which is difficult because in the cancer community there's I think still a tendency to think that people will prefer things online because they might still be iffy about meeting up in person, which maybe for people in treatment is a bigger thing, but like I know Trekstock the young adult cancer charity, they do Pilates classes online, but I've never been motivated to join one because I sit at a computer all day" (9)</i></p> <p><i>"I think everyone experiences a little bit of digital fatigue, just because of COVID. People are just sick and tired of using Zoom and all that. So yeah, I, for one definitely prefer in person. I need that contact with people face to face" (10)</i></p>

When asked about a hybrid model (in-person class with the ability to join virtually) participants felt this would be the best of both worlds. Providing support for both those wanting in-person and those who otherwise could not attend:

that would be a good idea. I'm more, I just like seeing people it's just my personality. But yeah, it would be great with the options for Zoom cause obviously everyone can't make it to different places and stuff" (2)

There is a lack of literature around preferences for instrumental PA support in the TYA cancer cohort. The scoping review revealed activity trackers (Fitbit) were only use in one previous intervention in the TYA oncology population (Yurkiewicz et al. 2018). Results found that TYA cancer patients enjoyed using digital technology to track their health with significant improvements in HRQoL seen post-intervention (Yurkiewicz et al. 2018). TYA patients reported mainly using Fitbits to track their steps, which anecdotally participants reported increased, however this was not an outcome of the study and therefore the effect of the Fitbit on PA behaviour is

unclear (Yurkiewicz et al. 2018). The majority of patients had poor adherence to wearing the activity tracker whilst in hospital (Yurkiewicz et al. 2018) so any future interventions would need to consider this.

The feasibility of a technology-enhanced (mobile app and Fitbit) in-person group-based fitness intervention, "FitSurvivor", has been assessed in AYASCC (mean age=18.5, 49% female) (Devine et al. 2020). Results revealed a significant improvement in lower-body strength of the intervention group, very high participant satisfaction with in-person training and moderately high satisfaction with the mobile app (Devine et al. 2020). However, participant engagement with the app was observed to decrease throughout the intervention (Devine et al. 2020).

Although not directly related as it was conducted in the broader AYA oncology population (18-39, mean age= 31.9+/- 4.9), Voland et al. (2023) investigated AYA preference between different modes of instrumental PA support (supervised, group-based, online exercise program vs. unsupervised, individual home-based training-app vs. supervised, personalised, in-person exercise program). All three delivery modes significantly increased participant PA behaviours and results found both online delivery programs to be feasible and acceptable (Voland et al. 2023). Participants selected the training-app program for weight loss, due to the flexibility in terms of time and for the personalised training schedule. The online group was selected due to its fixed training schedule and for PA co-participation with other cancer patients. Whereas in-person programs were selected for individual supervision from therapist, fixed schedule, close to residence and for social contact (Voland et al. 2023). Although participants found the technology-based delivery modes acceptable, COVID-19 was seen to impact delivery mode selection. AYAs indicated that under COVID-19 free conditions they were most interested in (1= not interested, 10= highly interested) the in-person PA program (mean=8.4 +/-2.1), followed by the unsupervised, individualised home-based program (mean= 7.2 +/- 2.8) and then the online, group-based program (mean= 5.1 +/- 2.6) (Voland et al. 2023).

These findings align with findings of this study, that fitness apps and technology-based interventions are accessible but when given option TYAs prefer face-face delivery preferred.

6.3.5.5 Timing of PA Support

With regards to what stage PA support should be given across the cancer continuum participants noted that the initial stages of diagnosis leading into treatment is a busy time where patients receive a lot of information so PA information may get lost at this time point.

"When you initially get your diagnosis, everything moves so quickly, and you're taking in so much information that it could get a bit lost at that initial time, but yeah, if you have like when you have a follow up with your surgeon or something like that, I think that'd be a really good time to talk about it" (8)

Once treatment has begun participants highlighted that everyone's situation is unique and that some people will manage PA during treatment and others may not. This again highlights that the HCP providing support should be mindful of the individual and their unique needs.

"I think it depends, really, because I was quite lucky that this didn't like, confine me to a bed. There's people that are going to be bed bounds for these sorts of things. So, it really depends on the situation" (12)

Table 71.0 illustrates participants PA support preferences across the cancer care continuum through quotes. Participants felt support throughout the whole journey was important. They viewed general PA encouragement and support during treatment as appropriate and beneficial for patients. Following this, participants felt there should be a focus on PA to rehabilitate patients and assist with return to normal activities.

Table 71.0 Physical activity support preferences across the cancer continuum from early treatment to recovery represented through quotes.

Physical activity support across the cancer continuum	
Early	<i>"I wasn't well, but it wasn't like that I was bed ridden. So, when I spoke to her right at the start it was all just very basic things. It was never too overwhelming" (7)</i>
→ → → → → → →	<i>"your body's at different stages...in the beginning, you're still kind of semi-normal and then in the middle, you're well and truly in the thick of it. So, I do you feel it's beneficial for all stages" (13)</i>
	<i>"I feel like the information would be good to have before starting treatment. But at the same time, there's also a lot of things that go through people's heads at this point in time. So maybe shortly after starting treatment, kind of start those discussions, and then probably a bigger focus on it coming out of treatment" (3)</i>
Later Stages	<i>"I think some sort of movement encouragement would have been nice during treatment. Nothing like "you have to do this". But like, "if it's possible, and you have the energy that day, maybe try do some of these", because I was never told to do anything with that. I was basically just told to rest and eat what I can. And then after treatment, just sort of a gradual build up to get back into stuff" (11)</i>
	<i>I just feel like there should be more of a rehabilitation side afterwards (13)</i>

This was summarised by one participant who described that based on their "emotional state" during treatment they would have required "gentle nudges and making it [physical activity] accessible" then once treatment had finished and they were more mentally ready they would have preferred someone working with them to create an exercise program, taking a "patient led approach" (9).

6.4 Interview Findings Summary

In summary, this chapter integrated the interview findings and discussed them in relation to previous literature. Four main themes were identified from the interview data analysis: COVID-19, Impact on behaviours, social support and TYA PA opinions and preferences. COVID-19 was a distinct theme which resulted from the social climate in which this piece of research was conducted and as such, findings

are only applicable to research also conducted during this time. The remaining three themes of impact on behaviours, social support and TYA PA opinions and preferences can be related to research conducted out with the COVID-19 context. As illustrated above the qualitative findings of this study largely supports and expands the literature base with regards to TYA oncology PA barriers and facilitators and the physical and psychological impact of cancer diagnosis and treatment in relation to PA.

The interview findings also highlighted the vital role of social support for PA in the TYA oncology population and adopted an innovative approach to analysis considering social support in relation to its different constructs rather than unidimensional. This demonstrated a clear need for TYA specific PA informational and instrumental support delivered in-person by a PA expert. Additionally, the findings of this study emphasised TYA cancer patients and survivors use of social media to access PA information and peer-support. Lastly, the theme of TYA PA opinions and preferences contributes to the knowledge base surrounding activity preferences with regards to activity type, support and timing.

CHAPTER 7: INTEGRATION**7.0 Integrated Quantitative and Qualitative***7.1 Introduction*

In keeping with an explanatory-sequential mixed methodology this chapter will now integrate and compare the findings from the quantitative and qualitative chapters. This section is largely descriptive as in-depth discussion supported by relevant literature was addressed in the quantitative discussion and qualitative findings chapters. As stated in the methodology chapter there were six research objectives to address the overarching research question of the study. For ease of reading these are restated below:

1. To identify self-reported physical activity levels of this population across the cancer continuum.
2. To explore the experiences this population has had with physical activity.
3. To identify the perceived barriers and facilitators to physical activity for this population. This includes exploring any potential group differences with regards to demographics, cancer type, treatment type on PA engagement.
4. To explore what individuals from this population feel is important to them, about physical activity.
5. To identify physical activity preferences in relation to type, setting, delivery method and support for this population.
6. To synthesise recommendations for physical activity in this group.

Overall, the qualitative findings largely support and explain the quantitative findings but these will be fully integrated below. Results from the survey and interview will be discussed in relation to each objective 1-5, with figures 35.0-39.0 the main findings for each objective. Please note some findings relate to more than one objective. Following this the impact of COVID-19 will be addressed. Information relating to objective six shall be discussed later in this thesis in section 9.1.

7.2 Objective 1.0: Self-reported PA Behaviour

Figure 35.0 illustrates the main findings of research objective 1.0 which relates to TYA cancer patients and survivors' current PA behaviours as measured through the

survey (SOC and IPAQ-SF) and interviews. This objective was not addressed as extensively within the interviews so the weighting of results is skewed towards the quantitative results. As mentioned previously it was not possible to assess for between group differences in PA behaviours based on cancer status (cancer type or treatment) or demographics due to the sample size of this study however, generally, the majority of participants in both the survey and interviews reported that they were physically active. High reporting of activity across both the quantitative and qualitative data and the large number of participants intending to increase their PA behaviours over the next 6-months suggests this cohort of TYA cancer patients and survivors to be skewed towards individuals who are highly motivated for activity. As such the results of this study may not be fully representative of the whole TYA cancer population as the views of individuals not motivated to be active may have been missed and as such results should be interpreted with consideration to this. Although high self-reporting of PA across both the survey and interviews only half of the interview participants and just over one third of survey participants (36.6%) were sufficiently active to meet PA guidelines.

Quantitative findings	Qualitative findings
<i>Objective 1.0: Self-reported PA behaviours of TYA cancer population</i>	
63% self-reported they engage in regular PA behaviour	Explanatory 87% reporting they were PA yet, 50% reported meeting PA guidelines.
50% TYAs in moderate IPAQ category	
36.6% meeting PA guidelines	Participants engaged in an array of leisure, domestic, transportation and occupational activities.
87% intend to become more active in the next 6-months.	
Walking most common activity	
A trend was found between increasing SOC and increasing PA behaviour (MET-minute/week) of walking, moderate-intensity activity, vigorous-intensity activity and total continuous score.	
Average weekday sitting: 8 hours (+/- 4.7)	

Figure 35.0: Juxtaposition of quantitative and qualitative findings for research objectives 1.0.

As seen in figure 35.0 results suggest that the interview sample as a whole were more physically active than the survey sample. Table 72.0 compares the quantitative and qualitative self-reported PA behaviours across the thirteen participants who took part in both phases of the study. Table 72.0 shows that five

out of the seven participants in the high IPAQ-SF category from the survey participated in the interview and only two of the interview participants were classified in the low IPAQ category. This suggests that survey participants who volunteered for the interview may be more active than the survey cohort as a whole. As discussed previously there is a recruitment bias towards active individuals participating in PA research, this may explain why more active individuals from the survey wanted to continue, and participate in the interview phase of the study.

Table 72.0 Comparison of the quantitative and qualitative self-reported PA behaviours across participants (n=13) who took part in both phases of the study.

P*	Survey self-report reg. active	IPAQ* Category	Meeting PA* Guidelines- total MET (minutes/week)	Interview Results (Are you active? Do you meet guidelines?)
1	Yes	High	Yes	Yes, but unsure if guidelines
2	No	Low	No	Yes, but not meeting guidelines
3	No	---	No	Yes, and meeting guidelines
4	Yes	Moderate	No	Yes, but not consistently meeting guidelines
5	Yes	Low	No	No
6	Yes	Moderate	Yes	Yes, and meeting guidelines
7	Yes	Moderate	Yes	Yes, and most weeks meeting guidelines
8	Yes	High	Yes	Yes, and meeting guidelines
10	Yes	----	Yes	Yes, and meeting guidelines
11	Yes	High	Yes	Yes, meeting guidelines
12	Yes	Moderate	No	Yes, to an extent, not consistently meeting guidelines
13	Yes	High	Yes	Yes, and meeting guidelines
14	Yes	High	Yes	Yes, and meeting guidelines

P*= participants; IPAQ*= International physical activity questionnaire; PA= physical activity

The traffic light colour coding of table 72.0 illustrates the agreement between survey and interview reporting with regards to PA behaviour. The green rows

indicate that there is complete consistency of reporting between the interview and survey results for eight of the thirteen participants. There was partial agreement for two participants (P1 and P7) and disagreement for three participants (P2, P3 and P5). Two of the three participants who had inconsistent self-reporting of PA behaviours had a change in cancer status between the survey and interview phases (<6-months post-treatment to >1-year post-treatment and on-treatment to <6-months post-treatment). Interestingly, the participant who transitioned from the active treatment to post-treatment status reported they were not active post-treatment but they were during treatment. Context provided from the interview highlighted this was due to poor mental health and fatigue both of which are commonly reported late-effects of treatment which impact PA behaviour (Spathis et al. 2017; Nass et al. 2015). The high consistency between survey and interview reporting suggests this mixed methods approach is a valid method for investigating PA behaviours as it provides both quantitative results for comparison with guidelines but also allows for context to be gathered providing a more holistic image of the individual and their PA behaviours. In the survey results discussion (section 5.3.1) it was suggested that an objective measure such as a pedometer or acetometer could be used alongside a subjective measure to collect PA behaviour information in future research. This integration has revealed another alternative method for PA behaviour data collection to be this mixed-methods approach utilising a self-report survey and semi-structured interviews to map behaviours.

Interview results revealed participants engaged in a variety of different types of PA during leisure-time, for work, around the house and to commute to and from places however, this was poorly captured in the survey. During the planning phase of this thesis the IPAQ-LF was not deemed to be the most appropriate measure to collect PA behaviour data due to its length however, this may be a better measure to use in future research compared to the IPAQ-SF, as it contains sections dedicated to different activity domains including (occupational, domestic, transportation and leisure-time activity) (Craig et al. 2003). This may be better for assessing the PA behaviours of this age group, as they have multiple external factors which can affect their behaviour (e.g., work, family, dependents, education etc.) due to their stage of life. As seen in figure 35.0 the interviews did not provide any further information about frequency or duration of weekly PA behaviours or time spent sedentary.

To summarise the study findings in relation to objective one, the majority of participants reported engagement in PA and an interest in increasing their PA behaviours however, only 50% of interview participants and 36.6% of survey participants currently met recommended PA guidelines. This study found a mixed-method approach to PA behaviour data collection to be effective.

7.3 Objective 2.0: Lived PA experiences

The main quantitative and qualitative findings for objective 2.0: lived PA experiences are displayed in Figure 36.0. This objective was measured predominantly through the interviews with participants providing a narrative of their PA experiences throughout the cancer care continuum. Interview narratives revealed participants engaged in less PA post-diagnosis compared to pre-diagnosis. This confirmed survey results which demonstrated a 37% reduction in the number of participants reporting they were active post-diagnosis compared to pre-diagnosis. Interviews revealed that the main reasons for this were due to treatment-related side-effects and the logistics of actually receiving treatment. Interview participants also reported that the magnitude of impact on behaviours varied depending on type of treatment received. Participants reported having to reduce the intensity of their activities during treatment and predominantly just walked. This was again supported by survey data which showed a reduction in the weekly duration and intensity of activity types participants engaged in pre- and post-diagnosis. Aside from treatment-related side-effects participants also reported that they were fearful about the impact being active whilst on-treatment may have on the efficacy of their treatment as well as expressing a lack of knowledge around exercise and cancer. Narrative description of return to activity post-treatment, whereby participants gradually increased their PA behaviours in a process of trial and error, was supported by open-text response from the survey. Furthermore, pre-diagnosis self-report PA behaviours observed in the survey were above expected based on self-reported age matched norms for Scottish 16-24-year-olds (87% compared to 74% respectively). Again, this suggests potential sample bias within this TYA cancer cohort.

Social support was found to be one of the four themes identified from the interviews yet, this was not a major component of the survey so limited direct comparison can be made. Survey results revealed participants had high satisfaction regarding the support available to them. This was predominantly provided from family, friends and partners although a small number of participants

also reported HCPs within their social network. The SSQ-6 measures unspecified social support, meaning it does not distinguish between different social support constructs whereas, the interview theme of social support comprised subthemes relating to distinct constructs of social support: informational, instrumental, emotional and companionship support. With regards to PA, the interview narrative revealed the social network described in the survey (family, friends and partners) predominantly provided TYA's with emotional support through encouragement to be active and companionship support through co-participation in activities. However, participants also expressed that their friends did not fully understand what they were going through in relation to their diagnosis and cancer journey.

Quantitative findings	Qualitative findings
<i>Objective 2.0: Explore the lived PA experiences of TYA cancer population</i>	
<p>Cancer diagnosis negatively affected PA behaviours: 87% engaged PA pre-diagnosis vs 50% post-diagnosis.</p> <p>Post-diagnosis participants engaged in more gentle/low intensity activities 87% reported they were active pre-diagnosis which is higher than age matched population norms suggesting potential recruitment bias towards TYA cancer patients and survivors who were predisposed to PA</p> <p>SSQ-6 indicated high satisfaction with available support however 23% had to be excluded due to poor completion of measure</p> <p>57% reported they did not receive PA information or advice Information was predominantly received from a physiotherapist (62%), CNS (31%), after treatment (77%).</p> <p>Physiotherapist more likely to provide exercises and advice, CNS and doctor more likely to provide general advice to keep active or signpost 50% self-sourced PA information, mainly from the internet (53%).</p>	<p>Explanatory/Confirmatory</p> <p>Treatment negatively affected PA behaviours due to treatment-related side-effects and logistics of receiving treatment.</p> <p>Impact of treatment on PA varied depending on treatment type.</p> <p>If they participated in activity during treatment participants reported they reduced the intensity of their activities and predominantly walked.</p> <p>Participants expressed a lack of knowledge regarding exercising during treatment and a fear of exercise impacting efficacy of their treatment.</p> <p>Recovery involved participants gradually increasing PA behaviours through a process of trial and error.</p> <p>Family, friends and partners provided emotional (encouragement) and companionship (co-participation) support regarding activity.</p> <p>Friends did not fully understand so seeking peer support from other TYA cancer patients and survivors'</p> <p>Lack of instrumental and informational support for PA from HCP's therefore they were seeking this.</p>

Figure 36.0: Juxtaposition of quantitative and qualitative findings for research objectives 2.0.

In terms of informational support, the majority of interview participants expressed receiving a lack of support during and after treatment and a want for more informational support from HCP's or an individual with an exercise background. Lack of provision of PA information or advice was also reported by the majority (57%) of survey participants, correlating with this qualitative finding. Half of the survey participants reported self-sourcing PA information from the internet. This was also found to be the most used resource to self-source PA information by interview participants however, a large number of interview participants reported using social media (Instagram and YouTube) for PA informational support yet only one participant in the survey reported using YouTube for this. Interview participants had mixed feelings regarding the trustworthiness of information available through social media associated many positives including video format, ease of finding information due to platform algorithms and the ability to find Tya information from members of TYA cancer community about their experiences. This suggests social media allowed for social comparison and thus provided validation support which another social support construct.

Interview participants also felt that they received an insufficient amount of instrumental support regarding PA during their cancer journey. Those who did receive support felt this positively impacted their PA behaviours and helped them in their recovery. Participants mainly received physiotherapy input or participated in charity run exercise classes.

The SSQ-6 was utilised in this exploratory survey as it has been previously validated in young adults (Tan, Barkus and Favelle 2021; Evangeli et al. 2023). However, as stated earlier 23% of survey participants responses had to be excluded due to poor completion, this coupled with the qualitative findings around this cohorts need for different constructs of PA social support suggests future studies should consider an alternative social support measure. The Physical Activity and Social Support Scale (PASSS) measures the five constructs of social support discussed in this study in relation to physical activity and could be considered in future research into TYA cancer patients and survivors and physical activity (Golaszewski and Bartholomew 2019).

To summarise in relation to objective two, participants reported a negative impact of cancer diagnosis and treatment on their PA behaviours. Interview results highlighted the important role social support from friends, family partners and HCP's plays with regards to PA across an individual's cancer journey. Lastly,

participants expressed a clear need for more informational and instrumental support from HCP.

7.4 Objective 3.0: Barriers and Facilitators

The third objective of this thesis was to identify the perceived PA barriers and facilitators for the TYA population. The main survey and interview findings are displayed in figure 37.0 and were both examined in relation to the SEM. Within the survey, barriers and facilitators were measured through agreement with statements on a 5-point Likert scale. Results found four main potential barriers, three within the intrapersonal component of the SEM: fatigue, fear of injury and low motivation, and one environmental barrier identified as bad weather. Bad weather has not been identified as a PA barrier within the TYA oncology population in previous literature. As these studies have predominantly taken place in countries with warmer climates than Scotland this finding adds to the literature. Within the interviews participants also perceived low motivation and fatigue to be a barrier to PA. Participants also discussed a lack of knowledge around being active whilst on treatment and fear of activity altered the efficacy of their treatment. Additional barriers that were identified in the interview include poor mental health, logistics of receiving treatment and side-effects from treatment. Survey results supported side-effects from treatment being a barrier as this was the most common additional barrier reported by participants in open-text responses. Interview narrative also identified geography and time to be barriers to attending a walking group.

Statistical analysis of survey data revealed barrier statements; too tired, too much pain, too lazy, can't be active out of my home due to covid-19 were negatively correlated to participants stage of change, suggesting these to be barriers for those in the early stage of change but not in the later stages of change. This suggests the individual providing PA support should be aware of TYA stage of change when considering their barriers. Also, future researchers should consider SOC when planning interventions as this suggests those in earlier stages of change may have more potential barriers to overcome than those in the later stages. This is supported by previous research into the TTM and PA, which has found SOC significantly affects PA self-efficacy ($p < 0.001$), perceived benefits of exercise ($p < 0.001$) and perceived barriers of exercise ($p = 0.022$) in university students (mean age = 19.81, range 17-27) (Liu et al. 2018).

Quantitative findings	Qualitative findings
<i>Objective 3.0: Identify perceived barriers and facilitators to PA for the TYA cancer population</i>	
<p>Barriers:</p> <p>Main intrapersonal PA barriers were: fatigue, fear of injury and low motivation</p> <p>Main environmental PA barrier: bad weather</p> <p>SOC negatively correlated with statements: too tired, too much pain, too lazy, can't be active out of my home due to covid-19</p> <p>Low IPAQ category correlated to self-perceived laziness</p> <p>Treatment side-effects most commonly reported additional barrier</p> <p>Facilitators:</p> <p>Highest levels of agreement with facilitator statements relating to the health benefits of PA</p> <p>Access to facilities and social support from friends/family also motivators</p>	<p>Confirmatory/Explanatory</p> <p>Barriers:</p> <p>Intrapersonal Barriers: Treatment side-effects; accumulative impact of treatment; fatigue/energy levels; low motivation, poor mental health (anxiety and depression)</p> <p>Organisational Barriers: logistics of receiving treatment</p> <p>TYA walking group was not attended due to barriers of geography (environmental) and time (intrapersonal)</p> <p>Facilitators:</p> <p>Intrapersonal Facilitators: PA as a coping mechanism for cancer (sense of normalcy, element of control and distraction from cancer), PA to improve mood, body image post-treatment, pre-diagnosis PA</p> <p>Interpersonal Facilitator: Social support from friends, family, partner companionship (co-participation), emotional support (encouragement), instrumental support (charity run exercise groups and physiotherapy input)</p>

Figure 37.0: Juxtaposition of quantitative and qualitative findings for research objectives 3.0.

With regards to PA facilitators the survey findings suggest participants had highest agreement with the health benefits of PA (mental and physical). This concurs with interview findings in which participants stressed that the benefits of engaging in PA were both mental and physical. Access to facilities and social support from friends and family were also found to be PA motivators from the survey. Although access to facilities was not reported to be a facilitator in the interviews social support was. The interviews provided greater depth into the mechanisms of how friends and family support facilitated PA, through co-participation in activities and encouragement, however it also revealed that TYA's felt their friends and family were apprehensive to provide too much encouragement or participate in activities which were too strenuous for TYA's. This highlights a need to provide education to social support networks as well as TYA's about the benefits of PA and recommended intensity and duration of activities, which would not have been uncovered if the survey alone was used to collect data. Interview data also provided a much deeper understanding of the mental impact of PA during cancer and how this impacted PA behaviours.

Interestingly survey participants did not agree that cancer motivated them to be more active which disagrees with the findings of Pugh et al. (2018) who reported cancer to be a catalyst for health behaviour change (diet, exercise, smoking, alcohol consumption and UV exposure) in UK TYACS. However, interview analysis found cancer-related physical changes such as weight gain and participants perception of their body image to be a driver behind PA engagement post-treatment. The benefits of PA on physical and mental health, increased strength and fitness and improved mood, and coping with cancer were also all discussed as PA motivators in interviews. This aligns with survey participants agreement with facilitator statements regarding wanting to increase their independence, improve their mental health and that being active provides them with a distraction from cancer. This suggests for PA the cancer diagnosis itself may not be motivator but the effects of treatment and benefits of PA on cancer itself may facilitate behaviour change. Furthermore, as discussed previously interviews also found both informational and instrumental support from HCP's and cancer charities facilitates PA behaviour in TYA's with a lack of this resulting in additional PA barriers to the population. The integration of barrier and facilitator quantitative and qualitative findings suggests that closed barrier and facilitator questions alone may be an insufficient data collection tool to explore these within TYA population as it does

not provide context for why these factors affect behaviour. This demonstrates that a mixed methods approach to explore barriers and facilitators provides more rich data which has more clinical relevance.

In conclusion, several intrapersonal, environmental and organisational PA barriers were identified within this TYA oncology cohort as well as a number of intrapersonal, interpersonal, organisational and environmental facilitators. Again, social support was found to play an important role in PA engagement. As with assessment of behaviours this study also found a mixed method approach to be appropriate for investigating barriers and facilitators.

7.5 Objective 4.0: What is important?

The fourth research objective: what is important about PA to the TYA cancer population, was explored through the qualitative interviews, as can be seen in figure 38.0. As outlined in the methodology chapter, objective four was only addressed during the interviews and was not investigated in the survey.

Quantitative findings	Qualitative findings
<i>Objective 4.0: Explore what is important about PA to the TYA cancer population</i>	
Not addressed by the survey	<p>Exploratory</p> <p>Participants were unaware of UK PA guidelines.</p> <p>Participants felt PA guidelines should be different for TYAs with cancer compared to healthy adults and instead want personalised PA targets</p> <p>Participants expressed a want for more PA support from HCPs in the form of informational and instrumental support.</p> <p>Personalised support (TYA specific and individual specific)</p> <p>Peer-support</p> <p>1-2-1 conversation with a professional with exercise background following treatment and across cancer continuum to provide informational and instrumental support.</p>

Figure 38.0: Juxtaposition of quantitative and qualitative findings for research objectives 4.0.

Almost all interview participants were unaware of the PA guidelines for adults in the UK. When asked their opinion of PA guidelines for TYA's with and after cancer a large number of participants expressed that the guidelines should be different from that of UK adults. This suggests participants may need educating regarding recommended PA frequency, intensity and durations and the associated health benefits for individuals with cancer. The main reason for participants feeling guidelines should be different was because of cancer treatment with participants perceiving the guidelines to be unrealistic and demotivational if they were unable

to achieve them. Many felt that TYA's should work with an HCP to come up with personal PA targets. Participants strongly felt that it is important for PA support to be personalised to the individual (personal interests, cancer type, treatment) and their situation as each individual experience is unique. Participants also wanted to receive more information tailored specifically towards the TYA population and wanted more opportunities for TYA peer-support. Reiterating the findings of object two it was important for TYA's to receive informational and instrumental PA support from HCP or individuals with a background in exercise across the cancer care continuum.

7.6 Objective 5.0: PA and support preferences

Figure 39.0 illustrates the main quantitative and qualitative findings regarding PA and support preferences. Preferred PA in relation to type and setting were primarily explored quantitatively through the survey. Results found participants preferred type of activity was walking and their preferred location to be active was outdoors or at home. It should be noted that this survey was live from February 2021-January 2022 therefore, COVID-19 may have had an impact over PA preferences however, this was not explicitly measured but the impact of COVID-19 on PA behaviours is addressed in section 7.7. From the interviews walking appeared to be participants most preferred activity during treatment however, some reported they were fearful of pushing themselves too far and were unaware of what they could be doing. Participants preference for outdoor activity was also seen to impact their PA barriers with bad weather being reported as a main barrier to this cohort. Some participants explained in the interviews that if the weather was good, they were more motivated to be active but this was not one of their main PA facilitators.

Survey data also revealed participants preferred to be active alone or with a friend. From the interviews, participants reported receiving companionship support from their friends, family and partners in the form of PA co-participation. Participants enjoyed the social aspect of being active with someone else and reported that it was motivational as you were held accountable and could push each other. Some participants also noted that they had someone with them when being active during treatment for safety concerns.

Quantitative findings	Qualitative findings
<i>Objective 5.0: Identify PA preferences in relation to type, setting and support for TYA cancer population</i>	
<p>Preferred activity type: walking</p> <p>Preferred format: alone or with a friend(s)</p> <p>Preferred PA location: outdoors followed by at home</p> <p>Preferred time of day to be active: no consensus however this is typically driven by fatigue/energy levels, other commitments and time when motivation is the highest.</p>	<p>Confirmatory/Explanatory</p> <p>Preferred information delivery methods: 1-2-1 conversation (benefits of PA, what to do during and after treatment, persons specific, additional diet/healthy eating) and video format.</p>
<p>PA program preferences: Multifaceted program including PA education, tailored gym program, cancer specific group fitness class, subsidised gym membership, emotional support group</p>	<p>Preference for a TYA specific group</p> <p>In-person PA support classes preferred over virtual but benefits of virtual include being able to attend from anywhere and can fit into your own schedule</p>
<p>Preferred time of PA support: before treatment (guidance) during treatment (reassurance) after treatment (capacity to focus on recovery)</p>	<p>Fitness app would be beneficial adjunct</p> <p>Tailored PA support throughout journey but moving from gentle support and encouragement during treatment to rehabilitation post-treatment.</p>

Figure 39.0: Juxtaposition of quantitative and qualitative findings for research objectives 5.0

Concerning their preferred time of day to be active, there was no consensus seen in the survey responses. Through open-text response participants reported that their preferred time to be active was dictated by their energy levels/fatigue, other commitments such as work or caring for dependants, and the time in which they felt most motivated. In the interviews participants discussed the influential role that fatigue had over their PA behaviours, particularly during treatment.

The interviews explored participants support preferences in much greater depth than the survey. Participants opinions and preferences of informational and various instrumental support delivery mechanisms and modes were explored. As mentioned previously, participants preferred PA informational delivery mechanism was a 1-2-1 conversation with an HCP or professional with an exercise background. Interview participants explained that this would allow for more personalisation of advice to their situation. As demonstrated above in section 7.2 personalised PA support was important the TYA population. Another preference of TYA's regarding PA was that they preferred advice about different exercises to contain videos. Participants felt this was more engaging than a list of exercises and allowed them to see the correct technique. This video format straddled informational and instrumental support as participants also preferred following workout videos or training programs than creating their own activity plans.

The survey explored what participants felt would be important to have a multifaceted program containing PA information and advice but also tailored gym program, cancer specific group fitness class, subsidised gym membership, and emotional support group. Within the interviews participants expressed a preference for support which was again tailored but also provided an element of TYA peer-support. The opportunity to meet other members of the TYA cancer community was expressed by participants to be their main driver for wanting to attend a TYA cancer class. However, the want for TYA specific support was not evident in the survey data with only one participant selecting they would want another element in a PA program than the options provided to choose from (PA information and advice, tailored gym program, cancer specific group fitness class, subsidised gym membership or emotional support group) which was tailored PA advice.

When discussing different delivery mechanism of instrumental support interview participants felt that a fitness app would be a beneficial adjunct that could be used during and after treatment, could store PA information as well as exercises and be

used with others. However, again they wanted the exercises on the app to be tailored. Interview participants also felt favourably about a PA group, with a preference for an in-person group over a virtual group. Participants liked the idea of a hybrid option which gave TYAs the choice between attending virtually or in-person.

The survey examined TYAs preferred time to receive PA information across the cancer continuum. Survey results were inconclusive for one time point, with almost half of participants selecting multiple points, however, participants felt information around diagnosis would be overwhelming and instead during or after treatment were preferred. Participants who favoured before treatment were seeking guidance on PA during treatment, participants who favoured during treatment sought reassurance and those who favoured after felt this was when individuals had capacity to think about being active. This supports interview findings which found participants felt PA support should be available throughout the cancer continuum and led by the patient as all support needs are different. Although participants did suggest that during treatment focus should be on encouragement of PA and then there be more of rehabilitation support after treatment. Although PA preferences was measured more in the survey and support preferences more in the interview both the quantitative and qualitative findings align regarding preferences.

7.7 Impact of COVID-19

Although not a main objective of this thesis, the impact of COVID-19 cannot be ignored, with this being identified as a main theme within the interviews. Figure 40.0 summarises the main quantitative and qualitative findings in relation to COVID-19.

Quantitative findings	Qualitative findings
COVID-19	
80% reported COVID-19 impacted PA behaviours	Confirmatory/ Explanatory Social isolation as a result of social distancing and lockdown measures negatively impacted mood and PA behaviour Impact on PA behaviours: both negative and positive
<ul style="list-style-type: none"> - Shielding; reduced access to facilities; mental impact (positive and negative); reduced PA; increased PA 	
63% had to alter PA behaviours	Altered PA support available
<ul style="list-style-type: none"> - Change from facility based to home workouts or outdoor activities 	
Negatively correlated with SOC	<ul style="list-style-type: none"> - Services not running or online

Figure 40.0: Summary of quantitative and qualitative findings regarding the impact of COVID-19.

The majority of survey participants reported that COVID-19 impacted their PA, mainly due to shielding, reduced access to facilities as a result of social distancing and lockdown measures as well as, having both a positive and negative effect on their mental health and PA levels. Regarding the mental impact most participants felt the lockdown reduced their motivation however, some felt it had the opposite effect. The same was the case for PA level, most felt that the effects of shielding, reduced access to facilities and altered motivation compounded to have a negative effect on their PA levels however a smaller number felt that they had more time and motivation to be active as a result of the pandemic. As illustrated above COVID-19 was found to be negatively correlated to SOC, meaning participants in the earlier stages of change were more likely to perceive being unable to be active out with their home due to COVID-19 as a PA barrier. Narrative data from the interviews confirmed this with again participants reporting both positive and negative impacts on COVID-19 on their PA behaviours due to altered motivation, social distancing and time. Interview participants provided greater depth into the mental impact of COVID-19 and expressed feelings of social isolation and

loneliness as a result of the additional social distancing measures placed on the cancer community compared to the general public.

Survey participants reported alterations in PA behaviours which consisted of changing from facility-based activities to engaging in PA outdoors within the local area or home-based activities, which was also supported in the interviews. Additionally, interview participants highlighted that they experienced or perceived there to be changes to the available PA support services with many describing services were not currently running as a result of the pandemic or that they had switched to an online format. The results of both the quantitative and qualitative findings demonstrate that COVID-19 had a large impact on both physical and mental health within the TYA cancer community however, this was not negative for all participants with some finding that the COVID-19 lockdown increased their PA behaviours.

7.8 Integration summary

In summary, the research objectives have been compared in relation to quantitative and qualitative findings. Largely these findings corroborate with one another with the interview findings adding depth or explaining the survey results. The next section will address the strengths and limitations of the study as a whole before recommendations for future research and implications for practice are discussed in the conclusion chapter.

CHAPTER 8: STRENGTHS AND WEAKNESSES

8.0 Study strengths and Limitations

This section will review the strengths and limitations of the overall study.

One of the main strengths of this study was the in-depth scoping review of physical activity within the TYA oncology population. This review demonstrated the need for more extensive mapping of TYA PA behaviours, lived experiences, barriers, facilitators and preferences to inform support and formed the basis of this thesis.

Another major strength of this study was the novel use of a mixed methods design. This allowed for a much deeper exploration of the gaps identified in the scoping review. With regards to PA behaviours mixed methods allowed for physical activity behaviours not only to be quantified, and compared to previous literature and used as a comparator for future research but also be explored qualitatively through TYA stories. A common issue in PA research of TYA cancer survivors is poor recall of PA behaviours during treatment. The use of both quantitative and qualitative data collection provides a richer picture of TYA cancer patients journey across the cancer care continuum from diagnosis through treatment and beyond. This also allowed for narrative investigation into the effects of different types of treatment on PA behaviours, which has not previously been explored in this cancer cohort. The same can be said for PA barriers, facilitators and preferences. Having both the quantitative and qualitative data not only provides comparison with previous research, and provides the opportunity for testing relationships between variables but also allows for explanation about why these factors affect behaviour. With the limited amount of previous research focusing on PA in the TYA population, this study has provided further insight into the PA behaviours, lived experiences and PA support needs of this population.

A limitation of this study was that it was conducted as part of a developmental doctoral research degree and was an unfunded project. This was a learning process for the researcher throughout study development, data collection and the analysis process.

As with previous research into the TYA oncology population small sample size is another limitation of this study. This was a result of two main factors: firstly, the small amount of patient contact information available in the BWoSCC patient database limited the number of potential study participants and secondly the low

participant response rate and high participant drop-out rate in the survey. The most likely contributing factor was the participant burden associated with completing the survey. As it was exploratory it was a lengthy survey and took a long time to complete. As previously stated, survey length has been found to be negatively associated with participant response rate (Wu, Zhoa and Fils-Aime 2022). The COVID-19 pandemic also impacted survey response rate as the majority of research at the time switched to an online model, typically adopting online surveys as other data collection methods were not feasible or safe during the pandemic (Hlatshwako et al. 2021). This led to survey saturation, which coupled with digital fatigue from work and education also being based online may have impacted the thesis survey response rate. The small sample size of the study meant that it was not possible to assess for group differences across PA behaviours or PA barriers and facilitators based on cancer type, treatment type or participant demographics as was originally planned. Also as stated earlier the small sample size of this study increased the risk of type one error when conducting the inferential statistics on the barrier and facilitator statements and as such results need to be interpreted with caution.

An additional impact of the COVID-19 pandemic was that planned face-face interviews had to change to remote interviews (virtual face-face or telephone). Although this reduced the number of non-verbal cues the novice interviewer was receiving from participants during the interviews it allowed expansion of participant recruitment from a single TYA treatment site to multiple sites across Scotland which was a positive advantage. Not only did this help with participant recruitment but it also meant that the data gathered was more representative of the Scottish TYA service as a whole.

A final limitation of this study was that, based on the high levels of self-reported PA behaviours, study participants were possibly more physically active than the general TYA cancer population. This recruitment bias towards active individuals is a general limitation within PA research as a whole (Harris et al. 2008). However, it may mean that the results do not fully reflect the experiences of less active TYA cancer patients and survivors.

CHAPTER 9: CONCLUSION

9.0 Chapter overview

This study aimed to explore the physical activity behaviours, lived experiences and preferences of individuals diagnosed with cancer between the ages of 16-25. This final chapter highlights recommendations for future research within PA in the TYA oncology population and discuss the implications of this research for clinical practice. Lastly, the extent to which the six research objectives were achieved will be illustrated and the findings summarised.

9.1 Recommendations for Future Research

The final objective of this study was to synthesise TYA PA recommendations for research and practice. Recommendations for future research based upon the findings of this study and the gaps identified within the scoping review shall now be discussed.

As this study was primarily focussed on Scottish TYA cancer services a four nations study could be conducted to map TYA PA behaviours, lived experiences and preferences across the UK to assess if findings are replicated as well as assess for service differences between the countries. This would increase the generalisability of findings to the UK TYA oncology population as this study focuses on a small Scottish TYA cohort. Future studies should also be conducted with a larger, more diverse sample in terms of equity and inclusion, as this study sample was primarily female, white and classified themselves as active. This is required to assess for differences between demographics with regards to PA barriers, facilitators and preferences and again ensure results are more representative of the whole TYA cancer population. However, due to this population being a small aspect of UK cancer population thought and planning needs to occur across the UK before larger studies can be conducted.

Alternatively, future research could be conducted in homogeneous sub-populations to assess in greater depths the effects of specific treatment types or cancer diagnosis on PA. Targeting sub-populations in future research may be beneficial given the small number of TYA diagnoses each year. To address bias in patient reported outcome measures, future studies measuring PA behaviour could consider the use of an objective measure, such as accelerometer, as an adjunct to a subjective measure which may be susceptible to self-report bias or recall bias (Fadnes, Taube and Tylleskar 2008). Alternatively, as demonstrated in this study,

mixed methods could also be used in conjunction with self-report measures. This method is recommended as it provides context and greater insight into behaviours.

Furthermore, based on the results of this study the IPAQ-LF is recommended in place of the IPAQ-SF as a self-report measure of PA behaviour. This is because it captures behaviours across different PA domains: occupation, domestic, transport and leisure-time (Craig et al. 2003) which will provide a more accurate picture of activity levels in comparison with UK norms and PA guidelines in this population. However, as this measure itself is lengthy, it is recommended that it be used as part of small surveys as opposed to being added into a larger exploratory survey like the one used in this study.

Moreover, research considering TYAs at various stages of the cancer continuum should be conducted to fully assess the impact of these different stages (cancer diagnosis, on-treatment, early off-treatment, long-term off-treatment) on TYA PA levels. This is recommended as participants within this study reported changes in their PA behaviours across their cancer journey however, this was not fully assessed due to the small sample size. Further research into this would provide greater insight into the TYA experience and provide more information to clinicians about when and why TYA PA behaviours are altered. This would then help guide future research into PA support.

Additionally, as with previous TYA PA literature this study only measured cancer patients and survivors' sedentary behaviour via time spent sitting as part of the IPAQ-SF. As previously outlined, sedentary behaviour is determinantal to health therefore, future research should consider the impact of sedentary behaviour across the cancer continuum, particularly during treatment as this study demonstrated this had the largest negative affect on TYA's PA behaviours. Research could focus on assessing sedentary behaviour differences between treatment status (on- and off-treatment) of cancer patients as well as differences between mode of treatment delivery (inpatient treatment vs outpatient treatment). Again, this information would help inform research regarding PA support during the cancer journey which would be beneficial for informing clinical practice.

As the importance of PA social support was a main finding within this study, future mixed methods research into the five constructs, information, instrumental, companionship, emotional and validation, is recommended. This will allow for a

deeper exploration of each construct. It will also allow for between group differences with regards to demographics and cancer type and/or treatment to be investigated quantitatively and explained qualitatively.

With regards to TYA PA intervention research, the scoping review illustrated that there is a lack of large, robust, RCT's within the literature. Further research is required to investigate: longitudinal or maintenance interventions, optimal exercise frequency, intensity and durations for TYA populations, as well as interventions utilising digital technology such as, fitness apps containing personalised activity plans and education or interventions utilising hybrid (in-person and virtual) delivery modes.

Future interventions should also consider the TYA PA barriers and facilitators identified in this study when planning interventions as well as potential participants TTM stage of change. Interventions should focus on more cognitive and affective processes for those in the early stages and progress to behavioural processes for those in the later stages (Norcross, Krebs and Prochaska 2011; Raihan and Cogburn 2023). Future research must consider how the intervention engages potential participants in the early stages.

As discussed previously AHPs have been shown to have the highest knowledge of guidelines yet, be least likely to provide PA advice to TYAs. Also, not being the right person has been found to be a barrier to HCP's providing lifestyle advice to TYAs. Future research could be conducted to mapped clinician's PA knowledge, PA advice self-efficacy and previous experiences of providing PA advice to establish who is the most appropriate person to provide TYA's with advice and what training they need to have undertaken. Based on the findings of this study, TYAs have an unmet need for informational and instrumental support therefore establishing clinician proficiency and confidence with delivery of PA support is important. This could then be considered in regards to TYA service pathways as well as be used to assess for potential clinician training needs.

9.2 Implications for practice

These practice recommendations apply to the Scottish TYA service. It was out with the scope of this study to explore TYA clinicians' (including TYA CNS, physiotherapist, doctors) opinions and needs with regards to TYA PA support. However, in relation to the findings of this study and identified support needs for PA from healthcare professionals, it is important to establish clinician's PA

knowledge, PA advice self-efficacy and previous experiences of providing PA advice. This could be achieved relatively swiftly through the staff development process and then considered with regard to TYA service pathways as well as a baseline assessment leading to the development of resources to support clinicians' continuing professional development (CDP) needs.

The study results should be shared with clinicians within the MSN CYPC to highlight the identified TYA cancer patients and survivors informational and instrumental support needs across the cancer continuum. Although a small sample size this study has highlighted gaps in current service provision and can be used to inform future research or evaluation of TYA service structure and pathways particularly with regards to instrumental and informational social support.

The results of this study further support the Scottish Government 2021-2026 strategy regarding the need for more AHP support within the MSN CYPC to enable ambitions 3 (incorporated supportive care services) and 5 (continuing care when treatment completes) to be met. The recommendation from the 2021-2026 strategy, regarding the creation of a health behavioural resource and the creation of a dedicated AHP lead position within the service pathway are also supported.

However, the current pathway for after treatment care involves signposting and referral to community services which may not be equipped to deal with TYA cancer survivors and a small number may receive support from a designated TYA physiotherapist but location dependent (as seen in table 1.0) (Scottish Government 2021). TYA's may also have access to charity run exercise programs but this is again restricted by geographic area and to adult cohorts which as seen from the results of the study may pose barriers to engagement.

Recommended solutions include development and or expansion of physiotherapy posts within the TYA service in order to address TYA cancer patients, survivors and their social networks need for education regarding PA guidelines and participation in activity during and after treatment. Alternatively, given the clinical landscape of the TYA service and limited staffing with exercise prescription background, an additional practice recommendation would be to consider additional training or CPD for current staff members around TYA PA guidance and exercise prescription.

A strong recommendation is the need for personalised PA support due to the differing presentations and individual responses to treatment. Participants felt quite strongly a one size fits all approach did not meet their needs. The results of

this study demonstrate TYAs preference for in-person support and suggest TYA's may feel favourably towards an in-person TYA PA group or end of treatment clinics, used in conjunction with a tailored exercise program and fitness app. This may allow for targeted behaviour change and provide the personalisation TYA's prefer thus, reducing their current unmet need for informational and instrumental PA support.

Peer support is also an important consideration and while there are additional challenges due to relatively small numbers over a wide geographic area further work is required to investigate possible solutions. Investigation to assess what type of peer support TYA's are seeking (emotional, companionship, validation) and how this relates to PA will provide clarity regarding future peer support integration into PA support pathways.

To fully address the points above, there is a requirement for co-production research between MSN CYPC clinicians, TYA cancer patients and survivors and third-party stakeholders. This is needed to combine the needs of TYA's with the challenges the clinical setting to facilitate the design of an effective PA support pathway within Scotland.

9.3 Achievement of Research Question

The extent to which the six research objectives were met in order to address the overarching research question is illustrated below.

1. To identify self-reported physical activity levels of this population across the cancer continuum. As demonstrated in section 7.2 this objective was achieved through both the quantitative and qualitative phases of the study.
2. To explore the experiences this population has had with physical activity. As seen in section 7.3 this objective was achieved with the interview data confirming and explaining the survey results.
3. To identify the perceived barriers and facilitators to physical activity for this population. This included exploring any potential group differences with regards to demographics, cancer type, and treatment type on PA engagement. This objective was only partially achieved during this study as perceived barriers and facilitators were identified. Due to the small sample size, it was not possible to conduct the planned inferential statistics to assess between group difference with regards to participant

demographics, cancer type or treatment type and PA barriers/ facilitators. However, interview analysis did illustrate differences with regards to PA engagement and treatment type (systemic treatment having a greater negative impact on PA than localised treatment) suggesting this to be a PA barrier within this cohort.

4. To explore what individuals from this population feel is important to them, about physical activity. As planned this objective was achieved through the qualitative phase of this study.
5. To identify physical activity preferences in relation to type, setting, delivery method and support for this population. Again, this objective was achieved through both the survey and interviews within this study. Preferences with regards to PA setting, delivery and type were obtained predominantly through the survey data whereas, preferences with regards to PA support were obtained during the interviews.
6. To synthesise recommendations for physical activity in this group. This objective was achieved and outlined above in section 9.1.

Through the achievement of the above research objectives this study successfully addressed the overarching research question: what are the physical activity behaviours, lived experiences and preference of individuals diagnosed with cancer between the ages of 16-25, including those with an active diagnosis (on or off treatment), those in remission or those cancer free? The findings of this study address a number of research gaps identified in the scoping review, chapter two. Results add to literature regarding TYA cancer patients and survivors' current PA behaviours, the impact of treatment on PA behaviours, barriers and facilitators to PA engagement as well as PA and support preferences in the TYA cancer population.

9.4 Conclusion of Study Findings

To summarise the findings, cancer and its subsequent treatment negatively affect TYA cancer patients and survivors PA behaviours. A number of PA barriers were found in this cohort with fatigue, low motivation and treatment-related side-effects having the largest impact on behaviour. Interview findings revealed type of treatment received also affect TYA's behaviours with the accumulative effects of systemic treatment having a larger negative impact on PA compared to localised treatment types. Emotional and companionship (co-participation) support from friends, family and partners, access to resources (instrumental support or PA

facilities), post-treatment body image and the physical and mental health benefits were all PA facilitators within the TYA population. PA was also found as coping mechanism for TYA's to deal with cancer.

Although some participants report they have managed to return to pre-diagnosis PA levels the majority of this cohort are insufficiently active and not meeting PA guidelines. The majority of this cohort were also unaware of the PA guidelines and a number had safety concerns surrounding exercise whilst on treatment. This illustrates a need for education regarding PA intensity, duration and the associated health benefits during and after cancer. Results also suggested it would be beneficial to provide this education to TYA's social networks to enhance PA social support.

This cohort of TYA cancer patients and survivors intend to improve their PA behaviours however they have a need for more PA support in the form of informational and instrument social support from a HCP. Although findings revealed there is some support currently available to TYAs this is not meeting this cohorts needs. Participants felt the PA advice they received was too general and instead felt personalised support, tailored to themselves and their cancer would be more beneficial. This TYA cohort wished to receive this information via a 1-2-1 conversation with an HCP or individuals with an exercise background. As a result of this lack of support participants reported self-sourcing PA information, primarily through the internet, using google or social media. This TYA oncology cohort particularly liked the video format and shared experiences of other TYA cancer patients and survivors available via social media, although not all participants trusted this to be a reliable source.

TYA cancer patients and survivors within this study also had a want for more TYA peer support as their friends did not fully understand their situation. They displayed a preference for in-person support over virtual support but acknowledged that virtual delivery can overcome geographic and accessibility barriers, and as a result, they felt favourably towards a hybrid model of support that incorporated in-person and online or technology-based formats. Participants expressed a preference for PA encouragement during treatment, followed by rehabilitation post-treatment.

In conclusion TYA cancer patients and survivors within this study were interested in PA and rehabilitation however, their situations are unique and as such they require personalised PA support.

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Appendix 1: TYA Cancer Specialist Workforce- Census March 2021 (pg. 80 Scottish Government 2021-2026 Cancer Strategy)

Funding Body	Post	Base	Hours	WTE
MSN CYPC & Teenage Cancer Trust (TCT)	TYA National Lead Nurse	National	37.5	1.0
MSN CYPC	TYA National Clinical Lead		8	2 PAs ²⁹
MSN CYPC & TCT	TYA National MDT Co-ordinator		37.5	1.0 ³⁰
TCT	Clinical Nurse Specialist	NHS Highland (Raigmore Hospital)	18.75	0.5
Young Lives vs Cancer	Social Worker		17.5	0.5
MSN CYPC	TYA Clinical Lead		4	1 PA
TCT	Clinical Nurse Specialist	NHS Tayside (Ninewells Hospital)	37.75	1.0
Young Lives vs Cancer	Social Worker		10	0.29
MSN CYPC	Clinical Lead		4	1 PA
TCT	Clinical Nurse Specialist	NHS Grampian (Aberdeen Royal Infirmary)	25	0.67
Young Lives vs Cancer	Social Worker		10	0.29
MSN CYPC	Principal Clinical Psychologist		18.75	0.5
MSN CYPC	Clinical Lead		4	1 PA
TCT	Clinical Nurse Specialist	NHS Lothian (Western General Hospital)	37.5	1.0
NHS Lothian	Clinical Nurse Specialist ³¹		34	0.91
TCT	Youth Support Co-ordinator ³²		37.5	1.0
Young Lives vs Cancer	Social Worker		30	0.86
MSN CYPC	Clinical Lead		4	1 PA
TCT	Youth Support Co-ordinator	NHS Greater Glasgow & Clyde (Beatson West of Scotland Cancer Centre)	37.5	1
NHS Greater Glasgow & Clyde	Clinical Nurse Specialist ³¹		37.5	1.0
	Clinical Nurse Specialist ³³		37.5	1.0
Young Lives vs Cancer	Social Worker		35	1.0
MSN CYPC	Principal Clinical Psychologist		18.75	0.5
MSN CYPC	Physiotherapist		18.75	0.5
MSN CYPC	Dietitian		7.5	0.2

29 PAs - Programmed activities or hours treated as whole time (10 PAs per week = 40 hours)

30 Post vacant since February 2020, cover provided by the MSN CYPC Network Support Officer

31 TCT adopted post

32 TCT fund additional 2.0WTE Youth Support Co-ordinators, working within the paediatric hospitals. These posts work with children and young people beyond 16 years. These are not TYA specific, therefore have not been included within the above data

33 Macmillan Cancer Support pump primed

Appendix 2: Search Strategy by Database**CHINAL**

Search terms	((AB "teenage* and young adult*" OR AB "adolescents* and young adult*" OR AB teenager* OR AB adolescent* OR AB "young adult*") AND (AB cancer* OR AB "cancer patients" OR AB "cancer surviv*" OR MH "cancer surviv*" OR MH neoplasms OR AB neoplasms OR AB lymphoma OR MH lymphoma OR MH oncology OR AB oncology OR AB survivorship OR MH survivorship) AND (MH "therapeutic exercise*" OR MH "physical fitness" OR AB fitness OR A "physical activit*" OR MH "physical activity" OR MH exerci* OR A exerci* OR AB rehabilitation OR MH rehabilitation MH "physical therapy" OR AB "physical therapy"))
Search 1	Refined by: January 2010- August 2021, English language and peer-reviewed 254 results
Search 2	Refined by: August 2021- July 2022, English language and peer-reviewed 42 results

MEDLINE

Search terms	((MH Cancer* OR AB cancer* OR AB "cancer patients" OR AB oncology OR AB lymphoma OR MH lymphoma OR MH neoplasms OR AB neoplasms OR AB "cancer surviv*" OR AB survivorship OR MH survivorship) AND ("adolescent* and young adult*" OR "teenage* and young adult*" OR AB teenager* OR AB adolescents* OR AB "young adult*") AND (AB exerci* OR MH exerci* OR AB "physical activi*" OR AB fitness OR MH "physical fitness" OR MH "exercise therapy" OR MH rehabilitation OR AB rehabilitation OR AB "physical therapy"))
Search 1	Refined by: January 2010- August 2021, English language and peer-reviewed 362 results
Search 2	Refined by: August 2021-July 2022, English language, peer-reviewed 79 results

AMED

Search terms	((AB "cancer surviv*" OR SU "cancer surviv*" OR AB neoplasms OR SU neoplasms OR SU oncology OR AB oncology OR AB "cancer patients*" AB cancer* OR SU cancer OR AB lymphoma OR SU lymphoma OR SU survivorship OR AB survivorship) AND (AB exerci* OR SU exerci* OR AB "physical activit*" OR AB fitness OR SU "physical fitness" OR SU "exercise therapy" OR AB rehabilitation OR SU rehabilitation SU "physical therapy" AB "physical therapy") AND (AB "young adult*" OR AB adolescents* OR AB teenager* OR AB "teenage* and young adult*" OR AB "adolescent* and young adult*"))
Search 1	Refined by: January 2010- August 2021, English language and peer-reviewed 24 results
Search 2	Refined by: August 2021-July 2022, English language, peer-reviewed 0 results

SPORTDiscus

Search terms	((SU exercise OR AB exerci* OR SU "physical activity" OR AB "physical activit*" OR AB fitness OR SU rehabilitation OR AB rehabilitation OR SU "exercise therapy" OR SU "physical fitness" OR SU "physical therapy" OR AB "physical therapy") AND (AB adolescent* OR AB teenager* OR AB "adolescents* and young adult*" OR AB "teenage* and young adult*" OR "young adult*") AND (AB cancer* OR SU cancer* OR SU "cancer patients" OR SU oncology OR AB oncology OR SU neoplasms OR AB neoplasms OR AB lymphoma OR SU lymphoma OR AB "cancer surviv*" OR AB survivorship))
Search 1	Refined by: January 2010- August 2021, English language and peer-reviewed 47 results
Search 2	Refined by: August 2021-July 2022, English language, peer-reviewed 12 results

Sage Journals

Search terms	((AB "physical activit*" OR AB exerci* OR AB fitness OR AB "physical fitness" OR AB "exercise therapy" OR AB rehabilitation OR AB "therapeutic exercise" OR "physical therapy") AND (AB adolescent* OR AB teenager* OR AB "adolescents* and young adult*" OR AB "teenage* and young adult*" OR "young adult*") AND AB cancer* OR AB oncology OR neoplasms OR "cancer patients" AB "cancer surviv*" OR AB lymphoma OR AB survivorship))
Search 1	Refined by 2010-current (2021) 49 results
Search 2	Refined by 2021-current (2022) 12 results

EMBASE

Search terms	((cancer* or "cancer patients" or "cancer surviv*" or neoplasms or oncology or lymphoma or survivorship) AND ("physical activit*" or exerci* or rehabilitation or fitness or "physical fitness" or "physical therapy") AND ("teenage* and young adult*" or "young adult*" or "adolescents*" or "adolescent* and young adult*" or teenager*))
Search 1	Refined by 2010- current (2021), English language 688 results
Search 2	Refined by 2021-current (2022), English language 102 results

PEDro

Search terms	Cancer* "physical activity" "young adult*"
Search 1	9 results
Search 2	1 result

Google Scholar

Search terms	((exercise* OR "physical activity") AND (cancer* OR survivorship) AND ("young adult* OR teenage* OR "adolescent and young adult*))
Search 1	Refined by 2010-2021, 15 pages screened 35 results
Search 2	Refined by 2021-2022, 40 pages screened 55 results

ISRCTNR

Search terms	(young adult) AND (physical activity) AND (cancer)
Search 1	1 result
Search 2	0 results

ClinicalTrials.gov

Search terms	(young adult) AND (physical activity) AND (cancer)
Search 1	1 result
Search 2	0 results

Appendix 3 Full-text excluded from scoping review and reasons for exclusion

ADAMOVICH, T. et al., 2022. Barriers and facilitators to physical activity participation for child, adolescent, and young adult cancer survivors: a systematic review. *Journal of cancer survivorship: research and practice*, pp.1-18. Reason for exclusion: unable to extract data.

ADAMS, S.C. et al., 2021. Young Adult Cancer Survivorship: Recommendations for Patient Follow-up, Exercise Therapy, and Research. *JNCI cancer spectrum*, 5(1). Reason for exclusion: Population not defined.

ADAMS, S.C. et al., 2021. Preferences for exercise and physical activity support in adolescent and young adult cancer survivors: a cross-sectional survey. *Supportive care in cancer: official journal of the Multinational Association of Supportive Care in Cancer*, 29(7), pp. 4113-4127. Reason for exclusion: wrong population.

AGGARWAL, R. et al., 2020. Health-related social media use and preferences of adolescent and young adult cancer patients for virtual programming. *Supportive care in cancer: official journal of the Multinational Association of Supportive Care in Cancer*, 28(10), pp. 4789-4801. Reason for exclusion: wrong population.

AMIRI, A. et al., 2021. Chemotherapy-induced toxicity in patients with testicular germ cell tumors: The impact of physical fitness and regular exercise. *Andrology*, 9(6), pp. 1879-1892. Reason for exclusion: wrong population.

ATKINSON, M. et al., 2021. A randomized controlled trial of a structured exercise intervention after the completion of acute cancer treatment in adolescents and young adults. *Pediatric Blood & Cancer*, 68(1), pp. 1-12. Reason for exclusion: duplicate.

BAIRD, H. et al., 2016. Model of psychosocial & supportive care in oncology for Australian adolescent & young adult cancer patients. *Supportive Care in Cancer*, 4(1), pp. S167-S168. Reason for exclusion: wrong concept.

BASHORE, L., ALEXANDER, G.K. and PARK, E., 2021. Engagement in Physical Activity Among Young Adult Childhood and Adolescent Cancer Survivors: Integration of Nature Technology. *Journal of adolescent and young adult oncology*, 10(6), pp. 740-744. Reason for exclusion: wrong study population.

BASHORE, L., ALEXANDER, G.K. and PARK, E., 2021a. Engagement in Physical Activity Among Young Adult Childhood and Adolescent Cancer Survivors: Integration of Nature Technology. *Journal of adolescent and young adult oncology*, 10(6), pp.740-744 Reason for exclusion: duplicate.

- BECZE, E., 2016. What Oncology Nurses Need to Know About Supporting AYAs With Cancer. *ONS Connect*, 31(4), pp. 24-25.
Reason for exclusion: wrong concept.
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Reason for exclusion: wrong study population.
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Reason for exclusion: wrong concept.
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Reason for exclusion: wrong study population.
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Reason for exclusion: wrong study population.
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Reason for exclusion: wrong study population.
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Reason for exclusion: wrong study population.
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Reason for exclusion: wrong study population.
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Reason for exclusion: wrong study population.
- BERG, C. and HAYASHI, R.J., 2013. Participation and Self-Management Strategies of Young Adult Childhood Cancer Survivors. *OTJR: Occupation, Participation and Health*, 33(1), pp. 21-30.
Reason for exclusion: wrong study population.
- BØHN, S. et al., 2021. Lifestyle among long-term survivors of cancers in young adulthood. *Supportive Care in Cancer*, (29), pp. 289-300.
Reason for exclusion: wrong study population.
- BRAAM, K.I. et al., 2013. Physical exercise training interventions for children and young adults during and after treatment for childhood cancer. *The Cochrane*

database of systematic reviews, (4).

Reason for exclusion: duplicate.

BRAAM, K.I. et al., 2016. Physical exercise training interventions for children and young adults during and after treatment for childhood cancer. *The Cochrane database of systematic reviews*, 3

Reason for exclusion: wrong study population.

BRADFORD, N.K. et al., 2022. Psychological, functional and social outcomes in adolescent and young adult cancer survivors over time: a systematic review of longitudinal studies. *Psycho-oncology*, pp. 1-11.

Reason for exclusion: wrong concept.

BRADFORD, N.K. and CHAN, R.J., 2017. Health promotion and psychological interventions for adolescent and young adult cancer survivors: A systematic literature review. *Cancer treatment reviews*, 55, pp. 57-70.

Reason for exclusion: wrong study population.

BRUNET, J. et al., 2014. Stress and physical activity in young adults treated for cancer: the moderating role of social support. *Supportive care in cancer: official journal of the Multinational Association of Supportive Care in Cancer*, 22(3), pp. 689-695.

Reason for exclusion: wrong study population.

BRUNET, J., WURZ, A. and SHALLWANI, S., 2017. A scoping review of research on the antecedents, correlates, and outcomes of physical activity in adolescents and young adults diagnosed with cancer. *Psycho-oncology*, 26, pp. 109-110.

Reason for exclusion: wrong population.

BRUNET, J., WURZ, A. and SHALLWANI, S.M., 2018. A scoping review of studies exploring physical activity among adolescents and young adults diagnosed with cancer. *Psycho-oncology*, 27(8), pp. 1875-1888.

Reason for exclusion: wrong study population.

BUCY, A.M. et al., 2022. Physical Activity in Young BRCA Carriers and Reduced Risk of Breast Cancer. *American Journal of preventative medicine*, 000(000), pp. 1-9.

Reason for exclusion: wrong concept.

BURKE, S. et al., 2017. Physical Activity and Quality of Life in Cancer Survivors: A Meta-Synthesis of Qualitative Research. *Cancers*, 9(5)

Reason for exclusion: wrong study population.

BURT, S., CURRAN, M.S. and SAYLOR, E., 2014. Comprehensive cancer wellness program for young adults. *Psycho-oncology*, 23, pp. 22.

Reason for exclusion: population not defined.

CAMPBELL, L., MERCER, L. and SMITH, E., 2019. Self-reported barriers and perceptions of physical activity among adolescent leukaemia patients during maintenance phase treatment. *Physiotherapy (United Kingdom)*, 105

Reason for exclusion: wrong study population.

CARRETIER, J. et al., 2016. A Review of Health Behaviors in Childhood and Adolescent Cancer Survivors: Toward Prevention of Second Primary Cancer. *Journal of adolescent and young adult oncology*, 5(2), pp. 78-90.

Reason for exclusion: population not defined.

- CARU, M. et al., 2022. A scoping review to map the evidence of physical activity interventions in post-treatment adolescent and young adult cancer survivors. *Critical reviews in oncology/hematology*, 171, pp. 103620.
Reason for exclusion: wrong study population.
- CHAN, Y.T. et al., 2021. Adventure therapy for child, adolescent, and young adult cancer patients: a systematic review. *Supportive Care in Cancer*, 29(1), pp. 35-48.
Reason for exclusion: wrong study population.
- CHAN, Y.T. et al., 2021a. Adventure therapy for child, adolescent, and young adult cancer patients: a systematic review. *Supportive care in cancer: official journal of the Multinational Association of Supportive Care in Cancer*, 29(1), pp. 35-48.
Reason for exclusion: duplicate.
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Reason for exclusion: wrong study population.
- CHANG, C. et al., 2013. Systematic review and meta-analysis of nonpharmacological interventions for fatigue in children and adolescents with cancer. *Worldviews on evidence-based nursing*, 10(4), pp. 208-217.
Reason for exclusion: wrong study population.
- CHOI, Y., RHEE, H. and FLANNERY, M., 2022. Health behaviors in adolescent survivors of cancer: An integrative review. *Journal of pediatric nursing*,
Reason for exclusion: wrong study population.
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Reason for exclusion: wrong study population.
- CHRISTOPHERSON, U. et al., 2021a. Use of active video games with or without videoconferencing on health outcomes in adolescent and young adult cancer survivors: a systematic review. *Journal of cancer survivorship: research and practice*,
Reason for exclusion: duplicate.
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Reason for exclusion: population not defined.
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Reason for exclusion: wrong study population.
- COOMBS, A., SCHILPEROORT, H. and SARGENT, B., 2020. The effect of exercise and motor interventions on physical activity and motor outcomes during and after medical intervention for children and adolescents with acute lymphoblastic leukemia: A systematic review. *Critical reviews in oncology/hematology*, 152, pp.

103004. Reason for exclusion: wrong study population.
- CROSS, A., HOWLETT, N. and SHEFFIELD, D., 2020. Social ecological interventions to increase physical activity in children and young people living with and beyond cancer: a systematic review. *Psychology & Health*, 35(12), pp. 1477-1496. Reason for exclusion: wrong study population.
- CROWDER, S.L., BURO, A.W. and STERN, M., 2022. Physical activity interventions in pediatric, adolescent, and young adult cancer survivors: a systematic review. *Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer*, 30(6), pp. 4635-4649. Reason for exclusion: wrong study population.
- CULOS-REED, S. et al., 2020. The international pediatric oncology exercise guidelines. *Pediatric Blood and Cancer*, 67. Reason for exclusion: population not defined.
- CURRAN, M.S. et al., 2013. Cancer to 5K. *Psycho-oncology*, 22, pp. 120. Reason for exclusion: population not defined.
- DA SILVA XAVIER, W. et al., 2020. Nonpharmacological interventions in the improvement of quality of life in children and adolescent cancer patients. *Acta Paulista de Enfermagem*, 33(1), pp. 1-11. Reason for exclusion: wrong study population.
- DALZELL, M. et al., 2010. Activity levels and fatigue related to exercise compliance in young adults with cancer. *Journal of Clinical Oncology*, 28(15), Reason for exclusion: unable to access.
- DALZELL, M. et al., 2010. Exercise compliance and intensity (MET-hours/week) related to stage of disease and fatigue (BFI) in young adults with cancer. *Psycho-oncology*, (19). Reason for exclusion: wrong study population.
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- DELEEMANS, J.M. et al., 2021. Associations Among Health Behaviors and Psychosocial Outcomes in Adolescent and Young Adult Cancer Survivors. *Journal of adolescent and young adult oncology*, 10(6), pp. 675-681. Reason for exclusion: duplicate.
- DEMERS, C. et al., 2020. The adoption of healthy behaviours or how to optimize patient outcomes in paediatric oncology: A scoping review. *Pediatric Blood and Cancer*, (67). Reason for exclusion: wrong study population.
- DEMERS, C., GÉLINAS, I. and CARRET, A., 2016. Activities of Daily Living in Survivors of Childhood Brain Tumor. *American Journal of Occupational*

- Therapy*, 70(1), pp. 1-8.
Reason for exclusion: wrong study population.
- DEMIR, N. et al., 2018. Investigation of quality of life and healthy life style behaviors of adolescents having undergone cancer treatment. *Pediatric Blood and Cancer*, 65, pp. S603-S604.
Reason for exclusion: wrong concept.
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Appendix 5 Study and participant characteristics of scoping review studies with corresponding reference number (ref no.)

Ref No.	Author, year, country	Study design	Sample size (n), gender (female (F), male (M)), race/ethnicity	Age of study participants (SD)	Cancer type (%)	Cancer status of participants (treatment= Rx)	Cancer treatment	Age at diagnosis (dx)/ time since dx
1	Aikinson et al 2021; Australia	RCT	n=43, F= 20; M= 23; ethnicity N/R	Mean age= 20 +/- 3	Sarcoma (12%), Leukaemia (9%) Hodgkin's lymphoma (37%), non-Hodgkin's lymphoma (21%), germ cell (19%), other (2%)	Completed Rx within 2 months of study participation	Chemotherapy and/or Radiation therapy, high intensity (35%), moderate intensity (65%)	N/R
2	Salchow et al 2021; Germany	RCT	n=89, F=49, M=40, ethnicity N/R	Mean age= 24.1 +/- 6.3	solid tumours (36%), Lymphoma (35%) and Leukaemia (18%)	Cancer survivors	Chemotherapy (84%), radiotherapy (44%), surgery (33%)	Mean age= 15.9 +/-9.0
3	Munsie ^a 2021; Australia	RCT	n=43, F=16; M= 27, ethnicity N/R	Mean age= 21.2	Hodgkin's Lymphoma (25%), Sarcoma (23%), CNS tumour (25%), germ cell tumour (12%), leukaemia (9%), melanoma (2%),	On-Rx	Chemotherapy or chemotherapy and radiation; high intensity (49%), low/moderate	N/A

Ref No.	Author, year, country	Study design	Sample size (n), gender (female (F), male (M)), race/ethnicity	Age of study participants (SD)	Cancer type (%)	Cancer status of participants (treatment= Rx)	Cancer treatment	Age at diagnosis (dx)/ time since dx
					Burkitt lymphoma (2%)		intensity (51%)	
4	Munsie ^b 2021; Australia	RCT	N=43, F=16; M= 27, ethnicity N/R	Mean age= 21.2	Hodgkin's Lymphoma (25%), Sarcoma (23%), CNS tumour (25%), germ cell tumour (12%), leukaemia (9%), melanoma (2%), Burkitt lymphoma (2%)	On-Rx	Chemotherapy or chemotherapy and radiation; high intensity (49%), low/moderate intensity (51%)	N/R
5	Murnane et al 2019; Australia	cohort study	n=51, F=20; M =31, ethnicity N/R	Mean age= 21.16 +/- 2.66	Sarcoma (39%), Lymphoma (27%), leukemia (14%), other (20%)	On-Rx and post-Rx	Chemotherapy, radiotherapy, surgery	N/R
6	Yurkiewicz et al 2018; USA	prospective cohort study	n=33; F=19, M=14, ethnicity N/R	Mean age=22	Leukaemia (48%) Sarcoma (21%) Lymphoma (15%) Other (15%)	Newly diagnosed	N/R	Median days since dx= 30
7	Smith et al 2019; Australia	prospective, descriptive cohort study	n=35, F=14, M=21, ethnicity N/R	Mean age=21.05 +/- 2.62	haematological malignancies (60%), solid tumours (20%)	Cancer survivors	Rx type N/R; Mean time since Rx	N/R

Ref No.	Author, year, country	Study design	Sample size (n), gender (female (F), male (M)), race/ethnicity	Age of study participants (SD)	Cancer type (%)	Cancer status of participants (treatment= Rx)	Cancer treatment	Age at diagnosis (dx)/ time since dx
							completion 4.22 +/-5.1 months	
8	Diorio et al 2018; USA	exploratory, cross-sectional study	n=118, F=54, M= 64, Hispanic (38%), non-Hispanic (62%)	Mean age= 17.97 +/- 3.34	ALL 28 (24%) AML 4 (3%) Lymphoma 30 (25%) Brain tumour 19 (16%) Solid tumour 35 (30%) Other 2 (2%)	Recently diagnosed (31%) Transitioning (20%) Survivor (49%)	N/R	N/R
9	Murnane, Kiss, Fraser & Lewin 2021; Australia	cross-sectional study	n=90, F=46, M=43, prefer not to say=1, ethnicity N/R	Mean age= 25.4 +/- 3.8	Sarcoma (34.4%) Lymphoma (27.8%) Germ cell (11.1%) Leukaemia (7.8%) Brain (6.7%) Other (Melanoma, colorectal, breast, head and neck) (12.2%)	Cancer survivors	Chemotherapy, surgery, radiotherapy, stem cell transplant, other	Months since dx= 61 +/- 19.3
10	Murnane et al 2015; Australia	Cross-sectional study	n=74, F=40, M=34, ethnicity N/R	Mean age= 23 +/- 4	Haematological (45%) Sarcoma (24%) Other (Brain, melanoma, prostate, colorectal,	Disease free= 78%; active diagnosis= 22%	Radiotherapy, chemotherapy, surgery, other	Months since dx=37 +/- 32

Ref No.	Author, year, country	Study design	Sample size (n), gender (female (F), male (M)), race/ethnicity	Age of study participants (SD)	Cancer type (%)	Cancer status of participants (treatment= Rx)	Cancer treatment	Age at diagnosis (dx)/ time since dx
					breast, cervix, parotid, ovarian) (31%)			
11	Pugh et al 2017; UK	Cross-sectional study	n=216, F =130, M= 86, white British (85%)	Mean age = 20 +/- 2.85	haematological malignancies (lymphoma/ leukaemia) (59%), bone tumours (10%), soft tissue sarcomas (n=20, 9%)	Completed Rx (69%)	N/R	Mean age =16.8 +/- 4
12	Sawyer et al 2017; Australia	Cross-sectional study	n=196, F=97, M=99, ethnicity N/R	mean age= 21.6 +/- 3.13	haematological (31%), Hodgkin's lymphoma (25%), Sarcoma (15%), Brain (9%), Germ cell (7%), Melanoma (4%), Thyroid (3%), Other (7%)	Active Rx (19%), finished Rx (81%)	Chemotherapy, radiotherapy, surgery, bone marrow transplant, alternative therapy, other	Mean age=19.85 +/- 3.17
13	Deleemans et al 2021; Canada	Cross sectional retrospective comparison study	n=60, F=37, M= 23, ethnicity N/R	Mean age= 25.3 +/- 4.6	Lymphoma (41.7%), solid tumours (36.7%), Leukaemia (50%), CNS (5%)	Cancer survivors	Chemotherapy, surgery, radiotherapy	N/R

Ref No.	Author, year, country	Study design	Sample size (n), gender (female (F), male (M)), race/ethnicity	Age of study participants (SD)	Cancer type (%)	Cancer status of participants (treatment= Rx)	Cancer treatment	Age at diagnosis (dx)/ time since dx
14	Spreafico et al 2021; Italy	Comparison study	n=44, F=20, M=24, ethnicity N/R	Median age= 15.5	Nasopharyngeal (2.3%), Thyroid (2.3%), non-Hodgkin's lymphoma (11.4%), Brain (18.2%), Neuroblastoma (11.4%), Osteosarcoma (18.2%), Soft tissue sarcoma (13.6%), Ewing sarcoma (13.6%), Abdominal desmoplastic tumour (4.5%), Wilms tumour (4.5%)	On-Rx (66%), follow-up (34%)	N/R	N/R
15	Pugh et al 2020; UK	Comparison study	patients (n=83) F= 46, M=37, White British= 75.9%; survivors (n=174): F=109, M=65,	patients mean age= 19 +/-3.06; survivors mean age= 20 +/- 2.78	Lymphoma (31.5%), Leukaemia (27.6%), Bone tumour (9.7%), soft tissue sarcoma (8.9%), CNS tumour (8.2%), germ cell (3.5%), carcinoma	Cancer survivor (68%), active diagnosis (32%)	Surgery, chemotherapy, radiotherapy, hormone therapy, other,	Mean age=16.5 +/- 4.43

Ref No.	Author, year, country	Study design	Sample size (n), gender (female (F), male (M)), race/ethnicity	Age of study participants (SD)	Cancer type (%)	Cancer status of participants (treatment= Rx)	Cancer treatment	Age at diagnosis (dx)/ time since dx
			White British= 77%		(4.3%), melanoma (1.6%), other (7%)			
16	Rosipal et al 2013; USA	Pilot intervention	n=18, F=7, M=11, ethnicity N/R	Mean age= 22.1 +/-2.41	Leukaemia (50%), Hodgkin's lymphoma (33%), Germ cell (4%) Mycosis fungoides (4%)	On-Rx	Hematopoietic stem cell transplant	N/R
17	Marec-Berard et al 2021; France	Feasibility study	n=59, F=21, M=38, ethnicity N/R	Mean age= 19.41 +/-3.3	Germ cell tumours (29%), Lymphomas (25%), Malignant bone tumours (15%), Soft tissue sarcomas (10%), Leukaemia (9%), Others (12%)	Newly diagnosed	Chemotherapy, surgery, radiotherapy, hormone therapy	Mean age= 19.41 +/- 3.3
18	Bekkering et al 2010; Netherlands	Mixed-method	n=81, F=41, M=40, ethnicity N/R	Quantitative data) mean age= 19.7 +/-2.6); Qualitative data mean age=16.9 +/- 4.2)	Osteosarcoma (83%), Ewing sarcoma (17%)	N/R	Lower limb surgery (limb sparing, ablative)	N/R

Ref No.	Author, year, country	Study design	Sample size (n), gender (female (F), male (M)), race/ethnicity	Age of study participants (SD)	Cancer type (%)	Cancer status of participants (treatment= Rx)	Cancer treatment	Age at diagnosis (dx)/ time since dx
19	Psihogios et al 2020; USA	Mixed-method	n=72 TYA's (stage 1), 11 TYA's (stage 2); F=36 (stage 1), 6 (stage 2), M=36 (stage 1), 5 (stage 2); Hispanic and/or racial minority stage 1= 26.4%, stage 2= 27.3%	Stage 1 mean age= 16.9 (+/- 2.5), stage 2 mean age= 17.1 (2.7)	Stage 1: Leukemia/lymphoma (50%), brain tumour (26.4%), solid tumour (23.6%). Stage 2: Leukemia/lymphoma (54.5%), brain tumour (18.2%), solid tumour (27.3%)	On-Rx	N/R	N/R
20	Wu et al 2019; Taiwan	Secondary data analysis	n=97, F=56, M=41	Mean age= 15.69 +/- 1.94	Leukaemia (43.30%), Lymphoma (12.37%), Bone tumour (34.02%), Other (10.31%)	On-Rx	N/R	N/R
21	Spathis et al 2017; UK	Qualitative	N=80, F=54, M=26, ethnicity N/R	Mean age=22.1 +/- 2.7	Leukaemia (25%), Lymphoma (44%), Sarcoma (8%), Brain (1%), Other (23%)	post-Rx	N/R	Mean age= 18.9 +/-3.1, median months

Ref No.	Author, year, country	Study design	Sample size (n), gender (female (F), male (M)), race/ethnicity	Age of study participants (SD)	Cancer type (%)	Cancer status of participants (treatment= Rx)	Cancer treatment	Age at diagnosis (dx)/ time since dx
								since dx= 31
22	Wu et al 2015; USA	Qualitative	n=25, F=17, M=8, White 100%, (Hispanic 4%)	Mean age= 27.6 +/- 6.6	Leukaemia/ lymphoma (40%), Solid tumour (48%), Brain tumour (12%)	Cancer survivors	N/R	Mean age=17.3 +/- 12.2
23	Mooney et al 2017; USA	Qualitative	n=25, F=17, M=8, White 100%, (Hispanic 4%)	Mean age= 27.6 +/- 6.6	Leukemia/lymphoma (40), Solid tumour (48), Brain tumour 3 (12)	Cancer survivors	N/R	Mean age=17.3 +/- 12.2
24	Wallis, Meredith and Stanley 2021; Australia	Qualitative	n=4, F=2, M=2, ethnicity N/R	Mean age= 22.75	Hodgkin's Lymphoma (75%), Acute Lymphoblast leukaemia (25%)	Cancer survivors	N/R	Mean age= 18.5
25	Smith et al 2021; USA	Qualitative	N=158, F=82, M=32, unknown=44, ethnicity N/R	Mean age= 26	Leukaemia/ lymphoma (17%), miscellaneous, in situ, unspecified (39%), gonadal/ genital (12%), head and neck (7%), urinary tract (1%), melanoma (1%), lung	Cancer survivors	Chemotherapy, radiotherapy, surgery, combined treatment	Mean age= 24

Ref No.	Author, year, country	Study design	Sample size (n), gender (female (F), male (M)), race/ethnicity	Age of study participants (SD)	Cancer type (%)	Cancer status of participants (treatment= Rx)	Cancer treatment	Age at diagnosis (dx)/ time since dx
					(1%), thyroid (2%), breast (4%), CNS/other intracranial and intraspinal neoplasms (4%), gastrointestinal tract carcinomas (6%), sarcomas (6%)			
26	Hanghoj et al 2021; Denmark	Qualitative	N=13, F=9, M=4, ethnicity N/R	Mean age= 23	Acute lymphocytic leukaemia (15%), Adrenal cortical cancer (7.6%), Brain (15%), Breast (15%), Colon (7.6%), Head and neck (7.6%), Hodgkin's lymphoma (7.6%), Malignant lymphoma (7.6%), Ovarian cancer (7.6%), Soft tissue sarcoma (7.6%)	On-Rx (31%), post-Rx (69%)	N/R	N/R
27	Kuntz et al 2019; USA	Qualitative	n=30, F=8, M=22, Hispanic	Mean age= 16.46	Leukaemia (80%) Solid tumours (20%)	On-Rx or recently completed Rx	N/R	N/R

Ref No.	Author, year, country	Study design	Sample size (n), gender (female (F), male (M)), race/ethnicity	Age of study participants (SD)	Cancer type (%)	Cancer status of participants (treatment= Rx)	Cancer treatment	Age at diagnosis (dx)/ time since dx
			(63.3%), Multiple Races (10%), Caucasian (13%), African-American (3%), Asian (6.6%), Middle Eastern (3%)					
28	Pugh et al 2018; UK	Qualitative	n=13, F=9, M=4, ethnicity N/R	Mean age= 22.9	Leukaemia (15%), Lymphoma (31%), Carcinoma (31%), CNS tumour (8%) Other (15%)	On-Rx (15%), <3 months since Rx (8%), 4-11 months post-Rx (38%), active surveillance (8%), unknown (23%)	N/R	Mean age=18.6
29	Devine et al 2018; USA	Narrative review	40 studies n=2,127, gender N/R, ethnicity N/R	Range 5-59 years	N/A	N/A	N/A	N/A
30	McGrady et al 2022; USA	Retrospective chart review	n=47, F=23, M=24, White (77%) Black or African	Mean age=21.26 +/- 4.87	Acute lymphoblastic leukaemia (47%), Acute myeloid leukaemia (26%),	Active diagnosis	N/R	N/R

Ref No.	Author, year, country	Study design	Sample size (n), gender (female (F), male (M)), race/ethnicity	Age of study participants (SD)	Cancer type (%)	Cancer status of participants (treatment= Rx)	Cancer treatment	Age at diagnosis (dx)/ time since dx
			American (4%) Asian (2%) Other (9%) Ethnicity Hispanic (6%), non-Hispanic (89%)		non-Hodgkin's lymphoma (11%), Hodgkin's lymphoma (8%) Chronic myeloid leukaemia (6%) Acute promyelocytic leukaemia (2%)			
31	Munsie ^c 2021; Australia	Retrospective audit	N=34 (exercise group n=13, control n=21), F=13, M=20, ethnicity N/R	Mean age exercise group= 21.6 +/-2.6, mean age control= 19.1 +/- 3.1	Haematological (79%), solid tumour (21%)	On-Rx	Chemotherapy, high intensity (41%), low/moderate intensity (59%)	N/R
32	Pitch et al 2022; Canada	Retrospective audit	Total sample n=1128 data extracted for 18-24 group n=355, gender N/R, ethnicity N/R	N/R	Lymphoma (22.2%), Leukaemia (18.4%), Breast (14.4%), Genitourinary (9.0%), Sarcoma (7.4%), Gynaecological (5.7%), CNS (5.3%), Gastrointestinal	N/R	N/R	N/R

Ref No.	Author, year, country	Study design	Sample size (n), gender (female (F), male (M)), race/ethnicity	Age of study participants (SD)	Cancer type (%)	Cancer status of participants (treatment= Rx)	Cancer treatment	Age at diagnosis (dx)/ time since dx
					(4.6%) Head and neck (3.2%), Other (3.2%)			
33	Baker et al 2021; UK	Service evaluation	Demographics all clinic patients (n=36) anonymous responses unable to link; n=29, F=22, M=14, ethnicity N/R	Mean age= 22	Carcinoma (14%), Lymphoma (47%), Germ cell (19%), Brain or CNS (3%), Leukaemia (17%)	End of Rx	Chemotherapy, radiotherapy, surgery, bone marrow transplant	Median 3 months off-treatment
34	Shaw et al 2022; USA	Quality improvement initiative	n=43, F=19, M=24, ethnicity N/R	Mean age= 18.2 +/- 4.1	N/R	Active diagnosis	N/R	N/R
35	Roggenkamp et al 2022; USA	Poster Abstract-additional information gained from author	Total n=98, 15-18 group n=32, F=23, M=3, ethnicity N/R 19-25 group n=66, F=60, M=3,	N/R	15-18 Group: Leukaemia (28%), ovarian (6%), lymphoma (22%), Hodgkin's lymphoma (34%), sarcoma (12%), thyroid (3%). 19-25 Group: Hodgkin's lymphoma	15-18 group: on-Rx (18.7%), finished Rx <2 years (16.6%), finished Rx>2yo (46.9%); 19-25 group: newly dx (3%), newly dx and on-Rx (7.6%), on-Rx (33.3%), finished	N/R	N/R

Ref No.	Author, year, country	Study design	Sample size (n), gender (female (F), male (M)), race/ethnicity	Age of study participants (SD)	Cancer type (%)	Cancer status of participants (treatment= Rx)	Cancer treatment	Age at diagnosis (dx)/ time since dx
			unknown=3, ethnicity N/R		(32%), ovarian (6%), thyroid (9%), leukaemia (18%), breast (13.6%), lymphoma (6%), sarcoma (6%), brain (3%), neuroendocrine (1.5%), colon (1.5%), melanoma (1.5%), cervical (1.5%)	Rx<2 years (39%), finished Rx>2 years (16.7%)		
36	Arbit, Buck & Ladas 2014; USA	Abstract	n=61, F=31, M=30, Hispanic (19%), Asian (11%), Black (10%)	Mean age=18.2	N/R	During and after Rx	N/R	N/R
37	Atkinson & Osborn 2012; Australia	Abstract	n=46, F=20, M=35, ethnicity N/R	N/R	N/R	On-Rx or recently completed Rx	N/R	N/R
38	MacKland & Chesman 2019; UK	Abstract	n=8, gender N/R, ethnicity N/R	N/R	N/R	N/R	Stem cell transplant	N/R

Ref No.	Author, year, country	Study design	Sample size (n), gender (female (F), male (M)), race/ethnicity	Age of study participants (SD)	Cancer type (%)	Cancer status of participants (treatment= Rx)	Cancer treatment	Age at diagnosis (dx)/ time since dx
39	Munsie, Collins & Plaster 2019; Australia	Poster Abstract	n=43, gender N/R, ethnicity N/R	N/R	N/R	Cancer survivors	N/R	N/R
40	Salchow et al 2017	Abstract	n=55, F=33, M=22, ethnicity N/R	Mean age= 23.9 +/- 6.1	Lymphoma (42%) solid tumours (38%), and leukaemia (20%)	Completed Rx	N/R	N/R
41	Schwartz et al 2016; USA	Poster Abstract	n=50, F=28, M=22, minority 31%	Mean age= 17	N/R	<1 year post-Rx	N/R	Time since completing Rx=5.8 months

Appendix 6 Grey literature websites

Search terms: "physical activity" and "young adults" and cancer were used to search the following websites:

EThoS: <https://ethos.bl.uk/Home.do>

National Institute of Health and Care Excellence (NICE) Evidence:
<https://www.nice.org.uk/>

Centers for Disease Control and Prevention (CDC):
<https://www.cdc.gov/index.htm>

Australian and New Zealand Clinical Trials Registry (ANZCTR):
<https://www.anzctr.org.au/TrialSearch.aspx>

National Institute of Health (NIH) National Cancer Institute (NCI):
<https://www.nih.gov/about-nih/what-we-do/nih-almanac/national-cancer-institute-nci>

International Standard Randomised Controlled Trials Number Registry (ISRCTN):
<https://www.isrctn.com/>

The terms "physical activity", "exercise", "young adult" "teenage" were used to search on:

McMillian Cancer Research: <https://www.macmillan.org.uk/>

Cancer Research UK: <https://www.cancerresearchuk.org/>

Move: <https://movecharity.org/>

Terms "physical activity" and "exercise were used to search on the following:

Shine Cancer Support:
https://shinecancersupport.org/getsupport/networks/manchester/?utm_medium=google_cpc&utm_campaign=&utm_source=&utm_content=&utm_term=shine%20cancer%20support&gclid=CjwKCAjwp8OpBhAFEiwAG7NaEILY17p88thEzsQ0QSoUGhD0fTKuRpZbERjjikEqtWW6V09e86_VhoCIVIQAvD_BwE

Teenage Cancer Trust: <https://www.teenagecancertrust.org/>

Teen Cancer America: <https://teencanceramerica.org/>

Trekstock:
<https://www.trekstock.com/pages/search.aspx?q=Physical%20activity>

Young Lives vs Cancer: <https://www.younglivesvscancer.org.uk/>

Canteen: <https://www.canteen.org.au/>

Appendix 7 RGU Ethics Approval**SCHOOL OF HEALTH SCIENCES**

The Isabel Gordon Building
Robert Gordon University
Garthdee Road
Aberdeen
AB10 7QG
United Kingdom
Tel: 01224 263250
www.rgu.ac.uk

Date 3rd July 2020

Dear Lyndsay

Re: School of Health Sciences Research Ethics Committee Application

Study Title: An exploration of the physical activity behaviours in adolescent and young adults living with cancer and beyond

Reference Number: SHS/20/02

Thank you for submitting the above study to this committee, and for addressing any points raised. I am pleased to inform you that you now have been given approval by the School Research Ethics Committee, and am happy for you to begin the IRAS process in relation to recruitment of participants and/or data from the NHS.

As you know, where research involves NHS staff or patients, approval should be sought via the IRAS system. Please email a copy of this approval letter along with your study protocol to Jill Johnston (j.johnston4@rgu.ac.uk) who tracks NHS IRAS applications on behalf of Sponsor Paul Hagan.

I wish you every success with this project.

Kind regards,

A handwritten signature in black ink, appearing to read 'Laura Blinnie'.

Convenor
School of Health Sciences Research Ethics Committee



Robert Gordon University, a Scottish charity registered under charity number SC013781

Acting Head of School
Laura Blinnie
MSc BSc FHEA

Appendix 8 IRAS Ethics Approval**North East - Newcastle & North Tyneside 2 Research Ethics Committee**

NHS BT Blood Donor Centre
Holland Drive
Newcastle upon Tyne
Tyne and Wear
NE2 4NQ

Telephone: 0207 1048091

28 October 2020

Dr Lyndsay Alexander
Lecturer
Robert Gordon University
Garthdee Road
Aberdeen
AB107QG

Dear Dr Alexander

Study title: An exploration of the physical activity behaviours in adolescent and young adults living with cancer and beyond.
REC reference: 20/NE/0235
IRAS project ID: 281795

Thank you for your letter of 26 October 2020, 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.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

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, 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 [Social media post]	V1	23 January 2020
Covering letter on headed paper [Letter to committee]		18 August 2020
Covering letter on headed paper [Provisional response]		26 October 2020
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [RGU indemnity insurance]		01 August 2020
Interview schedules or topic guides for participants [Topic guide]	V2	08 October 2020
IRAS Application Form [IRAS_Form_26102020]		26 October 2020
IRAS Checklist XML [Checklist_26102020]		26 October 2020
Letters of invitation to participant [Invitation letter]	V2	30 September 2020

A Research Ethics Committee established by the Health Research Authority

Non-validated questionnaire [Survey]	V2	08 October 2020
Other [Recruitment Poster]	V1	18 March 2020
Participant information sheet (PIS) [PIS]	V2	08 October 2020
Referee's report or other scientific critique report [SHS REC]		03 July 2020
Research protocol or project proposal [Proposal]	V1	23 January 2020
Summary CV for Chief Investigator (CI) [CI CV]		01 June 2020
Summary CV for student [Eilidh McLeod CV]	V1	19 August 2020
Summary CV for supervisor (student research) [Donna Wynne CV]		10 February 2020
Summary CV for supervisor (student research) [Juliet Harvey CV]		07 February 2020
Summary CV for supervisor (student research) [Liz Hancock CV]		28 May 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: 281795	Please quote this number on all correspondence
--------------------------------	---

With the Committee's best wishes for the success of this project.

Yours sincerely



pp
Dr Raymond Chadwick
Chair

Email: newcastlenorthtyneside2.rec@hra.nhs.uk

Enclosures: "After ethical review – guidance for researchers"

Appendix 9 NHS GGC Ethics Approval

Research & Innovation
 Dykebar Hospital, Ward 11
 Grahamston Road
 Paisley, PA2 7DE
 Scotland, UK

Administrator: Mr Scott Broadley
 Telephone Number: 0141 314 4001
 E-Mail: Scott.Broadley@ggc.scot.nhs.uk
 Website: <https://www.nhs.gov.uk/about-us/professional-support-sites/research-development/>

06 January 2021

Eilidh McLeod
 40 Main Street
 Mid Calder, West Lothian
 EH53 0AN

NHS GG&C Board Approval

Dear Eilidh McLeod,

Study Title:	An exploration of the physical activity behaviours in adolescent and young adults living with cancer and beyond.
Principal Investigator:	Miss Eilidh McLeod
GG&C HB site	Beatson West of Scotland Cancer Centre
Sponsor	Robert Gordon University
R&I reference:	GN200N483
REC reference:	20/NE/0235
Protocol no:	Version 1, 23/01/2020
(including version and date)	

I am pleased to confirm that Greater Glasgow & Clyde Health Board is now able to grant **Approval** for the above study.

Conditions of Approval

1. **For Clinical Trials** as defined by the Medicines for Human Use Clinical Trial Regulations, 2004
 - a. During the life span of the study GGHB requires the following information relating to this site
 - i. Notification of any potential serious breaches.
 - ii. Notification of any regulatory inspections.

It is your responsibility to ensure that all staff involved in the study at this site have the appropriate GCP training according to the GGHB GCP policy (www.nhs.gov.uk/content/default.asp?page=s1411), evidence of such training to be filed in the site file.

2. **For all studies** the following information is required during their lifespan.
 - a. First study participant should be recruited within 30 days of approval date.
 - b. Recruitment Numbers on a monthly basis
 - c. Any change to local research team staff should be notified to R&I team

2. **For all studies** the following information is required during their lifespan.
 - a. First study participant should be recruited within 30 days of approval date.
 - b. Recruitment Numbers on a monthly basis
 - c. Any change to local research team staff should be notified to R&I team



- d. Any amendments – Substantial or Non Substantial
- e. Notification of Trial/study end including final recruitment figures
- f. Final Report & Copies of Publications/Abstracts
- g. You must work in accordance with the current NHS GG&C COVID19 guidelines and principles.

Please add this approval to your study file as this letter may be subject to audit and monitoring.

Your personal information will be held on a secure national web-based NHS database.

I wish you every success with this research study

Yours sincerely,

Scott Broadley

Mr Scott Broadley
Senior Research Administrator

Appendix 10 NHS Tayside Ethics Approval

27 September 2021

Dr Lyndsay Alexander (La.alexander@rgu.ac.uk)

Dear Dr Alexander

R&D MANAGEMENT APPROVAL – TAYSIDE

Title: Exploring physical activity in young adults with cancer - An exploration of the physical activity behaviours in adolescent and young adults living with cancer and beyond.

Chief Investigator: Dr Lyndsay Alexander

Principal Investigator: Dr Michelle Ferguson

Tayside Ref: 2021ON05 **NRS Ref:** NRS21/281795 **IRAS ID:** 281795 **REC Ref:** 20/NE/0235

Sponsor: Robert Gordon University **Funder:** n/a

Many thanks for your application to carry out the above project here in NHS Tayside. I am pleased to confirm that the project documentation (as outlined below) has been reviewed, registered and Management Approval has been granted for the study to proceed locally in Tayside.

Please note that no interview activities should be performed by Eilidh McLeod on participants from NHS Tayside until a NHS to NHS Letter of Access has been provided to allow for these activities.

Approval is granted on the following conditions:-

- ALL Research must be carried out in compliance with the UK Policy Framework for Health & Social Care Research, Health & Safety Regulations, GDPR & data protection principles, statutory legislation and in accordance with Good Clinical Practice (GCP).
- All amendments to be notified to TASC R&D Office via the correct amendment pathway. Either direct to the R&D Office or via the Lead Co-ordinating Centre depending on how the study is set up.
- All local researchers must hold either a Substantive Contract, Honorary Research Contract, Honorary Clinical Contract or Letter of Access with NHS Tayside where required (<https://www.myresearchproject.org.uk/help/hlphrgoodpractice.aspx>).
- TASC R&D Office to be informed of change in Principal Investigator, Chief Investigator or any additional research personnel locally.
- Notification to TASC R&D Office of any change in funding or an extension to study timelines.
- As well as any obligations to your Sponsor, you are required to notify TASCGovernance@dundee.ac.uk of all serious breaches of GCP and Serious Unexpected Serious Adverse Reactions (SUSARs) for Hosted Clinical Trials of Investigational Medicinal Products (CTIMPs).
- As custodian of the information collated during this research project you are responsible for ensuring the security of all personal information collected in line with NHS Scotland IT Security Policies, until destruction of this data.
- All Eligible and Extended Review studies will be added to the Scottish Research Database (SReDA). Recruitment figures for Eligible and Extended Review studies must be recorded onto the Scottish Portfolio every month. It is the responsibility of Tayside Health board to ensure recruitment data is being routinely uploaded into SReDA by working closely with study teams across Tayside and gathering this information. For further information on how your study recruitment data will be captured and uploaded, please contact the local Portfolio team at tay.tascportfolio@nhs.scot

- Annual reports are required to be submitted to TASC R&D Office with the first report due 12 months from date of issue of this management approval letter and at yearly intervals until completion of the study.
- Notification of early termination within 15 days or End of Trial within 90 days followed by End of Trial Report within 1 year to TASC R&D Office.
- You may be required to assist with and provide information in regard to audit and monitoring of study.

Please note you are required to adhere to the conditions, if not, NHS management approval may be withdrawn for the study.

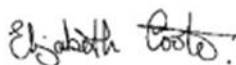
Approved Documents

Document	Version	Date
Completed amendment tool [Locked Amendment Tool - NSA]		11 June 2021
Copies of advertisement materials for research participants [Social media post]	V1	23 January 2020
Covering letter on headed paper [Letter to committee]		18 August 2020
Covering letter on headed paper [Provisional response]		26 October 2020
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [RGU indemnity insurance]		01 August 2020
Interview schedules or topic guides for participants [Topic guide]	V2	08 October 2020
IRAS Application Form [IRAS Form]		26 October 2020
Letters of invitation to participant [Invitation letter]	V3	29 March 2021
Non-validated questionnaire [Survey]	V2	08 October 2020
Organisation Information Document [OID]	V1	09 September 2020
Other [NSA notification]		19 August 2021
Other [Proportionate REC favourable opinion on further information]		28 October 2020
Other [Recruitment Poster]	V1	18 March 2020
Participant consent form [Study consent]	V2	29 March 2021
Participant information sheet (PIS) [PIS]	V3	29 March 2021
Referee's report or other scientific critique report [SHS REC]		03 July 2020
Research protocol or project proposal [Proposal]	V2	07 June 2021
Summary CV for Chief Investigator (CI) [CI CV]		01 June 2020
Summary CV for student [Eilidh McLeod CV]	V1	19 August 2020
Summary CV for supervisor (student research) [Donna Wynne CV]		10 February 2020
Summary CV for supervisor (student research) [Juliet Harvey CV]		07 February 2020
Summary CV for supervisor (student research) [Liz Hancock CV]		28 May 2020

May I take this opportunity to wish you every success with your project.

Please do not hesitate to contact TASC R&D Office should you require further assistance.

Yours sincerely



Elizabeth Coote
Head of Non-Commercial Research Services

TAside medical Science Centre (TASC)
Ninewells Hospital & Medical School, TASC Research & Development Office
Residency Block, Level 3
George Pirie Way,
Dundee DD1 9SY
Email: liz.coote@nhs.scot

Tel: 01382 383876; Mobile: 07876 104800

Appendix 11 NHS Grampian Ethics Approval

Research and Development Foresterhill House Annexe
 Foresterhill
 ABERDEEN
 AB25 2ZB



Dr Dominic Culligan	Date	22/10/2021
NHS Grampian	Project No	2021HA006E
Ward 309, Level 4 (Orange Zone)		
ANCHOR Unit	Enquiries to	Linda Leith
Aberdeen Royal Infirmary	Extension	53846
ABERDEEN	Direct Line	01224 553846
AB25 2ZN	Email	gram.randdpermissions@nhs.scot

Dear Dr Culligan

Management Permission for Non-Commercial Research

STUDY TITLE: An exploration of the physical activity behaviours in adolescent and young adults living with cancer and beyond.

PROTOCOL NO: V3, 23.8.21

REC REF: 20/NE/0235

IRAS REF: 281795

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 Dr Lyndsay Alexander
Jill Johnston
Kirsty Shearer
Jill Dixon
Research Monitor
Nicola Price
~~Ritika Richardson~~
Louise Milne

Sponsor: Robert Gordon University

Appendix 12 Participant Information Sheet**Participant Information Sheet**

IRAS ID: 281795

Reference number: SHS/20/02

Date: 02/09/2021 (Version 4)

Study title: **An exploration of physical activity behaviours in adolescent and young adults living with cancer and beyond.**

Introduction:

This research is being conducted as part of a Doctoral research degree at Robert Gordon University, the lead researcher is Eilidh McLeod and lead supervisor of this project is Dr Lyndsay Alexander. Contact details can be found at the end of this information sheet.

We are asking individuals who have received a cancer diagnosis when they were between the ages of 16-25 years old to take part in this study.

We would like to invite you to take part in this research study which involves a survey and interview. Joining the study is entirely up to you, before you decide we would like you to understand why the research is being conducted and what it would involve for you. Please read the following information carefully and, if you wish, discuss it with others, such as your family, GP or oncology specialist. You can ask us if there is anything that is unclear or if you would like more information. Take time to decide whether you wish to take part. Thank you for reading this.

This study will investigate the physical activity behaviours, experiences and preferences for people diagnosed with cancer when they were aged between 16-25 years old, to inform physical activity recommendations for this group and identify what further research is required.

Why have I been chosen?

People have been invited to join this study because:

- a) You are aged between 16-25 with a diagnosis of cancer and are currently undergoing active or palliative treatment
- b) You were diagnosed with cancer between the ages of 16-25 but are now classified as in remission or cancer free.
- c) you received your cancer diagnosis within the last 10 years

Do I have to take part?

No, participation is voluntary. You can decide to take part in all or part of this study (survey and interview or just the survey or just the interview). If you do decide to take part, you should click on the link attached below. If you decide to take part, you are still free to withdraw at any time, 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. Any data used will be fully anonymised and no-one will be able to identify you.

What is the purpose of the study?

National guidelines recommend that individuals diagnosed with cancer should engage in regular physical activity during and after cancer treatment. However, little is known about the physical activity behaviours, experiences and preferences of teenagers and young adults, as the majority of research has been carried out in older adults with cancer. In addition, there is no information about how the COVID-19 pandemic has affected physical activity for young adults with cancer.

Eilidh McLeod and the research team have developed an online survey to investigate teenage and young adults' physical activity levels, explore their experiences with physical activity during/after their cancer journey as well as investigate potential barriers and motivators and the impact of COVID-19 to being physically active.

What will happen to me if I decide to take part?

If you decide to take part in the study, click on the link below to complete the online survey in your own time. You will require a mobile phone, Tablet or computer with internet access. The first page of the survey will give you information about this study and ask for you to consent to take part (by ticking a box) before you can move on to complete the survey. The survey will require you to provide some background information about you including age, cancer diagnosis, treatment you have had and if you have received any physiotherapy/physical activity input from a health professional. You will then be asked to complete questions about your physical activity over the past 7-days, potential barriers and motivators to physical activity you've experienced, your physical activity preferences regarding type of activity, time of day, and where you are active as well as the impact from COVID-19 on your physical activity. The survey will take around 20 minutes to complete.

At the end of the survey, you will be asked if you wish to participate in a follow-up interview to discuss these topics in more detail. If you do wish to participate you will be asked to give your contact details (your name and a contact telephone number) which will be stored securely in a password protected file that only the research team can access. We aim to interview 24 participants during the follow-up phase of the project, this will be on a first-come-first served basis due to purposeful sampling. The interview will last no longer than 60-minutes and can be conducted virtually face to face on Microsoft Teams or via telephone depending on your personal preference. The interview audio will be recorded via an audio recorder and transcribed for analysis. The interview recording and transcribed interview will be anonymised and stored securely in a password protected site in the University server that only the research team can access.

You can decide to take part in both the survey and interview or just the survey or just the interview, it is up to you.

All information and data gathered during this study will be kept securely within a password protected file for 10 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. There is a small risk of emotional distress from discussing your cancer diagnosis and treatment and you can decide to withdraw your participation if you wish. If you choose to withdraw there will be no impact on any current or subsequent healthcare you receive. The research team will also provide information to all participants about where they can access emotional support should they require it. This will be

provided again at both the end of the survey and interview. **If you find any of the information discussed distressing, please contact one of the below support options:**

Maggie's: <https://www.maggies.org/cancer-support/> or phone on 0300 123 1801

CLIC Sargent: <https://www.clicsargent.org.uk/> or phone on 0300 330 0803

Beatson Cancer Charity: <https://www.beatsoncancercharity.org/>

Teenage Cancer Trust: <https://www.teenagecancertrust.org/>

What are the possible benefits of taking part?

We hope that the information gathered in this study will increase the knowledge base around physical activity in 16-25year olds with cancer and those now cancer free and the information can be used to make recommendations surrounding future research in this area and for physical activity interventions especially following the impact of COVID-19.

What will happen to the results of the research study?

The results from this study shall be documented and distributed for thesis examination in compliance with Robert Gordon University standards. They will also be presented nationally and internationally at relevant conferences and synthesised into research articles for academic distribution.

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 a 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: SH/20/02) and NHS HRA Research Ethics Committee North East - Newcastle & North Tyneside 2.

Who can I talk to about the study?

The Doctoral student conducting this study, Eilidh McLeod, 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. Eilidh McLeod, the lead researcher, or Lyndsay Alexander, the project supervisor, 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/pages/contact/feedback.php>

You can also make a complaint to Dr Arthur Stewart, convenor of the School of Health Sciences Research Ethics Committee, Robert Gordon University, Garthdee Road, Aberdeen AB10 7QG a.d.stewart@rgu.ac.uk or Mrs Laura Binnie, Acting Head of School of Health Sciences, Robert Gordon University, Garthdee Road, Aberdeen AB10 7QG l.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:

- Your survey responses (and transcribed interview if you chose to participate) will identify you using only a unique ID number.
- Your name and contact details will be stored separately from your responses 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 a Research “R”-Drive of the university server and will be accessed using University computers with password-protected access. We will also 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 in order 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 10 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, your local NHS trust 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. If you have signed up for the interview phase of the study but no longer wish to participate, please contact the researchers on the contact information provided below or let the researcher know when they contact you. Choosing to withdraw will not impact on your healthcare. If you chose to withdraw from the study any data collected prior to that point will be used unless you withdraw your consent. If you withdraw after your interview data has been analysed your data will still be used as it is not possible to withdraw data after this point.

What happens if I want to participate in the study?

If you wish to participate:

- a) To complete the survey please follow the link:
<https://robertgordonuniversity.onlinesurveys.ac.uk/physical-activity-in-young-adults-with-and-beyond-cancer>
- b) To take part in the interview only, please contact Eilidh on the email address below

Further information and contact details:

Lead Researcher: Eilidh McLeod (Doctorate of Physiotherapy Student)

School of Health Sciences, Robert Gordon University, Garthdee Road, Aberdeen AB10 7QG

Email: e.mcleod4@rgu.ac.uk

Project Supervisor: 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 13 Recruitment Poster**SEEKING YOUNG ADULTS DIAGNOSED WITH CANCER FOR A RESEARCH STUDY.**

Researchers at Robert Gordon University are seeking young adults, diagnosed with cancer to participate in research about physical activity. The purpose of this study is to explore how active young adults are and their experience of physical activity since their cancer diagnosis.

Who can take part?

Anyone who received a cancer diagnosis when they were between the ages of 16-25-years old. This includes; anyone with an active diagnosis or individuals now cancer free.

You must have been diagnosed with cancer within the last 10 years.

What do you need to do?

There are a couple of options, you can:

- complete an online survey, that should take approximately 20-30 minutes.
- Take part in an interview
- Or do both

**Want to take part?**

Please use this link, to access the online survey.

<https://robertgordonuniversity.onlinesurveys.ac.uk/physical-activity-in-young-adults-with-and-beyond-cancer>

Or Find the survey on Twitter @EilidhMcLeodPT

If you have any questions or are interested in taking part in the interview only, please contact Eilidh McLeod, Doctoral Student: e.mcleod4@rgu.ac.uk or Dr Lyndsay Alexander, Principal Supervisor: l.a.alexander@rgu.ac.uk.

This is a thesis study, completed in fulfilment of Doctorate in physiotherapy.



Appendix 14 Example Social Media Recruitment Post

EilidhMcLeod
@EilidhMcLeodPT



If you were diagnosed with [#cancer](#) as a [#teenager](#) or [#youngadult](#) please consider taking part in this research project! ...
tgordonuniversity.onlinesurveys.ac.uk/physical-activ...

SEEKING YOUNG ADULTS DIAGNOSED WITH CANCER FOR A RESEARCH STUDY.

Researchers at Robert Gordon University are seeking young adults diagnosed with cancer between the ages of 16 to 25 to participate in an online survey about physical activity. The purpose of this study is to explore how active young adults are and their experience of physical activity since their cancer diagnosis.

Who can take part?

Anyone who received a cancer diagnosis when they were between the ages of *16-25-years old*. This includes; anyone with an active diagnosis or individuals now cancer free.

You must have been diagnosed with cancer within the last 10 years.

What do you need to do?

Complete an online survey, that should take approximately 20 minutes.



Appendix 15 Interview Recruitment Email Template

Dear *name*,

You recently completed a survey on physical activity in cancer for young adults and left your contact details as you were interested in taking part in an interview (30-60 mins) to discuss this further. Thank you very much for taking the time to complete the survey!

My name is *name* and I'm the researcher on this project. I wondered if you would still be happy to speak to me and if so, could you let me know when would be a good time & date for you?

I have included the information sheet for you to read but please ask me any questions you may have. Taking part is voluntary but your experiences and thoughts would be invaluable to the project and really appreciated.

If you could reply to this email and tell me:

1. Days or times that you are available
2. If you would prefer to have the interview on Microsoft Teams or over the phone (please add your preferred contact number)
3. Or that you are not interested in taking part – this is so that I don't send reminder follow-up emails to you

I look forward to hearing from you.

Kind Regards,

Appendix 16 Survey Template

Participant ID number _____

Title: An exploration of physical activity behaviours in adolescent and young adults living with cancer and adolescent and beyond.

We are inviting you to take part in a research study. This research is being conducted as part of a Doctoral research degree at Robert Gordon University. Thank you for reading this.

About the study.

National guidelines (NICE 2005) recommend that individuals diagnosed with cancer engage in regular physical activity during and after cancer treatment. However, most of the research on physical activity and cancer has been carried out in older adults, meaning little is known about the young adult population.

This study will investigate the physical activity behaviours, experiences and preferences of individuals diagnosed with cancer when they were aged between 16-25 years old. The results will be used to inform physical activity recommendations for this population and identify further research areas.

People have been invited to join this study if you have received a cancer diagnosis when you were aged between 16-25 (within the last 10 years). Participants in active treatment, palliative care, remission or cancer free are all eligible to take part in this study.

Joining the study is entirely up to you, please take time to decide whether you wish to take part. Feel free to ask questions or discuss the study with your family, friends or your medical team. Any data provided will be fully anonymised and no-one will be able to identify you. You are free to withdraw at any time, or not to take part in this study; this will not affect the standard of care you receive.

An online survey has been developed by the research team; you can fill this out in your own time. Or if you prefer, we can provide you with a paper version of the

survey and a free returns envelope. Before beginning the survey, you must consent to take part by ticking the boxes below.

The survey will require you to provide some background information about yourself and your cancer diagnosis/treatment. You will then be asked to complete questions about your activity over the past 7-days, your support system, things that help and stop you being active, and your physical activity preferences. The survey will take around 20 minutes to complete.

At the end of the survey you will be asked if you wish to participate in a follow-up interview to discuss these topics in more detail. If you wish to participate you will be required to leave your contact details (your name and a contact telephone number) which will be stored securely in a password protected file that only the research team can access.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a 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: SH/20/02) and NHS [IRAS reference:].

What will happen to my data?

Robert Gordon University is the sponsor of this study. All data will be stored in password protected files accessible from Robert Gordon University computers for 10 years, in compliance with GDPR. All data collected will be anonymised and nobody will be able to identify you from any results reported. Your contact details will be stored separately from your survey responses. Certain individuals from Robert Gordon University, NHS Greater Glasgow and Clyde and regulatory organisations may look at your research records to check the accuracy of the research study.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways 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 results from this study will be documented and distributed for thesis examination in compliance with Robert Gordon University standards. They may

also be presented nationally and internationally at conferences and synthesised into research articles for academic distribution.

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.

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 (contact information below).

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/nhscomplaints/pages/contact/feedback.php>

You can also make a complaint to Dr 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 Mrs Laura Binnie, Acting Head of School of Health Sciences, Robert Gordon University, Garthdee Road, Aberdeen AB10 7QG l.binnie@rgu.ac.uk.

Further information and contact details:

If you have any questions about this study, please contact:

Lead Researcher: Eilidh McLeod (Doctorate of Physiotherapy Student), 1709110@rgu.ac.uk

School of Health Sciences, Robert Gordon University, Garthdee Road, Aberdeen AB10 7QG

Project Supervisor: Dr Lyndsay Alexander, l.a.alexander@rgu.ac.uk

School of Health Sciences, Robert Gordon University, Garthdee Road, Aberdeen AB10 7QG

Please tick each box, you must complete this before continuing onto the survey:

1. I confirm that I have read the information sheet dated 23/01/2020 (version 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

3. I understand that data collected during the study, may be looked at by individuals from Robert Gordon University or NHS Greater Glasgow and Clyde, where it is relevant to my taking part in this research.

4. I understand that the information collected about me will be used to support other research in the future and may be shared anonymously with other researchers.

5. I understand that my contact information will be stored securely on the Robert Gordon University site, for follow-up by researchers if necessary.

6. I agree to take part in the above study.

Stage of change

Table 1.
Physical Activity Stages of Change Questionnaire

For each of the following questions, please circle Yes or No. Please be sure to read the questions carefully.

Physical activity or exercise includes activities such as walking briskly, jogging, bicycling, swimming, or any other activity in which the exertion is at least as intense as these activities.

1) I am currently physically active. **NO** **YES**

2) I intend to become more physically active in the next 6 months. **NO** **YES**

For activity to be regular, it must add up to a total of 30 minutes or more per day and be done at least 5 days per week. For example, you could take one 30-minute walk or take three 10-minute walks for a daily total of 30 minutes.

3) I currently engage in regular physical activity. **NO** **YES**

4) I have been regularly physically active for the past 6 months. **NO** **YES**

Scoring Algorithm:

Precontemplation: Question One = No; Question Two = No

Contemplation: Question One = No; Question Two = Yes

Preparation: Question One = Yes and Question Three = No

Action: Question One = Yes; Question Three = Yes; and Question Four = No

Maintenance: Question One = Yes; Question Three = Yes; Question Four = Yes

Adapted from Marcus, Rossi et al., 1992.

Physical activity behaviours

INTERNATIONAL PHYSICAL ACTIVITY QUESTIONNAIRE

We are interested in finding out about the kinds of physical activities that people do as part of their everyday lives. The questions will ask you about the time you spent being physically active in the **last 7 days**. Please answer each question even if you do not consider yourself to be an active person. Please think about the activities you do at work, as part of your house and yard work, to get from place to place, and in your spare time for recreation, exercise or sport.

Think about all the **vigorous** activities that you did in the **last 7 days**. **Vigorous** physical activities refer to activities that take hard physical effort and make you breathe much harder than normal. Think *only* about those physical activities that you did for at least 10 minutes at a time.

1. During the **last 7 days**, on how many days did you do **vigorous** physical activities like heavy lifting, digging, aerobics, or fast bicycling?

_____ **days per week**

No vigorous physical activities → **Skip to question 3**

2. How much time did you usually spend doing **vigorous** physical activities on one of those days?

_____ **hours per day**

_____ **minutes per day**

Don't know/Not sure

Think about all the **moderate** activities that you did in the **last 7 days**. **Moderate** activities refer to activities that take moderate physical effort and make you breathe somewhat harder than normal. Think *only* about those physical activities that you did for at least 10 minutes at a time.

3. During the **last 7 days**, on how many days did you do **moderate** physical activities like carrying light loads, bicycling at a regular pace, or doubles tennis? Do not include walking.

_____ **days per week**

No moderate physical activities → **Skip to question 5**

4. How much time did you usually spend doing **moderate** physical activities on one of those days?

_____ hours per day

_____ minutes per day

Don't know/Not sure

Think about the time you spent **walking** in the **last 7 days**. This includes at work and at home, walking to travel from place to place, and any other walking that you have done solely for recreation, sport, exercise, or leisure.

5. During the **last 7 days**, on how many days did you **walk** for at least 10 minutes at a time?

_____ days per week

No walking → *Skip to question 7*

6. How much time did you usually spend **walking** on one of those days?

_____ hours per day

_____ minutes per day

Don't know/Not sure

The last question is about the time you spent **sitting** on weekdays during the **last 7 days**. Include time spent at work, at home, while doing course work and during leisure time. This may include time spent sitting at a desk, visiting friends, reading, or sitting or lying down to watch television.

7. During the **last 7 days**, how much time did you spend **sitting** on a **week day**?

_____ hours per day

_____ minutes per day

Don't know/Not sure

Experiences:

The following questions will ask you about your personal experiences with physical activity. Physical activity is defined as movement of the body which requires energy. Some examples of physical activity include; walking, jogging, housework, swimming, cycling etc.

1. a) Prior to your diagnosis of cancer did you participate in any physical activity (at school/home/gym/outdoors) YES/NO (if No go to Q2)

b) If so, what type of physical activity?

c) How often per week (approx. no. of hours)

2. a) After your diagnosis of cancer did you participate in any physical activity? (at school/home/gym/outdoors) YES/NO (if No go to Q3)

b) If so, what type of physical activity?

c) how often per week (approx. no. of hours).

3. a) During your cancer journey did a health professional provide you with any information or advice about physical activity? YES/NO (if no go to Q4)

b) If so, what was it?

c) who provided you with it?.....

d) At what stage of your cancer journey was this information provided? (eg. At diagnosis, during treatment, after treatment)

4. a) Have you ever found information by yourself about being active? Yes/No (If no go to preferences questions)

b) If so, where did you find this information from?

c) Why did you look for this information?

Physical activity preferences:

The following questions will ask you about your preferences surrounding physical activity.

1. Please indicate on the list what type of Physical activity you prefer? Tick all the boxes that apply to you. If "other" please specify. If team sport, please specify.

Activity	Tick
Walking	
Team sport	
Running	
Housework	
Badminton	
Swimming	
Cycling	
Going to the gym	

Fitness classes	
Other	

Other:

Team sport:

2. Where do you prefer to do physical activity? Tick all the boxes that apply to you. If "other" please specify.

Location	Tick
Home	
Gym	
Hospital or doctors	
Outdoors	
Swimming pool	
Sports centre	
Other	

Other:

3. a) What time of day would you prefer doing physical activity? Please tick the time which best applies to you.

Time	Tick
Morning	
Afternoon	
Evening	

b) Please indicate why this is your preference?

4. What type of physical activity format would you prefer? Tick all the boxes that apply to you. If "other" please specify.

Setting	Tick
Activity group	
With a friend	
With a family member	
Alone	
Healthcare professional led	
Other	

Other:

5. When do you feel it is best to receive information about physical activity in relation to your cancer? Tick all the boxes that apply to you. If "other" please specify.

Time	Tick
At diagnosis	
Before treatment	
During treatment	
After treatment	
Other	

Other:

6. Please indicate what you think would be important to be included in a physical activity program? Tick all the boxes that apply to you. If "other" please specify.

Included	Tick
Advice about physical activity	
Tailored gym program	
Cancer specific group fitness classes	
Subsidised gym/fitness memberships	
Emotional support group	
Other	

Other:

Barriers and facilitators:

We are interested in reasons that prevent you being physically active. For each of the following statements please rate how relevant you feel each statement is for you by ticking the appropriate response.

Factor	Not relevant	Somewhat relevant	Moderately relevant	Relevant	Highly relevant
I do not have the time					
I don't know how to be physically active					
I don't want to get injured					
I don't have transport					
I do not enjoy being active					
I am worried about looking silly whilst exercising					
I am too tired to be physically active					
Exercise not a priority for me					
I am in pain when I exercise					
I do not have access to a physical activity program/group					
I feel too weak to be active					
I do not have the appropriate equipment or facilities nearby					

I am worried about the way my body looks when I exercise					
Bad weather					
I am not motivated to exercise					
I am not interested in physical activity					
It is too expensive to be physically active					
I do not have the self-discipline to be physically active					
I do not have anyone to exercise with					
I have more important responsibilities at home					
I have more important responsibilities at work					
I have underlying health condition(s) other than cancer that make exercising difficult					

We are interested in reasons that help you be physically active. For each of the following statements please rate how relevant you feel each statement is for you by ticking the appropriate response.

Factor	Not relevant	Somewhat relevant	Moderately relevant	Relevant	Highly relevant
I want to meet new people					

I want to improve my strength					
I enjoy the social benefits of attending a sports club/fitness group and meeting new people					
My cancer diagnosis has motivated me to be more active					
I want to improve my mental health					
I want to increase my independence					
I want to improve my fatigue					
Having access to a physical activity program makes me/would make me more active					
Being physically active helps me regain normality					
I want to improve my general health and fitness					
Having someone to exercise with					
I received information about how to safely be active					
I enjoy being active					

Being active provides a distraction from having cancer					
--	--	--	--	--	--

Social Support (SSQ-6):

The following questions ask about people in your environment who provide you with help or support. Each question has two parts. For the first part, list all the people you know, excluding yourself, whom you can count on for help or support in the manner described. You may either

give the person's initials or their relationship to you. You can list up to nine individuals. For the second part, indicate how satisfied you are with the overall support you have.

If you have no support for a question, please write "No one," but still rate your level of satisfaction.

Then please indicate on a scale of 1-6 how satisfied you are with this support (1= not satisfied, 2= somewhat satisfied, 3= neutral, 4= satisfied, 5= moderately satisfied, 6= highly satisfied).

Question 1	Whom can you really count on to be dependable when you need help?	
Question 2	Please circle how satisfied are you with the support you receive?	1 2 3 4 5 6
Question 3	Whom can you really count on to help you feel more relaxed when you are under pressure or tense?	

Question 4	Please circle how satisfied are you with the support you receive?	1 2 3 4 5 6
Question 5	Who accepts you totally, including both your worst and your best points?	
Question 6	Please circle how satisfied are you with the support you receive?	1 2 3 4 5 6
Question 7	Whom can you really count on to care about you, regardless of what is happening to you?	
Question 8	Please circle how satisfied are you with the support you receive?	1 2 3 4 5 6
Question 9	Whom can you really count on to help you feel better when you are feeling generally down-in-the-dumps?	
Question 10	Please circle how satisfied are you with the support you receive?	1 2 3 4 5 6
Question 11	Whom can you count on to console you when you are very upset?	
Question 12	Please circle how satisfied are you with the support you receive?	1 2 3 4 5 6

General demographics.

Age:

Age at time of diagnosis:

Gender: M/ F/ Other

Occupation: full time employment/ part-time employment/ student/ unemployed/ parent/ other

If employed, please specify occupation and no. hours/week:

Marital status: Unmarried/ Married/ Divorced / Other

Do you have dependants? If so, please specify who and how many:

Ethnicity: White/ Black/ Asian/ Mixed/ Other/ prefer not to say

Religion: Christian/ Muslim/ Hundi/ Islamic/ Not religious/ Other/ prefer not to say

Cancer diagnosis:

Date diagnosis received (MM/YY):

Cancer stage: Active/ Maintenance/ No active treatment/ Palliative/ survivor

Please provide information regarding the treatment you have received since your cancer diagnosis. Please indicate type(s) of treatment (eg. Chemotherapy, surgery, radiotherapy etc), dose, frequency, duration and when you received the treatment in the box below. Please also provide the name of the hospital where you received your treatment:

.....

Thank you for completing this survey.

We would like to invite you to take part in an interview to discuss these topics further. The interview can be conducted in person or via telephone and should take no longer than 60 minutes. If you would like to take part in this, please provide your name and preferred contact information below:

Name:

Contact Number:

If you would like further information about the interviews, please contact Eilidh McLeod (Doctorate of Physiotherapy Student): Email 1709110@rgu.ac.uk

Appendix 17 Interview topic guide

Interview Topic Guide

Hello my name is Eilidh, I am a physiotherapist and a research student at Robert Gordon university. Firstly, I would just like to thank you for your time today.

How this will work is we will have a chat about your experiences of cancer and physical activity. I will ask you some questions and I would just like you to answer them however you want- there is no right or wrong answer, this is really just exploring your opinions and experiences so we get a better understanding of the area to develop the young adult cancer service.

If at any point you during the interview, you feel upset, do not want to answer a particular question or do not wish to continue with the interview please let me know- this is entirely voluntary. I will also provide you with contact information for TYA cancer support networks if you wish to chat with someone further.

The interview will be recorded today so that the research team can analyse the data later. The recording will only be viewed by myself when typing up the interview transcript and will then be stored on a secure RGU server which can only be accessed by the research team. If you feel more comfortable you can switch your camera off.

Do you have any questions before we begin?

Next, I will read you out some consent statements, if you are happy with these please yes after each statement. I will also begin the recording; you should see a message on your screen asking you to accept recording.

Consent statements.

1. I confirm that I have read the information sheet dated 02.09.21 (Version 4) for the study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or rights being affected.
3. I understand that data collected during the study, may be looked at by individuals from Robert Gordon University or my local NHS trust, where it is relevant to my taking part in this research.
4. I understand that information collected about me will be used to support other research in the future and may be shared anonymously with other researchers.
5. I understand that anonymised quotes may be used in publications about the research.
6. I agree to take part in this interview.

Questions

1. Can you start by telling me a little bit about yourself?
 - Age
 - Work/school
 - Family/social network
 - Hobbies/social life

2. Can you tell me about your diagnosis?

- Cancer type
- when/age
- stage
- treatment you received
- where are you now

3. So, what physical activity means to you?

WHO defines physical activity as any bodily movement, produced by skeletal muscles that requires energy. So, today when we are talking about physical activity, we are talking about activities of daily living like going to the shops, walking the dog, getting dressed etc as well as sport and exercise.

4. Do you think there are any benefits to physical activity?

- Why? / what are they?
- If not why?

5. Currently, would you describe yourself as physically active? (Walk? Garden? Run after kids? Active @ work? Play sports?)

- Is it a priority for you atm?
- What do you do to keep active?
- Team sports/clubs? Were you involved before/ this the same before diagnosis?

6. Before your diagnosis would you describe yourself as active?

- What did you do to keep active?
- Did being active before influence your relationship with PA after diagnosis? Could you tell me why you think this?

7. Thinking about your diagnosis, could you tell me a little about how you have found physical activity to be after that?

- Have there / were there changes I your PA since your diagnosis?
- Did it effect how active you were?
- Did the types of activity you were interested in change?
- Did the types of activity you could do change?

8. How did treatment affect your activity?

- If so how?
- How did you cope with these changes?
- If not why?
- Was physical activity a priority for you/ do you think it's something that should be priorities at this stage? Why?
- Different types of treatment and the effects of these?

9. Did anyone speak to you about physical activity after your diagnosis?

- Healthcare professional/ family member/ friend/ charity staff?
- What did they say?
- Was it helpful/ Do you feel like you needed this? If so, why?
- Was it enough information/was It too much?
- Was there anything missing from this?
- When was this provided and was it at the best time? If not, why?

10. Did you ever look up any information or ask anyone about physical activity after your diagnosis?
 - Why?
 - Where did you get your information/who did you ask?
 - Why did you get it this way?

11. Did you feel you had support to engage in physical activity after your cancer diagnosis?
 - If yes, how did that come about?
 - At what point during your cancer journey was this?
 - Was that in place before your diagnosis?
 - Who supports you/social support? (medical and personal support?)
 - Was this helpful?
 - Who would be best?

12. Do you feel you have support now to engage in physical activity?
 - Who?
 - Is this helpful?

13. Can you tell me about the things you find help or motivate you to be active?
 - Can you expand on that?
 - Why do you feel this/these help?
 - Was there any changes in these things across your cancer journey?

14. Is there anything you find that stops you being active?
 - can you tell me a bit more about that?
 - were these things present before your diagnosis? Or have they come up since treatment?
 - what would you describe as the biggest issues for you being active are?
 - are you aware of anything that could improve this? Is there anything you do to help you overcome this?
 -

15. Have you tried anything to get more active?
 - If so, what worked?
 - what didn't?
 - why did you try this?
 -

16. Do you think that during treatment is an appropriate time to be thinking about physical activity?
 - Why?

17. What do you think can be done to help people be physically active during treatment?
 - Who should give this?
 - How is it best delivered?
 - Is this something that should be prioritised? Why?

18. What do you think can be done to help people be physically activity after treatment?
 - Is this different from on treatment?

- Is this something that should be prioritised? Why?
19. How do you feel you could be best supported to improve your physical activity?
- What do you think of Exercise groups? Walking groups? Why?
 - Fitness apps? Why?
 - Websites? Why?
 - Charities? Why?
 - Step-counters or fitness watches? Why?
 - In person vs virtual. Why?
20. What do you think about the role of social media in physical activity?
- Promotion?
 - Advice?
 - Social network/support group?
 - Negative effects?
21. I know we may have touched on this already but can you tell me about the impact of covid-19 on your physical activity?
- Treatment alone?
 - Activity preferences?
 - Support side of things?
 - If covid-19 was not present would your activity levels be different?
22. What advice would you give someone going through treatment about physical activity? And staying active?
23. What advice would you give someone after treatment about physical activity?
24. Are you aware of the physical activity guidelines for adults over 18 in the UK? If so, can you tell me what they are?
25. Do you feel you meet the guidelines currently?
26. Do you feel you could be more active?
27. How would you achieve this?
28. How do you feel about these in relation to cancer treatment and recovery?
29. Is there anything else you feel I've missed when considering physical activity in cancer? Do you have any other comments/thoughts you'd like to share with me?

Thank you very much for your time today, your participation is invaluable at increasing our knowledge in this area and helping us to improve the TYA cancer service. If you found any of the topics we covered today distressing there are support networks available

<https://www.teenagecancertrust.org/get-help>

<https://www.cancerresearchuk.org/about-cancer/coping/emotionally>

If you are looking for some more information and advice about physical activity

<https://www.trekstock.com/>

<https://www.macmillan.org.uk/cancer-information-and-support/stories-and-media/booklets/physical-activity-and-cancer>

Would you like to receive a summary about the results of the project? This may be for some time as the results will need to be analysed and collated into a summary document. If so, are you happy for me to send these to you via email?

Appendix 18 All participant responses regarding the effect of covid-19 on their physical activity behaviours. Responses are grouped based on content analysis.

Effect of Covid-19 on PA	Main impact of Covid-19 on PA	Adaption to PA due to Covid-19
<p>Shielding/Social Distancing</p> <p><i>"Shielding and closed gyms at work"</i> (Female, 23, cancer free)</p> <p><i>"Stuck in the house I have two children one of which is also shielding"</i> (Male, 24, no active treatment)</p> <p><i>"Swimming pool is closed, and shielding means I can only go on walks close to my home in quiet areas I know I will not come into close contact with others. My usual walking routes are on narrow pathways where there are usually a lot of other people"</i> (Female, 25, active treatment).</p> <p><i>"Shielding has meant I can't go to the gym/classes/rock climbing, and I definitely prefer to exercise indoors"</i> (Female, 25, cancer free)</p> <p><i>"Fewer facilities open and can't meet people to exercise with. Staying at home more"</i> (Female, 26, no active treatment)</p>	<p>Shielding/Social Distancing</p> <p><i>"Mainly not being able to use the swimming pool, which is closed, and not being able to walk wherever I like. I live in a busy part of Glasgow, so it's not easy to find areas to walk where I won't be around other people. The route to parks I would usually walk to are along main roads, so I've not been able to go at all"</i> (Female, 25, active treatment).</p> <p><i>"Shielding has limited the types of exercise I can do"</i> (Female, 25, cancer free).</p> <p><i>"Having to stay at home more"</i> (Female, 26, no active treatment)</p> <p><i>"Keeping socially distanced does distract me/knock off my focus when running"</i> (Female, 30, cancer free).</p> <p><i>"The social side of activity and the ability to travel and exercise indoors other than my house"</i> (Female, 26, cancer free).</p>	<p>Change activity</p> <p><i>"I've had to stop swimming, and shorten my walks and go to quiet places only"</i> (Female, 25, active treatment).</p> <p><i>"I used to go the gym but my gym was put online and I used to kayak on the water but I changed that to cycling and I have a turbo trainer in the garage"</i> (Female, 16, no active treatment).</p> <p><i>"I've moved from my regular cardio to muscular exercises that I can do at home. Cardio is now either a short walk outside or a lot of stair climbs"</i> (20, Female, active treatment)</p> <p><i>"Lack of the gym has allowed me to do workouts at home"</i> (Female, 19, cancer free).</p> <p><i>"I have had to change the way I work out due to not being able to attend gym"</i> (Female, 24, Maintenance treatment)</p>

<p>"I had to shield and was advised to not to leave my home, therefore was not able to walk as much or meet friends to go for walks" (Female, 26, cancer free).</p> <p>"Currently shielding" (Female, 27, cancer free)</p> <p>"Initially it reduced my activity as at the beginning of sheilding I wasn't meant to be leaving my house/garden. More recently however I have been able to do more activity as I am only back to work part time" (Female, 29, cancer free).</p> <p>"As I received chemotherapy, I was immunocompromised, so was put on the shielding list. Throughout my cancer treatment, I was discouraged from leaving my house for any reason" (Male, 18, cancer free)</p> <p>"I can no longer fence. I am scared to go outside too much in case I get ill as a lot of people don't follow the guidelines". (20, Female, active treatment)</p>	<p>"I became less active as a result as i had to shield and could not walk as much as I would have liked" (Female, 26, cancer free).</p> <p>"Stay at home I can't go to the college or have extra classes to improve my English because I am not familiar with online learning" (Female, 23, active treatment).</p> <p>"Mental and physically can't attend anywhere at the moment" (Male, 32, cancer free)</p> <p>"Being put on the shielding list restricted the exercise I could do. So even on days where I was a little better, I still couldn't do much physically" (Male, 18, cancer free)</p>	<p>"Use of an app to support/subsidise my workouts/classes. Finding walks to do in my area" (Female, 24, cancer free).</p> <p>"I've had to stop swimming, and shorten my walks and go to quiet places only" (Female, 25, active treatment).</p>
Access to facilities	Access to facilities	Home workouts

<p><i>"I can no longer fence. I am scared to go outside too much in case I get ill as a lot of people don't follow the guidelines". (20, Female, active treatment)</i></p> <p><i>"In both a positive and negative way. I have started to walk more however have not been able to attend the gym as often as I would have liked" (Female, 19, cancer free).</i></p> <p><i>"I enjoy the gym to destress, however unable to go because of Covid" (Female, 24, Maintenance treatment)</i></p> <p><i>"Fewer facilities open and can't meet people to exercise with. Staying at home more" (Female, 26, no active treatment)</i></p> <p><i>"I used to go rock climbing in and outdoors. Walls aren't open and outdoors seems a too high a risk in such a hard time for the nhs. I used to go to yoga classes, online groups are not the same. Swimming pools aren't open and I don't have nearby lakes to swim. Mountain biking nearby isn't so great I'd normally travel for it. We go for lunch time runs at work but now I work from home</i></p>	<p><i>"No gym facilities for upper body" (Female, 23, cancer free)</i></p> <p><i>"Mainly not being able to use the swimming pool, which is closed, and not being able to walk wherever I like. I live in a busy part of Glasgow, so it's not easy to find areas to walk where I won't be around other people. The route to parks I would usually walk to are along main roads, so I've not been able to go at all" (Female, 25, active treatment).</i></p> <p><i>"The loss of facilities and the emotional impact" (20, Female, active treatment)</i></p> <p><i>"Not being able to continue my treadmill and weights" (Female, 24, Maintenance treatment)</i></p> <p><i>"Can't attend physio sessions at the hospital" (Female, 24, cancer free)</i></p> <p><i>"Gyms being closed has meant that I can't build my muscles back up" (Female, 24, cancer free)</i></p> <p><i>"Access to regular places of activity" (Female, 25, active treatment)</i></p> <p><i>"If anything, use of indoor sports facilities" (Female, 22, no active treatment)</i></p>	<p><i>"Lack of the gym has allowed me to do workouts at home" (Female, 19, cancer free).</i></p> <p><i>"I have tried to do more home workouts by using YouTube" videos (Female, 26, cancer free).</i></p> <p><i>"Small home workouts, and minimal walks" (Female, 24, cancer free)</i></p> <p><i>"Can't attend the gym, so have been doing home workouts" (Female, 29, cancer free).</i></p> <p><i>"Home training" (Female, 25, active treatment)</i></p> <p><i>"I started and have continued with doing home workouts" (Female, 21, cancer free)</i></p> <p><i>"I've moved from my regular cardio to muscular exercises that I can do at home. Cardio is now either a short walk outside or a lot of stair climbs" (20, Female, active treatment)</i></p>
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<p><i>without a running partner it is hard to motivate myself" (Female, 26, cancer free).</i></p> <p><i>"Not getting out as much and gyms are closed" (Female, 24, cancer free)</i></p> <p><i>"I would have liked to have been able to start building up my exercise again by swimming but this was not possible. Also, my gym is closed and did not feel comfortable going even when it was open" (Female, 25, active treatment)</i></p> <p><i>"Can't to swimming or other sports I enjoy" (Male, 32, cancer free)</i></p> <p><i>"Swimming pools closed" (Female, 27, cancer free)</i></p> <p><i>"Used to go to gyms before lockdowns, had no motivation to partake in adapted exercises whilst at home even with the equipment" (Male, 21, cancer free)</i></p>	<p><i>"Restrictions at gyms" (Male, 25, cancer free)</i></p>	
<p>Increased pa</p> <p><i>"I was diagnosed when the first lockdown was lifted. I did a fitness challenge in the first lockdown. I did Lands' end to John O'Groats in lockdown on the bike and running. It was</i></p>	<p>Increased pa</p> <p><i>"I felt more active in the first lockdown, before diagnosis and if I wasn't for my diagnosis, I would have continued my</i></p>	<p>Walking</p> <p><i>"Resorting to just walking" (Female, 23, cancer free)</i></p>

<p>874 miles" (Female, 16, no active treatment).</p> <p>"In both a positive and negative way. I have started to walk more however have not been able to attend the gym as often as I would have liked" (Female, 19, cancer free).</p> <p>"If anything, it has made me more active as staring at the same four walls is mind-numbing" (Female, 24, cancer free).</p> <p>"Ran a lot more during lockdown so if anything, it helped" (Male, 27, maintenance treatment)</p> <p>"It has given me the time to focus on it more" (Female, 21, cancer free)</p>	<p>physical activity" (Female, 16, no active treatment).</p> <p>"An increase" (Female, 19, cancer free).</p> <p>"I actually improved prior to cancer diagnosis as did more running abs home workouts then gym" (Female, 25, active treatment)</p> <p>"It has increased my physical activity and improved my fitness" (Female, 21, cancer free).</p>	<p>"I do more outdoor walking as a way to keep both mentally and physically well" (Female, 24, cancer free)</p> <p>"Use of an app to support/subsidise my workouts/classes. Finding walks to do in my area" (Female, 24, cancer free).</p> <p>"Small home workouts, and minimal walks" (Female, 24, cancer free)</p> <p>"I wasn't able to do anything just walking or housework because of lockdown and social distance" (Female, 23, active treatment).</p>
<p>No Effect</p> <p>"I regularly go on walks with my son and enjoy solo running so have kept that going" (Female, 30, cancer free).</p> <p>"I used to work out at home, I live in the country so lots of opportunities to walk. Also, my personal trainer has her own personal gym that I used "(Female, 22, no active treatment)</p>	<p>No Effect</p> <p>"It's not made much difference" (Male, 27, maintenance treatment)</p> <p>N/A</p>	<p>Local activities</p> <p>"Staying closer to home / at home more often" (Female, 26, no active treatment)</p> <p>"Use of an app to support/subsidise my workouts/classes. Finding walks to do in my area" (Female, 24, cancer free).</p> <p>"I am unable to do many things due to distance or places being closed. Running local to my house is most of my activity" (Female, 26, cancer free).</p>

<p>"It hasn't affected it" (Female, 22, no active treatment)</p> <p><i>"It hasn't affected me"</i> (Male, 25, cancer free).</p>		
<p>Motivation</p> <p><i>"First lockdown I had zero motivation but this second lockdown something just clicked and I had the motivation to be more active"</i> (Female, 24, cancer free).</p> <p><i>"Used to go to gyms before lockdowns, had no motivation to partake in adapted exercises whilst at home even with the equipment"</i> (Male, 21, cancer free)</p> <p><i>"I used to go rock climbing in and outdoors. Walls aren't open and outdoors seems a too high a risk in such a hard time for the n's. I used to go to yoga classes, online groups are not the same. Swimming pools aren't open and I don't have nearby lakes to swim. Mountain biking nearby isn't so great I'd normally travel for it. We go for lunch time runs at work but now I work from home without a running partner it is hard to motivate myself"</i> (Female, 26, cancer free).</p>	<p>Motivation/ emotional impact</p> <p><i>"Motivation/drive"</i> (Male, 24, no active treatment)</p> <p><i>"The loss of facilities and the emotional impact"</i> (20, Female, active treatment)</p> <p><i>"Sometimes I feel so motivated to move and work out to do something but other times I feel completely drained and lazy. Major mood swings due to COVID have definitely had an impact"</i> (Female, 24, cancer free).</p> <p><i>"During lockdowns, i had little to no activity but post I probably did more exercise than before due to a desire to get out the house more"</i> (Male, 21, cancer free)</p> <p><i>"First lockdown i had zero motivation but this second lockdown something just clicked and i had the motivation to be more active"</i> (Female, 24, cancer free).</p> <p><i>"See it as a way to escape stresses"</i> (Female, 29, cancer free).</p>	<p>Housework</p> <p><i>"More house related work a lot more sitting doing nothing"</i> (Male, 24, no active treatment)</p> <p><i>"I wasn't able to do any thing just walking or housework because of lockdown and social distance"</i> (Female, 23, active treatment).</p> <p><i>"Not now, since covid is withering away. But at the height of the pandemic, indeed, I was restricted to domestic activity, which took some adjustment"</i> (Male, 18, cancer free)</p>

	<i>"Mental and physically can't attend anywhere at the moment"</i> (Male, 32, cancer free)	
<p>Other</p> <p><i>"Had Covid in October which fell me off my stride of training and starting a new job so never got back to my proper routine of gym before getting moles removed"</i>(Female, 25, active treatment)</p> <p><i>"Before the lockdown I go shopping a lot and visiting my friends also due to COVID-19 my mum can't get a visa to come to Uk To support me"</i> (Female, 23, active treatment).</p>	<p>Reduced function</p> <p><i>"Fatigue has worsened and lung function"</i> (Female, 27, cancer free)</p> <p><i>"Less active which makes my body sore"</i> (Female, 27, cancer free)</p> <p><i>"during lockdowns, i had little to no activity but post I probably did more exercise than before due to a desire to get out the house more"</i> (Male, 21, cancer free)</p>	<p>Other</p> <p><i>Unable to meet with friends outside and unable to exercise in areas close by as risk of other people</i> (Female, 27, cancer free)</p> <p><i>gym not open, gymnastics club not open</i> (Female, 25, active treatment)</p> <p><i>Swimming helped pain in body</i> (Female, 27, cancer free)</p> <p><i>As the gyms re-opened i returned and slowly re introduced it into my daily schedule in order to avoid injury</i> (Male, 21, cancer free)</p> <p>No change</p> <p><i>No, I just keep distanced when I run/walk</i> (Female, 30, cancer free)</p> <p><i>I just run outdoors so no change</i> (Male, 27, maintenance treatment)</p> <p>N/A</p> <p>No</p> <p><i>I haven't had to adapt</i> (Female, 22, no active treatment)</p> <p><i>It hasn't stopped me</i> (Male, 25, cancer free)</p>

Appendix 19 Full Table of SOC, IPAQ category, Cancer Status and Barrier/Facilitator Statements

Barrier statement	Stage of change* (correlation coefficient**, p-value***)	Cancer stage* (correlation coefficient**, p-value***)	IPAQ category* (correlation coefficient**, p-value***)
I don't know how to be active	Chi (30, 3)= 1.54, p=0.673 Rho (30)= -0.012, p=0.951	Chi (30, df=1) = 0.19, p=0.661 Rho (30)= -0.08, p=0.674	Chi (26, 2)= 0.929, p=0.629 Rho (26)= 0.188, p=0.356
I don't have time to be active	Chi (30, 6)= 2.49, p=0.870 Rho (30)= 0.104, p=0.585	Ch (30, df 2)= 5.17, p=0.075 Rho (30) = 0.266, p=0.156	Chi (26, 4)= 1.96, p=0.743 Rho (26)= -0.163, p=0.427
I don't want to get injured	Chi (30,6)= 6.99, p=0.321 Rho (30)= -0.238, p=0.205	Chi (30, df 2)= 1.89, p=0.389 Rho (30)= -0.056, p=0.768	Chi (26, 4)= 4.56, p=0.335 Rho (26)= -0.124, p=0.546
I don't have transport to take me to where I can be active	Chi (30,6)= 3.18, p=0.786 Rho (30)= -0.055, p=0.774	Chi (30, df 2)= 2.05, p=0.359 Rho (30)= 0.226, p=0.231	Chi (26, 4)= 0.93, p=0.920 Rho(26)= -0.079, p=0.702
I don't enjoy being active	Chi (30,6)= 4.96, p=0.549 Rho (30)= 0.054, p=0.775	Chi (30, df 2)= 2.22, p=0.329 Rho (30)= 0.272, p=0.146	Chi(26, 4)= 1.98, p=0.704 Rho(26)= 0.155, p=0.450
I am too tired to be active	Chi (30,6)= 11.87, p=0.065 Rho (30)= -0.429, p=0.018	Chi (30, df 2)= 0.833, p=0.659 Rho (30)= 0.164, p=0.387	Chi(26, 4)= 6.0, p=0.199 Rho (26)= -0.368, p=0.064
Being active is not a priority for me	Chi (30, 6)= 10.94, p=0.09 Rho (30)= -0.279, p=0.135	Chi (30, df 2)= 0.63, p=0.732 Rho (30)= -0.142, p=0.456	Chi(26, 4)= 4.25, p=0.373 Rho(26)= -0.224, p=0.272
I am in too much pain when I exercise	Chi (30, 6)= 6.98, p=0.323 Rho (30)= -0.388, p=0.034	Chi (30, 2)= 1.48, p=0.477 Rho (30)= 0.073, p=0.702	Chi (26, 4) = 3.15, p=0.534 Rho (26) = -0.161, p=-0.431
I feel too weak to be active	Chi(30,6)= 10.99, p=0.089 Rho (30)= -0.419, p=0.021	Chi (30, 2)= 3.46, p=0.177 Rho (30)= -0.079, p=0.677	Chi (26, 4) = 6.28, p=0.179 Rho (26) = -0.221, p=0.277
I don't have access to equipment or a facility	Chi (30, 6)= 6.25, p=0.396 Rho (30)= -0.313, p=0.093	Chi (30, 2)= 0.875, p=0.646 Rho (30)= 0.092, p=0.630	Chi (26, 4) = 6.19, p=0.186 Rho (26) = -0.282, p=0.163
I worry about the way my body looks when I exercise	Chi (30, 3)= 1.40, p=0.705 Rho (30)= -0.190, p=0.315	Chi (30, 1)= 0.81, p=0.367 Rho (30)= 0.165, p=0.384	Chi (26, 2) = 0.720, p=0.698 Rho (26) = -0.04, p=0.846
Bad weather stops me from being active	Ch (30, 6)= 3.18, p=0.786 Rho (30)= -0.113, p=0.552	Chi (30, 2)= 1.76, p=0.415 Rho (30)=0.073, p=0.702	Chi (26, 4) = 3.80, p=0.434 Rho (26) = -0.261, p=0.197
I am too lazy	Chi (30, 6)= 13.38, p=0.037 Rho (30)= -0.490, p=0.006	Chi (30, 2)= 1.70, p=0.427 Rho (30)= -0.021, p=0.912	Chi (26, 4)= 6.68, p=0.154, rho (26)= -0.429, p=0.029

I it is too expensive to be active	Chi (30, 6)= 2.56, p=0.861 Rho (30)= 0.028, p=0.883	Chi (30, 2)= 0.89, p=0.640 Rho (30)= 0.117, p=0.536	Chi (26, 4)= 2.17, p=0.706 Rho (26)= 0.129, p=0.529
I lack the motivation to keep myself active.	Chi (30, 6)= 8.09, p=0.231 Rho (30)= -0.351, p=0.057	Chi (30, 2)= 1.30, p=0.523 Rho (30)= 0.190, 0.315	Chi (26, 4) 3.97, p=0.410 Rho (26)= -0.209, p=0.306
I don't have anyone to exercise with.	Chi (30, 6)= 5.50, p=0.481 Rho (30)= 0.127, p=0.502	Chi (30, 2)= 3.09, p=0.213 Rho (30)= 0.214, p=0.256	Chi (26, 4)= 4.73, p=0.316 Rho (26)= -0.031, p=0.881
I can't be active outside my house due to COVID-19	Chi (30, 6)= 13.69, p=0.033 Rho (30)= -0.381, p=0.038	chi (30, 2)= 2.91, p=0.234 rho (30)= 0.229, p=0.223	Chi (26, 4)= 7.33, p=0.119 Rho (26)= -0.161, 0.432
I have underlying health condition(s) other than cancer that makes exercising difficult.	Chi (30, 3)= 3.47, p=0.325 Rho (30)= -0.95, p=0.617	Chi (30, 1)= 3.44, p=0.064 Rho (30)= 0.339, p=0.067	Chi (26, 2)= 0.973, p=0.626 Rho (26)= 0.079, p=0.703
Facilitator			
Being physically active helps me meet new people	Chi (30, 6)= 2.68, p=0.848 Rho (30)= -0.213, p=0.258	Chi (30, 2)= 3.28, p=0.194 Rho (30)= -0.332, p=0.082	Chi (26, 4)= 2.56, p=0.633 Rho (26)= -0.084, p=0.683
I want to improve my strength	Chi (30, 3)= 4.14, p=0.247 Rho (30)= 0.268, p=0.153	Chi (30, 1)= 1.55, p=0.213 Rho (30)= 0.227, p=0.227	Chi (26, 2)= 3.47, p=0.177 Rho (26)= 0.290, p=0.150
I enjoy the social benefits of attending a sports club/fitness group and meeting new people	Chi (30, 6)= 4.73, p=0.579 Rho (30)= -0.163, p=0.389	Chi (30, 2)=4.11, p=0.128 Rho (30)= -0.175, p=0.355	Chi (26, 4)= 0.442, p=0.979 Rho (26)= -0.076, p=0.712
My cancer diagnosis has motivated me to be more active	Chi(30,6)= 10.26, p=0.114 Rho (30)= 0.231, p=0.219	Chi (30, 2)= 0.646, p=0.724 Rho (30)= -0.139, 0.464	Chi (26, 4)= 8.56, p=0.073 Rho (26)= 0.0263, p=0.195
I want to improve my mental health	Chi (30,3)= 1.83, p=0.609 Rho (30)= -0.053, p=0.781	Chi (30, 1)= 0.19, p=0.661 Rhgo (30)= 0.08, p=0.674	Chi (26, 2)= 4.73, p=0.094 Rho (26)= 0.031, p=0.881
I want to increase my independence	Chi (30,6)= 6.12, p=0.410 Rho (30)= 0.149, p= 0.432	Chi (30, 2)= 1.59, p=0.453 Rho (30)= 0.230, p=0.22	Chi (26, 4)= 6.26, p=0.181 Rho (26)= 0.207, p=0.310
I want to improve my fatigue	Chi(30, 3) = 2.72, p=0.438 Rho (30) = -0.147, p=0.439	Chi (30, 1)= 0.99, p=0.320 Rho (30)= 0.181, p=0.337	Chi (26, 2)= 3.39, p=0.183 Rho (26)= 0.026, p=0.899

Having access to a physical activity program makes me/would make me more active	Chi (30, 6)= 5.49, p=0.482 Rho (30)= 0.080, p=0.674	Chi (30, 2)= 0.24, p=0.888 Rho (30)= -0.088, p=-.644	Chi (26, 4)= 4.85, p=0.303 Rho (26)= 0.037, p=0.857
Being physically active helps me feel normal	Chi (30, 6)= 4.62, p=0.593 Rho (30)= -0.255, p=0.173	Chi (30, 2)= 2.22, p=0.329 Rho (30)= 0.024, p=0.899	Chi (26, 4)= 2.17, p=0.711 Rho (26)= -0.241, 0.236
I want to maintain/improve my general health and fitness	100% agree with statement	100% agree with statement	100% agree with statement
Having someone to exercise with helps me be active	Chi(30,6)= 11.59, p=0.072 Rho (30)= -0.056, p=0.767	Chi (30, 2)= 2.75, p=0.252 Rho (30)= -0.277, p=0.139	Chi (26, 4)= 7.07, p=0.095 Rho (26)= -0.049, p=0.814
I know how to safely exercise	Chi (30, 6)= 5.72, p=0.456 Rho (30)= 0.152, p=0.422	Chi (30, 2)= 2.75, 0.252 Rho (30)= -0.277, p=0.139	Chi (26,4)= 2.40, p= 0.633 Rho (26)= 0.028, p=0.893
If someone gave me information about how to safely exercise it would make me more active	Chi (30, 6)= 3.99, p=0.679 Rho (30)= -0.008, p=0.965	Chi (30, 2)= 1.37, p=0.503 Rho (30)= -0.174, p=0.357	Chi (26, 4)= 8.30, p=0.081 Rho (26)= 0.091, p=0.658
I enjoy being active	Chi (30, 6)= 8.35, p=0.214 Rho (30)= 0.170, p=0.370	Chi (30, 2)= 2.22, p=0.329 Rho (30)= -0.272, p=0.146	Chi (26, 4)= 2.31, p=0.679 Rho (26)= 0.185, p=0.364
Being active before my diagnosis helped me remain active	Chi (30, 6)= 8.53, p=0.202 Rho (30), 0.146, p=0.442	Chi (30, 2)= 3.99, p=0.135 Rho (30)= -0.356, p=0.047	Chi (26, 4)= 2.25, p=0.690 Rho (26)= 0.045, p=0.826
Being active provides a distraction from cancer	Chi (30, 6)= 7.48, p=0.279 Rho (30)= 0.021, p=0.914	Chi (30, 2)= 1.19, 0.553 Rho (30)= -0.188, 0.319	Chi (26, 4)= 8.27, p=0.082 Rho (26)= 0.051, p=0.803
Having encouragement and support from my family and/or friends helps me be active	Chi (30, 6)= 1.04, p=0.916 Rho (30)= -0.027, p=0.886	Chi (30, 2)= 1.07, p=0.585 Rho (30)= -0.117, p=0.538	Chi (26, 4)= 3.45, p=0.485 Rho 926)= 0.202, p=0.323
I live close to facilities where I can be active	Chi (30, 6)= 7.55, p=0.273 Rho (30)= 0.124, p=0.512	Chi (30, 2)=0.063, p=0.969 Rho (30)= -0.025, p=0.894	Chi (26, 4)= 4.83, p=0.306 Rho (26)= 0.038, p=0.853

Appendix 20 Full list of Thematic Analysis codes with groupings

Meaning of physical activity

- Meaning of PA - PA and health behaviours pre-diagnosis
- Physical activity means exercise
- Physical means keeping fit and active
- Physical activity means working out
- Physical activity means running
- Physical activity means swimming
- Physical activity means dancing
- I don't know what physical activity means.
- PA means walking
- PA means sport
- PA means going to the gym
- PA means not sitting around
- Diagnosis has changed what physical activity means`
- Classes to help you be better with things

Current PA behaviours

- Not currently meeting PA guidelines
- Currently meeting PA guidelines
- PA is a priority for me
-

Physical activity behaviours pre-diagnosis

- Always been an active person
- Describes self as active
- being active is part of my identity
- Pre-diagnosis I would motivate others to be active

Physical activity behaviours post diagnosis

- Reduced physical activity due to diagnosis
- Symptoms of cancer affecting physical activity behaviours
- PA behaviours switched to walking post-diagnosis
- Relationship with exercise has changed since diagnosis
-

Effect of treatment on PA

- Reduced physical activity due to treatment
- Frustrated at not managing pre-diagnosis activity levels
- No effect of treatment on PA levels
- Thinking about activity levels was not on radar during treatment
- Effects of treatment on PA vary with treatment type
- Walking main activity during treatment
- Did not expect treatment to have effected activity levels as much as it did
- Mental benefit of being active but physically causes exhaustion
- Reduced exercise tolerance
- Reduced appetite, weight loss, low energy levels, reduced muscle mass=
reduced activity levels

Cognitive aspects of PA post diagnosis

- Learning new normal
- Struggling with new baseline
- Wanting to improve strength
- Feeling fed up
- Fear of cancer recurrence
- Low self-efficacy to be active
- cancer is very isolating
- feeling a lack of control over own health
- cancer as time of reflection/re-evaluation of priorities
- learning to be kind to myself and lower expectations
- Exercise not a priority during treatment
- Keeping active was a priority for me

Benefits of physical activity

- Physical activity has physical and mental benefits
- Physical activity improves mood
- Physical activity as a coping mechanism
- Sense of control over health
- Sense of achievement
- Energy boost from being active
- PA reduces stress/anxiety
- Return to normalcy
- PA allows socialisation
- PA = distraction from cancer
-

Effect of cancer on the individual

- Poor mental health during treatment

Barriers to PA

- Low mood= PA barrier
- Sweating= PA barrier
- Self-conscious wearing gym clothes
- Self-conscious of red face when exercising
- Geographical barrier to PA
- Weather = barrier
- Hospitalisation= PA barrier
- Nausea= PA barrier
- Covid-19/shielding= PA barrier
- Fatigue= PA barrier
- Pain = PA barrier
- Shortness of breath PA barrier
- Lack of energy
- Low energy reserves- having to decide what to expend energy on can be PA barrier

- Worried about future health = reduced mood = reduced motivation to be active
- Fear of injury
- Fear of pain/exacerbating pain
- Fear of pushing self too hard
- Fear of negatively influencing treatment
- Scared to cause harm by being too active during treatment
- PICC line cause PA restrictions during treatment as infection risk
- Feeling self-conscious about hair loss = PA barrier
- Weakness= PA barrier
- Wanting to feel better in body = PA motivator
- Poor mental health during treatment
- Low self-efficacy to be active
- Laziness= PA barrier
- Low motivation= PA barrier
- Time = PA barrier
- English as second language= barrier to attending group setting
- Treatment side effects= barrier
- Post-surgical restrictions = PA barrier
- Lack of equipment at home= barrier
- Long day at work=barrier
- Busy = barrier
- Bloating/fluid retention= PA barrier
- caution with surgical wound site = pa barrier
- post-op complication = pa barrier
- living in flat= environmental barrier to PA as not wishing to disturb neighbours
- Sleep issues exacerbate fatigue
- Going to the gym is intimidating
- Moved home so no friends to be active with after treatment
- Family as a barrier/ caring commitments
- Lack of knowledge of how to be active= barrier
- Lack of knowledge of where to start to be active
- Financial costs= barrier

Support offered to be active

- Frustrated with lack of PA discussion
- Lack of advice about PA modifications
- Nobody discussed physical activity post-diagnosis
- Nobody discussed physical activity after treatment
- Lack of advice about how to be more active
- PA not priority of medical team
- Support from charities to be active
- Attended charity run PA class to get back into PA- lead to increased confidence in PA ability
- Given fitbit by TYA unit which was motivational
- differences between hospitals re. physical activity advice given
- Physio provided exercises to help return to activity

- Physio provided exercises for back pain
- Post-op physical activity advice/restrictions
- Health visitor gave PA advice
- online exercise class was good but too easy- needed more exercise variations
-

Physical activity advice received

- Was told to keep as active as possible during treatment
- Received general post-op advice re. movement restrictions

Facilitators/motivators of PA

- Goal setting= PA motivator
- Counting steps = PA motivator
- Doing exercise with someone/group = motivator
- Personal trainer = motivator
- Weight loss= motivator to be active
- Weight gain= motivator to be active
- Hated how I looked after treatment so motivator for activity
- Gain muscle = PA motivator
- Working a sedentary job= motivator to walk at lunch break
- Getting outside= motivator to be active
- Future health concerns = PA motivator
- Living near nice walks= motivator
- Weather= motivator
- Son/family= motivator
- Internally motivated to be active
- Shared experience through Instagram = motivational
- Covid-19 allowed for time to be active (motivator)
- Reduced cancer recurrence risk= motivator
- Worried about osteoporosis = PA motivator
- Social media challenge= motivational
- Meetings/social events with other TYA cancer patients would encourage active
- Given fitbit by TYA unit which was motivational
- PA equipment on ward facilitated activity
- Seeing progression /physical changes = motivational
- Religion as motivator
- Pre-existing health condition= get on with things attitude which =motivator
- Active pre-diagnosis= facilitator for activity post diagnosis

Social support

- Friends support me to be active
- Family supports me to be active
- Support from partner to be active
- No change in support from family to be active
- Family/friends worried about pushing too hard

- Role reversal with PA support – friends/partner now encourage me to be active
- Friends don't understand what you are going through
- Did not tell family/friends about diagnosis

TYA unit

- Would have preferred to be treated on TYA ward rather than adult ward
- Too old for TCT events/activities
- TYA's at different stage of life from older adults
- Cancer specific more important than TYA specific- can learn from older individuals

Effect of covid-19

- Covid-19= isolating/ loss of social interaction
- Covid-19 impacted mental health
- Covid-19 affected treatment plan
- COVID-19= unable to attend gym/ limited PA options
- Shielding
- Uncomfortable in gyms due to covid-19
- lockdown= sedentary behaviours

Physical activity information preferences

- Prefer a conversation about PA than written information
- Nurse/ PA expert/ physio good people to lead PA discussion
- Advice from expert in PA and cancer
- Prefer visual information/videos to written information
- Like having someone leading exercise/someone to follow
- PA should be part of a patient's treatment plan
- Talking about PA at diagnosis would have been overwhelming as too much information

-

Source of PA information

- Social media easy way to find PA information
- YouTube= location for PA exercises/classes
- Instagram= location of PA information
- There is information out there but hard to find as no centralised location
- Overwhelming amount of written information provided during cancer journey
- Websites are impersonal

Social media

- Social media can be negative space as causes sense of pressure to be active
- Social media offers shared experience and is motivation as see what other patients went through/did
- Social media=convenient, easy to access information sharing
- Social media not a reliable source
- social media can promote unrealistic workouts

-

Group exercise

- Doing exercise with someone/group holds you accountable
- Having active people around you is motivational
- Like having someone leading exercise/someone to follow
- Classes more motivation than solo exercise as someone is pushing you
- peer support from other TYA cancer patients/survivors as they understand what you are going through

Solo exercise

- Do not enjoy solo exercise
- Do not mind solo exercise

Personalisation

- Cancer patients all react to treatment different so have individual PA needs
- Effects of treatment on PA vary with treatment type

In-person vs virtual

- Virtual activity classes are accessible as carried out in own home, at time that suits me
- Virtual classes can be performed anywhere
- Prefers in-person classes
- Prefers virtual classes
- Both in-person and virtual classes have their place/ are good

Getting back into activity

- Gradually increased activity levels
- started with low impact activities and gradually increased
- Couch to 5K helped gradually increase activity levels
- Attended charity run PA class to get back into PA- lead to increased confidence in PA ability
- Pre-diagnosis PA behaviours helped with after treatment physical activity
- Used social media/YouTube workouts at home
- Walking to increase PA

Effect of cancer on life

- Signed off work due to cancer
- Worked t/o cancer
- Had to work t/o treatment
- Moved back in with parents
- Had to pause life

What can be done to help tyA patients/survivors be more active

- PA should be part of a patient's treatment plan
- Patients need support on what to do/how to be active
- PA advice should be personalised not general

- Meetings/social events with other TYA cancer patients would encourage active
- Pretreatment advice would help set expectations during treatment
- Discussion of PA benefits important
- information needed on activity progression/modifications
- Sign posting to online resources
- Tailor exercise program
- Information from exercise expert
- Information about diet
- Interested in TYA exercise class
- Uses fitness app on phone for classes/workouts
- Avoid putting too much pressure on the individual to be active
- Don't put pressure on yourself to be active during treatment. Do what you can
- Interested in walking group
- Not interested in walking group
- Interested in fitness app with tailored gym program (provided by healthcare professional)
- Step count not used as motivator
- Step counter used to track activity levels
- active gaming

Physical activity guidelines

- A guideline should be different for cancer patients
- PA guidelines achievable now but not during treatment/early recovery
- PA guidelines during treatment are overwhelming `
- Unaware of PA guidelines
- Knowledge of PA guidelines