The development, implementation and evaluation of a physical activity intervention for individuals living with and beyond cancer

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A thesis submitted for the award of PhD

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#### Declaration

I hereby certify that this material, which I now submit for assessment on the programme of study leading to the award of PhD is entirely my own work, and that I have exercised reasonable care to ensure that the work is original, and does not to the best of my knowledge breach any law of copyright, and has not been taken from the work of others save and to the extent that such work has been cited and acknowledged within the text of my work.

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#### Publications

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- Cooney, M., Moyna, N., Walsh, D., Furlong, B., Loughney, L., Boran, L., Smyth, S. & Woods, C. (2017). Cancer Survivors' Experiences of Physical Activity: Exercise as a Vehicle For Recovery? *Medicine & Science in Sports & Exercise, 49*(5S), 565. doi: 10.1249/01.mss.0000518468.57191.f4

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#### Communications

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- Cantwell, M., Moyna, N.M., Furlong, B., McCaffrey, N., & Woods, C. (2017). Long term physical activity levels among cancer survivors – can participation in a 12 week community-based exercise programme help? *Proceedings of the 2017 Health-Enhancing Physical Activity (HEPA) Europe Annual Conference*. Zagreb, Croatia.
- Cooney, M., Walsh, D., Moyna, N.M., & Woods, C. (2017). Physical activity promotion for individuals living with and beyond cancer: are we sending the right message? *Proceedings of the 2017 Faculty of Sports and Exercise Medicine (FSEM Royal College of Surgeons) Annual Scientific Conference*. Dublin, Ireland.
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- Cooney, M., McCaffrey, N., Furlong, B., Walsh, D., Smyth, S., Boran, L., & Woods, C. (2015). Optimising the referral process to community-based exercise rehabilitation programmes for cancer survivors: a Delphi study. *Faculty of Sports and Exercise Medicine (FSEM Royal College of Surgeons) Spring Study Day.* Dublin, Ireland.

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	informed physical		conducted the data
	activity behaviour		collection and
	change		analysis procedures
	intervention for		and wrote the
	individuals living		manuscript
	with and beyond		presented in Chapter
	cancer.		5.
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Study 4	the investigation of	awaiting submission	author on this
	the feasibility and	to a scientific journal	publication and was
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#### List of abbreviations

- ACS = American Cancer Society
- BC = Behaviour change
- BCTs = Behaviour change techniques

BCW = Behaviour Change Wheel

BMI = Body mass index

CBERPs = Community-based exercise rehabilitation programmes

CG = Control group

CRF = Cardiorespiratory fitness

CVD = Cardiovascular disease

D&I = Dissemination and implementation

FACT = Functional Assessment of Cancer Therapy

FGs = Focus groups

GRIPP2-SF = Guidance for Reporting Involvement of Patients and the Public - short form checklist

HRQoL = Health-related quality of life

IG = Intervention group

IPAQ = International Physical Activity Questionnaire

LIPA: Light-intensity physical activity

MedEx IMPACT = MedEx Improved Physical Activity after Cancer Treatment

MMO = MedEx Move On

MRC = Medical Research Council

MVPA = Moderate-to-vigorous intensity physical activity

OHPs = Oncology healthcare professionals

PA = Physical activity

PHQ-8 = Patient health questionnaire

PPI = Patient and public involvement

QoL = Quality of life

RCTs = Randomised controlled trials

SCT = Social Cognitive Theory

SEP = Stakeholder export panel

SWEMWBS= Short Warwick-Edinburgh Mental Well-being scale

SWLS = Satisfaction with Life scale

T2DM = Type 2 diabetes mellitus

TDF = Theoretical Domains Framework

TIDieR Checklist = The Template for Intervention Description and Replication checklist

TTM = Transtheoretical Model of Behaviour Change

WCRF = World Cancer Research Fund

WHO = World Health Organisation

6MTT = 6-minute time trial

#### **Definition of Terms**

**Behaviour change techniques (BCTs):** are defined as observable, replicable and irreducible components of an intervention that aim to change, or redirect causal processes that determine behaviour (Michie et al., 2018).

**Behaviour change interventions:** "Co-ordinated sets of activities designed to change specified behaviour patterns" (Michie, van Stralen & West, 2011, p.1)

**Behaviour theory:** A set of inter-related concepts that outline relationships among variables in order to explain behaviour (Kerlinger, 1986).

**Cancer:** is a generic term applied to a large group of diseases characterised by the growth of abnormal cells beyond their usual boundaries (WHO, 2019b).

**Cancer survivor:** The term cancer survivor can be applied to an individual from the point of cancer diagnosis throughout the remainder of life (Centers for Disease Control and Prevention, 2011; Finne et al., 2018).

**Physical activity:** Any bodily movement produced by the skeletal muscles that uses energy (WHO, 2019c)

**Exercise training:** Structured PA for the purpose of conditioning the body to improve health and fitness (Cormie et al., 2018).

**Light-intensity physical activity (LIPA):** LIPA is defined as activity performed <25 steps per 15 second epoch excluding sitting, lying and standing.

**Moderate-to-vigorous intensity physical activity (MVPA):** MVPA is defined as activity performed  $\geq$  25 steps per 15 second epoch (Aoyagi & Shephard, 2010).

#### Abstract

# The development, implementation and evaluation of a physical activity intervention for individuals living with and beyond cancer

#### Mairéad Cantwell

The aim of this study was to develop, implement and evaluate a physical activity (PA) behaviour change (BC) intervention to increase cancer survivors' PA levels, cardiorespiratory fitness (CRF) and health-related quality of life (HRQoL). Formative research, consisting of a Delphi study with oncology healthcare professionals (OHPs) and focus groups (FGs) with cancer survivors, was first conducted to inform the intervention design. A two-arm non-randomised comparison trial was conducted to test the intervention. Participants recruited to the trial completed accelerometry, the 6 minute time trial and the Functional Assessment of Cancer Therapy General questionnaire at baseline and months 3 and 6. Participants in the intervention group (IG) received a home-based PA programme, 4 PA information sessions and a one-to-one exercise consultation, in addition to 12 weeks of twiceweekly supervised exercise classes. The control group (CG) received 12 weeks of twice-weekly supervised exercise classes only. The majority of OHPs did not provide PA recommendations to patients that align with the current PA guidelines. Seven FGs with 41 cancer survivors were conducted. Participants highlighted the need for a holistic approach to rehabilitation. One-hundred and ninety-one cancer survivors participated in the trial (CG, n= 87; IG, n=104; mean age (± SD) 56 ± 10y, 73% female). The trial completion rate was 51%. PA levels, CRF and HRQoL increased for both groups from baseline to 3 months. Improvements achieved at 3 months in CRF were maintained by both groups at 6 months. In addition, increases in lightintensity PA (LIPA), daily steps and HRQoL observed at 3 months, were maintained for IG at 6 month follow-up. Participation in a 12-week exercise programme has a positive long-term effect on cancer survivors' CRF. The inclusion of additional BC strategies augmented the benefits achieved by also maintaining improvements in daily steps, LIPA and HRQoL at 6 months.

Chapter 1 Introduction

#### 1.1 Introduction

Cancer is the second leading cause of global mortality from noncommunicable diseases and is associated with significant morbidity and mortality contributing to over 3 million disability-adjusted life-years and 2.9 million years of life lost in the United States of America in 2010 (Murray, Phil & Lopez, 2013). It is estimated that globally, cancer is responsible for over 9 million deaths annually (World Health Organisation, (WHO), 2019). The burden of cancer is estimated to increase by 20 million cases on an annual basis by 2025 (WHO, 2014) and the economic projections estimate that by 2030 all aspects of global cancer care will total US\$458 billion (Bloom et al., 2011).

Improvements in cancer diagnosis, treatment and management have contributed to increased survival rates and extended longevity for this population (Allemani et al., 2018; Bluethmann, Mariotto & Rowland, 2016). However, cancer treatment can be associated with significant toxicity, result in many negative treatment-related side-effects, and give rise to other chronic conditions including cardiovascular disease (CVD) and osteoporosis (Cormie et al., 2018; Ewer & Ewer, 2015; Florescu, Cinteza & Vinereanu, 2013; Guise, 2006; Mehta et al., 2018; Rock et al., 2012). The full extent of the aftereffects of cancer treatment have not been fully elucidated, and while there is much yet that is not known regarding the potential negative impact of cancer treatment on parameters of health, there is evidence that mortality among cancer survivors is more likely to be attributable to a non-cancer cause such as CVD (Zaorsky et al., 2017).

The inclusion of physical activity (PA) as part of usual cancer care has been advocated to assist in the management of treatment-related side-effects and optimise patient outcomes (Ashcraft, Warner, Jones & Dewhirst, 2019; Cormie et al., 2018). There is a strong evidence base to support the efficacy for PA and exercise for individuals living with and beyond cancer (Rock et al., 2012; Schmitz et al., 2010). The benefits associated with regular PA in this cohort include a reduction in the risk of cancer recurrence, cancer-mortality and all-cause mortality (Cormie, Zopf, Zhang & Schmitz, 2017; Ibrahim & Al-Homaidh, 2011; Rock et al., 2012) and improvements in indices of physical and psycho-social well-being including cardiorespiratory fitness (CRF), strength, anxiety, fatigue, depression and healthrelated quality of life (HRQoL) (Spence, Heesch and Brown, 2010; Schmitz et al., 2010; Rock et al., 2012; Meneses-Echávez et al., 2015; Turner et al., 2018).

It is recommended that cancer patients avoid inactivity and aim to achieve a minimum of 150 minutes of moderate intensity PA, along with two strengthening exercise sessions, each week (Rock et al., 2012). However, the majority of individuals living with and beyond cancer do not meet these recommendations (Rock et al., 2012; Liu et al., 2016; LeMasters, Madhavan, Sambamoorthi & Kurian, 2014; Bourke et al., 2013; Turner et al., 2018). A number of challenges have been reported by survivors of cancer that limit regular PA participation including fatigue, pain and lack of motivation (Blaney et al., 2010; Gho et al., 2014; Fisher et al., 2016).

Oncology healthcare professionals (OHPs) have been identified by patients as important sources of information and motivators for positive lifestyle change (Damush, Perkins & Miller, 2006; Jones, Courneya, Fairey & Mackey, 2004; Shea-Budgell, Kostaras, Myhill & Hagen, 2014). Despite recommendations for PA to be embedded within usual care for every patient, the extent of PA promotion by OHPs throughout the cancer journey is not well understood.

OHPs are being challenged to shift their scope of practice from acute treatment to long-term management in survivorship (Demark-Wahnefried, Aziz, Rowland, & Pinto, 2005; Keogh et al., 2017). Cancer diagnosis provides an opportunity to begin the process of guiding individuals towards positive lifestyle behaviours, in particular, PA (Demark-Wahnefried, Aziz, Rowland, & Pinto, 2005). A number of challenges to PA promotion have been identified by OHPs including a lack of- knowledge regarding PA prescription, time with patients and patient interest (Karvinen, McGourty, Parent & Walker, 2012; Spellman, Craike & Livingston, 2014; Williams, Beeken, Fisher & Wardle, 2015). There is a need to identify effective strategies that OHPs can adopt to promote PA to their patients. Referral of patients to external PA services could provide access to the expertise required to support the provision of tailored exercise interventions, and a support structure to aid long-term PA adherence. Exploration of the barriers and motivators to referring patients to such programmes has received limited attention and investigating how the referral process to such programmes can be optimised to maximise OHP engagement warrants investigation.

While the positive impact of PA on indices of health and well-being among survivors of cancer is well established, there is however, a lack of understanding of how to support this population to engage in regular PA (Bluethmann et al., 2015; Groen, van Harten & Vallance, 2018; Lahart, Metsios, Nevill & Carmichael, 2018; Turner et al., 2018). Of the relatively few published PA behaviour change (BC) interventions for cancer, the majority included the use of self-report measures of PA, lacked long-term follow-up and had inadequate reporting of intervention parameters including development procedures, content and adverse reporting (Bluethmann et al., 2015; Finlay, Wittert & Short, 2018; Groen, van Harten & Vallance, 2018; Lahart, Metsios, Nevill & Carmichael, 2018; Stacey et al., 2015; Turner et al., 2018). A minority of trials, conducted predominantly among survivors of breast cancer, have been successful in producing long-term increases in PA (Kanera et al., 2017; Rogers et al., 2015; Sturgeon et al., 2017; Witlox et al., 2018). While these findings are positive, the majority of studies did not use an objective measure of PA. Furthermore, it is unclear whether the benefits reported from trials conducted within controlled research environments, using primarily breast cancer survivors, can be translated into effective programmes and services delivered within real-world settings (Courneya, Rogers, Campbell, Vallance & Friedenreich, 2015). Such studies, known as dissemination and implementation (D&I) research, are urgently needed to progress our understanding of PA adherence among this population, advance efforts to include PA within usual cancer care and optimise patient health and well-being through regular PA participation (Basen-Enquist et al.,

2017; Brownson, Jacobs, Tabak, Hoehner & Stamatakis, 2013; Courneya, Rogers, Campbell, Vallance & Friedenreich, 2015; Santa Mina et al., 2017).

The inclusion of patients in formulating the research question, designing the intervention and implementing and evaluating research protocols has been advocated to ensure that research is meaningful and relevant to the intended population (Johnson, Bush, Brandzel & Wernli, 2016). To date, there is limited published literature available regarding the inclusion of patient recommendations in the development of PA interventions for survivors of cancer.

#### 1.2 Aims and Objectives of the Research

#### 1.2.1 Aim:

The aim of this research was to explore PA across the cancer journey from OHPs' and patients' perspective and to develop, implement and evaluate a PA BC intervention for survivors of cancer delivered within a community-based setting.

## 1.2.2 Objectives

- To identify OHPs' knowledge, barriers and practices in relation to PA promotion for cancer survivors, and to generate guidance regarding the optimisation of the referral process to community-based exercise programmes (Chapter 3 – Study 1).
- To explore individuals' experiences of PA across the cancer journey (Chapter 4 – Study 2).

- To develop strategies to support regular PA participation and adherence to community-based exercise programmes based on recommendations from individuals living with and beyond cancer (*Chapter 4 – Study 2*).
- To develop a patient-centred, theoretically-informed and evidenced-based PA BC intervention to increase cancer survivors' PA levels, CRF and HRQoL (Chapter 5 – Study 3).
- To map the links between the sources of data used to inform intervention development and content to facilitate intervention replication (*Chapter 5 – Study 3*).
- 6. To investigate the feasibility and clinical effectiveness of an intervention delivered within a community-based setting, designed to optimise PA levels and indices of physical and psycho-social health among survivors of cancer (Chapters 6 and 7 – Studies 4 and 5).
- 7. To provide recommendations to inform the development, implementation and evaluation of future PA BC interventions conducted in both controlled research environments and real-world settings (*Chapter 9*).

#### **1.3 Thesis structure**

Chapter 2 presents an overview of the evidence base that underpins the promotion of PA throughout the cancer journey. Theoretical frameworks to support the development of PA interventions, determinants of PA behaviour and PA interventions for survivor of cancer, are critically reviewed and evaluated. The research objectives are addressed in a series of separate, but inter-related studies, presented in Chapters 3 to 7. Chapters 3 and 4 describe formative research, that consisted of a Delphi study with OHPs and focus groups with survivors of cancer, that were used to inform the development of the PA BC intervention for individuals living with and beyond cancer. Chapter 5 describes the development process for the MedEx IMPACT PA BC intervention for survivors of cancer. This chapter outlines how theoretical frameworks guided, and were embedded within, the intervention development process and how findings from Study 2 were synthesised with results from a review of literature to inform the development of intervention components. The methods and results of a two-arm non-randomised comparison trial that investigated the effectiveness of the intervention within a community-based setting are presented in Chapters 6 and 7.

The studies presented in Chapters 3 and 4 have been published in peerreviewed scientific journals. The research presented in Chapter 5 is currently undergoing peer-review. Due to the nature of this work, the submission of studies to scientific journals occurred sequentially to ensure that all stages of the process of intervention development, implementation and evaluation were documented to highlight the scope of the work completed. Therefore, studies 4 and 5, presented in Chapters 6 and 7, are pending submission following the publication of study 3. A discussion of this work in its entirety is presented in Chapter 8. A conclusion to the thesis is presented in Chapter 9, where the strengths, limitations and impact of this research, and recommendations for future work, are also outlined.

#### Chapter 2: Review of the Literature

The extant PA and cancer literature related to this doctoral thesis, including PA promotion among OHPs, PA participation among survivors of cancer and PA interventions for this population, is critically reviewed and evaluated. The review of literature will provide a study rationale and an overview of the key concepts and frameworks that underpin the research. In addition, it will identify gaps in our current understanding of issues related to this work.

Chapter 3: Study 1: Healthcare professionals' knowledge and practice of physical activity promotion in cancer care: challenges and solutions

A Delphi study was conducted to identify OHPs knowledge, barriers and practices in relation to PA promotion for cancer survivors, and to generate guidance regarding the optimisation of the referral process to community-based exercise programmes.

Chapter 4: Study 2: Physical Activity Across the Cancer Journey: Experiences and Recommendations from People Living with and Beyond Cancer

This qualitative investigation used focus groups to explore individuals' experiences of PA behaviour across the cancer journey. It also identified strategies to support habitual PA and adherence to community-based exercise programmes based on information provided by individuals living with and beyond cancer. Chapter 5: Study 3: The development of the MedEx IMPACT intervention: A patientcentred, evidenced-based and theoretically-informed physical activity behaviour change intervention for individuals living with and beyond cancer

This study describes the development of a PA BC intervention, the MedEx IMPACT (IMprove Physical Activity after Cancer Treatment) intervention, which aims to increase cancer survivors' long-term PA levels, CRF and HRQoL. The development of MedEx IMPACT was guided and informed by: i) the Medical Research Council's (MRC) framework for the development, implementation and evaluation of complex interventions (Craig et al., 2008), ii) the Behaviour Change Wheel (BCW) (Michie, van Stralen & West, 2011), iii) the Theoretical Domains Framework (TDF) (Cane, O'Connor & Michie, 2012), iv) a review of the literature and v) findings generated by focus group participants in study 2.

Chapter 6: Study 4: Study protocol for the investigation of the feasibility and clinical effectiveness of a physical activity behaviour change intervention for individuals living with and beyond cancer

The purpose of this study was to describe the protocol to assess the feasibility and clinical effectiveness of the MedEx IMPACT intervention using a twoarm non-randomised comparison trial that was undertaken in a community-based setting. Chapter 7: Study 5: The feasibility and clinical effectiveness of a physical activity behaviour change intervention for individuals living with and beyond cancer.

This study investigated the effects of the MedEx IMPACT intervention, compared to a general chronic illness rehabilitation programme, on indices of physical and psycho-social health, and mediators of PA BC, among survivors of cancer within a two-arm non-randomised comparison trial.

#### Chapter 8: Discussion

The findings from studies 1 to 5 are summarised and contextualised within the existing scientific literature.

#### Chapter 9: Conclusion and Future Recommendations

The strengths and limitations of this work are described and recommendations to inform future research in this area are provided. The chapter concludes with a summary of the implications of this research.

A schematic overview of the research project is presented in Figure 1.1.

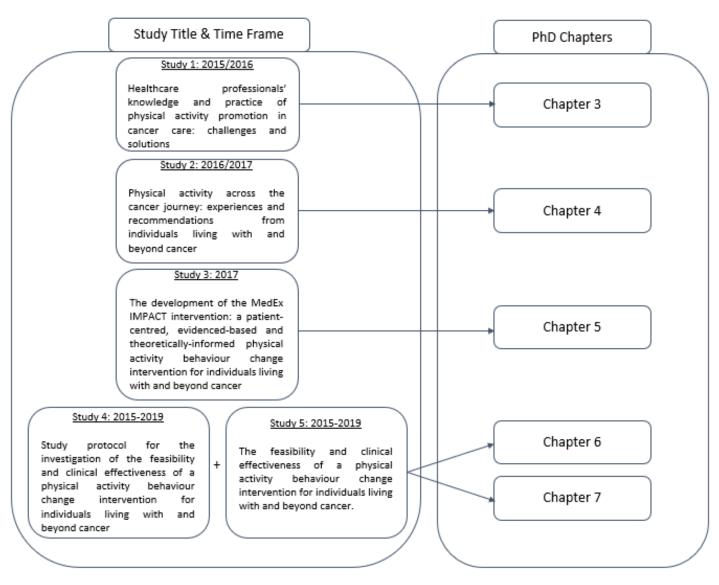


Figure 1.1 Schematic overview of the research project.

# Chapter 2 Review of the Literature

## 2.1 Epidemiology of Cancer

As the second leading cause of mortality and years of life lost globally, cancer represents a major cause of death and disability (Murray, Phil & Lopez, 2013; World Health Organisation (WHO), 2019a). According to the World Cancer Research Fund (WCRF) (2018), there were 18 million cancer cases worldwide in 2018, with the most common diagnoses occurring in cancers of the lung (12.3%), breast (12.3%), colon (10.6%), prostate (7.5%) and stomach (6.1%) (Bray et al., 2018). The global burden of cancer shows no signs of abatement with projections indicating that by 2025, in excess of 20 million new cases will be diagnosed on an annual basis (WHO, 2014). By 2040, it is estimated that cancer incidence rates will increase by 62% globally (Cancer Research UK, 2019). Many factors including population growth, ageing and societal, economic and lifestyle changes are contributing to the increasing burden of cancer (WHO, 2014).

Cancer also represents a significant economic burden with projections estimating that by 2030, the global cost of cancer will be US\$458 billion (Bloom et al., 2011). The highest incidence rates for all cancers combined (excluding nonmelanoma skin cancer), have been observed within high-income countries including North America, Australia, Japan and New Zealand (WHO, 2014).

Advances in the diagnosis, treatment and management of cancer have contributed to an increase in the number of individuals living with and beyond the condition (Allemani et al., 2018; Bluethmann, Mariotto & Rowland, 2016). According to findings published from the CONCORD-3 programme, 5-year survival estimates, an index which has long been considered by oncology clinicians as a

marker of cancer treatment effectiveness, of >80, 70 and 50% for breast, prostate and colon cancer have been reported (Allemani et al., 2018). However, there are significant differences in 5-year survival estimates worldwide, with the highest estimates for most cancers being reported in the United States of America, Canada, Australia, New Zealand, Finland, Iceland, Norway and Sweden (Allemani et al., 2018). Improvements in survival rates have led to increases in the number of individuals living with and beyond cancer where in 2012, it was estimated that there were 32 million people living with and beyond the condition worldwide (Jemal, 2015). In the United States of America, it has been estimated that there are 15.5 million individuals living with and beyond cancer, with adults over the age of 65 constituting the majority of this population (62%) (Bluethmann, Mariotto & Rowland, 2016). In the Irish context, there are over 167,000 cancer survivors (National Cancer Registry, 2017). The term cancer survivor can be applied to an individual from the point of cancer diagnosis throughout the remainder of life (Centers for Disease Control and Prevention, 2011; Finne et al., 2018).

#### 2.2 Pathophysiology of Cancer

Cancer is a generic term applied to a large group of diseases characterised by the growth of abnormal cells beyond their usual boundaries (WHO, 2019b). This process of unregulated cell growth can result in the invasion of adjoining parts and/or organs of the body and subsequent disruption to normal structure and function. The tissue formed as a result of uncoordinated and unregulated cell proliferation is known as a neoplasm. Cancer can affect almost all cells within the human body and as a result there are many different types of cancer, each

characterised by its anatomical location and molecular composition (WHO, 2019b). For example, cancer that originates in connective tissue is known as a sarcoma while cancer originating in the bone marrow and blood is referred to as leukaemia.

Normal cells undergo a process known as cell differentiation whereby cells transform to become specialised cell types that have a specific structure, function and life expectancy characteristics. This process is tightly regulated by a number of factors including the expression of specific genes, referred to as internal programming, external stimuli generated by nearby cells and the presence of growth factors and nutrients. In normal conditions, the rate of cell production and differentiation are evenly matched to ensure both processes cease once the required number and types of cells have been formed (Porth, 2003). Cancer occurs when cells do not adhere to this process and instead follow their own agenda for proliferation. A cell will deviate from the typical pathway for cell proliferation and all cells that stem from the division of this first cell will display the same abnormal cell proliferation characteristics (National Institutes of Health, 2007).

A malignant tumour primarily develops following four mutations however the exact number of mutations required to transform a normal cell to a malignant cell has not yet been fully elucidated. Malignant neoplasms contain cells that have undergone incomplete differentiation. Tumour development begins when a mutation causes a cell to divide at an accelerated rate in a process known as hyperplasia. At a point in this process, an altered cell can undergo further mutation, and compounds the increase in rapid cell division. This step is referred to as dysplasia. Over the course of time, a third mutation can occur and cells and their

descendants, are characterised by significant abnormality in terms of both growth and appearance. Cells aggregate to form a tumour and when it is contained within the tissue where it originated, it is referred to as in situ cancer (See Figure 2.1). Further mutation can occur which enables the tumour to invade neighbouring tissues and these cancerous cells have the ability to enter the body's circulatory systems and form a secondary neoplasm at another location. This process is referred to as metastasis (National Institutes of Health, 2007).

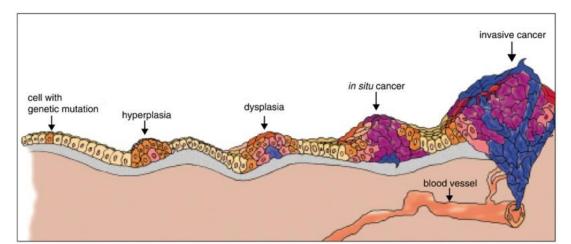


Figure 2.1. The stages of cancer tumour development (National Institutes of Health, 2007).

Malignant neoplasms can be fatal if they remain untreated or uncontrolled. Malignant neoplasms outgrow their blood supply and can cause ischemia and subsequent tissue necrosis. In addition, these neoplasms release toxins that kill both normal and abnormal tissue and deprive healthy cells of essential nutrients required for normal function. A benign neoplasm is a mass that contains welldifferentiated cells that have aggregated in a tissue or organ. Such neoplasms are not considered fatal with the exception of when their location or size impairs vital functions (Porth, 2003). The genetic mutations that give rise to cancer occur as a result of the interaction between a person's genetic profile and external agents known as carcinogens, or cancer-causing agents. Carcinogens can be classified within the 3 main categories of physical- (e.g. radiation), chemical- (e.g. components of tobacco) and biological- (e.g. infection from certain viruses) carcinogens. Cancer risk is also influenced by a number of risk factors that are common for the development of other noncommunicable diseases including alcohol consumption, an unhealthy diet low in fruit and vegetable intake and physical inactivity (WHO, 2019c).

# 2.3 Clinical Features of Cancer

The location of a neoplasm and its molecular profile can influence the clinical manifestations of cancer. For example, clinical features of breast cancer may include a palpable lump within the breast, changes in the size or shape of the nipple and/or changes of the skin on the breast (Barlow et al., 2002), while symptoms of colorectal cancer can include changes in bowel habits (e.g. diarrhoea or constipation), abdominal pain and/or weight loss (Astin, Griffin, Neal, Rose & Hamilton, 2011). Some symptoms can be observed across several cancers. For example, the presence of blood when coughing or in urine or bowel movements may be indicative of lung, bladder or colorectal cancer while weight loss, not related to decreased calorie intake, has been associated with a number of cancers including lung, colorectal, stomach and pancreatic cancer (American Cancer Society, 2019a).

# 2.4 Cancer Treatment

The treatment given to a patient is influenced by a number of factors including the type and stage of the cancer, the scientific evidence supporting the effectiveness of the treatment for a particular type of cancer and the individual's preferences for treatment (WHO, 2019d). Surgery, radiotherapy and systemic therapy (e.g. chemotherapy, hormonal therapy) are considered the major therapeutic modalities in the treatment of cancer (WHO, 2019d). Neo-adjuvant and/or adjuvant therapy, which aim to reduce the size of the tumour prior to surgical intervention, optimise treatment effectiveness and reduce the risk of cancer recurrence, are common features of patients' treatment plans (e.g. in breast, colorectal and lung cancer). Each therapeutic modality can be associated with a number of acute, latent and/or long-lasting side effects including pain, infection, incontinence, fatigue, lymphoedema, anaemia, skin irritation and nausea (American Cancer Society, 2019b, 2019c).

While effective in the treatment of cancer, the side-effects associated these therapeutic modalities can significantly reduce patients' HRQoL in both the shortand long- term (Siegel, Naishadham & Jemal, 2012). As the number of individuals living with and beyond cancer continues to grow, more and more individuals are living with these negative side-effects and the subsequent challenges they present during cancer survivorship including reduced physical function, increased risk of cancer morbidity and mortality and increased risk for the development of other chronic conditions (e.g. CVD) (Siegel, Naishadham & Jemal, 2012).

## 2.5 Physical Activity

The inclusion of physical activity (PA), defined as any bodily movement produced by the skeletal muscles that uses energy (WHO, 2019c), as an adjunct to therapeutic modalities in the treatment of cancer has been advocated to assist in the management of treatment-related side effects and support the optimisation of patient outcomes (Ashcraft, Warner, Jones & Dewhirst, 2019; Cormie et al., 2018). Indeed, in light of the myriad of benefits associated with PA for individuals living with and beyond cancer, many organisations and governing bodies have published recommendations for PA for this population, including The American College of Sports Medicine, The British Association of Sport and Exercise Sciences and The American Cancer Society (Campbell, Stevinson & Crank, 2012; Rock et al., 2012; Schmitz et al., 2010). Such recommendations advocate that survivors of cancer aim to achieve at least 150 minutes of moderate intensity PA each week and include strength training exercises on at least 2 days during a 7 day period (Rock et al., 2012).

#### 2.5.1 Benefits of Physical Activity throughout the Cancer Journey

As highlighted by the inclusion of PA within the European Code Against Cancer (WHO, 2016), regular PA can play an important role in cancer prevention, as overweight/obesity, physical inactivity and/or poor nutrition have been shown to be related to up to one-third of cancers in economically developed countries and could therefore be prevented (WCRF, 2007). Indeed, results from a recent systematic review reported that PA reduces the risk of cancers of the breast, colon,

endometrium, bladder, stomach, oesophagus and kidney, with 10-20% reductions in relative risk being observed (McTiernan et al., 2019).

CRF has been shown to significantly decrease following cancer treatment (Loughney & Grocott, 2016; Loughney et al., 2016; Loughney, West, Kemp, Grocott & Jack, 2018). In conjunction with reduced nutritional status, lower CRF is associated with prolonged hospitalisation, greater levels of treatment-related toxicity, increased post-operative morbidity and poorer prognosis (Loughney & Grocott, 2016; Loughney et al., 2016; Loughney, West, Kemp, Grocott & Jack, 2018). An increasing amount of scientific research is investigating the benefits of PA and exercise training, defined as "structured PA for the purpose of conditioning the body to improve health and fitness" (Cormie et al., 2018, p1), during this time.

Pre-operative exercise training has resulted in functional and clinical benefits including improved CRF and muscular strength (Singh, Newton, Galvão, Spry & Baker, 2013). It has also been suggested that exercise training during neoadjuvant chemotherapy may have positive effects on patient symptoms while also potentially altering the tumour phenotype and patient response to treatment (Ashcraft, Warner, Jones & Dewhirst, 2019; Jones et al., 2013). Emerging evidence indicates that exercise training may increase the efficacy of chemotherapeutic agents (Ashcraft, Warner, Jones & Dewhirst, 2019; Bland et al., 2019; van Waart et al., 2015). This is an important potential benefit of exercise as an adjunct cancer treatment, as completion of the entire prescribed chemotherapy regime is associated with increased treatment efficacy and patient survival following cancer diagnosis (Ashcraft, Warner, Jones & Dewhirst, 2019; Bland et al., 2019).

In survivorship, exercise interventions have been shown to improve body composition, aerobic fitness, muscular strength, fatigue, anxiety, self-esteem, depression and HRQoL, and reduce the risk of cancer recurrence, cancer mortality and all-cause mortality (Ibrahim & Al-Homaidh, 2011; Meneses-Echávez, González-Jiménez & Ramírez-Vélez, 2015; Rock et al., 2012; Spence, Heesch & Brown, 2010; Schmitz et al., 2010; Turner et al., 2018). The efficacy and clinical effectiveness of PA interventions for survivors of cancer is discussed in further detail in a later section of this chapter.

For patients on a palliative treatment pathway, exercise has been shown to have a positive effect on life expectancy, which may be mediated by improvements in physical function and psychological symptoms (Albrecht & Taylor, 2012; Eickmeyer, Gamble, Shahpar & Do, 2012; Eyigor & Akdeniz, 2014).

#### 2.5.2 Physical Activity Promotion throughout the Cancer Journey

Despite the wealth of evidence to support the beneficial effects of PA and exercise training for individuals living with and beyond cancer, they do not currently feature as a cornerstone of usual cancer care for all patients (Cormie et al., 2018; Haussmann et al., 2018). Policies to guide the implementation and integration of findings from best practice to clinical practice are needed. In the Irish context, The National Physical Activity Plan aims to incorporate training for all healthcare professionals regarding the preventative and treatment role of PA within health as a core component of both undergraduate and in-service training by 2020 (Health Ireland, 2016). The Health Service Executive in partnership with Third Level Institutions in Ireland are responsible for the achievement of this action. While

encouraging, this recommendation is not specific to the oncology context and therefore information regarding the achievement of this aim, is likely not to specifically delineate PA training opportunities for those working in cancer care.

Healthcare providers have been identified by patients as the most trusted source of information regarding cancer (Shea-Budgell, Kostaras, Myhill & Hagen, 2014). This is reflected in studies that have reported that recommendations from oncologists have been shown to positively influence cancer survivors' levels of PA participation (Damush, Perkins & Miller, 2006; Jones, Courneya, Fairey & Mackey, 2004). All healthcare professionals are encouraged to capitalise on the 'teachable moment' associated with a cancer diagnosis and embed PA promotion into usual care for every patient in order to support the adoption/maintenance of positive lifestyle behaviours and the optimisation of physical and psycho-social well-being (Cormie et al., 2018; Demark-Wahnefried, Aziz, Rowland & Pinto, 2005; Maxwell-Smith, Zeps, Hagger, Platell & Hardcastle, 2017). Despite this, low rates of PA promotion of approximately 20-60% have been observed among healthcare professionals to patients with cancer (Demark-Wahnefried, Peterson, McBride, Lipkus, and Clipp, 2000; Haussmann et al., 2018; Kenzik, Pisu, Fouad & Martin, 2016; Nyrop et al., 2016). A lack of exercise expertise and insufficient time with patients to discuss PA are among the barriers reported by oncology healthcare professionals (OHPs), which may contribute to the low rates of PA promotion observed (Keogh, Olsen, Climstein, Sargeant & Jones, 2017; Nadler et al., 2017; Santa Mina et al., 2018).

While OHPs acknowledge the beneficial effects of PA for their patients and express a willingness to promote it (Haussmann et al., 2018), effective strategies need to be identified and implemented to empower and support OHPs to embed PA promotion within routine cancer care. Such strategies could include the provision of educational opportunities regarding exercise, and the integration of an appropriately qualified exercise specialist within multi-disciplinary teams (Nadler et al., 2017). Santa Mina et al. (2018) suggest implementation of a conceptual framework to assist in bridging the gap between patient interactions with OHPs regarding PA, and the gaining of access to exercise and PA resources by individuals living with and beyond cancer (See Figure 2.2).

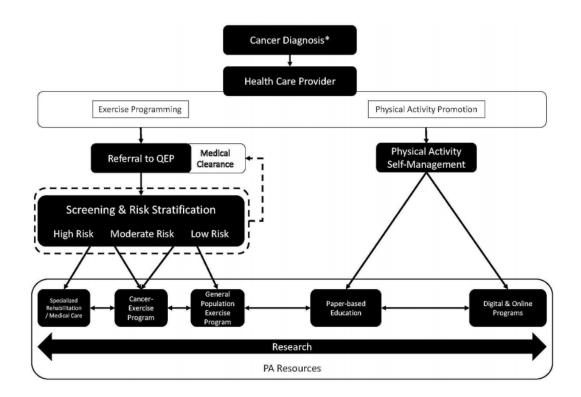


Figure 2.2. Conceptual framework proposed by Santa Mina et al. (2018) to support access to PA services and resources by individuals living with and beyond cancer. \*Cancer survivors can enter the pathway at any point after diagnosis. Abbreviations: QEP=qualified exercise professional; PA=physical activity

Within the framework, healthcare providers, defined as clinicians responsible for the management of cancer care, promote PA to patients during interactions and assess available opportunities for patients to access suitable PA resources (e.g. referral to an exercise specialist, tools to support self-management). OHPs and patients with local access to dedicated oncology PA services (e.g. community-based exercise oncology rehabilitation programmes (CBERPs)) can follow the exercise programming arm of the framework which includes risk stratification and referral to a suitable exercise programme. In the absence of access to such specialised PA services, the PA promotion arm of the framework can be followed which includes the identification of suitable self-management PA tools (e.g. online exercise programmes). This model offers a pragmatic approach to PA promotion for OHPs. However, more research examining how this pathway affects PA and exercise participation among survivors of cancer is needed, in addition to economic evaluations of the model and assessment of its acceptability to OHPs (Santa Mina et al., 2018).

Perhaps one of the most promising solutions to address the challenges experienced by OHPs in the promotion of PA to patients with cancer, is to refer individuals to external sources for more comprehensive, community-based support (Keogh, Olsen, Climstein, Sargeant & Jones, 2017). The development of referral pathways between OHPs and community-based PA services has been recommended to improve patient access to information regarding PA as well as levels of PA participation (Keogh, Olsen, Climstein, Sargeant & Jones, 2017, McPhail & Schippers, 2012). CBERPs have been shown to increase the physical and psycho-

social well-being of survivors of cancer (Cheifetz et al., 2014; Knobf, Thompson, Fennie & Erdos, 2014; Santa Mina et al., 2017). However, how engagement by OHPs in referral and the referral process to such programmes can be optimised remains unclear and warrants exploration.

# 2.5.3 Levels of Physical Activity Participation Among Survivors of Cancer

Research shows that many individuals living with and beyond cancer do not meet the recommended levels of PA participation (Lucas, Levine & Avis, 2017; Short et al., 2014; Troeschel, Leach, Shuval, Stein & Patel, 2018). Cancer diagnosis has been associated with decreased levels of PA participation that can persist following treatment completion (Blanchard et al., 2003; Bluethmann, Vernon, Gabriel, Murphy & Bartholomew, 2015; Courneya, Karvinen & Vallance, 2007; Lee et al., 2012; Phillips & McAuley, 2015). Research has shown that patients with breast cancer decreased their total PA by 2 hours/week following cancer diagnosis, representing an 11% decrease (Irwin et al., 2003). The greatest reduction in sportrelated PA was observed among women who had received radiation and chemotherapy (50% decrease) compared with women who underwent surgery or radiotherapy only (24 and 23% decrease) (Irwin et al., 2003). Significantly greater reductions in sport-related PA were also observed among obese patients compared to individuals with a normal body weight (41% vs. 24% decrease) (Irwin et al., 2003). Among patients diagnosed with colorectal cancer, research has shown that the percentage of individuals achieving the recommended PA guidelines (Schmitz et al., 2010) significantly reduced from 27% prior to cancer diagnosis to 10% during treatment (Chung et al., 2013). This reduction was mediated by reduced

participation in strenuous intensity PA as total- and mild-intensity PA remained unchanged (Chung et al., 2013). Among survivors of lung cancer, 8.6% of patients reported meeting the PA guidelines prior to cancer diagnosis, with 2.9% of individuals achieving this level of PA participation during the post-treatment period (Coups et al., 2009). In the same study, 62% of participants (n=107) were classified as being inactive prior to diagnosis, during the post-treatment period and in longterm survivorship (Coups et al., 2009). Only a minority of individuals (8.1%) who were classified as inactive in the pre-diagnosis and post-treatment phases of the cancer journey reported achieving the recommend levels of PA in survivorship (defined as 1-6 years post-surgical treatment) (Coups et al., 2009).

While treatment completion represents a major milestone for patients with cancer, initiating, re-initiating and maintaining PA participation during this time can be particularly challenging (Bluethmann, Vernon, Gabriel, Murphy & Bartholomew, 2015). The majority of individuals living with and beyond cancer fail to meet the recommended PA guidelines (Rock et al., 2012; Liu et al., 2016; LeMasters, Madhavan, Sambamoorthi & Kurian, 2014; Bourke et al., 2013; Turner et al., 2018). Surveillance data indicates that approximately 31.5% of survivors of cancer had not participated in any leisure time PA during the previous month and that among survivors of breast cancer, only 16.4% engaged in at least 150 minutes of moderate intensity PA each week (Underwood et al., 2012; Smith & Chagpar, 2010). Rates of adherence to the PA guidelines among survivors of cancer of between 17 and 47% have been reported within the literature (Blanchard, Courneya & Stein, 2008; Courneya, Katzmarzyk & Bacon, 2008; Forbes, Blanchard, Mummery & Courneya,

2014; Speed-Andrews et al., 2012; Nayak, Holmes, Nguyen & Elting, 2014). It should be noted that the majority of studies reported PA levels using self-report measures which are known to be subject to over-estimation. This has been demonstrated in a study that assessed agreement between accelerometer-assessed and self-reported PA in survivors of colon cancer where total mean minutes of moderate-to-vigorous intensity PA (MVPA) was 12 mins according to accelerometer data and 26 mins using self-report measures (Boyle, Lynch, Courneya & Vallance, 2015).

The sub-optimal rates of PA adherence reported within the literature using self-report measures may in fact underestimate the proportion of survivors of cancer who meet the recommended levels of PA. Indeed, this hypothesis is supported by a study that investigated accelerometer-derived PA and sedentary time among survivors of cancer (n=508), where only 8% of participants met the recommended PA guidelines (Thraen-Borowski, Gennuso & Cadmus-Bertram, 2017). While patterns of PA and sedentary behaviour varied by cancer diagnosis, demographic variables and time since diagnosis, survivors were shown on average to engage in 16 minutes of MVPA and >8 hours of sedentary time per day. Data from survivors of cancer was compared to age-matched controls who had not had a cancer diagnosis. Following adjustment for potential confounders, it was shown that cancer survivors engaged in less light-intensity PA and were more sedentary than their age matched peers. This finding is supported by results from another investigation which demonstrated that survivors of colon cancer had significantly lower levels of PA than adults without cancer and had greater sedentary time (Shi et al., 2017). However, in contrast to the findings reported by Thraen-Borowski,

Gennuso and Cadmus-Bertram (2017), Shi et al. (2017) reported that survivors of breast cancer engaged in more MVPA than females who had not had a cancer diagnosis (29 vs. 22 mins/day).

#### 2.5.4 Challenges to Physical Activity Participation

Among individuals living with and beyond cancer, a number of barriers have been cited that limit PA participation. Findings from a postal-questionnaire survey among 456 survivors of cancer identified that the top 10 barriers that most frequently interfered with exercise participation were illness/other health problems (37.3%), joint stiffness (36.9%), fatigue (35.7%), pain (30.1%), lack of motivation (26.5%), weather extremes (26.2%), lack of facilities (25.5%), weakness (21.5%), lack of interest (20.7%) and fear of falling (19.5%) (Blaney, Lowe-Strong, Rankin-Watt, Campbell & Gracey, 2013). Similar findings have been reported in other investigations (Blaney et al., 2010; Gho, Munro, Jones & Steele, 2014; Fisher et al., 2016).

Qualitative investigations can provide further detail regarding exercise barriers experienced by individuals living with and beyond cancer. Results from such studies reported that not being the sporty type and having poor motivation, characterised by a lack of effort and discipline, have been described by survivors of breast and colorectal cancer as contributors to physical inactivity (Hefferon, Murphy, McLeod, Mutrie, & Campbell, 2013; Maxwell-Smith, Zeps, Hagger, Platell & Hardcastle, 2017). Being unaware of the recommended PA guidelines for survivors of cancer and overestimating daily PA have been reported by colorectal cancer

survivors as challenges to PA participation (Maxwell-Smith, Zeps, Hagger, Platell & Hardcastle, 2017).

In a large scale qualitative study (n=83) exploring barriers to exercise participation among survivors of breast cancer who were 5-years post-diagnosis, participants reported fears of engaging in PA, such as sustaining an injury and slipping in poor conditions, and disliking gym environments due to disengagement, lack of privacy and a lack of belief in gym/programme instructors (Hefferon, Murphy, McLeod, Mutrie, & Campbell, 2013). Participants reported that side effects from cancer treatment, fatigue, weight gain and other physical co-morbidities had a negative impact on their levels of PA participation in the 5 years since first receiving their diagnosis. Contextual and environmental barriers that contributed to reduced PA levels included returning to work and family commitments, such as running a home, and caring for family including children, ill spouses and elderly parents.

## 2.5.5 Determinants of Physical Activity among Survivors of Cancer

Research has sought to identify determinants of PA among survivors of cancer in order to gain an understanding of the factors associated with varying levels of PA participation. The identification of such factors may assist in tailoring exercise oncology interventions, programmes and services to more suitably address the needs of individuals living with and beyond cancer, and therefore contribute to successful, sustained increases in PA levels among this population.

Determinants of exercise adherence have been investigated among individuals receiving chemotherapy for breast cancer who were randomised to

different types and doses of supervised PA (Courneya et al., 2014). The highest rates of exercise adherence were observed among individuals with higher VO<sup>2</sup>peak scores, who achieved a minimum of 75 mins/week of vigorous aerobic exercise, received fewer cycles of chemotherapy and had fewer exercise limitations and endocrine symptoms (e.g. hot flashes, night sweats). Exercise adherence rates of >78% were observed to the standard dose of aerobic exercise prescribed (i.e.  $\geq$ 75 mins/week of vigorous aerobic exercise) among patients who had advanced disease or were overweight/obese. However, these patient cohorts were less able to tolerate higher exercise doses as was demonstrated by the lower rates of exercise adherence reported.

Limited research is currently available which explores the determinants of exercise adherence during the treatment phase of the cancer journey, particularly for non-breast cancer populations and those receiving different treatment modalities. Given the benefits of exercise participation during this stage of the cancer journey, additional research in this area is vital to identify the factors that influence PA participation during cancer treatment and support the optimisation of patient outcomes at this time.

Results from a systematic review, that used a socio-ecological model to assess determinants of exercise adherence and maintenance among survivors of cancer, demonstrated moderate evidence that exercise history was positively associated with exercise adherence during and after cancer treatment (Kampshoff et al., 2014). In this study, adherence was defined as "the degree of attendance or completion of prescribed exercise sessions" (Kampshoff et al., 2014, p2). Due to

inconsistent findings within the literature, insufficient evidence was available for an association between exercise adherence and gender, cancer treatment modality, CRF, fitness centre, perceived behavioural control, stage of change, self-efficacy or extraversion (Kampshoff et al., 2014). Similarly, due to inconsistent findings, valid conclusions regarding associations between exercise maintenance (referred to as regular PA behaviour following exercise intervention), and age, education, baseline levels of PA participation, body mass index (BMI), CRF, fatigue, HRQoL, self-efficacy, instrumental and affective attitude, intention or adherence to PA intervention could not be drawn (Kampshoff et al., 2014).

Contrasting findings were reported in a similar systematic review and metaanalysis by Husebø, Dyrstad, Søreide & Bru (2013) who investigated predictors of exercise programme adherence among survivors of cancer. Exercise stage of change was identified as a statistically significant and strong predictor of exercise adherence while significant correlations were observed between exercise adherence and intention to engage in a health-changing behaviour, and perceived behavioural control. It is important to note that different analyses were employed by the authors in these investigations, with Husebø, Dyrstad, Søreide & Bru (2013) using univariate analysis which could have led to an overestimation of the strength of associations observed (Kampshoff et al., 2014).

Charlier et al. (2013) compared the contribution of cancer-related and noncancer related/general determinants to PA levels among survivors of breast cancer who were 3 weeks to 6 months post-treatment completion (n=464). The results showed that both cancer-related determinants, including returning to normal life as

a benefit of PA, and general determinants, such as self-efficacy and social support from family and friends for PA, were important in explaining PA behaviour among this population. Interestingly, differences were observed among working and nonworking survivors of cancer for other cancer-related determinants. PA behaviour was also explained by perceived cancer-related barriers (e.g. fatigue, treatmentrelated side effects) in the non-working group, compared to self-efficacy in overcoming such barriers in those who were working (Charlier et al., 2013). Work status was also shown to influence levels of moderate-to-vigorous PA (MVPA) where 54% of non-working women reported achieving <210 MVPA/mins per week compared to 25% of individuals who were working (Charlier et al., 2013). These findings highlight the need to tailor interventions to factors that are salient to the intended population. For example, PA interventions for working survivors of breast cancer could achieve greater success by prioritising increasing self-efficacy for PA in the face of cancer-related symptoms while interventions for non-working survivors of breast cancer should prioritise changing individuals' perceptions of symptoms as barriers to PA participation (Charlier et al., 2013).

### 2.5.6 Physical Activity and Exercise Interventions for Survivors of Cancer

The scientific literature investigating PA interventions for individuals living with and beyond, particularly in the period acutely following treatment completion leading into long-term survivorship, will be reviewed in subsequent sections in relation to efficacy, adherence, maintenance, and methodological limitations that have been identified within this literature.

### 2.5.6.1 Efficacy of PA interventions for survivors of cancer

The efficacy of PA interventions conducted in survivorship is well established with studies documenting improvements in body composition, CRF, self-esteem, muscular strength, depression, HRQoL and reductions in the risk of cancer recurrence, cancer mortality and all-cause mortality (Ibrahim & Al-Homaidh, 2011; Rock et al., 2012; Schmitz et al., 2010; Turner et al., 2018). PA intervention at this time has also been associated with effective management of treatment related side-effects including lymphedema and fatigue (Rock et al., 2012). Indeed, the quality and abundance of this evidence has led to the development of expert statements and recommendations endorsing the inclusion of PA within cancer care (Cormie et al., 2018; Schmitz et al., 2010; Rock et al., 2012).

What is less well-known however, is what intervention characteristics are associated with intervention efficacy. In a recent Cochrane review, Lahart, Metsios, Nevill & Carmichael (2018) assessed 63 trials, that conducted PA interventions among women who had completed adjuvant therapy for breast cancer (n=5761), to determine intervention efficacy. Significant heterogeneity across studies was observed with regard to PA intervention characteristics (e.g. mode, frequency, intensity) and outcome measures, which lead the authors to conclude that future work is required to determine optimal PA prescription and mode of delivery, and to address the methodological limitations identified within the existing literature, in order to improve indices of health and well-being among this population.

These recommendations for future work were addressed in part by Abdin, Lavallée, Faulkner and Husted (2019) who conducted a systematic review to determine if the efficacy of interventions was influenced by the type of PA completed, and the intervention delivery format (i.e. group-based vs. individual interventions). The results indicated that the type of PA was not associated with significant differences in outcomes, and that both individual- and group-basedinterventions were effective in increasing PA among individuals with breast cancer. There was some evidence of greater efficacy among group-based-, compared to individual-, PA interventions. However, the authors concluded that a number of methodological limitations inhibited definitive conclusions from being drawn. Leach, Mama & Harden (2019) extended this preliminary finding reported by Abdin and colleagues (2019), by conducting a review of 23 studies that investigated if group-based components within PA interventions were associated with intervention effectiveness. Specific group dynamic strategies were not included within the majority of studies (n=15), and of those that did (n=8), the number of strategies implemented ranged from 1 to 3. The results showed that face-to-face exercise interventions that incorporated a group-based element can effectively increase PA among survivors of cancer.

While the efficacy of PA interventions for individuals in the survivorship phase of the cancer journey is widely acknowledged and accepted, there is no consensus within the literature regarding the characteristics of PA interventions that are associated with intervention success, and long-term PA adherence in particular (Turner et al., 2018). Much of the research to date is flawed by

methodological limitations including incomplete reporting of the PA prescription used within studies, insufficient detail of intervention content and delivery, differences in outcome measures, lack of long-term follow-up procedures and limited objective assessment of PA (Turner et al., 2018). Further work that addresses these methodological issues is required in order to validate the preliminary findings reported by Abdin et al. (2019) and Leach, Mama & Harden (2019) and elucidate the optimal type and mode of delivery for PA interventions for survivors of cancer.

2.5.6.2 Adherence and maintenance of physical activity behaviour for individuals living with and beyond cancer and related methodological limitations within the existing literature

Randomised controlled trials (RCTs) that aimed to identify the most effective strategies to promote and sustain exercise participation among sedentary survivors of cancer were reviewed in a recent Cochrane investigation (Turner et al., 2018). Twenty-three studies that employed a variety of intervention delivery methods (e.g. supervised-, home-based-, technology-focused PA interventions) were included. The authors applied a criterion of  $\geq$ 75% of participants adhering to an exercise prescription that meets the Rock et al. (2012) PA guidelines, in an attempt to evaluate 'intervention success'. A detailed discussion of the primary publications included in the review by Turner and colleagues (2018), and further studies identified within the scientific literature, that discuss adherence and maintenance to PA interventions and PA behaviour, as well as the limitations of

these studies, are presented below, under headings related to the delivery methods employed within interventions.

### Supervised exercise interventions

Of the 10 RCTs using supervised exercise only that met the inclusion criteria outlined by Turner and colleagues (2018) (Al-Majid, Wilson, Rakovski & Coburn, 2015; Cantarero-Villanueva et al., 2012; Cavalheri et al., 2017; Daley et al., 2007; Kaltsatou, Mameletzi & Douka, 2011; Kim et al., 2017; McKenzie & Kalda, 2003; Mohamady, Elsisi & Aneis, 2017; Scott et al., 2013; Thomas, Alvarez-Reeves, Lu, Yu & Irwin, 2013), 3 studies reported adherence rates of ≥75% to an exercise prescription that meets the recommended Rock et al. (2012) PA guidelines (Al-Majid, Wilson, Rakovski & Coburn, 2015; Cantarero-Villanueva et al., 2012; Scott et al., 2013). All 3 studies were conducted among survivors of breast cancer with 1 investigation occurring during chemotherapy (Al-Majid, Wilson, Rakovski & Coburn, 2015) and 2 taking place following treatment completion (Cantarero-Villanueva et al., 2012; Scott et al., 2013). Exercise modalities varied from individually progressed supervised treadmill exercise (Al-Majid, Wilson, Rakovski & Coburn, 2015), to a water-based exercise programme that included low-intensity aerobic endurance exercise and core stability training (Cantarero-Villanueva et al., 2012), to supervised aerobic and resistance exercise using gym based equipment (e.g. treadmill, crosstrainer, weights) (Scott et al., 2013). Two studies reported improvements from baseline to post-intervention, including reduced pain (Cantarero-Villanueva et al., 2012) and increased CRF and HRQoL (Scott et al., 2013). However, none of the studies conducted long-term follow-up and therefore the effectiveness of the

interventions in supporting continued and sustained PA engagement among survivors of breast cancer remains unclear.

While limited research has investigated the long-term effects of supervised exercise only interventions on levels of PA participation, one study by Witlox et al. (2018) did assess the effects of an 18-week supervised exercise programme on PA levels 4 years post-baseline assessment for individuals receiving adjuvant treatment for breast or colon cancer. The intervention group reported significantly greater levels of total MVPA compared to the usual care control group at 4 year follow-up. However, findings should be interpreted with caution as PA levels were assessed using a self-report measure of PA and such methods are subject to multi-various bias, including over-reporting (Witlox et al., 2018). Research investigating the longterm effects of supervised exercise only interventions using objective tools of PA measurement among all cancer cohorts are required in order to determine the potential benefits of such programmes in supporting habitual PA participation among survivors of cancer.

#### Home-based physical activity interventions

Among the 4 RCTs adopting a solely home-based exercise intervention (Drouin et al., 2006; Musanti, 2012; Pinto, Frierson, Rabin, Trunzo & Marcus, 2005; Pinto, Papandonatos, Goldstein, Marcus & Farrell, 2013), that were included in the review by Turner et al. (2018), none reported adherence rates of  $\geq$ 75% to an exercise prescription that meets the recommended Rock et al. (2012) PA guidelines. The nature of the home-based exercise programmes varied. Examples included

weekly telephone PA counselling and print- based materials (i.e. written exercise guidebook, exercise log sheet) to guide 3 exercise sessions of 15-30 mins each week for 12 weeks (Musanti, 2012), and PA logs and pedometers to guide weekly PA participation that aimed to accumulate the recommended PA guidelines over a 12 week period (Pinto, Frierson, Rabin, Trunzo & Marcus, 2005; Pinto, Papandonatos, Goldstein, Marcus & Farrell, 2013). Improvements in indices of physical and psychosocial health were observed from baseline to post-intervention including increases in CRF (Drouin et al., 2006) and PA levels (Pinto et al., 2005). Long term follow-up was conducted in 2 studies, however improvements obtained post-intervention were not maintained (Pinto, Frierson, Rabin, Trunzo & Marcus, 2005; Pinto et al., 2008) or attenuated over time (Pinto, Papandonatos, Goldstein, Marcus & Farrell, 2013).

While home-based interventions offer appeal in the context of pragmatism and economics, such interventions that require participants to self-report their PA, in either written or verbal format, raise substantial concerns regarding the potential for reporting bias (Daley et al., 2007) and this may have been reflected in the lack of long-term effectiveness reported by Pinto and colleagues (2008, 2013). It is also likely that an individual's level of motivation significantly influences their level of engagement with a home-based PA programme and such programmes may be more beneficial among certain sub-groups of survivors of cancer, including those who demonstrate high levels of intrinsic motivation, have a previous history of PA participation or express a preference for individual PA as opposed to group-based programmes. Social support for PA has been reported as an important determinant

of PA behaviour among survivors of cancer (Charlier et al., 2013). The independent nature of the home-based programmes described and subsequent absence of social support for PA may also have contributed to the lack of long-term effectiveness observed. Further studies, with larger sample sizes conducted among more diverse cancer survivor populations that implement objective PA assessment and reliable measurement of level of engagement are required to further develop our understanding of the potential of home-based programmes to support habitual PA participation among individuals living with and beyond cancer.

#### *Combined supervised and home-based physical activity interventions*

Ten RCTs that incorporated both supervised and home-based exercise elements were included in the review by Turner et al. (2018). Of these, 6 reported adherence rates of ≥75% to an exercise prescription that met the recommended PA guidelines (Bourke et al., 2011; Bourke et al., 2014; Campbell et al., 2017; Kim, Kang, Smith & Landers, 2006; Pinto, Clark, Maruyama & Feder, 2003; Rogers et al., 2015). Studies were conducted among: i) survivors of breast cancer during (Kim, Kang, Smith & Landers, 2006) and after treatment (Campbell et al., 2017; Pinto, Clark, Maruyama & Feder, 2003; Rogers et al., 2015), ii) survivors of colon cancer who had completed treatment (Bourke et al., 2011) and iii) individuals with locally advanced or metastatic prostate cancer on long-term androgen deprivation therapy (Bourke et al., 2014). Exercise interventions largely consisted of 12-week supervised and home-based aerobic and resistance exercise programmes conducted in research facilities, gyms and independently by participants at home. Improvements from baseline to post-intervention in a number of outcome variables were reported

across studies, including increases in fatigue, PA levels, resting and maximal systolic blood pressure, body image, HRQoL and CRF (Bourke et al., 2011; Bourke et al., 2014; Kim et al., 2006; Pinto, Clark, Maruyama & Feder, 2003; Rogers et al., 2015). Long term follow-up was assessed in 3 of the 6 studies at 3- (Rogers et al., 2015), 4-(Kim, Kang, Smith & Landers, 2006) and 6- months (Bourke et al., 2014) postintervention. No significant intervention effect on long-term PA levels between intervention and control groups was reported by Kim, Kang, Smith & Landers, 2006. Bourke et al. (2014) and Rogers et al. (2015) reported statistically significant differences between the control and intervention groups for self-reported PA and CRF 3-months post-intervention, however this finding was not reflected within objective accelerometry data collected by Rogers et al. (2015).

The Godin Leisure-Time Exercise Questionnaire was used in 3 of the reviewed studies to assess PA levels. Despite its widespread use in exercise oncology research, limited evidence supporting the validity of the questionnaire among survivors of cancer has been accumulated (Amireault, Godin, Lacombe & Sabiston, 2015). Recall bias may be more prevalent among individuals living with and beyond cancer compared to healthy populations given the potential negative impact of cancer and its treatment on cognitive function (Campbell et al., 2017), particularly among older survivors of cancer and individuals with metastatic disease (Amireault, Godin, Lacombe & Sabiston, 2015). In a systematic review assessing the extent to which validity evidence supports the use of this questionnaire among cancer survivors, the authors stated that in the absence of sufficient evidence regarding the questionnaire's ability to accurately assess changes in light-intensity

PA, confidence in studies reporting this measure across the cancer trajectory is limited (Amireault, Godin, Lacombe & Sabiston, 2015).

The highlighted RCTs that investigated the effects of a combined supervised and home-based exercise programme on PA levels among survivors of cancer are limited by a narrow scope of investigation, with the majority being conducted among breast cancer survivors who have completed cancer treatment, and the use of self-report measures to assess PA. While a combined supervised and homebased approach to PA appears to offer more promise in terms of adherence among this population, further RCTs using objective assessment of PA among all of cohorts of survivors of cancer are required to consolidate our understanding of the role of such programmes in supporting continued PA engagement.

# Technology-based physical activity interventions

The use of novel technology-based interventions, including electronic health (e-Health/internet based interventions) and mobile health (m-Health) or mobile device delivered interventions, to support habitual PA among survivors of cancer has received increasing amounts of attention within the scientific literature. Proposed benefits of such approaches include reducing cost, increasing convenience and overcoming isolation for end-users, while also offering greater control for those delivering interventions in terms of the ease of updating and storing information (Griffiths, Lindenmeyer, Powell, Lowe & Thorogood, 2006).

In a systematic review of the evidence regarding the effectiveness of e-Health interventions in increasing PA levels among survivors of cancer, the results were promising with 8 out of 10 studies reporting statistically significant increases in PA levels as assessed by self-report measures (Haberlin et al., 2018). The majority of studies were conducted among survivors of breast cancer with sample sizes ranging from 35 to 368 and intervention durations ranging from 22 days to 12 months. Different e-Health platforms were used for intervention delivery; 4 interventions were web-based (Lee et al., 2014; Kanera et al., 2017; Short et al., 2017; Sturgeon et al., 2017), 5 incorporated a web- and/or mobile- app (O'Carroll Banturn et al., 2014; McCarroll et al., 2015, Hong et al., 2015; Hooke, Gilchrist, Tanner, Hart, & Withycombe, 2016; Uhm et al., 2017), and 1 was conducted via email (Hatchett, Hallum & Ford, 2013). All studies used self-report measures of PA assessment bar one investigation which measured average steps per day using Fitbit technology (Hooke, Gilchrist, Tanner, Hart, & Withycombe, 2016). Two studies conducted 12 month follow-ups with both reporting significant improvements in self-report PA among the intervention groups compared to control participants (Kanera et al., 2017; Sturgeon et al., 2017). Similar findings have also been reported within a systematic review and meta-analysis that explored digital health PA BC interventions for cancer survivors (Roberts, Fisher, Smith, Heinrich & Potts, 2017). However, limitations of the evidence reviewed included the high degree of heterogeneity among the small number of included studies and a high risk of bias (Roberts, Fisher, Smith, Heinrich & Potts, 2017).

While the results of e-Health interventions appear to hold promise in terms of their ability to positively influence long-term PA adherence among survivors of cancer, RCTs conducted among all cohorts of cancer survivors that include long

term follow-up procedures and objective PA assessment is required before valid conclusions can be drawn (Haberlin et al., 2018). The optimal e-Health delivery method has yet to be determined (Haberlin et al., 2018) and given the rapid growth and rate of progression of such interventions, accessing the results of evaluations may lag behind, and limit the potential to influence the rate of present change.

Limited research is currently available which has investigated cancer survivors' preferences for technology-based interventions, and this information is vital in understanding factors that could influence participant engagement with an intervention and therefore determine the likelihood of intervention success (Roberts, Fisher, Smith, Heinrich & Potts, 2017). In addition, little is known regarding the barriers associated with technology-based interventions for this population. Research investigating this would be valuable in providing information regarding the acceptability of such interventions to participants, which may be of particular importance among certain sub-groups of cancer survivors (e.g. elderly participants). As participants are engaging in independent PA remotely, particular attention should also be given to adverse reporting within future studies as it has been suggested that technology-based interventions could lead to harm in a number of different contexts including the provision of unsuitable advice (Michie, Yardley, West, Patrick & Greaves, 2017).

# 2.5.7 The Role of Behaviour Change Theory within Physical Activity Interventions

It has been suggested that embedding a theoretical framework with an intervention may optimise intervention effectiveness by linking relevant causal

factors of the target behaviour with appropriate behaviour change techniques (BCTs) (Bartholomew & Mullen, 2011; Bluethmann, Bartholomew, Murphy & Vernon, 2017). BCTs are defined as observable, replicable and irreducible components of an intervention that aim to change, or redirect causal processes that determine behaviour (Michie et al., 2018). Characterising interventions in the context of theoretical constructs and BCTs provides valuable information regarding the processes through which such factors influence behaviour and as such, their use and application within previous studies should be assessed (Michie et al., 2018). Indeed, in the development of complex behaviour change (BC) interventions, defined as those that contain several interacting components, the Medical Research Council (MRC) recommend that as one of the first steps, intervention designers should develop a theoretical understanding of how changes in the target behaviour are likely to be mediated (Craig et al., 2008). This recommendation is widely supported (Bartholomew, Parcel & Kok, 2008; Michie, Johnston, Francis, Hardeman & Eccles, 2008; Short, James, Stacey & Plotnikoff, 2013).

Kerlinger (1986) defined behaviour theory as a set of inter-related concepts that outline relationships among variables in order to explain behaviour. Theory provides a framework for the systematic development and evaluation of BC interventions and may provide valuable information regarding how components within an intervention have contributed to successful performance of the target behaviour (Bluethmann, Bartholomew, Murphy & Vernon, 2017; McEwan et al., 2019). According to Michie, Johnston, Francis, Hardeman & Eccles (2008), there are 3 main reasons for advocating the use of theory in the development of

interventions. Firstly, theory assists in the identification of mechanisms of change and that targeting these causal determinants of behaviour is likely to increase intervention effectiveness (Michie, Johnston, Francis, Hardeman & Eccles, 2008). Secondly, theory-based interventions provide opportunities to test and develop theory. Finally, theory provides a framework to facilitate an understanding of what works within interventions and therefore contributes to the development of better theory that can be applied within different contexts, populations and behaviours (Michie, Johnston, Francis, Hardeman & Eccles, 2008). This information is vital to inform intervention replication and assist in the identification of interventions that effectively support habitual PA among individuals living with and beyond cancer.

Poor reporting of the application of theory within intervention development, implementation and evaluation within the literature has inhibited efforts to evaluate the effectiveness of theory in contributing to successful BC (Bluethmann, Bartholomew, Murphy & Vernon, 2017; Turner et al., 2018). In addition, assessing the intensity of theory application and its impact on BC within interventions has been limited due to significant variations in how theory has informed, and is embedded, within interventions described within the literature (Bluethmann, Bartholomew, Murphy & Vernon, 2017; Turner et al., 2018; Wallace, Brown & Hilton, 2014). In a recent Cochrane review assessing the effectiveness of PA interventions to support habitual PA among sedentary survivors of cancer (Turner et al., 2018), the authors commented that across the 23 studies included in the review "interventions frequently consisted of little more than telling people how to exercise and providing opportunities for this to occur, with little

consideration of the psychological aspects of changing behaviour" (Turner et al., 2018, p. 22). An analysis of BCTs related to outcome variables was not possible given the absence of a theoretical basis for intervention development within the majority of included studies (Turner et al., 2018).

Bluethmann, Bartholomew, Murphy and Vernon (2017) applied a framework to determine the intensity of theory application and its association with intervention effectiveness within PA interventions for post-treatment survivors of breast cancer. Across the 14 studies included, the overall mean intensity of theory application score was 3.78 out of a maximum score of 8. This score was based on a number of criteria including each intervention technique being explicitly linked to at least one theoretical construct and discussion of the results in relation to theory. Five studies were classified as having implemented extensive use of theory within the interventions described (defined as Level 3 studies) and within these studies, the mean intensity score for theory application was 6. The results showed that Level 3 studies had the largest overall effect in increasing PA levels among survivors of breast cancer compared to the other 2 levels (level 1 (defined as sparse use of theory) and level 2 (defined as moderate use of theory)). It was reported that while most studies had stated a theoretical framework and offered a rationale regarding the links between how theory was hypothesised to be related to PA, the application of theory within later stages of intervention planning and evaluation was insubstantial (Bluethmann, Bartholomew, Murphy & Vernon, 2017). This evidence suggests that a more concentrated and consistent application of theory throughout all stages of the intervention process (i.e. development, implementation and

evaluation) may enhance intervention effectiveness (Bluethmann, Bartholomew, Murphy & Vernon, 2017). Similar findings regarding the effectiveness of behavioural PA interventions among survivors of breast and endometrial cancer, that are grounded in theory, have also been reported (Rossi, Friel, Carter & Garber, 2018; Short, James, Stacey & Plotnikoff, 2013).

# 2.5.8 Physical Activity Behaviour Change Interventions for Survivors of Cancer

To date, limited research in the field of PA and cancer survivorship has focused on BC, with a significant majority of studies reporting on the efficacy of interventions on physiological (e.g. CRF, strength) and psychological (e.g. QoL) outcomes only (Bluethmann, Vernon, Gabriel, Murphy & Bartholomew, 2015). For interventions to be effective and elicit performance of a desired behaviour, it has been suggested that the active components of an intervention (i.e. BCTs) should target relevant mechanisms of action that have been identified through the application of theory (Michie et al., 2018). Characterising interventions in the context of theoretical constructs and BCTs provides valuable information regarding the processes through which a BCT influences behaviour (Michie et al., 2018). In essence, this approach helps intervention designers to understand why an intervention has, or has not worked. Understanding why interventions were successful, or unsuccessful, is key to advancing our understanding of behavioural science in this area and facilitating the replication of effective interventions.

Given that the factors associated with PA participation and BC are complex (Thomson, 2000), multiple component or complex interventions that target

different theoretical constructs are likely required to address the unique needs and challenges facing individuals living with and beyond cancer. Michie, van Stralen and West (2011, p.1) define BC interventions as "co-ordinated sets of activities designed to change specified behaviour patterns". In a recent systematic review and metaanalysis of RCTs that targeted PA BC among survivors of breast cancer, it was reported that interventions had a moderate positive effect on participants' PA levels (Bluethmann, Vernon, Gabriel, Murphy & Bartholomew, 2015). Intervention success across studies was associated with a number of commonalities, including the use of: i) self-monitoring or coaching techniques in various combinations with different mediums (e.g. provision of pedometers/accelerometers in conjunction with self-report tools), ii) group-based workshops or peer support sessions, iii) individual counselling regarding the benefits and barriers to PA participation, iv) home-based exercise and v) walking as the primary exercise modality (Bluethmann, Vernon, Gabriel, Murphy & Bartholomew, 2015). While larger effects on PA levels were observed among interventions that employed higher levels of participant supervision, 5/6 of the largest effect sizes came from trials that were classified as having 'medium' intensity supervision/monitoring of participants (e.g. home-based programmes) (Bluethmann, Vernon, Gabriel, Murphy & Bartholomew, 2015). This finding may bare important consideration for intervention designers operating within limited intervention resources (Bluethmann, Vernon, Gabriel, Murphy & Bartholomew, 2015). Only a minority of trials included in this review conducted long-term follow-up where modest increases in PA levels that were observed postintervention were generally not maintained, or could not be evaluated in light of the data available (Bluethmann, Vernon, Gabriel, Murphy & Bartholomew, 2015).

A systematic review of PA BC interventions for men with prostate cancer recently sought to identify the characteristics associated with intervention success but were unable to generate results due to the heterogeneity within the included studies (Finlay, Wittert & Short, 2018). In contrast, a recent Cochrane review reported that the BCTs of goal setting, instruction on how to perform behaviour and setting graded tasks were implemented in a number of studies that achieved  $\geq$ 75% adherence to the aerobic or resistance PA guidelines among sedentary survivors of cancer (Turner et al., 2018).

In light of the dearth of scientific evidence evaluating PA BC interventions for survivors of cancer and the heterogeneity of study quality within the limited research that has been conducted in this area, the question of sustainability of PA BC interventions for survivors of cancer still remains largely unanswered (Bluethmann, Vernon, Gabriel, Murphy & Bartholomew, 2015). To advance of our understanding in this area, further research with high methodological quality that is conducted among all age-groups and all cancer survivor cohorts is required to support the identification of the most effective ways to support individuals living with and beyond cancer to be habitually physically active (Bluethmann, Vernon, Gabriel, Murphy & Bartholomew, 2015; Finlay, Wittert & Short, 2018; Stacey, James, Chapman, Courneya & Lubans, 2015; Turner et al., 2018). Comprehensive reporting of adverse effects, the inclusion of objective assessment of PA and details of the frequency, intensity, duration and modality of the exercise undertaken by participants, as well as standardised reporting of adherence and drop-out rates within studies should be advocated (Turner et al., 2018). The Template for

Intervention Description and Replication (TIDieR) checklist has been developed to assist researchers in addressing these gaps within the literature and enable the standardised reporting, and subsequent replication, of interventions (Hoffman et al., 2014). Its use within studies is recommended.

# 2.5.9 The Application of Behaviour Change Theory within Physical Activity Behaviour Change Interventions

### 2.5.9.1 Social Cognitive Theory

Of the myriad of theories available within the scientific literature, Social Cognitive Theory (SCT) and the Transtheoretical Model of Behaviour Change (TTM) are the most commonly cited within PA BC interventions for survivors of cancer (Bluethmann, Bartholomew, Murphy & Vernon, 2017; Stacey, James, Chapman, Courneya & Lubans, 2015; Turner et al., 2018). Bandura's SCT posits a multifaceted causal structure whereby beliefs regarding self-efficacy operate reciprocally with behavioural-, environmental- and personal- factors to regulate behaviour (Bandura, 1998) (Figure 2.3). Perceived self-efficacy is viewed as a key component of the model as it influences motivation and action directly while also impacting other determinants (Bandura, 1998). Outcome expectations, which are the expected results following performance of the target behaviour, are another important construct within this theory that influences behaviour (Rogers et al., 2004).

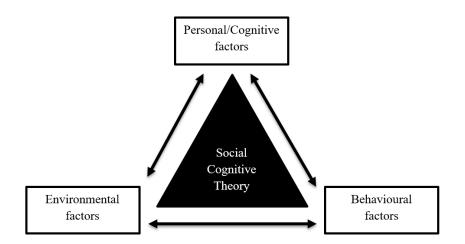


Figure 2.3. Social Cognitive Theory (Bandura, 1998)

Stacey, James, Chapman, Courneya and Lubans (2015) conducted a systematic review and meta-analysis to determine the benefits of SCT-based PA and nutrition interventions for individuals living with and beyond cancer and identify factors associated with intervention success. While the results showed that SCTbased PA interventions had a small-to-medium effect on participants' PA levels, no SCT constructs (e.g. self-efficacy, outcome expectations, knowledge, goals) were associated with the improvements observed. The included studies were associated with methodological limitations previously reported within the broader literature in this area, namely small sample sizes, use of self-report measures of PA, lack of longterm follow-up, absence of studies evaluating resistance exercise and the majority of trials being conducted among survivors of breast cancer who have completed treatment. Further research is required to address these limitations and establish if SCT constructs are linked with intervention success, and how findings from efficacy trials can be translated to real-world PA programmes and services to support habitual PA among survivors of cancer. One of the limitations of SCT is its broad scope, as it is often cited within studies as having informed the intervention development process but the details of how it has are often poorly reported or absent entirely (Stacey, James, Chapman, Courneya & Lubans, 2015).

## 2.5.9.2 The Transtheoretical Model of Behaviour Change

The TTM postulates that BC occurs following progress through stages of change, namely precontemplation, contemplation, preparation, action, maintenance and relapse (Prochaska & Velicer, 1997) (Figure 2.4).



Figure 2.4. The Transtheoretical Model of Behaviour Change

Processes of change have been linked with progress through the stages and include the strategies of consciousness raising (defined as exploration of information related to the individual and the problem to create awareness), counterconditioning (defined as the identification and testing of alternatives for problem behaviours) and reinforcement management (defined as reward provision contingent upon progress towards goal attainment) (Prochaska & Velicer, 1997). Core concepts that underpin the model include decisional balance and self-efficacy and acknowledgement that individuals can enter and exit the stages of change by relapsing (Prochaska & Velicer, 1997). Husebø, Dyrstad, Søreide & Bru (2013) reported that exercise stage of change was a relatively strong predictor of exercise adherence among survivors of cancer. However, this finding was not supported by two subsequent systematic reviews and as previously discussed the use of univariate analysis may have led to an overestimation of the strength of associations observed (Kampshoff et al., 2014; Turner et al., 2018). The TTM has been criticised due to rejection of the notion that BC occurs through progress across discrete stages and there is strong evidence to suggest that a model structured around an earlier motivational phase followed by a volitional phase would more accurately reflect the changes that occur in PA behaviour (Armitage, 2009; Green et al., 2014). Such a model would likely better reflect the needs of different individuals at different stages of PA adoption and maintenance. West (2005) also outlines criticisms of the TTM, including the arbitrary differentiation between the stages, and suggests that definitions of stages represent a mixture of different theoretical constructs which are largely incoherent.

While it is advocated that intervention designers draw on theory to inform intervention development, implementation and evaluation (Craig et al., 2008), no guidance is offered regarding how theory should be selected or applied (Michie, van Stralen & West, 2011). It has also been suggested that intervention designers currently do not use available frameworks as the starting point for the development of new interventions or in the evaluation of interventions to determine the factors that underpinned success, or lack thereof (Michie, van Stralen & West, 2011). It has

been suggested that a potential reason for this is that existing theories and frameworks are not meeting intervention designers' needs (Michie, van Stralen & West, 2011).

# 2.5.9.3 The Behaviour Change Wheel

The Behaviour Change Wheel (BCW) was developed for two reasons (Michie, Atkins & West, 2014; Michie, van Stralen & West, 2011) (see Figure 2.5). Firstly, it was developed to address the limitations of existing theoretical frameworks, and secondly, to provide a systematic method for understanding BC and how to characterise interventions to make use of this understanding. This systematic approach provides a means to measure and replicate theory application.

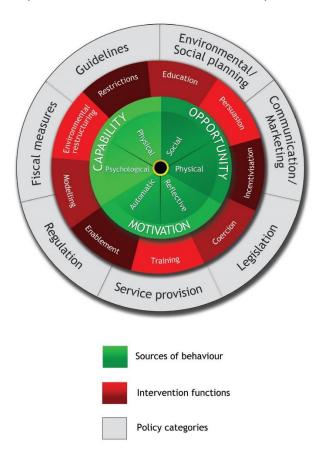


Figure 2.5. The Behaviour Change Wheel (Michie, Atkins & West, 2014).

The BCW was produced following a systematic review and synthesis of 19 existing frameworks of BC (Michie, Atkins & West, 2014; Michie, van Stralen & West, 2011). At the centre of the wheel is the COM-B model, which focuses on how an individual's capability, opportunity and motivation interact to perform a desired behaviour (See Figure 2.6). Capability refers to a person's physical and psychological capacity to engage in the target behaviour (e.g. PA participation). Motivation, which includes reflective and automatic motivation, reflects the cognitions or brain processes that guide behaviour (e.g. emotional responding). Opportunity, which encompasses physical and social opportunity, delineates all factors external to the individual that facilitate or prompt performance of the target behaviour. The COM-B model is used to perform a behavioural diagnosis to assist in the identification of a target behaviour for an intervention (Michie, van Stralen & West, 2011).

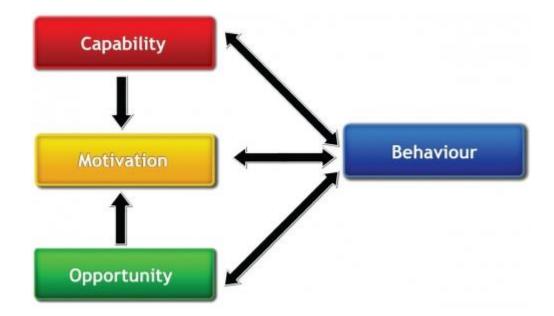


Figure 2.6. The COM-B Model (Michie, Atkins & West, 2014).

Once a target behaviour has been chosen, intervention designers select which intervention functions (i.e. education, persuasion, incentivisation, coercion, training, enablement, modelling, environmental restructuring and restrictions) to implement to support performance of the target behaviour by the intended population. Each intervention function can in turn be linked with specific BCTs which can be embedded within interventions to change behaviour (Michie, Atkins & West, 2014).

To the authors knowledge, the BCW has not previously been used in the development, implementation or evaluation of PA BC interventions for individuals living with and beyond cancer. Webb and colleagues (Webb, Foster & Poulter, 2016; Webb, Hall, Hall & Fabunmi-Alade, 2016) used the BCW to develop a very brief PA advice intervention for delivery by nurses to patients with cancer. The steps within the intervention development process have been published and provide a transparent overview of how the BCW informed, and was embedded within, the resultant intervention (Webb, Foster & Poulter, 2016). The very brief advice intervention adopted an 'Ask, Advise and Act' approach. Nurses asked patients about their current levels of PA participation and if they were aware of the benefits of PA for individuals living with cancer. Patients were advised of the benefits associated with PA and specifically, how it could be of benefit to them (e.g. assist in overcoming fatigue). Finally, nurses signposted patients to further help and facilitated referral to local services and/or other resources. The intervention was associated with improvements in nurses' capability, opportunity and motivation to deliver very brief PA advice to patients with cancer, and an increase in the provision of such advice to patients (Webb, Hall, Hall & Fabunmi-Alade, 2016). In a qualitative exploration of participants' experiences of the intervention, it was reported that

the intervention had had a positive impact on nurses' potential to influence other healthcare professionals regarding the promotion of PA to patients, and it was highlighted that this could contribute to changes in culture and practice within organisations (Webb, Hall, Hall & Fabunmi-Alade, 2016). It has been advocated that all members of the multi-disciplinary oncology team promote PA to patients with cancer (Cormie et al., 2018), and so interventions such as this could provide a viable medium to achieve this aim. While it is important to note some of the limitations of this investigation, including the absence of a control group and use of predominantly non-validated self-report measures, this feasibility study provides evidence of the acceptability and practicability of a very brief PA advice intervention designed using the BCW for nurses working in oncology (Webb, Hall, Hall & Fabunmi-Alade, 2016).

Within the broader literature, the application of the BCW in the development of interventions for other health behaviours including weight loss, medication adherence and smoking cessation have been reported (Beleigoli et al., 2018; Chiang, Guo, Amico, Atkins & Lester, 2018; Fulton, Brown, Kwah & Wild, 2016). However, given the time-consuming nature associated with this approach (Webb, Foster & Poulter, 2016), it is not surprising that results from such interventions have not yet been published. The BCW has been used in the development of PA BC interventions for non-cancer populations, including individuals with multiple sclerosis (MS) and adolescent girls (Casey, Coote & Byrne, 2018; Murtagh, Barnes, McMullen & Morgan, 2018). While the findings from the PA intervention for individuals with MS have not yet been reported, evidence from a

feasibility study suggest that a BCW-guided, 6 week mother-daughter walking programme was deemed acceptable and significantly increased participants' daily steps (Corr, Morgan, McMullen, Barnes & Murtagh, 2018).

## 2.5.9.4 Theoretical Domains Framework

As part of the BCW method, intervention designers are encouraged to apply the Theoretical Domains Framework (TDF) (Cane, O'Connor & Michie, 2012; French et al., 2012; Michie, Atkins & West, 2014). This framework assists in further subdividing the factors identified in the COM-B behavioural diagnosis into 14 theoretical domains that are specified within the TDF. The TDF provides comprehensive coverage of the possible influences on the target behaviour and can address implementation problems by linking theories of BC with techniques of BC (Cane, O'Connor & Michie, 2012; French et al., 2012). It has also been suggested that use of the TDF may further improve the planning and reporting of theory application within interventions and provide evidence for the use of specific BCTs and overall theoretical coherence (Bluethmann, Bartholomew, Murphy & Vernon, 2017; Gardner, Whittington, McAteer, Eccles & Michie, 2010).

This thesis is underpinned primarily by the COM-B model of BC, the BCW and the TDF (Cane, O'Connor & Michie, 2012; French et al., 2012; Michie, van Stralen & West, 2011) and is reported using the Template for Intervention Description and Replication (TIDieR) checklist to support the standardised reporting and replication of interventions (Hoffman et al., 2014).

## 2.5.10 The Need for Implementation Research

A research priority identified for the field of PA and cancer by Courneya, Rogers, Campbell, Vallance & Friedenreich (2015) in an article that proposed the Top 10 research questions related to PA and cancer survivorship, was the need to identify how findings from PA interventions conducted in research settings can be translated into effective clinical and community oncology practice. Few effective interventions to support habitual PA among survivors of cancer have been identified (Bourke et al., 2013; Turner et al., 2018) and even less is known about how to translate such findings into disseminable interventions for delivery in real world settings (Courneya, Rogers, Campbell, Vallance & Friedenreich, 2015). As a result, effective programmes to support continued engagement with healthy lifestyle behaviours for individuals living with and beyond cancer are not widely available within cancer care or community-based settings (Basen-Enquist et al., 2017). To address this, dissemination and implementation (D&I) research that prioritises the development and testing of strategies that aim to maximise D&I research in non-research settings is urgently needed (Brownson, Jacobs, Tabak, Hoehner & Stamatakis, 2013; Courneya, Rogers, Campbell, Vallance & Friedenreich, 2015; Santa Mina et al., 2017). D&I trials that investigate the: i) most effective strategies to enlist OHPs support within clinical care settings for PA, ii) impact of the inclusion of PA promotion and referral within survivorship care on changing clinical practice and iii) identification of the optimal methods for upholding intervention fidelity when training for intervention implementation is delivered to non-research personnel, are particular priorities within the field of PA and cancer survivorship

research (Courneya, Rogers, Campbell, Vallance & Friedenreich, 2015). Despite the publication of research agendas and recommendations to expedite D&I research in the identification of effective PA BC interventions for survivors of cancer (Basen-Engquist et al., 2017; Phillips, Alfano, Perna & Glasgow, 2014; Pollack, Hawkins, Peaker, Buchanan & Risendal, 2011), significant advancements in this area have not yet been made. Phillips, Alfano, Perna and Glasgow (2014) suggest that the absence of D&I research from the scientific literature regarding PA and cancer survivorship may be influenced by a number of factors that are common to other scientific disciplines including limited study relevance and efficiency, poor collaboration and co-ordination between researchers and stakeholders and a primary focus on discovery. Pollack and colleagues (2011) suggest that the gap between efficacy trials and their subsequent translation into everyday practice may exist given that the theoretical understanding, skills and experience of those tasked with developing and testing novel interventions within controlled research environments differ from those who are responsible for disseminating evidence-based practice.

### 2.5.11 The Role of Community-based Exercise Rehabilitation Programmes

One solution to address the challenges experienced by OHPs in the promotion of PA and the low levels of PA participation reported by individuals living with and beyond cancer is the inclusion of an exercise rehabilitation pathway within patients' cancer care plan. It has been suggested that a structure similar to cardiac and pulmonary rehabilitation could be applied where patients could access rehabilitative services within both in- and out- patient settings in a staged approach following treatment completion (Alfano, Ganz, Rowland & Hahn, 2012; Schmitz,

2011). CBERPs could provide a potential model for the delivery of PA services in the out-patient context. While more research evaluating existing exercise oncology rehabilitation programmes is needed, findings to date suggest that participation is associated with increases in HRQoL, CRF and PA levels for individuals living with and beyond cancer (Knobf, Thompson, Fennie & Erdos, 2014; Cheifetz et al., 2014; Santa Mina et al., 2017). Beidas et al. (2014) published the findings of an effectiveness-implementation trial which demonstrated that a strength training programme for survivors of breast cancer could be successfully adapted from delivery in a controlled research environment to delivery in a community-based setting and still retain its effectiveness and safety. Such findings suggest that effectiveness-implementation trials are feasible and that success in the translation of knowledge from the research setting to real-world programmes is achievable. More research exploring the potential of these programmes in supporting habitual PA participation among survivors of cancer is therefore warranted.

### 2.6 Summary of the Evidence

This review of the literature summarises the benefits of PA and exercise for individuals living with and beyond cancer, as well as individuals' levels of PA participation throughout the cancer journey and the challenges associated with PA promotion, by OHPs, and PA adherence by survivors of cancer. Despite the significant body of evidence supporting the efficacy of PA interventions for this population to increase physical and psycho-social well-being, reduce the risk of cancer recurrence and increase longevity, limited research has investigated the most effective strategies to support habitual PA participation for survivors of

cancer, with even fewer studies reporting intervention success. The available evidence has been limited by a number of factors including a focus on interventions for post-treatment survivors of breast cancer, the use of self-report measures of PA and the absence of long-term follow-up. Subsequently, the question of how best to support individuals living with and beyond cancer to make PA part of everyday life remains largely unanswered. Theoretically informed interventions may provide a more detailed understanding of the factors associated with intervention success, or lack thereof.

CBERPs may offer a scalable and sustainable solution to address the decreases in physical and psycho-social well-being experienced by survivors of cancer following treatment completion and support the optimisation of patient health outcomes. As such, exploration of patient-centred, theoretically informed PA interventions within community settings is warranted. Models to support the development of such interventions have been described and implemented within this research in efforts to support the identification of the most effective way to support individuals living with and beyond cancer to be regularly physically active.

Chapter 3 Study 1

#### 3.1 Study 1

Cantwell, M., Walsh, D., Furlong B., Moyna, N., McCaffrey, N., Boran, L., Smyth, S. & Woods, C. (2018). Healthcare professionals' knowledge and practice of physical activity promotion in cancer care: challenges and solutions. *European Journal of Cancer Care, 27*(2), e12795 doi: 10.1111/ecc.12795

**Statement of contribution:** Prof. Niall Moyna, Dr. Bróna Furlong, Dr. Deirdre Walsh, Dr. Noel McCaffrey and Prof. Catherine Woods supervised this project, and were involved in the development of the study concept and research design, and in reviewing the manuscript. Dr. Lorraine Boran and Dr. Sinéad Smyth provided guidance and feedback on the research design and data analysis.

## 3.1.1 Abstract

Limited research exists regarding healthcare professionals' knowledge and practice of physical activity promotion for cancer survivors in Ireland. There is also a lack of research identifying the barriers experienced by oncology professionals when promoting physical activity, or referring patients to community-based exercise programmes. This study aims to identify healthcare professionals' knowledge, barriers and practices in relation to physical activity promotion for cancer survivors, and to generate guidance regarding the optimisation of the referral process to community-based exercise programmes. Oncology healthcare professionals (n=114) were invited to participate in two rounds of an online Delphi study. The response rates in rounds one and two were 38% (43/114) and 70% (30/43). Most respondents acknowledged the value of physical activity for cancer survivors (≥86%) and agreed that discussing physical activity with cancer patients was part of their role (88%). However, the majority of recommendations provided to patients did not align with the current physical activity guidelines. Strategies related to four themes that could optimise the referral process to communitybased exercise programmes achieved consensus, including providing education to healthcare professionals and patients regarding the benefits of physical activity and the logistics and quality of programmes, and optimising the logistics of the referral process.

Keywords: cancer, physical activity, healthcare professional, referral

# 3.1.2 Introduction

Despite a significant body of research supporting the use of exercise as a therapeutic modality for individuals living with and beyond cancer, healthcare professionals working in oncology experience many barriers when promoting physical activity to their patients (Karvinen, McGourty, Parent & Walker, 2012; Keogh, Olsen, Climstein, Sargeant & Jones, 2017; Williams, Beeken, Fisher & Wardle, 2015). Limited evidence is available regarding the challenges healthcare professionals encounter when promoting physical activity to cancer survivors in Ireland (O'Hanlon & Kennedy, 2014). Research exploring healthcare professionals' knowledge and practices of exercise prescription in cancer care within the Irish context (O'Hanlon & Kennedy, 2014) is also lacking. One solution to address some of the challenges experienced by healthcare professionals is to refer patients to external exercise programmes for comprehensive community-based support (McPhail & Schippers, 2012). Exercise referral schemes have been shown to be effective in increasing short term physical activity levels among sedentary and older adult populations (Campbell et al., 2015; Hanson, Allin, Ellis & Dodd-Reynolds,

2013; National Institute for Health and Care Excellence, 2014; Pavey et al., 2011), and evaluating their effectiveness for increasing physical activity among individuals living with and beyond cancer is warranted. However, more research is needed to optimise issues of adherence and uptake, and to identify strategies to promote successful referrals to community-based programmes in order to increase the physical activity levels of inactive patients (McPhail & Schippers, 2012; Morgan, 2005).

A number of organisations have developed physical activity guidelines for cancer survivors (Campbell, Stevinson & Crank, 2012; Hayes, Spence, Galvão & Newton 2009; Rock et al., 2012; Schmitz et al., 2010). The guidelines developed by the American Cancer Society (ACS) recommend that cancer survivors achieve at least 150 minutes of moderate intensity or 75 minutes of vigorous intensity aerobic physical activity each week, with the inclusion of strength training involving all major muscle groups on at least 2 days per week (Rock et al., 2012). While exercise prescription should be tailored to each individual and cancer type-specific guidance is available, the ACS recommend that all cancer survivors should aim to achieve the physical activity guidelines irrespective of cancer diagnosis or phase of the cancer journey (e.g. treatment, survivorship) (Rock et al., 2012). The majority of cancer survivors do not meet these guidelines, and male and female colorectal cancer survivors have been found to have lower levels of physical activity compared to age and gender matched peers who do not have a cancer diagnosis (LeMasters, Madhavan, Sambamoorthi & Kurian, 2014). Data from the United Kingdom (UK) states that almost 30% of cancer survivors report doing no physical activity, and

only one fifth of participants surveyed report meeting the aerobic physical activity guidelines of 30 minutes or more of activity on at least 5 days of the week (Department of Health, 2012). Barriers to physical activity participation that have been reported by cancer survivors include physical de-conditioning, fatigue, cost and lack of motivation (Blaney et al., 2010; Blaney, Lowe-Strong, Rankin-Watt, Campbell & Gracey, 2013).

According to a recent report, there were approximately 124,000 cancer survivors living in Ireland in 2013 (National Cancer Registry Ireland, 2015). As a result of improved diagnosis and treatment, the number of individuals living with and beyond cancer continues to grow. While healthcare professionals' primary focus traditionally was to treat and cure cancer, clinicians are now being challenged to shift from acute treatment to long-term management and encouraged to expand their scope of practice to include physical activity promotion as part of usual care for all cancer patients (Demark-Wahnefried, Aziz, Rowland & Pinto, 2005; Irwin & Mayne, 2008; Keogh et al., 2017). Indeed, recommendations from oncologists have been shown to positively influence cancer survivors' physical activity levels (Damush, Perkins & Miller, 2006; Jones, Courneya, Fairey & Mackey, 2004). However, Demark-Wahnefried, Peterson, McBride, Lipkus and Clipp (2000) reported that only 35% of breast and prostate cancer survivors received physician recommendations regarding physical activity and a survey in the UK highlighted that a minority (13%) of breast cancer patients are referred to exercise referral schemes (Queen et al., 2016). Healthcare professionals experience many barriers in the promotion of physical activity, including a lack of time with patients to discuss

physical activity and a lack of knowledge in physical activity promotion (Keogh et al., 2017).

Patients should be given an overview of the evidence-based literature regarding the benefits of physical activity during the cancer journey (Keogh et al., 2017). Given that this depth of knowledge may be beyond some healthcare professionals as a result of lack of training or resources (Irwin, 2009), it has been recommended that healthcare professionals strengthen their referral networks with physical activity specialists who can facilitate the provision of a detailed exercise prescription and/or access to cancer rehabilitation programmes (Keogh et al., 2017). Community-based exercise rehabilitation can play an important role in supporting individuals living with and beyond cancer to increase their physical and psychological wellbeing (Irwin et al., 2017; Mutrie et al., 2007; Rajotte et al., 2012). In addition, referring patients to external physical activity programmes could provide an attractive means to support cancer survivors to adopt regular physical activity, while also reducing the time and resource demands on healthcare professionals (McPhail & Schippers, 2012). The development of referral pathways to community-based exercise programmes has been recommended to improve patient access to knowledge and support for physical activity (Keogh et al., 2017; McPhail & Schippers, 2012).

The information obtained from this investigation aims to address: 1) the gaps identified in the existing scientific literature regarding the physical activity promotion practices of oncology healthcare professionals and 2) the need to identify how referral processes to community-based programmes can be optimised.

Thus, the purpose of this study was to: i) identify oncology healthcare professionals' knowledge, barriers and practices in relation to physical activity promotion for cancer survivors, ii) generate guidance regarding the optimisation of the referral process to community-based exercise programmes and iii) provide potential solutions regarding how physical activity can be incorporated into cancer care in Ireland.

## 3.1.3 Methods

#### 3.1.3.1 Study Type – The Delphi Method

The Delphi method is an iterative process which aims to achieve consensus on a topic from experts in a field where there may be a lack of information or guidance to direct practice (Linstone & Turoff, 2002; Vernon, 2009). While there are a number of variations of the Delphi technique, the approach is characterised by four main features (Vernon, 2009). Firstly, an expert panel is sought. The criteria for expertise is determined by the context of the study (Vernon, 2009). The Delphi method does not call on the expert panel to be a representative sample for statistical purposes (Powell, 2003). Representativeness is based on the qualities of the expert panel rather than the number of experts involved (Powell, 2003). Panel sizes ranging from 4 to 1000 have been reported within the literature (Vernon, 2009). Secondly, the Delphi method is characterised by having more than one round. The data collected in each round is collated and participants receive a summary of the group response. Panel members have the opportunity to consider the group's response when providing answers in subsequent rounds (Thangaratinam & Redman, 2005). The third characteristic is that the collated

information is presented to the group in a statistical summary such as providing percentage scoring or ranking according to the group mean (Vernon, 2009). The final characteristic is that the anonymity of the panel members is upheld. This eliminates the potential effect of status or group pressure for participants when providing responses (Thangaratinam & Redman, 2005).

Two rounds of an online Delphi study were conducted via e-mail and a webbased survey tool (SurveyMonkey<sup>®</sup>). Data was collected between November 2015 and April 2016. Ethical approval for the study was granted by the Dublin City University Research Ethics Committee (DCUREC2015203).

The round one survey consisted of: i) questions regarding healthcare professionals' demographic information and knowledge, attitude and practices regarding physical activity promotion for cancer survivors and ii) three open-ended questions regarding the barriers and motivators experienced when referring patients with cancer to community-based physical activity programmes and potential strategies to optimise the referral process to programmes of this nature. The round two survey consisted of 34 statements, generated from the responses provided in round 1, regarding the barriers and motivators to referral and strategies to optimise this process. The round two survey sought to achieve consensus from participants regarding the optimisation of the referral process to community-based physical activity programmes.

# 3.1.3.2 Participants and Procedures

Hospital-based oncology healthcare professionals and community-based general practitioners who had previously referred individuals living with and beyond cancer to a community-based exercise programme for cancer survivors were invited to take part (n=50). An additional 64 oncology healthcare professionals who had not previously referred patients with cancer to a community-based exercise programme were also invited to participate. Healthcare professionals' contact information was obtained online, over the telephone or from the community-based exercise programme's database. A total of 114 healthcare professionals were invited to participate in round 1.

Within the context of this study, the term healthcare professional refers to medical and allied health professionals working in oncology. Recruitment focused on targeting healthcare professionals involved in the provision of cancer care including oncologists, surgeons, nursing professionals, physiotherapists and general practitioners. Hospital-based healthcare professionals worked in 4 Dublin-based hospitals and general practitioners were predominantly located in the North Leinster area. All healthcare professionals were identified as experts as they are involved in the provision of care for individuals living with and beyond cancer.

In order to optimise response rates and ensure adequate sampling throughout the oncology community, the round two survey was also circulated at a national oncology research group meeting. At the meeting, only healthcare

professionals who were involved in the provision of care for cancer survivors were invited to take part.

## 3.1.3.3 Strategies to Increase Recruitment and Response Rates

Successful strategies drawn from the literature were implemented to increase participant recruitment and ensure the design of user-friendly surveys that would maximise response rates (Dillman, Tortora & Bowker, 1998; Edwards et al., 2009). They included adopting a personalised approach to communication regarding study participation, providing a deadline for responses, presenting questions in a conventional format that is similar to paper-based questionnaires and providing information to respondents regarding the percentage of the survey that has been completed as they progress through the survey.

#### 3.1.3.4 Advisory Panel

An advisory panel was established and was comprised of a representative from each hospital that was contacted regarding the study (n=4). Panel members were chosen based on their experience as a previous referrer to a communitybased exercise programme for cancer survivors and/or their expertise in research in the oncology setting. The panel members were an oncology nurse specialist, an oncology liaison nurse, and two research nurses. Meetings took place in person or over the phone and panel members were consulted regarding the acceptability of participation requirements. Panel members were encouraged to highlight the study to their colleagues in order to assist with recruitment. Panel members were contacted when the e-mails containing the links to the online surveys had been circulated and were encouraged to remind their colleagues to respond. Panel members were also encouraged to highlight the survey during team meetings.

# 3.1.3.5 Letters of Invitation

A member of the research team (MC) mailed a personalised invitation letter to participate in the study to each member of the expert panel (n=114) in November and December 2015. The letter was signed by a medical doctor who was a member of the research team. The letter included an overview of the study aims and what participation would involve (i.e. completion of two rounds of an online survey). It also informed healthcare professionals that they would be contacted by e-mail by a member of the research team (MC) with a link to the online survey in January 2016.

#### 3.1.3.6 Round One

Healthcare professionals received a personalised e-mail from MC containing information regarding study aims, participation requirements, a link to the online survey, a plain language statement and an informed consent. Respondents were asked to provide informed consent at the start of the survey. Healthcare professionals were requested to complete the survey within a two and a half week period. Non-responders were contacted via e-mail on two further occasions and were again invited to participate.

## 3.1.3.7 Round Two

Healthcare professionals who participated in round one (n=43) were contacted via email by MC and provided with a link to the online version of the round two survey one month after round one had been completed. A shorter paper-based version of the round two survey was also circulated at a national oncology research group meeting. Round two involved identical follow-up procedures to round one.

#### 3.1.3.8 Instruments

#### Round One Survey

A survey consisting of 32 items was developed by the research team and supplemented by questions adapted from previous literature (O'Hanlon & Kennedy, 2014; Spellman, Craike & Livingston, 2013). The format of questions posed included open text boxes, multiple choice single answer and matrix style questions. Questions regarding healthcare professionals' demographic information and knowledge, attitude and practices regarding physical activity promotion for cancer survivors were included. Examples of questions included: i) "By which methods do you usually give physical activity advice to your cancer patients (please tick as many as apply): verbal advice; literature/pamphlets; refer to an exercise specialist or physiotherapist; refer to a community-based exercise rehabilitation programme; not applicable (I don't give physical activity advice to patients); Other (please specify)", and ii) "For those cancer patients that you do recommend physical activity to, what are your general recommendations in regards to the following

(options were followed with an open text box): Frequency (e.g. number of sessions per week); Intensity (e.g. light, moderate, vigorous, symptom-limited); Minutes per session; Type of activity (e.g. aerobic, strength training, stretching); If you do not provide patients with general recommendations regarding physical activity, please type N/A in this box". Healthcare professionals were also asked to indicate their level of agreement/disagreement with statements regarding exercise and cancer on a five point Likert scale (strongly agree, agree, neither agree nor disagree, disagree and strongly disagree). Examples of these statements included 1) 'There are some risks for patients participating in regular physical activity with a diagnosis of: breast cancer, colorectal cancer and prostate cancer, and 2) regular physical activity can improve quality of life for patients with a diagnosis of: breast cancer, colorectal cancer and prostate cancer. Statements were presented in a matrix format where the same set of column choices could be applied (i.e. strongly agree, agree, neither agree nor disagree, disagree and strongly disagree) and each row represented a different cancer diagnosis (i.e. breast, colorectal and prostate cancer).

Three open-ended questions were also included. Two of the open-ended questions were related to barriers and motivators that healthcare professionals' experienced, or could experience, when referring patients with cancer to community-based physical activity programmes. The third open-ended question referred to strategies respondents thought would optimise the referral process to community-based physical activity programmes. An example of the open-ended question format was: "What strategies do you think would optimise the referral process and facilitate greater ease of referral for health care professionals when

referring cancer patients to community-based exercise rehabilitation programmes? (Please provide as much detail as possible)". Open-ended questions were accompanied by an open-text box. The survey took approximately 15 minutes to complete.

In round one, healthcare professionals were asked to outline their general recommendations for physical activity for cancer survivors with regard to the current physical activity guidelines. Answers were collected using open text boxes and a content analysis was conducted on the responses. Each response was coded according to its level of agreement with the American Cancer Society's physical activity guidelines for cancer survivors, with regard to the frequency, intensity, duration and type of activity (Rock et al., 2012). Responses that were coded 'PA advice meeting the guidelines' had to accurately reference each of the 4 components outlined in the PA guidelines, i.e. Frequency: minimum of 5 days per week; intensity: moderate or vigorous intensity; duration: minimum of 150 minutes per week (if moderate intensity was cited) or a minimum of 75 minutes per week (if wigorous intensity was cited); type: aerobic and resistance exercise. Reponses that did not align with these categories were coded according to the level of agreement criteria outlined in Table 3.2.

Prior to study commencement, a link to the online survey was circulated to members of a research group. Researchers were asked to complete the survey to identify any technical issues and to evaluate the clarity of the questions being posed and the length of time required to answer all questions. An identical protocol was followed for the round two survey.

# Round Two Survey

A round two survey consisting of 34 statements was developed using the results of an inductive content analysis that was performed on the responses provided to the open-ended questions in round one. The round two survey included statements regarding the motivators (n=6 statements) and barriers (n=13 statements) healthcare professionals experience, or envisaged experiencing, when referring patients with cancer to community-based exercise programmes and strategies to optimise this process (n=15 statements). Each statement was accompanied by a percentage which reflected the proportion of healthcare professionals who had reported each motivator, barrier or strategy in the round one survey. Participants were encouraged to consider these ratings when providing Respondents were asked to indicate their level their answers. of agreement/disagreement with each statement on a five point Likert scale (strongly agree, agree, neither agree nor disagree, disagree and strongly disagree). Consensus criteria were set at 70% where a statement was accepted or rejected if 70% of respondents indicated strongly agree/agree or strongly disagree/disagree on the Likert scale. While the consensus criteria applied within Delphi studies varies, a criterion of 70% has commonly been reported (Vernon, 2009), and was chosen for this study as it reflects the 'majority' view shared by healthcare professionals. Healthcare professionals were invited to share any additional comments or feedback regarding the statements in an open text box at the end of the survey.

To ensure adequate sampling throughout the oncology community, a shorter paper-based version of the round two survey was developed and circulated at a national oncology research group meeting. Due to the limited time available for questionnaire completion at the meeting, a shorter version of the questionnaire was required. The paper-based version included statements regarding the barriers healthcare professionals experience, or could experience, when referring cancer patients to community-based exercise programmes (n=13 statements) and strategies to optimise this process (n=15 statements). The Delphi study concluded when the second round had been completed. Figure 3.1 provides an overview of recruitment and response rates to both rounds of the Delphi survey.

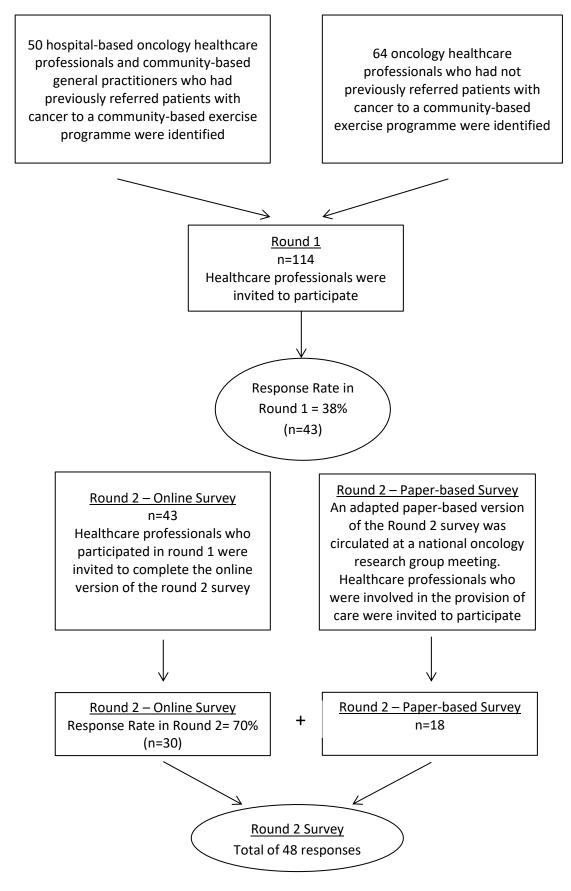


Figure 3.1. Flow chart outlining recruitment and response rates to both rounds of the Delphi survey.

#### 3.1.3.9 Data Analysis

### Inductive Content Analysis

An inductive content analysis as described by Elo and Kyngäs (2008) was conducted on the responses provided to the open-ended questions in round one using NVivo qualitative data analysis software (version 10) for Windows. Open coding was performed to generate initial categories, which were then reviewed in order to condense the data and where appropriate, categories were merged or further separated. A section of the data included in the content analysis was independently coded by four members of the research team. This section of coded data was reviewed by the same members of the research team to identify consistencies and differences in interpretation with regard to the coding. Differences were resolved following group discussion. The results of the content analysis were used to formulate the round two survey questions. Topics identified within the categories were translated into statements regarding the motivators and barriers that health care professionals' experience, or could experience, when referring patients with cancer to community-based physical activity programmes and strategies to optimise this process.

#### **Descriptive Statistics**

Descriptive statistics were performed on the responses to the round one and two surveys using the Statistical Package for the Social Sciences (SPSS) 24.0 for Windows. A subgroup analysis was conducted to examine differences between the barriers to physical activity promotion reported by healthcare professionals who

had referred patients to a community-based physical activity programme within the last 6 months (i.e. referrers) and those who had not (i.e. non-referrers).

# 3.1.4 Results

# 3.1.4.1 Round One Survey

The response rate was 38% (n=43) for the round one survey. Table 3.1 summarizes respondents' demographic characteristics. 42% of healthcare professionals had referred patients to a community-based exercise programme within the last 6 months. Healthcare professionals reported participating in physical activity on at least 2 days each week, where 19% reported being physically active on 5 or more days each week. The weekly average number of minutes of physical activity reported by healthcare professionals was 131 minutes (± 65).

	% (n=Respondents in Round One)	% (n=Respondents in Round Two)
Gender		
Male	35 (15)	31 (15)
Female	65 (28)	69 (33)
Profession		
Clinical Nurse Specialist	21 (9)	19 (9)
Radiation Oncologist	14 (6)	13 (6)
Medical Oncologist	12 (5)	15 (7)
GP	12 (5)	4 (2)
Oncology Liaison Nurse	9 (4)	8 (4)
Breast Surgeon	7 (3)	4 (2)
Colorectal Surgeon	7 (3)	4 (2)
Research Nurse	7 (3)	8 (4)
Advanced Nurse	5 (2)	4 (2)
Practitioner		
Physiotherapist	2 (1)	2 (1)
Plastic Surgeon	2 (1)	0 (0)
Clinical Nurse Manager	2 (1)	0 (0)
Nurse (not specified)	0 (0)	13 (6)
Radiation Therapist	0 (0)	2 (1)
Other	0 (0)	4 (2)
Age (yr)		
<30	2 (1)	8 (4)
31-40	28 (12)	25 (12)
41-50	51 (22)	48 (23)
51-60	14 (6)	17 (8)
>60	5 (2)	2 (1)

Table 3.1. Characteristics of respondents to the round one and round two surveys.

# 3.1.4.2 Knowledge and Attitude regarding Physical Activity Promotion for Cancer Survivors

The majority of healthcare professionals (≥86%) agreed or strongly agreed that physical activity: i) is possible during treatment, ii) can improve quality of life, iii) is associated with reduced fatigue, iv) can play an important role in the management of long-term treatment-related side effects and v) enhances behavioural changes (e.g. adopting a healthier diet) linked with minimising lifestyle risk factors for patients with breast, colorectal and prostate cancer. Just over half of respondents (51%) disagreed or strongly disagreed that there were some risks for patients with breast cancer participating in regular physical activity, and this decreased to 44% and 42% for prostate and colorectal cancer, respectively.

## 3.1.4.3 Physical Activity Recommendations

At all stages of the cancer journey with the exception of advanced progressive disease, physical activity was recommended more frequently to breast cancer patients than colorectal and prostate cancer patients. In contrast, among patients with advanced progressive disease, physical activity was recommended more frequently to prostate (61%) and breast cancer (59%) survivors than to individuals with a colorectal cancer diagnosis (42%). Physical activity was more frequently recommended to breast and prostate cancer survivors post-treatment than during treatment for colorectal cancer patients. At all stages of the cancer journey, physical activity was recommended by 53%, 44% and 29% of healthcare professionals to breast, prostate and colorectal cancer patients, respectively.

Almost three quarters (74%) of health care professionals recommended physical activity to  $\geq$ 75% of their patients with breast cancer. The proportion of healthcare professionals recommending physical activity to  $\geq$ 75% of their prostate and colorectal cancer patients was 59% and 57% respectively. Figure 3.2 illustrates the most commonly reported methods used to provide physical activity advice to patients with cancer.

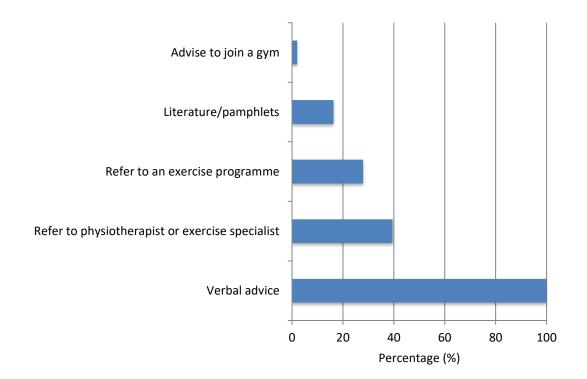


Figure 3.2. Methods used by healthcare professionals to provide physical activity advice to patients with cancer.

All of the healthcare professionals reported that physical activity advice was given verbally. The next most common method was referral to a physiotherapist or exercise specialist (40%) followed by a referral to a community-based exercise programme (28%).

The physical activity recommendations provided by healthcare professionals to cancer survivors are summarised in Table 3.2. 42% of respondents provided physical activity advice that did not align with the current physical activity guidelines.

% of Healthcare Professionals (n=43)	Level of Agreement Rating	Level of Agreement Criteria
16 (7)	PA advice meeting the guidelines	All 4 components of the FITT acronym in line with the guidelines
30 (13)	PA advice somewhat reflects the guidelines	>2 but <4 components of the FITT acronym in line with the guidelines
42 (18)	PA advice not in line with the guidelines	<2 components of the FITT acronym in line with the guidelines
12 (5)	PA Advice Not Provided	If participants entered NA into question 13

Table 3.2. Physical activity recommendations provided by healthcare professionals to cancer survivors.

Note: Frequency=Preferably all, with a minimum of 5 days per week; Intensity= moderate or vigorous intensity; Time= Minimum of 150 minutes per week (if moderate intensity was cited) and a minimum of 75 minutes per week (if vigorous intensity was cited); Type=Aerobic and resistance exercise

#### 3.1.4.4 Barriers to Physical Activity Promotion

Almost nine out of every 10 respondents (88%) either agreed or strongly agreed that discussing physical activity with cancer patients was part of their role. Table 3.3 identifies the barriers reported by healthcare professionals when promoting physical activity to cancer survivors. The top three barriers were: 1) limited time with patients, 2) lack of community-based exercise rehabilitation programmes to refer to, and 3) lack of resources (e.g. education leaflets and materials) regarding physical activity for cancer survivors. The results of a sub-group analysis showed that there were differences in the order of ranking of the most commonly reported barriers among healthcare professionals who had referred cancer survivors to a community-based exercise programme within the last 6 months (i.e. referrers) and those who had not (i.e. non-referrers) (See Table 3.3). The main barrier to physical activity promotion reported by referrers was limited time with patients, as opposed to a lack of community-based programmes to refer to which was cited most commonly by non-referrers. Table 3.3. Survey responses regarding the barriers reported by healthcare professionals when promoting physical activity to cancer survivors.

Barrier	% (No. of Total Respondents) (n=43)	% (No. of Referrers) (n=18)	% (No. of Non-Referrers) (n=25)
Limited time with patients	56 (24)*	61 (11)*	52 (13)*
Lack of community-based exercise rehabilitation programmes to refer to	56 (23)*	50 (9)	56 (14)*
Lack of resources regarding physical activity for cancer survivors (e.g. education leaflets and materials)	49 (21)*	56 (10)*	44 (11)
Lack of knowledge regarding physical activity prescription for cancer survivors	42 (18)	44 (8)	40 (10)
Poor physical activity compliance among cancer patients	40 (17)	28 (5)	48 (12)
Lack of motivation/interest from cancer patients in physical activity	40 (17)	22 (4)	52 (13)*
Patients' family/friends advise patients to rest and avoid activity	40 (17)	28 (5)	48 (12)
Existing community-based exercise programmes are not in patients'	35 (15)	56 (10)*	20 (5)

## locality

Patients' health status deems physical activity promotion inappropriate	26 (11)	17 (3)	32 (8)
Patients are already overloaded with information	2 (1)	6 (1)	0 (0)
Societal barriers regarding the lack of importance of physical activity	2 (1)	0 (0)	4 (1)
Treatment related side effects limit patients' ability for physical activity	2 (1)	0 (0)	4 (1)
The waiting list to community- based exercise rehabilitation programmes is long	2 (1)	6 (1)	0 (0)
None of the above	5 (2)	0 (0)	8 (2)

Note: \* denotes the top three barriers reported by i) all respondents, ii) referrers to community-based physical activity programmes for cancer survivors, and iii) non-referrers to community-based physical activity programmes for cancer survivors.

## 3.1.4.5 Round Two Survey

The content analysis generated 34 statements regarding the motivators (n=6 statements) and barriers (n=13 statements) that healthcare professionals experienced, or envisaged experiencing, when referring patients with cancer to community-based exercise programmes, and strategies to optimise this process (n=15 statements).

A total of 18 healthcare professionals completed the shorter, paper-based version of the round two survey regarding the barriers to referral to community-based exercise programmes and strategies to optimise this process. The online version of the round two survey was completed by 30 healthcare professionals which represented a 70% response rate (30/43). Table 3.1 presents the characteristics of the respondents to both versions of the round two survey (n=48). 69% of respondents were female and 52% were nursing professionals.

#### 3.1.4.6 Motivators to Refer Cancer Survivors to Physical Activity Programmes

Four of the six statements regarding what motivates or would motivate healthcare professionals to refer patients with cancer to community-based exercise programmes achieved consensus (See Table 3.4). They focused predominantly on the beneficial effects healthcare professionals reported exercise had for their patients, including improved physical and mental well-being.

Table 3.4. Statements (n=6) regarding what motivates or would motivate healthcare professionals to refer patients with cancer to community-based exercise programmes (n=30).

I am/would be motivated to refer cancer patients to community-based exercise rehabilitation programmes because:	Strongly Agree/ Agree % (n)	Neither Agree nor Disagree % (n)	Strongly Disagree/ Disagree % (n)	Outcome
It is beneficial for the patient (incl. physical and mental well-being)	100 (30)	0	0	Accept
Patients ask for help and a programme can assist with the return to 'normal' life	87 (26)	7 (2)	7 (2)	Accept
The patient is interested and has a positive attitude about attending a programme	87 (26)	4 (2)	4 (2)	Accept
It is important to treat patients holistically and support them to live a healthy lifestyle	100 (30)	0	0	Accept
Patients who have participated in programme have reported positive experiences	60 (18)	40 (12)	0	Reject
I have received education/training regarding the benefits of these programmes for cancer patients	30 (9)	30 (9)	40 (12)	Reject

Note: Statements were generated from the content analysis conducted on the responses to open-ended questions in round one. Survey responses were obtained in round two.

#### *3.1.4.7 Barriers to Referring Cancer Survivors to Physical Activity Programmes*

Three of the thirteen statements regarding the barriers that healthcare professionals experience or could experience when referring cancer patients to community-based exercise programmes achieved consensus (See Table 3.5). Barriers to referral focused on a lack of community-based exercise programmes to refer patients and a lack of information regarding existing programmes, as well as poor access to programmes in terms of cost and transport.

Table 3.5. Statements (n=13) regarding the barriers healthcare professionals experience or could experience when referring cancer patients to community-based exercise programmes (n=48).

A barrier I experienced/could experience when referring cancer	Strongly	Neither	Strongly	Outcome
patients to community-based exercise rehabilitation	Agree/	Agree nor	Disagree/	
programmes is, that some cancer patients	Agree % (n)	Disagree %	Disagree %	
		(n)	(n)	
Have a negative perception of these programmes	19 (9)	33 (16)	48 (23)	Reject
Are not motivated to attend	56 (27)	15 (7)	29 (14)	Reject
Mental and physical health, and disease status deems referral inappropriate	48 (23)	29 (14)	23 (11)	Reject
May not attend a programme if this decision is not supported by their main care provider (e.g. Consultant, spouse, family member)	60 (29)	19 (9)	21 (10)	Reject
A barrier I experienced/could experience when referring cancer patients to community-based exercise rehabilitation	Strongly Agree/	Neither Agree nor	Strongly Disagree/	Outcome
programmes is that there is	Agree % (n)	Disagree % (n)	Disagree % (n)	
A lack of programmes to refer to	85 (41)	8 (4)	6 (3)	Accept
A lack of information regarding existing programmes	85 (41)	8 (4)	6 (3)	Accept
Poor access to programmes (e.g. in terms of transport, cost, location, waiting lists)	81 (39)	13 (6)	6 (3)	Accept
location, waiting lists)	116			

A lack of training opportunities for health care professionals to learn about physical activity for cancer patients (incl. benefits and appropriate exercise prescription)	65 (31)	10 (5)	25 (12)	Reject
A barrier I experienced/could experience when referring cancer patients to community-based exercise rehabilitation programmes is, that as a healthcare professional, I	Strongly Agree/ Agree % (n)	Neither Agree nor Disagree % (n)	Strongly Disagree/ Disagree % (n)	Outcome
Don't have enough time to discuss referral with patients	31 (15)	13 (6)	56 (27)	Reject
Lose contact with patients after they complete treatment	31 (15)	6 (3)	63 (30)	Reject
Lack knowledge regarding the referral process to programmes of this nature (e.g. how to access the referral form, what information is required)	56 (27)	8 (4)	35 (17)	Reject
A barrier I experienced/could experience when referring cancer patients to community-based exercise rehabilitation programmes is that the referral form	Strongly Agree/ Agree % (n)	Neither Agree nor Disagree % (n)	Strongly Disagree/ Disagree % (n)	Outcome
Takes too long to complete	23 (11)	43 (20)	34 (16)	Reject
Needs to be completed by a medical professional	13 (6)	47 (22)	40 (19)	Reject

Note: Statements were generated from the content analysis conducted on the responses to open-ended questions in round one. Survey responses were obtained in round two.

# 3.1.4.8 Strategies to Optimise the Referral Process to Community-based Exercise Programmes

Twelve of fifteen statements regarding strategies to optimise the referral process to community-based exercise programmes achieved consensus (Table 3.6) and focused on four central themes: i) optimising the logistics of the referral process (e.g. making it standardised, electronic), ii) improving access and awareness for patients and healthcare professionals (with regard to information about the benefits of physical activity as well as information about existing exercise programmes; increasing access to programmes), iii) providing education to both healthcare professionals and patients regarding the benefits of physical activity and the logistics and quality of programmes, and iv) providing feedback to healthcare professionals on patients progress in a programme.

Table 3.6. Statements (n=15) regarding strategies that healthcare professionals reported would optimise the referral process to community-based exercise programmes (n=48).

The following strategies would optimise the referral process to community-based exercise rehabilitation programmes:	Strongly Agree/ Agree % (n)	Neither Agree nor Disagree % (n)	Strongly Disagree/ Disagree % (n)	Outcome
Feedback is provided regarding patients' attendance at the programme and their physical test results	83 (40)	6 (3)	10 (5)	Accept
Programme accessibility for patients is improved (in terms of information, availability, location(s), cost, classes provided for specific groups of cancer patients)	85 (41)	13 (6)	2 (1)	Accept
Access to information and awareness of existing programmes is improved (e.g. through newsletters, a website, information leaflets)	94 (45)	2 (1)	4 (2)	Accept
Education for patients regarding the benefits of physical activity is provided at the programme	90 (43)	8 (4)	2 (1)	Accept
The referral form can be completed by all health care professionals	94 (44)	4 (2)	2 (1)	Accept
I had more time with my patients to discuss referral	58 (28)	25 (12)	17 (8)	Reject
All healthcare professionals support community- based exercise rehabilitation for cancer patients	83 (40)	15 (7)	2 (1)	Accept
Greater public awareness of the benefits of physical activity for cancer patients	98 (47)	2 (1)	0	Accept

Availability of a national register of existing programmes and physical activity resources for cancer patients	92 (44)	8 (4)	0	Accept
Staff from the programme invite patients to attend during their clinic appointments at the hospital or surgery	69 (33)	17 (8)	14 (7)	Reject
Receiving an acknowledgement that the referral was received (either via post or e-mail)	75 (36)	15 (7)	10 (5)	Accept
An online/electronic referral process	90 (43)	8 (4)	2 (1)	Accept
The following strategies would optimise the referral process to community-based exercise rehabilitation programmes:	Strongly Agree/ Agree % (n)	Neither Agree nor Disagree % (n)	Strongly Disagree/ Disagree % (n)	Outcome
A patient led referral process	48 (23)	38 (18)	14 (7)	Reject
A standardised referral process (e.g. clear referral system, how to access it, who to contact, what information is required, concise referral form)	96 (46)	4 (2)	0	Accept
Education for staff regarding physical activity promotion for cancer survivors, and information regarding the logistics and quality (i.e. medically supervised, evidence-based, exercise prescribed is individualised) of a programme is available	96 (46)	2 (1)	2 (1)	Accept

Note: Statements were generated from the content analysis conducted on the responses to open-ended questions in round one. Survey responses were obtained in round two.

#### 3.1.5 Discussion

The results of the present investigation provide insight into the knowledge and practice of physical activity promotion for cancer survivors among healthcare professionals in Ireland. Although the majority of healthcare professionals valued physical activity participation for cancer survivors, it was not routinely discussed with every patient. As the majority of recommendations did not align with the current physical activity guidelines for cancer survivors (Rock et al., 2012), the value of this recommendation for patients is unclear.

O'Hanlon and Kennedy (2014) found that irrespective of the type of cancer, 75% of physiotherapists recommended exercise to ≥81% of cancer patients over a 6 month period. While similar recommendation rates were reported by healthcare professionals in the present study for breast cancer, rates were lower for both prostate and colorectal cancer. Opinion was divided among healthcare professionals regarding the risk associated with regular physical activity participation for patients with breast, colorectal or prostate cancer diagnosis. Healthcare professionals' concerns about providing physical activity advice have been found to centre on issues related to immune compromise, appropriate safety and screening procedures as well as prescribing exercise in cases of advanced disease (Courneya, Rogers, Campbell, Vallance & Friedenreich, 2015). Establishing consensus regarding the safety of exercise for all cancer survivors has been limited by a number of factors including a lack of comprehensive adverse event reporting in the literature and the selective recruitment of participants (Courneya, Rogers, Campbell, Vallance & Friedenreich, 2015). While additional research is required to

comprehensively address these issues, there is now accumulating evidence to suggest that exercise is safe and feasible for cancer survivors (Rock et al., 2012; Schmitz et al., 2010). Guidelines and recommendations are currently available which outline contraindications and precautions for exercise for individuals living with and beyond cancer and can guide clinical practice (Rock et al., 2012; Schmitz et al., 2010).

The majority of physical activity recommendations reported by healthcare professionals within this study did not align with the current physical activity guidelines for cancer survivors (Rock et al., 2012). Studies have shown that an exercise recommendation from an oncologist can positively influence cancer survivors' physical activity levels and their decision to participate in an exercise programme (Jones & Courneya, 2002; Livingston et al., 2015). Interestingly, in a three-armed randomized controlled trial comparing the impact of an oncologist exercise recommendation only, with an oncologist exercise recommendation plus referral to an exercise specialist and usual care on self-reported total exercise, the results favoured the oncologist exercise recommendation only group (Jones, Courneya, Fairey & Mackey, 2004). However, the referral (a business card with contact information for a free fitness assessment) provided may not have simulated structured referral processes that are familiar to patients (Jones, Courneya, Fairey & Mackey, 2004) and this may have limited its motivational potential. In addition, patients' exercise levels were assessed using self-report measures and may have been subject to recall bias.

A number of the barriers reported by healthcare professionals within this study are likely to have contributed to the paucity of detailed exercise prescription including a lack of: i) training opportunities for healthcare professionals to learn about physical activity for cancer patients, ii) knowledge regarding physical activity prescription for cancer survivors, iii) time with patients and iv) resources. Similar findings regarding the barriers reported by healthcare providers in the promotion of physical activity to cancer survivors have also been reported in other studies (Karvinen, McGourty, Parent & Walker, 2012; Puig Ribera, McKenna & Riddoch, 2005; Spellman et al., 2013; Williams et al., 2015). These findings are also reflected by patients with cancer, who reported that the key barriers to expressing concerns during consultations with their healthcare professional included a lack of suitable information being provided and limited time during the consultation (Brandes, Linn, Smit & van Weert, 2015). The results of the sub-group analysis showed patientcentred barriers (e.g. lack of motivation or interest for physical activity among cancer survivors, poor physical activity compliance, patients' family/friends advise patients to rest and avoid activity) were more frequently cited among non-referrers to community-based physical activity programmes than referrers, who more frequently cited environmental constraints (such as lack of time and lack of resources). Consequently, advice regarding strategies to overcome barriers to physical activity promotion may need to be tailored to the barriers that are salient to the healthcare professional.

Clearly, healthcare professionals working in oncology are faced with a variety of challenges in promoting regular physical activity to their patients.

However, given the influential role healthcare professionals can play in catalysing the adoption of healthy lifestyle behaviours by patients (McPhail & Schippers, 2012), they are encouraged to provide advice regarding physical activity and nutrition to cancer survivors and to capitalise on the "teachable moment" associated with a cancer diagnosis (Demark-Wahnefried et al., 2005, pg. 5815). Nursing professionals in particular, may have an integral role to play in providing information about and supporting positive lifestyle change among cancer survivors given the regularity with which they see patients (Murphy & Girot, 2013). It has been suggested that patients may be more receptive to health promotion messages from nursing professionals as a result of the relationship developed throughout a patient's cancer journey (Karvinen, McGourty, Parent & Walker, 2012). Ultimately, however, it is important that all healthcare professionals involved in the delivery of patient care are united in their support for the promotion of physical activity and a healthy diet as it has been reported that conflicting messages from healthcare professionals could inhibit successful behaviour change (Murphy & Girot, 2013). Indeed, this was reflected within the current study where 60% of healthcare professionals agreed/strongly agreed that a barrier to referral to community-based exercise programmes was that some patients with cancer may not attend if the decision is not supported by their main care provider, which included their consultant.

Many healthcare professionals have reported not receiving formal education regarding exercise in cancer care during academic training in Ireland (O'Hanlon & Kennedy, 2014). There is a need to develop formal guidelines

regarding physical activity prescription in cancer care in Ireland to direct healthcare professionals when providing physical activity advice to patients (O'Hanlon & Kennedy, 2014). These guidelines need to include detailed information regarding the benefits of physical activity for different cancer diagnoses, precautions for activity and procedures for safety and screening for cancer survivors. The provision of such detailed guidelines would provide support and guidance to healthcare professionals and empower them to integrate physical activity promotion into usual care for every patient. While the development of policy to direct practice within the parameters of the Irish context is required, existing guidelines and recommendations from international organisations can be adopted to guide clinical practice in the interim (Rock et al., 2012; Schmitz et al., 2010). More continuous professional development opportunities are required to provide healthcare professionals with the necessary skills and confidence to prescribe individualised exercise regimes to cancer survivors. This recommendation aligns with The National Physical Activity Plan for Ireland which has identified the provision of training for healthcare professionals regarding the preventative and treatment role of physical activity within health as an action point to be achieved by 2020 (Healthy Ireland, 2016). It also supports the Irish Cancer Society's (2013) strategy to ensure that each individual can make informed decisions about their cancer care based on the provision of appropriate and relevant information.

A multi-component approach is required in order to address the barriers experienced by healthcare professionals to support the integration of physical activity promotion into usual care for all individuals living with and beyond cancer.

Recommendations to address these challenges include the development of formal guidelines in Ireland to direct exercise prescription, increased provision of formal training opportunities for healthcare professionals regarding exercise in cancer care and increased availability of community-based physical activity programmes for healthcare professionals to refer patients to. These recommendations support those proposed in The Toronto Charter for Physical Activity, where key recommendations include investment in physical activity and the integration of physical activity into the primary healthcare setting, with the provision of brief intervention advice and referral to community-based physical activity programmes for individuals who are not sufficiently active (Global Advocacy Council for Physical Activity, 2010).

The majority of the healthcare professionals surveyed in this study acknowledged the value of physical activity for their cancer patients and agreed that discussing physical activity with patients was part of their role. The physical activity guidelines for cancer survivors advocate for the avoidance of inactivity and recommend achieving a minimum of 150 minutes of moderate intensity activity each week plus two strength training sessions that target the major muscle groups (Rock et al., 2012). However, only a minority of the healthcare professionals surveyed provided guidance to patients that align with these guidelines. Healthcare professionals are encouraged to integrate physical activity promotion into usual care for all patients on the cancer journey (Keogh et al., 2017) and there are a number of potential solutions to support the logistical challenges presented by this integration. Schmitz (2011) suggests adopting a structure similar to cardiac

rehabilitation where cancer survivors would receive short-term rehabilitation immediately post-surgery within the in-patient setting, followed by attendance at a supervised out-patient programme and subsequent referral to unsupervised community-based physical activity services. This suggestion to adapt the current model for cardiac and pulmonary rehabilitation to suit the needs of cancer survivors is supported by Alfano, Ganz, Rowland and Hahn (2012). Schmitz (2011) also proposes a model to facilitate the appropriate and safe referral of individuals living with and beyond breast cancer to community-based rehabilitation programmes. A number of European countries including Sweden, Denmark and Germany provide rehabilitative support for cancer survivors (Hellbom et al., 2011). While there are differences between countries in terms of their social security and health-care systems, all programmes share a 'similar, multidimensional and multidisciplinary understanding of cancer rehabilitation' (Hellbom et al., 2011, p. 185). Lessons can be learned from other countries regarding the provision of rehabilitative services for individuals living with and beyond cancer and help shape a more holistic approach to rehabilitation within the Irish context.

#### 3.1.5.1 Strengths and Limitations

To the authors' knowledge, this study is the first to generate a consensus agreement among healthcare professionals working in oncology regarding the optimisation of referral processes to community-based exercise programmes for cancer survivors. Clear, actionable strategies have been presented and can guide new and existing services in optimising the referral pathway to community-based programmes. Streamlining the referral process may encourage more healthcare

professionals to engage in referral and therefore facilitate greater access for individuals living with and beyond cancer to health promotion services. To date, there has been a dearth of research exploring the health promotion practices of healthcare professionals working in oncology and the factors influencing the provision of this information (Keogh et al., 2017), particularly within the Irish context. This study addresses this gap and highlights a number of important issues. These include identifying the need to develop national physical activity guidelines for cancer survivors to guide clinical practice in Ireland, and the need for formal training, as part of undergraduate study and in-service programmes, to support and enable oncology healthcare professionals to prescribe exercise for their patients.

There were a number of limitations within this study. Despite the implementation of strategies to increase response rate, including the formation of the study advisory panel, a low response rate was still observed in round one. However, low response rates have been acknowledged as a limitation of the Delphi method (Hsu & Sandford, 2007). While it is encouraging that the majority of healthcare professionals believed in the value of physical activity for their cancer patients, there may have been a response bias present where only healthcare professionals who had an interest in physical activity for cancer participated in the study. This has also been reported as a limitation for other studies conducted in this area (Keogh et al., 2017). The structure of some of the questions within the survey did not permit detailed statistical analysis of the data.

## 3.1.6 Conclusion

Healthcare professionals can play a central role in motivating cancer survivors to adopt positive lifestyle changes, but may lack the specialist knowledge to provide detailed recommendations for physical activity. Community-based physical activity programmes can help to bridge this gap by providing the necessary expertise that can support individuals living with and beyond cancer to lead physically active, healthier lives. Detailed, pragmatic guidance regarding the optimisation of the referral process to community-based physical activity programmes has been presented and could support greater engagement by healthcare professionals and increased access to physical activity services by individuals living with and beyond cancer. Chapter 4 Study 2

#### 4.1 Study 2

Cantwell, M., Walsh, D., Furlong, B., Loughney, L., McCaffrey, N., Moyna, N., & Woods, C. (2019). Physical activity across the cancer journey: experiences and recommendations from people living with and beyond cancer. *Physical Therapy, (In Press).* 

**Statement of contribution:** Prof. Niall Moyna, Dr. Bróna Furlong, Dr. Deirdre Walsh, Dr. Noel McCaffrey and Prof. Catherine Woods supervised this project, and were involved in the development of the study concept and research design, and in reviewing the manuscript. Dr. Lisa Loughney assisted with data collection.

## 4.1.1 Abstract

The majority of individuals living with and beyond cancer are not sufficiently active to achieve health benefits. The aim of this study was to explore individuals' experiences of physical activity (PA) behaviour across the cancer journey and to ask individuals living with and beyond cancer to identify strategies to support habitual PA. An exploratory, descriptive, qualitative design was used. Purposive sampling methods were used to recruit individuals living with and beyond cancer who had been referred to, and/or participated in, a community-based exercise programme or were attending a cancer support centre. The focus group discussions were audio recorded, transcribed verbatim and analysed using a thematic analysis approach. Seven focus groups were conducted with 41 participants. Many individuals reported that regular PA provided a vehicle for recovery which created a sense of 'self-power'- defined as taking ownership and control of one's health to increase well-being. Barriers to PA participation included environmental-, patient- and

treatment-related challenges. Recommendations to support long-term adherence to PA included completion of fitness assessments at regular intervals and provision of a home-exercise programme. The benefits and barriers to PA participation for individuals diagnosed with cancers that were not represented may not have been identified. The strategies recommended to support habitual PA may only be salient to individuals whose cancer diagnoses were represented. Exercise is seen as a vehicle for recovery from cancer but long-term adherence for individuals is complex. The findings from this study can inform the development of exercise oncology rehabilitation programmes and could support a greater likelihood of programme success, and thereby optimise the health, well-being and quality of life of survivors of cancer.

*Keywords:* Physical activity, adherence, cancer, qualitative research

#### 4.1.2 Introduction

Exercise is strongly advocated as a targeted rehabilitative intervention in standard cancer care given its ability to increase indices of physical well-being, ameliorate many of the negative physical and psychological effects of cancer and/or its treatment, and reduce the risk of cancer recurrence and mortality (Cormie et al., 2018; Lakoski, Eves, Douglas & Jones, 2012; Meneses-Echávez, González-Jiménez & Ramírez-Valez, 2015; Rock et al., 2012; Schmitz et al., 2010; Segal et al., 2017; Spence, Heesch & Brown, 2010). The majority of individuals living with and beyond cancer are not sufficiently active to achieve health benefits (Bourke et al., 2013; LeMasters, Madhavan, Sambamoorthi & Kurian, 2014; Liu et al., 2016; Turner et al., 2018). To date, few studies have demonstrated effectiveness in increasing the long-

term physical activity (PA) levels of this population (Bourke et al., 2013; Turner et al., 2018; Williams, Steptoe & Wardle, 2013). The absence of a theoretical basis, a lack of clarity regarding the application of behaviour change theory and/or poor integration of behaviour change techniques (BCTs) may have contributed to the absence of effective strategies and programmes to support habitual PA among survivors of cancer (Turner et al., 2018). The development of effective PA behaviour change (BC) interventions for individuals living with and beyond cancer is a priority (Bourke et al., 2013; Courneya, Rogers, Campbell, Vallance & Friedenreich, 2015; Turner et al., 2018; Williams, Steptoe & Wardle, 2013). Exploring the individual cancer experience in order to more fully understand user needs and developing recommendations from survivors of cancer regarding strategies to support long-term PA adherence could facilitate the identification of meaningful components that should be targeted within such interventions and optimise the likelihood of intervention success.

Qualitative research methods can provide valuable insight and greater detail regarding individuals' experiences and behaviour than can be captured by quantitative means (Malterud, 2001). Conducting such qualitative explorations is essential to understand how to support individuals living with and beyond cancer to adopt or maintain habitual PA participation and is therefore considered a fundamental part of the intervention development process (Craig et al., 2008; Yardley, Morrison, Bradbury & Muller, 2015). Adoption of a person-based approach provides intervention designers with a definitive and systematic process for exploring and understanding the attitudes, needs and circumstances of intervention

end-users to assist in the identification of acceptable, feasible and salient intervention components (Yardley, Morrison, Bradbury & Muller, 2015).

Recent meta-syntheses of qualitative research have reported that participation in PA during and after cancer treatment was associated with physical, psychological, social and spiritual benefits including the ability of exercise to enhance physical recovery, affirm health status and restore a sense of structure and purpose to everyday life (Burke et al., 2017; Midtgaard et al., 2015). Barriers that limit PA participation have also been identified and include ill health, fatigue, pain, social isolation and concerns regarding the safety of exercise (Blaney, Lowe-Strong, Rankin-Watt, Campbell & Gracey, 2013; Henriksson, Arving, Johansson, Ingelström & Nordin, 2015; Keogh, Patel, MacLeod & Masters, 2014; Ottenbacher et al., 2011; Smith et al., 2017). A number of gaps are still apparent in understanding individual experiences of PA throughout the cancer journey (Burke et al., 2017, Emslie et al., 2007). Research in this area has been limited by a narrow scope of investigation and prioritising the use of quantitative methods (Burke et al., 2017, Emslie et al., 2007). Much of the qualitative research has reported on the experiences of middle aged women following treatment for breast cancer (Burke et al., 2017). There is a need to examine the experiences of PA throughout the cancer journey among other cohorts, including men, younger and elderly survivors of cancer and individuals on a palliative treatment pathway (Burke et al., 2017).

The purpose of this study was to: i) explore individuals' experiences of PA behaviour across the cancer journey, and ii) ask individuals living with and beyond cancer to identify strategies to support habitual PA. The information generated was

used to create new knowledge regarding how to support PA participation among survivors of cancer.

## 4.1.3 Methods

## 4.1.3.1 Design

An exploratory, descriptive qualitative research design was adopted. Focus groups were selected as the method for data collection to capture a broad range of opinions and experiences.

#### Participants

Adults ≥ 18 years of age who had a diagnosis of cancer and completed their adjunctive therapy (e.g. chemotherapy, radiation therapy) were recruited from a cancer support centre and a community-based exercise rehabilitation programme (CBERP) that offers 12-weeks of twice-weekly supervised exercise classes to individuals who have completed cancer treatment. The programme aims to optimise participants' physical and psycho-social well-being. The classes are delivered by exercise instructors accredited by the British Association of Cardiac and Pulmonary Rehabilitation who have experience in delivering exercise oncology rehabilitation programmes. Classes focus on a combination of aerobic and resistance exercise.

Purposive sampling methods were used to recruit male and female survivors of cancer who were either currently physically active or inactive. Participants PA status was categorised using the PA screening questionnaire outlined in the

National Exercise Referral Framework (Woods et al., 2016). The questionnaire determines whether individuals are meeting the recommended PA guidelines as outlined by the Department of Health and Children (2011) and assesses individuals' readiness to change their behaviour according to statements regarding PA participation (e.g. I am not regularly physically active and do not intend to be in the next 6 months).

Individuals recruited from the cancer support centre participated in the same focus group. Individuals recruited from the CBERP were allocated to a focus group depending on their level of engagement with the programme and their current level of PA (Table 4.1). Ethical approval for this study was granted by the Dublin City University Research Ethics Committee (DCUREC2015203).

		No. of Participants	Current PA level	Engagement with a community- based exercise programme
Focus	Group	4	Active	Currently attending
Focus	Group	8	Active	Currently attending
Focus	Group	6	Inactive	Graduated
Focus	Group	7	Active	Graduated
Focus	Group	7	Both	Never referred
Focus	Group	4	Inactive	Non-uptakers*
Focus	Group	5	Both	Dropped out

Table 4.1. Focus group characteristics

\*denotes definition of non-uptakers: individuals who attended an assessment for a community-based exercise programme but did not join the programme.

Abbreviations: PA (physical activity)

#### 4.1.3.2 Measures

### Questionnaire

Prior to the focus group, participants completed an investigator-developed questionnaire which included questions regarding participants' demographic information and preferences for PA. The development of the questionnaire was informed by results from a review of the literature which identified strategies that had been implemented within PA BC interventions for survivors of cancer to optimise PA participation (e.g. face-to-face counselling regarding PA, text messaging support for PA participation). Nine strategies were included in the questionnaire and participants were asked to rank the top 3 strategies that would be most beneficial to include within an exercise programme and support regular PA participation. Additional information about each strategy was provided during the focus groups (Appendix A).

#### Semi-structured Interview Guides

Semi-structured interview guides were developed using The Behaviour Change Wheel's COM-B model (Michie, van Stralen & West, 2011) to guide the focus group discussions. Topics focusing on individuals' capability, opportunity and motivation to be regularly physically active were included within the interview guide, including: individual experiences of PA across the cancer journey, benefits of, and challenges to, PA participation, discussion of participants' responses to the investigator developed questionnaire and strategies to support habitual PA participation. The application of the COM-B model in the development of the interview guides provided a useful approach for the identification of factors associated with PA participation for survivors of cancer that may explain behaviour across a number of components (e.g. physical capability, social opportunity) (Rubinstein, Marcu, Yardley & Michie, 2015). Discussions were not limited to these areas and this provided opportunities for the exploration of additional topics, related to PA participation, that were highlighted by focus group participants.

Examples of questions generated from the COM-B model (Michie, van Stralen & West, 2011) are presented in Appendix B.

## 4.1.3.3 Data Collection

Focus groups were conducted and digitally recorded by trained qualitative researchers (MC, LL) until data saturation was reached. An assistant moderator recorded observations from the focus groups and summarised key points in a written log. Each focus group lasted between 50 and 90 minutes. Focus groups were conducted in the cancer support centre, where participants were recruited from, or on a University campus, where the CBERP was located.

## 4.1.3.4 Data Analysis

NVivo qualitative data analysis software (version 10) for Windows was used. All transcripts and paper-based questionnaires were imported into NVivo to enable an integrated analysis of the data. The focus group discussions were transcribed verbatim by a research team member (MC) and analysed using the six-step approach to thematic analysis outlined by Braun and Clarke (2006). An inductive approach to the identification of themes was adopted. Phase one of the analysis involved reading all transcripts a number of times to gain an initial insight into the data and to explore initial codes and themes. Phase two involved coding interesting features within the data in a systematic way across all transcripts. Efforts were made to: i) code for as many themes as possible, ii) include surrounding text for key extracts to provide context and iii) actively look for deviant cases within the data. In phase three of the analysis, codes and all other relevant data were collated into potential themes. Phase four was conducted in two parts.

Firstly, all coded extracts within each potential theme were reviewed to determine coherency within the data. Secondly, themes were reviewed within the context of the entire data set to ensure that the themes identified reflected the experiences and opinions of focus group participants as a whole. At the end of phase four, thematic maps were developed which outlined key themes and the relationship between these themes. Phase five of the analysis involved the refinement and defining of themes. A semantic level of qualitative inquiry was conducted in order to provide a rich, overall description of the data as explicitly described by participants. This analysis was further developed to examine underlying ideas and to theorize the significance of the patterns identified and their implications for intervention design. The identification of such latent themes facilitated the development of recommendations to inform future PA BC interventions. The final phase of the analysis involved the development of a written report, which provided a detailed account of the findings. A detailed logbook was kept throughout the analysis to document analytic decisions and changes in the coding process. Quality checks to ensure the validity of the findings included testing conclusions by returning to the data to assess the evidence and searching for data that supported alternative explanations. Key themes that were highlighted by focus group participants to support habitual PA and adherence to CBERP, and the top 3 strategies identified within the investigator developed questionnaire, were labelled as recommendations and are presented in Table 4.3. In a subsequent investigation, conducted upon completion of the current study, we viewed our inductive qualitative findings through a COM-B lens to inform the development of a PA behaviour change intervention for survivors of cancer.

## 4.1.4 Results (\* Please see Appendix C for additional results)

Forty-one individuals living with and beyond cancer were recruited and 7 focus groups consisting of 4-8 participants were conducted. Two participants were receiving on-going treatment for advanced prostate cancer. All other participants were in the survivorship phase of the cancer journey. Focus group characteristics are presented in Table 4.1. Participants' demographic information is presented in Table 4.2.

	% (n)
Gender	
Male	44 (18)
Female	56 (23)
Cancer Diagnosis	
Breast	41 (17)
Prostate	27 (11)
Colorectal	20 (8)
Lung	5 (2)
Cervical	2 (1)
Melanoma	2 (1)
Leukaemia	2 (1)
Age (yr)	
31-40	2 (1)
41-50	15 (6)
51-60	51 (21)
61-70	17 (7)
>71	15 (6)

Table 4.2. Participant demographic information.

## 4.1.4.1 Physical Activity and the Cancer Journey

## 4.1.4.1.1 Patterns of Physical Activity Across the Cancer Journey

## Physical Activity Levels Prior to Cancer Diagnosis and During Treatment

Participants reported their PA level prior to their cancer diagnosis when responding to an open question phrased by the researcher conducting the focus group. Advancing age was recognised by some as a contributing factor to gradual declines in PA levels over time. During diagnosis and treatment individuals reported a decrease in their PA as a result of side effects from treatment and the emotional and mental stress of coping with cancer. Participants reported that it wasn't possible to be active as treatment procedures were aggressive and many felt too ill to consider being physically active.

"When I got the treatment I just couldn't do anything because my treatment was very aggressive, I had a lot of chemo and a lot of radiotherapy and it was just, it was not even up for discussion, I couldn't do anything" (FG1, ID04, 60 year old survivor of breast cancer).

A minority of participants reported maintaining light-intensity activity, predominantly walking, during treatment.

#### Physical Activity Levels following Cancer Treatment Completion

The importance of having a period of recuperation following treatment completion before engaging in an exercise rehabilitation programme was highlighted. Participants reported a number of different experiences of PA following completion of cancer treatment. Some individuals found it difficult to be active as a result of treatment-related side effects and pre-existing medical conditions, while other participants were motivated by their cancer diagnosis to improve their health and increased their PA levels. Two different experiences were identified by individuals who participated in an exercise rehabilitation programme following treatment. Many participants reported increases in their levels of PA as a result of participating in an exercise programme, which were maintained following programme completion. Other participants reported increasing their PA levels while attending an exercise programme, which was followed by a return to previously lower levels of activity after completion of the programme.

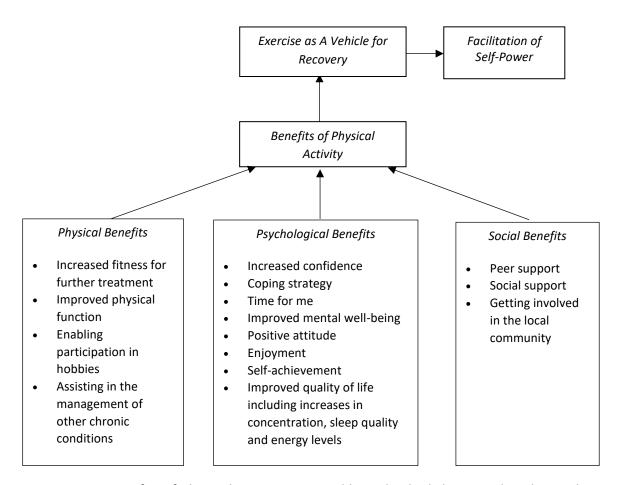


Figure 4.1 provides a summary of the benefits of PA reported by participants.

Figure 4.1. Benefits of physical activity reported by individuals living with or beyond cancer.

Benefits included improvements related to physical (e.g. physical function and quality of life) and psycho-social well-being (e.g. mental well-being and confidence, positive attitude and sense of self-achievement). The combined benefits resulted in many individuals viewing exercise as a vehicle for recovery as it facilitated 'self-power' - whereby participants took ownership and control of their PA to increase well-being. For many individuals, this was associated with increases in self-confidence and belief in physical capabilities. PA assisted in the transition from 'cancer patient' to 'cancer survivor' and provided individuals with a medium through which they could learn what their physical capabilities were.

"When you get into the cycle of exercise you think, well you've been fed a bit of information, information is power...I can do this for myself...You know, you're reclaiming a bit of yourself... and it does, it really motivates you" (FG1, ID01, 59 year old survivor of breast cancer).

Individuals who had participated in a community-based exercise programme for survivors of cancer reported that the social and peer support they received by exercising within the group environment was very beneficial. Exercising with others who had shared similar experiences created an accepting and supportive environment for exercise where participants did not feel self-conscious.

*"I love the support, I feel just the general, general support of being part of a group of people who you all understand. We all know what every one of us is going through" (FG2, ID07, 58 year old male survivor of colorectal cancer).* 

Other reported benefits of PA included that it: i) provided a strategy to cope with cancer, and time to focus on one's health and well-being, ii) increased fitness for further treatment, iii) assisted in the management of other chronic conditions (i.e. osteoporosis, depression and musculoskeletal conditions), and iv) provided opportunities to take part in hobbies and to engage with others in the community through PA.

# 4.1.4.1.3 Challenges to Physical Activity Participation

Figure 4.2 provides a summary of the challenges to PA participation reported by focus group participants that were categorised as environmental-, patient- and treatment-related barriers.

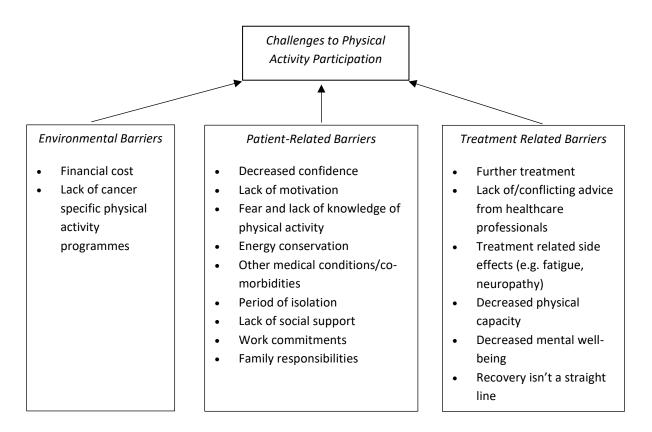


Figure 4.2. Challenges to physical activity participation reported by individuals living with or beyond cancer.

# 4.1.4.1.4 Period of Isolation

Many individuals reported experiencing a period of isolation following treatment completion. As a result of reduced contact with treatment centres and a lack of direction regarding how to recover following cancer treatment, many participants reported a decrease in their physical and psycho-social well-being. This was viewed as a gap in the cancer care pathway and many participants reported the lack of cancer-specific PA programmes available at this time, and voiced the need for a holistic approach to rehabilitation after treatment completion.

"Then suddenly you're discharged and you're out on your own. I was in absolute limbo...you're just in a very lonely place to cope with all this" (FG7, ID45, 61 year old survivor of breast cancer).

For many individuals, this period of isolation was compounded by decreased physical fitness following cancer treatment and reduced confidence in physical capabilities. For some participants, this led to a fear of PA. Many individuals were unsure what types of activity were safe for them to participate in and what intensity of activity was suitable.

"You don't know what you can do because you feel, you get an ache or I don't know, or you've a pain...and you're saying 'Aw dear God, what's the pain from...'" (FG3, ID15, 50 year old survivor of breast cancer).

### 4.1.4.1.5 Other Challenges to Physical Activity Participation

Participants felt that their expectations of the recovery journey and the reality of it did not align. One participant commented: *"Where I was after 2 years is where I thought I'd be after a year. I'm talking about every way – I'm talking about emotionally, physically, every way" (FG7, ID43, 53 year old survivor of breast cancer).* 

Fatigue dictated many participants' energy levels and was variable in its presentation. Individuals also reported the need to learn how to manage treatment related side effects (e.g. fatigue, neuropathy, bone pain). These factors impeded participants' recovery, quality of life and PA participation. Individuals found it challenging and frustrating to adapt to daily fluctuations in energy levels.

"You've had to adapt to a new way of living, and coping, that's not the same as it was before. Because you can't, that's not going to work, it's a different formula, it won't fit. So the formula has changed...it's difficult to try and re-adjust then" (FG7, ID44, 52 year old female survivor of acute myeloid leukemia).

Many individuals felt that their physical capacity had changed as a result of their cancer treatment and that they, and their families, needed to adapt accordingly. The acceptance of the 'new' version of oneself was challenging.

"Do you know what, that's a big thing to accept that the old you isn't there any more...you have to learn to accept the new you for what you are and your limitations" (FG4, ID24, 53 year old survivor of breast cancer).

Work and family responsibilities as well as activities of daily life also presented challenges to PA participation. Some individuals referred to a need to conserve their energy for recovery and activities of daily living (e.g. cooking, cleaning).

Other significant challenges to PA participation included: i) a lack of social support for PA, ii) prioritising family responsibilities over one's health and wellbeing, iii) treatment-related side effects, including fatigue, neuropathy, lymphedema, weight gain, poor balance and memory and concentration problems, iv) the financial cost associated with some forms of PA and v) further medical treatment.

## 4.1.4.2 The Role of the Healthcare Professional

Participants viewed healthcare professionals (e.g. medical oncologists, nurses, physiotherapists, psycho-oncologists) as credible and important sources of information. For some participants, recommendations from healthcare professionals had a significant impact on individuals' decision to be physically active. However, the lack of suitable advice and/or conflicting information from healthcare professionals regarding PA was reported by many participants. It was reported that healthcare professionals' concerns for PA participation focused on issues relating to immune compromise and safety, particularly during treatment. This further compounded some individuals' fears for being active during their cancer journey.

"You were told what you couldn't do" (FG5, ID31, 67 year old male survivor of colorectal cancer).

Some participants reported that advice and recommendations received from healthcare professionals acted as a motivator for the adoption of positive lifestyle changes with regard to PA and nutrition. For some individuals who attended an exercise rehabilitation programme after treatment completion, they expressed an "if I knew then, what I know now" attitude towards PA. Participants felt they would have made a greater effort to engage in PA, both during and after treatment, had they been made aware of its importance at the time.

"I probably wouldn't have felt well enough to do exercise until after the treatment...But I think had I been told in time, the benefit of it, I would have pushed myself further" (FG1, ID01, 59 year old survivor of breast cancer).

# 4.1.4.3 Cancer Survivors' Preferences and Recommendations for Physical Activity

Appendix D provides a table of results from the questionnaire completed by participants regarding their preferences for PA. Aerobic, flexibility and strengthening exercises were the most popular (90, 68, 66%), followed by pilates, circuit training, swimming and step aerobics (37, 17, 15, 12%). Yoga, aqua aerobics and horse riding received limited support (<7%). Two participants reported having no preferences for PA.

The items reported by participants as being the most beneficial to include within an exercise rehabilitation programme and support habitual PA participation are summarised in Appendix E. Follow-up exercise testing was the most popular strategy to optimise PA participation (71%) and was defined as completing field-

based tests that measure different components of fitness (e.g. CRF, lower body strength, flexibility) at the start of an exercise rehabilitation programme and after 3, 6 and 12 months. As part of this process, participants would receive feedback reports detailing changes in their fitness over time. An exercise-how-to guide, defined as the provision of a home-based exercise programme to supplement attendance at supervised exercise classes as part of an exercise rehabilitation programme, was the second most popular strategy (68%). The third most popular strategy was face-to-face counselling from exercise specialists regarding PA (44%), which was defined as attending educational sessions delivered by PA experts regarding the benefits of PA and strategies to incorporate PA into everyday life.

Participants identified other key components that are important to support habitual PA and adherence to community-based exercise programmes. Table 4.3 provides a summary of these recommendations. Table 4.3. Summary of recommendations from focus group participants for strategies to support habitual physical activity and adherence to community-based exercise programmes for individuals living with and beyond cancer.

Recommendation	Rationale
Individualised exercise	It is important to provide information to guide individualised exercise prescription within a group
prescription	setting. This enables individuals to learn how to tailor their physical activity to their personal
	exercise goals. For example: Survivors of prostate cancer are interested in learning more about
	core strength and pelvic floor exercises while survivors of breast cancer are interested in
	learning more about exercises to increase their upper body muscle strength and shoulder range
	of motion.
Exercising as part of a group of	Exercising with others who have shared similar experiences creates an accepting and supportive
individuals who have	environment for exercise where participants do not feel self-conscious. Exercising as part of a
completed treatment for	group provides comradery and generates increased motivation and confidence for physical
cancer	activity. Participants value the social and peer support they receive from the group.
Goal setting and action	Setting meaningful goals for physical activity is important. Developing an individualised action
planning	plan for physical activity is also fundamental to long term physical activity adherence.

Quantifying and measuring	Quantifying and measuring physical activity is important for feedback and to provide continued
physical activity	motivation for physical activity participation.

Information regarding	Receiving additional information about other health behaviours (e.g. healthy eating, smoking
additional health behaviours	cessation, alcohol consumption and stress management) is appealing to some participants. For
	those who were interested, nutrition and stress management are the two most popular topics.

Supervised exercise classes and	Participating in both supervised exercise classes and a home-based exercise programme is
a home-based exercise	appealing. The supervised classes increase confidence to be active while the home programme
programme	can guide independent physical activity.

Fitness Assessments Intermittent fitness assessments can track progress ar	nd provide motivation for physical activity
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Face-to-face counselling from	Individuals are interested in receiving face-to-face counselling from exercise specialists regarding
exercise specialists regarding	physical activity to learn about the benefits of physical activity and address concerns regarding
physical activity	physical activity participation following cancer treatment (e.g. advice for physical activity for
	individuals who have fatigue, neuropathy, lymphoedema, bone pain).

## 4.1.5 Discussion

To the author's knowledge, this study is the first to qualitatively document the PA experiences of a large, diverse group of individuals living with and beyond cancer and their recommendations regarding strategies to support habitual PA and adherence to community-based exercise programmes. There is a need to obtain a better understanding of the most effective way to support survivors of cancer to be habitually physically active in order to increase the number of individuals experiencing the benefits associated with PA (Courneya, Rogers, Campbell, Vallance & Friedenreich, 2015). Our findings contribute to further develop this understanding and provide tangible strategies that could be implemented to support long-term PA adherence among individuals living with and beyond cancer.

Our findings show that exercise was viewed by many participants as a vehicle for recovery as it empowered ownership of health to improve physical function and psycho-social well-being. This current work extends a recent meta-synthesis finding, which reported that participation in exercise-based cancer rehabilitation provided individuals with a means to redefine themselves as physically fit, affirm health status and enhance physical performance (Midtgaard et al., 2015), by illuminating this concept qualitatively within this diverse population.

The results from the current investigation also highlight the period of isolation, and associated decreases in physical and psycho-social well-being, that was experienced by many individuals following cancer treatment completion. These findings are supported by previous investigations where concerns regarding the loss of support and reassurance from hospital staff, in addition to fatigue management,

were rated as the most common issues surrounding treatment completion by survivors of cancer, who also reported feelings of isolation, vulnerability and alienation (Department of Health, 2017; Jefford et al., 2008).

The findings from this investigation contribute to the literature exploring the challenges faced by survivors of cancer in the context of PA participation. To address the period of isolation and associated decreases in well-being reported by participants in the post-treatment period, the current study strongly re-iterates the urgent need for holistic rehabilitation programmes within cancer care, that provide nutritional, PA and psycho-social support and assist in the optimisation of patient health outcomes (Cormie et al., 2018).

Similar findings regarding the decrease in PA levels following cancer diagnosis and treatment experienced by individuals in this study have been reported by Fernandez et al. (2015), who found that two thirds of individuals reduced their exercise levels during cancer treatment and Irwin et al. (2003), who found that individuals experienced a significant decrease in their PA levels following a breast cancer diagnosis. In the current investigation barriers were identified which contributed to reduced PA participation including environmental- (e.g. lack of cancer specific PA programmes), treatment- (e.g. treatment related side effects e.g. fatigue) and patient-related barriers (e.g. lack of motivation). Similar findings regarding barriers to exercise participation have been reported (Blaney et al., 2010; Blaney, Lowe-Strong, Rankin-Watt, Campbell & Gracey, 2013, Ottenbacher et al., 2011). Recommendations outlined by participants in this study could address many of the barriers reported and support greater PA participation by individuals living

with and beyond cancer. Follow-up exercise testing, combined with the provision of feedback regarding physical function and well-being, could increase participants' confidence to be active and provide a source of continued motivation. An exercisehow-to guide and face-to-face counselling regarding PA could address the 'fear and lack of knowledge of PA' barrier by educating participants about the benefits of exercise, providing examples of aerobic and resistance exercises and providing strategies to support long-term adherence to PA. The exercise-how-to guide would also provide participants with a resource for PA that could support greater freedom, enabling participants to exercise at home, at a time that suits them, and could therefore address the barriers of work and family commitments. Interestingly, a number of the strategies to support long-term adherence to PA that were highlighted by participants in this study, including goal setting and the provision of both supervised and home-based PA programmes, were associated with greater adherence and a higher percentage of participants meeting the recommended PA guidelines in a recent Cochrane review of interventions that promote habitual PA to individuals living with and beyond cancer (Turner et al., 2018).

The results of the present study support previous research indicating the important role of healthcare professionals as powerful motivators for initiating positive lifestyle changes among patients (McPhail & Schippers, 2012). The findings also highlight the negative impact that concerns regarding the safety of exercise can have on an individual's decision to be active during the cancer journey. All members of the multidisciplinary cancer team should promote PA (Cormie et al., 2018), and

capitalise on the teachable moment described by Demark-Wahnefried and colleagues (Demark-Wahnefried, Aziz, Rowland & Pinto, 2005). Referral to an exercise specialist (e.g. accredited exercise physiologist, physiotherapist) with experience in cancer care is considered best practice as such health professionals possess the necessary expertise to provide detailed exercise prescription that is tailored to individuals' needs and abilities (Cormie et al., 2018). Healthcare professionals have reported a number of barriers to the promotion of PA to patients with a cancer diagnosis including limited time with patients and a lack of CBERPs to refer patients to (Cantwell et al., 2018). We have advocated for a multicomponent approach, including the provision of formal training opportunities on the role of exercise in cancer care for oncology healthcare professionals, to address the barriers reported and support the integration of PA promotion into standard care for every patient with a cancer diagnosis (Cantwell et al., 2018).

Participation in CBERPs for individuals living with and beyond cancer is associated with a myriad of benefits including the optimisation of physical, psychosocial and functional well-being (Cheifetz et al., 2014; Knobf, Thompson, Fennie & Erdos, 2014; Santa Mina et al., 2017). Such programmes support sustainability and accessibility to PA services for survivors of cancer and offer access to exercise specialists with expertise in exercise science and oncology (e.g. exercise physiologists, physiotherapists) who can provide survivors of cancer with an individually tailored exercise programme aimed at optimising individuals' well-being and quality of life (Santa Mina et al., 2017). The findings presented in the current investigation provide valuable information regarding salient strategies to support

habitual PA among individuals living with and beyond cancer that could be integrated within CBERPs to optimise the effectiveness of such services.

## 4.1.5.1 Strengths and Limitations

A limitation of previous qualitative research is that the majority of studies have focused on capturing the experiences of post-treatment survivors of breast cancer (Burke et al., 2017), with few investigations exploring the barriers to PA participation facing other cohorts of individuals living with and beyond cancer. A strength of the current investigation was the recruitment of survivors with different cancer diagnoses, of all ages, who reported varying levels, and stages of participation (e.g. pre-initiation, initiation, maintenance) across different types of PA (e.g. home-based/independent PA, participation in a community-based exercise programme). This approach ensured that a broad range of opinions and experiences of PA throughout the cancer journey could be captured, and thus contribute to the existing scientific literature by providing an understanding of the challenges facing other cancer survivor cohorts, including those who have had a previous prostate, colorectal or lung cancer diagnosis. The inclusion of patients as active partners in the development, implementation and evaluation of research studies is becoming increasingly recognised (Johnson, Bush, Brandzel & Wernli, 2016). Involving patients in all aspect of a study can help to ensure that the research is relevant, meaningful and of benefit to the intended population (Johnson, Bush, Brandzel & Wernli, 2016). In subsequent research, following inductive analysis of the data, the COM-B model was then applied as an interpretative framework to inform the development of the PA BC intervention for

survivors of cancer. The resultant intervention is being implemented and its effectiveness in supporting habitual PA is being evaluated.

For many participants, their experience of PA throughout the cancer journey was affected by cancer type and treatment modality. Therefore, the benefits and barriers of PA participation for individuals diagnosed with cancers that were not represented may not have been identified. Similarly, the strategies recommended to support regular PA participation could address the challenges reported by the survivorship cohorts who participated within this study, but may not be as effective for individuals with a cancer diagnosis that was not represented.

# 4.1.6 Conclusion

Many individuals living with and beyond cancer viewed exercise as a vehicle for recovery, and a means through which they could optimise their physical and psychosocial well-being. The cancer experience can also present a number of unique challenges that negatively impact PA participation. The valuable insights regarding the benefits and barriers to PA participation and the recommendations to support habitual PA can inform future research and assist in the development of PA BC interventions and CBERPs for this population. These user-centred interventions underpinned by theory have the potential of increasing the likelihood of intervention success and thereby optimise the health, well-being and quality of life of survivors of cancer.

Chapter 5 Study 3

#### 5.1 Study 3

Cantwell, M., Walsh, D., Furlong, B., Moyna, N., McCaffrey, N., & Woods, C.
(2019). The development of the MedEx IMPACT intervention: a patient-centred, evidenced-based and theoretically informed physical activity behaviour change intervention for individuals living with and beyond cancer. *Under Review.*

**Statement of contribution:** Prof. Niall Moyna, Dr. Bróna Furlong, Dr. Deirdre Walsh, Dr. Noel McCaffrey and Prof. Catherine Woods supervised this project, and were involved in the development of the study concept and research design, and in reviewing the manuscript.

### 5.1.1 Abstract

Regular physical activity (PA) can address many of the negative side-effects experienced by individuals following cancer treatment and support the optimisation of physical and psycho-social well-being. However, many survivors of cancer are not sufficiently active to achieve these health benefits. The purpose of this study was to describe the development of a PA behaviour change (BC) intervention, MedEx IMPACT (IMprove Physical Activity after Cancer Treatment), which aims to increase cancer survivors' PA levels. A review of the literature and focus groups with survivors of cancer were conducted in order to generate recommendations to inform the intervention development process. This process was guided and informed by: i) the Medical Research Council's (MRC) framework for the development, evaluation and implementation of complex interventions, ii) the Behaviour Change Wheel (BCW), and iii) the Theoretical Domains Framework (TDF). Recommendations for strategies to support habitual PA and adherence to community-based exercise programmes, generated by survivors of cancer who

participated in 7 focus groups (n=41), were synthesised with 13 statements of findings that were generated from 10 studies included within the review of the literature. Detailed mapping exercises are presented which outline the link between these sources, the MRC framework, the BCW and TDF, and the intervention content. The MedEx IMPACT intervention is the first PA BC intervention for survivors of cancer to be developed through the application of the MRC framework, BCW and TDF. The next phase in this research is to test the acceptability and effectiveness of MedEx IMPACT.

## Key words: physical activity, behaviour change, intervention, cancer

#### 5.1.2 Introduction

Advances in the screening, diagnosis and treatment of cancer have contributed to significant increases in the number of individuals living with and beyond the condition (Cormie, Zopf, Zhang & Schmitz, 2017). Prevalence estimates from the World Health Organisation (WHO) indicate that globally, there are 32.6 million people alive who had a cancer diagnosis in the previous 5 years (WHO, 2014). The long-term and latent effects of cancer and its treatment can pose a number of challenges for survivors including reductions in physical function and quality of life, the presence of cancer-related fatigue, increased risk of cancer morbidity and mortality and increased risk for the development of other chronic conditions (e.g. CVD, osteoporosis) (Keogh, Patel, MacLeod & Masters, 2013; McMillan & Newhouse, 2010; Miller et al., 2016; Schmitz, Speck, Rye, DiSipio & Hayes, 2012; Zamorano et al., 2016).

To assist in addressing many of these negative consequences and to support the optimisation of physical and psycho-social well-being, the inclusion of exercise as an adjunct to cancer treatment has been advocated (Cormie et al., 2018; Hayes, Johansson, Alfano & Schmitz, 2011). This is important in light of the fact that the majority of individuals living with and beyond cancer are not sufficiently active to achieve the health benefits associated with regular exercise (Bourke et al., 2013; LeMasters, Madhavan, Sambamoorthi & Kurian, 2014; Liu et al., 2016; Turner et al., 2018).

While the benefits of physical activity (PA) and exercise throughout the cancer journey have been well documented (Meneses-Echávez, González-Jiménez & Ramírez-Valez, 2015; Rock et al., 2012; Schmitz et al., 2010; Spence, Heesch & Brown, 2010), there is a dearth of evidence demonstrating the effectiveness of existing exercise interventions to support sedentary individuals living with and beyond cancer to meet the recommended PA guidelines (Bourke et al., 2013; Turner et al., 2018). The need to identify the most effective methods to support survivors of cancer to increase and achieve long-term adherence to PA was highlighted in a recent publication which proposed the top 10 research questions for the field of PA and cancer survivorship (Courneya, Rogers, Campbell, Vallance & Friedenreich, 2015). Most of the available evidence regarding adherence to PA among individuals living with and beyond cancer is drawn from studies with shortterm interventions (<12 weeks) and follow-up (3-6 months) (Lahart, Metsios, Nevill & Carmichael, 2018; Turner et al., 2018). As a result, the long-term impact of interventions remains unclear (Groen, van Harten & Vallance, 2018; Turner et al.,

2018). In addition, many studies have used self-report measures to assess PA levels, which can be subject to multifarious bias (Bourke et al., 2013; Turner et al., 2018).

Theoretically informed interventions enhance the effectiveness of behaviour change (BC) components (Bluethmann, Bartholomew, Murphy & Vernon, 2017; Michie et al., 2005), as the relation between constructs, that are predictive of BC, can be understood, translated into intervention content and then examined for an explanation of how an intervention achieved, or not, its desired outcome (Keller, Fleury, Sidani & Ainsworth, 2009). The use of theory and the level of detail regarding its application within intervention design studies varies widely (Bluethmann, Bartholomew, Murphy & Vernon, 2017; Wallace, Brown & Hilton, 2014). Consequently, assessing the intensity of theory application and its impact on BC can be difficult (Bluethmann, Bartholomew, Murphy & Vernon, 2017; Wallace, Brown & Hilton, 2014). In a recent Cochrane review of interventions for promoting habitual exercise in people living with and beyond cancer, an analysis by BC theory and outcome was not possible given that only a minority of trials had stated a theoretical basis for their intervention (Turner et al., 2018). The Medical Research Council's (MRC) framework for the development, implementation and evaluation of complex interventions was designed to assist researchers in adopting suitable methodologies (Craig et al., 2008). According to the framework, within the development phase of complex interventions, researchers should identify the existing evidence for the topic under discussion (i.e. review the existing literature) in order to gain an in-depth understanding of the problem, and subsequently

identify relevant theory to inform the intervention development process (Craig et al., 2008).

To address the limitations of existing theoretical frameworks, the Behaviour Change Wheel (BCW) was developed (Michie, Atkins & West, 2014; Michie, van Stralen & West, 2011). The BCW provides a comprehensive and systematic approach to intervention design (Michie, Atkins & West, 2014; Michie, van Stralen & West, 2011). Its purpose is to synthesise BC theory and scientific evidence to promote a systematic and comprehensive analysis of all available options for an intervention (Cane, O'Connor & Michie, 2012; Michie, Atkins & West, 2014). Through this application of behavioural science, it aims to ensure that intervention components act synergistically (Cane, O'Connor & Michie, 2012; Michie, Atkins & West, 2014). This approach supports intervention designers to make the best use of the understanding of the target behaviour and the resources available in order to arrive at a particular strategy (West & Michie, 2015).

Details of the BCW and its method of application are described elsewhere (Michie, Atkins & West, 2014). In short, at the centre of the BCW is the COM-B model, which focuses on how an individual's capability, opportunity and motivation interact to influence behaviour. The COM-B model is used to perform a behavioural diagnosis to assist in the identification of a target behaviour for an intervention. Intervention designers then select which intervention functions to implement in order to support performance of the target behaviour by the intended population. Each intervention function can in turn be linked with behaviour change techniques (BCTs) which are specific strategies, embedded within an intervention, designed to

change behaviour (Michie, Atkins & West, 2014). As part of the BCW method, intervention designers are encouraged to apply the Theoretical Domains Framework (TDF) (Cane, O'Connor & Michie, 2012; Michie, Atkins & West, 2014). This framework assists in further subdividing the factors identified in the COM-B behavioural diagnosis into 14 theoretical domains (e.g. knowledge, skills, goals). The TDF provides comprehensive coverage of the possible influences on the target behaviour and can address implementation problems by linking theories of BC with techniques of BC (Cane, O'Connor & Michie, 2012). Further details of the TDF are described elsewhere (Cane, O'Connor & Michie, 2012; French et al., 2012).

Another strategy that has received increasing attention for its potential to make research more relevant is the promotion of patient and public involvement (PPI) (Johnson, Bush, Brandzel & Wernli, 2016). PPI is defined by INVOLVE (2013) as research that is being conducted with or by members of the public rather than to, about or for them. The inclusion of members of the public as active partners can ensure that all aspects of a project, from design to dissemination, are influenced by individuals' real-life experiences and therefore ensures that the research is relevant and meaningful to the intended population (McKirdy, 2015). There is also evidence to suggest that PPI can improve research quality (McKirdy, 2015).

MedEx is a community-based exercise rehabilitation programme that offers supervised exercise classes to individuals living with chronic conditions. The MedEx IMPACT (IMprove Physical Activity after Cancer Treatment) intervention was developed to be delivered to individuals living with and beyond cancer who were referred to the MedEx programme. An investigation into the feasibility and

effectiveness of the MedEx IMPACT intervention versus usual care (supervised exercise classes only) has been conducted and is presented in Chapter 7. The purpose of this study is to systematically describe the development process of the MedEx IMPACT intervention, which adopted a patient-centred, evidenced-based and theoretically-informed approach. The primary aim of the IMPACT intervention is to increase the PA levels of individuals living with and beyond cancer who have been referred to a community-based exercise programme.

### 5.1.3 Methods

The intervention development process was guided by findings from a review of the literature, end-user recommendations (presented in Chapter 4), the MRC's framework for the development, implementation and evaluation of complex interventions (Craig et al., 2008), the BCW (Michie, Atkins & West, 2014) and the TDF (Cane, O'Connor & Michie, 2012).

The development of the MedEx IMPACT intervention consisted of 5 phases:

- i. a review of literature to: i) establish the determinants of PA behaviour, adherence and maintenance for survivors of cancer, and ii) review physical activity (PA) behaviour change (BC) interventions for this population.
- ii. engagement with individuals living with and beyond cancer through focus groups to: i) explore individuals' experiences of PA throughout the cancer journey, ii) understand the factors that influence PA participation, and iii) obtain recommendations regarding strategies to

support habitual PA and adherence to community-based exercise programmes (as described in Chapter 4).

- iii. theoretical framework selection and application.
- iv. operationalising findings into intervention components.
- v. engagement with a stakeholder expert panel (SEP) to determine intervention acceptability.

Table 5.1 presents an overview of how the intervention development phases were aligned with the stages of the MRC framework for the development, implementation and evaluation of complex interventions (Craig et al., 2008).

Table 5.1. Phases of the MedEx IMPACT intervention development process aligned with stages of the MRC framework for the development, implementation and evaluation of complex interventions (Craig et al., 2008).

Key elements from the MRC		Phases	s of	the	MedEx	IMPA	СТ
Framework for the		intervention development proce					
development of complex							
interventions							
Identifying the evidence	>	i)	Revie	ew of t	he literat	ure	
base		ii)	Focus groups with individuals				als
			living	with	and beyo	nd can	cer
Identify/develop theory		iii)	Theo	retical	fr	amewo	ork
			selec	tion a	nd applica	ation	
Modelling process and	>	iv)	Enga	gemer	nt w	ith	а
outcomes			stake	holde	r expert p	anel	

#### 5.1.3.1 Procedure

*MRC* Framework - Stage 1 - Identifying the evidence base

### *i) Review of Literature*

The following databases were searched during the review of the literature: The Cochrane Library, EMBASE, MEDLINE, CINAHL, PsycINFO and SportDiscus from inception to May 2016. Grey literature and conference proceedings were also searched. Details of the methodology for the review of the literature including key search terms and inclusion and exclusion criteria are presented in Appendix F. Four searches were conducted to identify the determinants of (i) PA behaviour, adherence, and maintenance, for individuals living with and beyond cancer, and (ii) to identify components and/or strategies from previous BC interventions that have been effective in increasing the PA levels of individuals living with and beyond cancer. Recommendations were generated from the studies included within the review of the literature to inform intervention development.

# ii) Focus groups

Individuals were recruited from a community-based exercise programme for survivors of cancer and from a cancer support centre. Participants were allocated to a focus group depending on their current level of PA (categorised as currently active or inactive based on the PA screening questionnaire outlined in the National Exercise Referral Framework (Woods et al., 2016)) and their level of engagement with the community-based exercise programme (e.g. current attender, nonattender or graduate of the programme). Individuals recruited from the cancer support centre participated in the same focus group.

Semi-structured interview scripts developed using the COM-B model (Michie, Atkins & West, 2014) were used to guide the focus group discussions. Questions focused on exploring individuals' capability, opportunity and motivation to be regularly physically active. Prior to the focus group, participants completed an investigator developed questionnaire regarding preferences for PA and opinions regarding strategies to support habitual PA. The focus groups included a discussion of the participants responses to this questionnaire and on potential strategies to support adherence to community-based exercise programmes. Each focus group was audio recorded and conducted by a trained qualitative researcher. Each focus group lasted between 50 and 90 minutes. Audio recordings were transcribed verbatim and analysed using a thematic analysis approach (Braun & Clarke, 2006). Further detail regarding the methods for recruitment, data collection and analysis have been reported elsewhere (Cantwell et al., 2019). Details of PPI within this study are outlined in the Guidance for Reporting Involvement of Patients and the Public short form checklist (GRIPP2-SF) presented in Appendix G (Staniszewska et al., 2017).

### *MRC* Framework - Stage 2 - Identify/develop theory

#### *iii)* Theoretical framework selection and application

A review of existing theoretical frameworks was undertaken and the BCW and the TDF were selected to guide the intervention development (Cane, O'Connor & Michie, 2012; Michie, Atkins & West, 2014). In the first stage of the BCW process, the problem was defined in behavioural terms whereby the target population and behaviour were selected. The target behaviour, to increase cancer survivors' PA levels, was selected based on a number of criteria outlined by Michie and colleagues, including how easy it is likely to be to change the behaviour (which may be influenced by a number of factors including financial and/or human resources, acceptability and preference) and the ease of measurement (Michie, Atkins & West, 2014). The target behaviour was specified according to the criteria presented in Table 5.2 (Michie, Atkins & West, 2014).

Table 5.2. Specification of the target behaviour according to the Behaviour Change Wheel criteria (Michie, Atkins & West, 2014).

The target behaviour	To increase indices of physical activity among survivors of cancer (i.e., daily minutes of light- and moderate-to- vigorous- intensity physical activity; daily step count)
Who needs to perform the behaviour?	Individuals who have completed adjunctive cancer treatment who have been referred to a community-based exercise rehabilitation programme
What does the person need to do differently to achieve the desired change?	Attend the community-based exercise programme and engage in regular independent physical activity
When will they do it?	Mondays and Wednesdays (attendance at supervised exercise classes) and independent PA on other days of the week
Where will they do it?	At the centre for the community-based exercise programme and at home/ independently
How often will they do it?	Progressively increase PA levels with the aim of being active on $\geq 5$ days a week
With whom will they do it?	Fellow participants of the community- based exercise programme; family and friends; alone

A behavioural diagnosis was undertaken which involved synthesising findings from the focus groups and the review of the literature with COM-B model constructs to identify what strategies should be implemented to support performance of the target behaviour.

In stage 2, the behavioural diagnosis was linked with intervention functions (e.g. education, training, enablement) that were likely to increase cancer survivors' PA levels. The APEASE criteria acknowledge that BC interventions are conducted within a social context and list important factors that should be considered during the intervention design process including affordability, practicability, effectiveness, cost-effectiveness, acceptability, safety and equity (Michie, Atkins & West, 2014). The APEASE criteria were applied in the selection of intervention functions. Policy categories were not applied within this intervention.

In stage 3, BCTs that could deliver the identified intervention functions were selected from the Behaviour Change Technique Taxonomy (Michie et al., 2013). The final stage in the intervention design process identified the optimal mode of delivery. The selected BCTs and mode of delivery were translated into intervention components.

Mapping exercises were undertaken to outline the links between intervention components, intervention functions, TDF constructs and BCTs (Tables 5.4 and 5.5).

### *iv)* Operationalising findings into intervention components

Upon completion of phases i-iii, the key findings and recommendations from each phase were synthesised. In phase iv, the intervention content and format was developed based on this information. The BCW and TDF provided the theoretical framework for intervention design, while the recommendations, generated by focus group participants regarding strategies to support habitual PA and adherence to community-based exercise programmes, formed the foundation for intervention content development. These recommendations were analysed within the context of the results from the review of the literature and the intervention content was further refined.

### MRC Development Stage 3 - Modelling process and outcomes

# v) Stakeholder Expert Panel (SEP)

To determine the acceptability of the intervention to the intended population, and obtain stakeholder feedback, the intervention was presented at a 2-hour workshop to a SEP (n=11) which included: i) individuals who were currently attending or had graduated from a community-based exercise programme for survivors of cancer (n=4), ii) representatives from a national cancer charity (n=3), iii) an oncology liaison nurse (n=1), iv) exercise instructors involved in the delivery of a community-based exercise programme for survivors of cancer (n=2) and v) a Medical Director for a community-based chronic illness exercise rehabilitation programme (n=1). During the workshop, an overview of the proposed intervention was presented, and stakeholders were asked to discuss questions that had been generated by the research team, regarding intervention acceptability and

effectiveness. Following this exercise, the discussion was opened to the floor and stakeholders asked questions of the research team and shared their comments and recommendations to inform intervention design.

# 5.1.4 Results

The results from each stage of the intervention development process are outlined below.

## 5.1.4.1 MRC Development Stage 1 - Identifying the evidence base

# *i) Findings from the review of literature*

From the 4 searches that were conducted during the review of the literature, 10 studies were identified to inform the intervention development process. Table 5.3 provides an overview of statements of findings that were generated from the review of the literature to inform the intervention development process.

Table 5.3. Statements of findings generated from the review of the literature to inform the intervention development process.

Staten	nents of Findings	Source
(gener	ated from literature that investigated the determinants of physical activity behaviour,	First Author, Year
adhere	ence or maintenance among survivors of cancer)	
1.	BMI, emergency room visits in the past year, and number of co-morbidities were associated with	Liu, 2016
	lower levels of PA among overweight or obese breast cancer survivors.	
2.	Baseline fatigue and chronic musculoskeletal symptoms were significant determinants of PA	Lee, 2016
	maintenance accounting for 20% of the variance among survivors of breast cancer following	
	participation in a community-based PA programme.	
3.	Colorectal cancer survivors at risk for physical inactivity were those with low perceived behavioural	Packel, 2015
	control for PA, low social norm for PA, who had neuropathy and were older.	
4.	Older age, higher BMI, lower self-efficacy, and less social support were significantly correlated with	Kampshoff, 2014
	lower PA among breast cancer survivors.	
5.	Task self-efficacy played a more important role in exercise adoption among post-treatment breast	Short, 2014
	cancer survivors, whereas barrier self-efficacy played a more important role in exercise maintenance.	
6.	Higher task self-efficacy for resistance training and greater goal-setting behaviour were identified as	Short, 2014
	significant predictors of meeting the resistance training guidelines among post-treatment breast	
	cancer survivors.	
7.	Breast cancer survivors with poorer quality of life and higher fatigue, as well as those reporting lower	Short, 2014
	confidence to change behaviours and overcome barriers, less social support and use of goal setting,	
	may be most in need of physical activity intervention and/or additional support during intervention.	
8.	General self-efficacy and enjoyment were fundamental and important determinants in explaining PA	Charlier, 2013
	among breast cancer survivors. In contrast, the relationship between social support, lack of time and	
	lack of company and PA was more dynamic and dependent on the working status of the women. Only	
	in working breast cancer survivors did lack of time and lack of company prevent PA, whereas social	
	support from partner and friends contributed to more PA.	

Statements of Findings	Source
(generated from literature that investigated physical activity behaviour change interventions for survivors of cancer)	First Author, Year
9. Community-based interventions that met in groups and used behaviour change strategies (e.g. cognitive behavioural therapy) produced the largest improvement in physical functioning among survivors of cancer.	Swartz, 2017
<ol> <li>Interventions that were associated with increased PA behaviour among cancer survivors shared common characteristics, including:         <ul> <li>self-monitoring or coaching techniques in various combinations, with varying media. E.g. several studies supplied research-grade pedometers or accelerometers to participants, in addition to self-report tools, a strategy known to support measurement validity and help participants monitor their progress.</li> <li>workshops (including PA-specific and non-specific workshops) and/or peer support groups of some kind during the intervention.</li> <li>individual counselling to motivate participants and address barriers to PA.</li> <li>home exercise and walking as the primary type of exercise were emphasized in all the interventions in some form, which has also been a successful component in lifestyle studies with similar populations.</li> </ul> </li> </ol>	Bluethmann, 2015
11. An intervention based on social cognitive theory that included supervised and home-based exercise sessions, face-to-face counselling sessions with an exercise specialist, and group discussion sessions regarding self-efficacy, exercise barriers, behavioural capability, goal setting with self-monitoring, behavioural modification strategies, time management, stress management, safety, cognitive reframing, relapse prevention and role models was effective in increasing PA, aerobic fitness, and quality of life among survivors of breast cancer.	Rogers, 2015
	Bourke, 2013
13. Programming set goals, prompting self-monitoring and practicing and generalising behaviour are	Bourke, 2013

## *ii) Focus group findings*

Seven focus groups with 41 individuals living with and beyond cancer were conducted (56% female; mean (± SD) age 57.7 (± 9.1 years)). Participants had a cancer diagnosis of breast (41%), prostate (27%), colorectal (20%), or 'other' (12% including lung, cervical and melanoma) cancer. The focus group discussions provided valuable information regarding individuals' experiences of PA throughout the cancer journey and the factors that influence PA participation. The 5 main themes and further subthemes, which included the 8 recommendations for strategies to support habitual PA and adherence to community-based exercise programmes, that were generated from the discussions are described in detail elsewhere (Cantwell et al., 2019) (Chapter 4 - Study 2). In summary, the 8 recommendations outlined in Theme 5 (Cancer Survivors' Recommendations for Physical Activity) advocated for the inclusion of: i) individualised exercise prescription, ii) group-based supervised exercise classes with peers who have also completed cancer treatment, iii) goal setting and action planning, iv) quantification and measurement of PA, v) provision of information regarding additional health behaviours (i.e. healthy eating, smoking cessation, alcohol consumption and stress management, vi) both supervised and home-based PA sessions, vii) assessments of fitness, and viii) face-to-face counselling from exercise specialists regarding PA within a community-based exercise programme to support long-term PA adherence.

### 5.1.4.2 MRC Development Stage 2

*iii)* Application of theoretical frameworks to inform intervention development

The target behaviour selected for the MedEx IMPACT intervention, upon completion of stage 1 of the BCW process, was to increase cancer survivors' levels of PA. Factors that influence cancer survivors' capability, opportunity and motivation to be physically activity were identified through the BCW, TDF and findings from the focus groups and review of the literature (see Appendix H). The salient COM-B and TDF constructs that were identified were mapped to 5 intervention functions and 35 BCTs which were included within the MedEx IMPACT intervention. Table 5.4 provides an overview of the mapping process and links intervention components with the selected BCTs. Table 5.5 provides an overview of the mapping process between the intervention components and the COM-B model, TDF and the selected intervention functions. Table 5.4. Mapping of the MedEx IMPACT intervention components to the selected behaviour change techniques.

	Intervention components						
Behaviour Change Techniques	Supervised exercise classes	Physical activity manual	Physical activity logbook	Pedometer	Physical activity information sessions	1:1 Exercise consultation	Assessments of physical and psychological health
1.1 Goal setting behaviour					$\checkmark$	$\checkmark$	$\checkmark$
1.2 Problem solving					$\checkmark$	$\checkmark$	$\checkmark$
1.3 Goal setting (outcome)					$\checkmark$	$\checkmark$	
1.4 Action planning					$\checkmark$	$\checkmark$	$\checkmark$
1.5 Review behaviour goal(s)					$\checkmark$	$\checkmark$	$\checkmark$
1.6 Discrepancy between current behaviour and goal					$\checkmark$	$\checkmark$	
1.7 Review outcome goal(s)					$\checkmark$	$\checkmark$	
1.8 Behavioural contract					$\checkmark$	$\checkmark$	
1.9 Commitment					$\checkmark$		
2.2 Feedback on behaviour	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$		$\checkmark$	$\checkmark$
2.3 Self-monitoring of behaviour	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	
2.4 Self-monitoring of outcome of behaviour	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	
2.6 Biofeedback							$\checkmark$
2.7 Monitor and provide feedback on the outcome of performance of the behaviour	$\checkmark$					$\checkmark$	$\checkmark$
3.1 Social support (unspecified)					$\checkmark$	$\checkmark$	$\checkmark$
4.1 Instruction on how to perform the behaviour	$\checkmark$	$\checkmark$			$\checkmark$		

5.1 Information about health					$\checkmark$		
consequences	<b> </b>						
5.2 Salience of consequences	ļ				$\checkmark$		
5.3 Information about social and					$\checkmark$		
environmental consequences							
5.4 Monitoring of emotional					$\checkmark$	$\checkmark$	
consequences							
5.6 Information about emotional					$\checkmark$		
consequences							
6.1 Demonstration of the behaviour	$\checkmark$	$\checkmark$					
7.1 Prompts/cues					$\checkmark$		
8.1 Behavioural practice/rehearsal	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	
8.2 Behaviour substitution						$\checkmark$	
8.3 Habit formation					$\checkmark$	$\checkmark$	
8.4 Habit reversal						$\checkmark$	
8.6 Generalisation of a target behaviour	$\checkmark$	$\checkmark$	$\checkmark$		$\checkmark$	$\checkmark$	
8.7 Graded tasks	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	
9.1 Credible source					$\checkmark$		
9.2 Pros and cons					$\checkmark$		
12.1 Restructuring the physical					$\checkmark$	$\checkmark$	
environment							
12.2 Restructuring the social environment					$\checkmark$	$\checkmark$	
15.1 Verbal persuasion about capability					$\checkmark$	$\checkmark$	
15.3 Focus on past success					$\checkmark$	$\checkmark$	$\checkmark$

Intervention Component	COM-B Constructs	TDF Constructs	BCW Intervention Functions
Supervised exercise classes	Capability – Physical	Knowledge	Education
	& Psychological	Skills	Training
		Memory, attention and decision processes	Environmental Re-Structuring
	Opportunity –	Behavioural regulation	Enablement
	Physical & Social	Environmental context and resources	
		Goals	
Physical activity manual	Capability – Physical	Knowledge	Education
	& Psychological	Skills	Training
		Memory, attention and decision processes	Environmental Re-Structuring
	Opportunity –	Behavioural regulation	Enablement
	Physical	Environmental context and resources	
		Goals	
Physical activity logbook	Capability –	Knowledge	Education
	Psychological	Skills	Training
		Memory, attention and decision processes	Environmental Re-Structuring
	Motivation –	Behavioural regulation	Enablement
	Reflective	Environmental context and resources	
		Goals	
Pedometer	Capability –	Knowledge	Education
	Psychological	Skills	Training
		Memory, attention and decision processes	Environmental Re-Structuring
	Motivation –	Behavioural regulation	Enablement
	Reflective &	Environmental context and resources	
	Automatic	Goals	

Table 5.5. Mapping of the MedEx IMPACT intervention components to the COM-B model, TDF and the selected intervention functions.

Physical activity information	Capability –	Knowledge	Education
sessions	Psychological	Memory, attention and decision processes	Persuasion
		Behavioural regulation	Training
	Opportunity –	Beliefs about capabilities	Environmental re-structuring
	Physical & Social	Beliefs about consequences	
		Goals	Enablement
	Motivation –	Environmental context and resources	
	Reflective &		
	Automatic		
1:1 exercise consultation	Capability –	Knowledge	Education
	psychological	Skills	Persuasion
		Behavioural Regulation	Training
	Opportunity –	Beliefs about capabilities	Environmental re-structuring
	Physical & Social	Intentions	Enablement
		Goals	
	Motivation –		
	Reflective &		
	Automatic		
Assessments of physical and	Motivation –	Knowledge	Education
psychological health	Reflective &	Environmental context and resources	Persuasion
	Automatic	Behavioural regulation	Environmental restructuring
		Beliefs about capabilities	Enablement
		Beliefs about consequences	
		Goals	
		Reinforcement	

# *iv)* Operationalising findings into intervention components

Table 5.6 details the mapping of focus group recommendations and statements of findings generated from the review of the literature to intervention components. In the first column in Table 5.6, relevant papers which supported focus groups findings are listed. This is to aid the incremental advances within this area through synthesis of existing evidence-building within intervention development.

	Statements of tatement Number	Focus Group Recommendation	Intervention Component
1	8	Individualised exercise prescription	Supervised exercise classes
3	10		
4	11	Exercising as part of a group of individuals who have	
5-7	12-13	completed treatment for cancer	
		Supervised exercise classes and a home-based exercise programme	
1	8	Supervised exercise classes and a home-based	Physical activity manual
3	10	exercise programme	
4	11		
5-7	12-13		
1	8	Goal setting and action planning	Physical activity logbook
3	10		

Table 5.6. Mapping of focus group recommendations and statements of findings generated from the review of the literature to the MedEx IMPACT intervention components.

4	11	Quantifying and measuring physical activity	
5-7	12-13		
1	8	Quantifying and measuring physical activity	Pedometer
3	10		
4	12-13		
5-7			
1	8	Face-to-face counselling from exercise specialists	Physical activity information sessions
3	10	regarding physical activity	
4	11		
5-7	12-13	Individualised exercise prescription	
		Goal setting and action planning	
1	8	Individualised exercise prescription	1:1 exercise consultation
3	10		
4	11	Goal setting and action planning	
5-7	12-13		
1	8	Goal setting and action planning	Assessments of physical and psychological
4	11		health
5-7	12-13	Fitness Assessments	

#### 5.1.4.3 MRC Development Stage 3

# v) SEP Findings

An overview of the feedback from the SEP is reported in Appendix I under the following headings: i) description of expert feedback; ii) illustrative quote of the issue and iii) recommendation/how it is addressed within the MedEx IMPACT intervention.

The range of experts deemed that the intervention was acceptable and would educate, motivate and encourage participants attending the 12-week programme to continue to be physically active upon completion of the supervised exercise classes. A number of recommendations to optimise intervention implementation and impact were proposed and are presented in Appendix I. An example of feedback received from the SEP was that within the 1:1 exercise consultations, there was the potential for participants to disclose or discuss issues of a personal/sensitive nature that may not directly relate to PA participation. To address this, the lead investigator (MC) responsible for intervention implementation received training from a cancer patient support services coordinator regarding how the boundaries of consultations could be clearly defined to ensure participants were aware of the aims of the session. Members of the research team involved in intervention delivery received training from MC following this session. Protocols were also developed to clearly describe how issues raised by participants, that were beyond the scope of the intervention, should be addressed. This included identifying external support services that participants could be signposted and/or referred to.

An overview of the proposed components and timeline for the MedEx IMPACT intervention are presented in Tables 5.7 and 5.8. Appendix J includes the Template for Intervention Description and Replication (TIDieR) checklist to ensure the completeness of reporting and replicability of interventions (Hoffman et al., 2014). Table 5.7. The components of the MedEx IMPACT intervention.

Intervention Component	Description
Supervised Exercise Classes	Participants attend a community-based exercise programme that consists of two 60-minute supervised exercise classes each week for 12 weeks.
Independent Physical Activity Programme	This consists of a PA manual, a pedometer and a PA logbook. Participants receive these materials in week 4 of the 12-week programme.
Physical Activity Manual	Participants receive a PA manual and are encouraged to supplement attendance at the supervised exercise classes with use of this manual at home.
Pedometer	Participants receive a research-grade pedometer and are encouraged to wear the pedometer daily.
Physical Activity Logbook	Participants receive a PA logbook and are encouraged to record their daily step counts and minutes of PA.
Physical Activity Information Sessions	Participants attend four 30-minute PA information sessions in weeks 0, 4, 6 and 10 of the intervention. Session 1 discusses the benefits of PA for health and an overview of the MedEx IMPACT Intervention is presented. Issues and concerns for being physically active after cancer treatment are also discussed. Session 2 focuses on introducing participants to the PA manual, pedometer and PA log book. Session 3 focuses on setting individualised PA goals. The group discusses challenges to PA participation and solutions to overcome these difficulties. Session 4 focuses on reviewing PA goals. Long-term strategies to support habitual PA and manage lapses in PA behaviour are discussed.
1:1 Exercise Consultation	Participants attend a 15 minute 1:1 exercise consultation in week 10, 11 or 12 of the intervention which focuses on developing an individualised action plan for PA to guide PA upon completion of the supervised exercise classes.
Assessments of physical and psychological health	Participants complete assessments of physical function, PA levels and quality of life at baseline and months 3, 6 and 12. Participants attend a group exercise consultation at each assessment and receive feedback reports at months 3, 6 and 12.
Abbreviations: PA=nbysical activity	

Abbreviations: PA=physical activity

Table 5.8. The MedEx IMPACT intervention components and timeline

	Twice-weekly supervised exercise classes	Physical activity manual (Used to supplement attendance at supervised exercise classes)†*	Pedometer (Worn daily)*	Physical activity logbook (Records kept daily)*	Physical activity information sessions	1:1 Exercise consultation††	Assessments of physical and psychological health
Week							
0					$\checkmark$		$\checkmark$
1	$\checkmark$						
2	$\checkmark$						
3	$\checkmark$						
4	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$		
5	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$			
6	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$		
7	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$			
8	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$			
9	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$			
10	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	
11	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$		$\checkmark$	
12	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$		$\checkmark$	$\checkmark$
24							$\checkmark$
52							$\checkmark$

\*Participants are encouraged to continue use of this component of the intervention following completion of the 12-week supervised exercise classes; † Participants are encouraged to supplement attendance at the supervised exercise classes with i)  $\geq$  1 independent exercise session(s) from week 4-8, ii)  $\geq$  2 independent exercise sessions from week 9-12; †† The exercise consultation took place in either week 10, 11 or 12.

## 5.1.5 Discussion

The aim of this paper was to systematically describe the development of the MedEx IMPACT intervention, a multi-component PA BC intervention that aims to increase cancer survivors' PA levels. This intervention extends behavioural science methodology as it is, to the authors' knowledge, the first PA BC intervention for survivors of cancer that has been developed using the MRC framework for the development, implementation and evaluation of complex interventions, the BCW and TDF.

Theoretically informed interventions have the potential to increase the efficacy of PA BC interventions for survivors of cancer by providing a valuable insight into the relation between targeted constructs and their impact on the desired behaviour (Bluethmann, Bartholomew, Murphy & Vernon, 2017). However, the application of theory within PA BC studies for individuals living with and beyond cancer is generally poor, with many studies failing to outline explicit links between the theoretical framework cited and the design, implementation and evaluation of the intervention (Bluethmann, Bartholomew, Murphy & Vernon, 2017). Systematic reporting and greater transparency regarding how theory has informed and is embedded within PA BC interventions is required in order to further advance our understanding of its role in optimising intervention effectiveness and to facilitate intervention replicability (Bluethmann, Bartholomew, Murphy & Vernon, 2017; Michie et al., 2005). The use of the TIDieR checklist is advocated to overcome insufficiently detailed reporting within interventions and assist the implementation of interventions in clinical practice (Hoffman et al., 2014).

The development of the MedEx IMPACT intervention contributes to the advancement of implementation science and intervention design research by providing a detailed account of the intervention development process and clearly outlining how BC theory has informed, and been embedded within, a PA BC intervention for individuals living with and beyond cancer. The systematic approach to the design process led to the development of a novel intervention that is patientcentred, evidenced-based and theoretically-informed. It is becoming increasingly recognised that implementation strategies are essential to achieving the full benefits of evidence-based healthcare (McHugh et al., 2018). The delivery of this intervention within a real-world setting will provide important insights regarding intervention implementation and effectiveness to that end. Given that the ultimate goal of intervention development is to optimise patient care, the need for an understanding of the factors that contribute to intervention success and/or failure are urgently needed in order to facilitate greater likelihood of intervention success and more appropriate resource allocation (Cantwell et al., 2019).

As the burden of cancer continues to grow (WHO, 2014), so too does the need to develop effective interventions that can support individuals living with and beyond cancer to become habitually physically active, optimise their physical and psycho-social well-being and reduce their risk of cancer morbidity and mortality (Bourke et al., 2013; Courneya, Rogers, Campbell, Vallance & Friedenreich, 2015). The potential impact of previous PA BC interventions may have been limited due to a poor understanding of the needs and challenges facing survivors of cancer in adopting PA, and the poor application/lack of theory within the intervention

development process. Selected intervention strategies may be chosen to overcome expected barriers based on previous experience, as opposed to systematically identifying salient barriers for the chosen population prior to intervention implementation (McHugh et al., 2018). In addition, healthcare professionals may not be providing sufficient guidance to survivors of cancer to achieve PA adoption and adherence due to a lack of knowledge of PA prescription for survivors of cancer and a lack of resources regarding PA for this population (Cantwell et al., 2018).

As individuals' PA behaviour can be affected by cancer type, treatment modality and stage of the cancer journey, it is essential that intervention designers identify the motivators and barriers to PA participation that are salient to the cancer cohort that an intervention is intended to benefit. This information can inform a more appropriate selection of BCTs to support the desired BC and could therefore contribute to an increased likelihood of intervention success.

## 5.1.5.1 Strengths and Limitations

The intervention development process was iterative and sought input and feedback from both end-service users and stakeholders. Recommendations generated by individuals living with and beyond cancer were the foundation for intervention content development. Many of the studies regarding the determinants of PA behaviour, adherence and maintenance that were included in the review of the literature focused on survivors of breast cancer. As a result, determinants of PA behaviour, adherence and maintenance that may be salient for other cancer cohorts may not have been considered during intervention development. Of the individuals who participated in the focus group study, 88% had a breast, colorectal

or prostate cancer diagnosis. The recommendations generated by focus group participants may not be salient to individuals with a cancer diagnosis that was not represented.

# 5.1.6 Conclusion

The integration of patient developed recommendations with evidence from the scientific literature and theoretical frameworks of BC could assist in the development of effective PA BC interventions for survivors of cancer. The absence of this combined approach may have contributed to the dearth of effective interventions for this population to date. The synthesis of findings from this formative research guided by the MRC framework, BCW and TDF has resulted in the development of a novel intervention to support increased PA participation by individuals living with and beyond cancer. The next phase in this research is to test the acceptability and effectiveness of the MedEx IMPACT intervention. Chapter 6 Study 4

#### 6.1 Study 4

Cantwell, M., Furlong B., Moyna, N., McCaffrey, N., Skelly, F., Loughney, L., Walsh, D., Dowd, K., McCarren, A., & Woods, C. (2019). Study protocol for the investigation of the feasibility and clinical effectiveness of a physical activity behaviour change intervention for individuals living with and beyond cancer.

**Statement of Contribution:** Prof. Niall Moyna, Dr. Bróna Furlong, Dr. Deirdre Walsh, Dr. Noel McCaffrey and Prof. Catherine Woods supervised this project, and were involved in the development of the study concept and research design, and in reviewing the manuscript. Dr. Lisa Loughney and Ms. Fiona Skelly assisted with data collection. Dr. Kieran Dowd and Dr. Andrew McCarren provided guidance on the statistical analysis of the data.

# 6.1.1 Abstract

Most survivors of cancer are not sufficiently active to achieve the health benefits associated with regular physical activity (PA). The purpose of this study was to describe the study protocol for a two-arm non-randomised comparison trial conducted within a community-based setting, which aimed to investigate the feasibility and clinical effectiveness of a cancer-specific PA BC intervention, namely MedEx IMPACT (Improve Physical Activity after Cancer Treatment), compared to a general exercise rehabilitation programme, among survivors of cancer. Individuals who had completed active-cancer treatment who were referred to a communitybased exercise rehabilitation programme were invited to participate in the trial. Participants in the control group (CG) attended twice-weekly supervised exercise classes for 12 weeks. Classes were delivered as part of a chronic illness exercise rehabilitation programme. Participants in the MedEX IMPACT intervention group (IG) also attended the twice-weekly supervised exercise classes for 12 weeks and received cancer-specific materials, namely an independent PA programme, 4 PA information sessions and a 1:1 exercise consultation. The primary outcome was PA levels measured by 6-day accelerometry and self-report PA. Secondary outcomes included CRF, HRQoL and sedentary behaviour. An exploration of psychosocial determinants of PA was conducted to determine changes that mediate PA levels. Outcomes were measured at baseline and months 3, 6 and 12. A process evaluation was conducted and included intervention debrief questionnaires and focus groups. Few effective PA BC interventions for individuals living with and beyond cancer have been identified. Furthermore, there is an even greater lack of such interventions that have investigated long-term adherence to PA. The results of this study will have implications for the planning and provision of community-based exercise oncology rehabilitation programmes for survivors of cancer.

*Keywords:* Oncology, survivorship, physical activity, behaviour change, adherence

#### 6.1.2 Introduction

Regular physical activity (PA) is associated with reductions in the risk of cancer development and recurrence (Cormie, Zopf, Zhang & Schmitz, 2017; McTiernan et al., 2019). In addition, PA can also assist in mitigating many of the negative side effects associated with cancer treatment including fatigue and psychosocial distress (Cormie, Zopf, Zhang & Schmitz, 2017). Many individuals experience a decline in PA levels following a cancer diagnosis, which can persist during treatment and survivorship (Blanchard et al., 2003; Bluethmann, Vernon, Gabriel, Murphy & Bartholomew, 2015; Courneya, Karvinen & Vallance, 2007;

Phillips & McAuley, 2015). Indeed, the majority of individuals living with and beyond cancer do not achieve the minimum recommended levels of daily PA (Bourke et al., 2013; LeMasters, Madhavan, Sambamoorthi & Kurian, 2014; Liu et al., 2016; Rock et al., 2012; Turner et al., 2018). Effective PA behaviour change (BC) interventions are required to increase PA levels among individuals living with and beyond cancer (Courneya, Rogers, Campbell, Vallance & Friedenreich, 2015).

The efficacy of PA interventions to increase physical and psycho-social wellbeing among survivors of cancer is well-established when investigated within controlled research settings (Courneya, Rogers, Campbell, Vallance & Friedenreich, 2015). However, due to the dearth of effectiveness trials, little is known about how to translate these findings into real-world programmes and services (Courneya, Rogers, Campbell, Vallance & Friedenreich, 2015; Pollack, Hawkins, Peaker, Buchanan & Risendal, 2011; White, McAuley, Estabrooks & Courneya, 2009). Courneya and colleagues recently highlighted the need for more dissemination and implementation (D&I) research within cancer survivorship, with a particular focus on strategies to increase intervention uptake and minimise the loss of efficacy that can occur when interventions are translated from research-settings to real-world programmes (Courneya, Rogers, Campbell, Vallance & Friedenreich, 2015).

The absence of D&I research in PA and cancer survivorship has been influenced by limited study relevance and efficiency, inadequate collaboration and co-ordination among scientists and stakeholders and a lack of economic analyses of PA interventions (Courneya, Rogers, Campbell, Vallance & Friedenreich, 2015; Phillips, Alfano, Perna & Glasgow, 2014). While a number of publications have

presented research agendas and recommendations in an attempt to accelerate the D&I of effective evidenced-based PA interventions into cancer care (Basen-Engquist et al., 2017; Phillips, Alfano, Perna & Glasgow, 2014; Pollack, Hawkins, Peaker, Buchanan & Risendal, 2011), a paucity of research in this area still remains. Knowledge translation studies that evaluate interventions delivered within community-based settings are warranted in order to contribute real-world experiences that can inform decisions regarding programme development and dissemination (Santa Mina et al., 2017).

Community-based exercise rehabilitation programmes (CBERPs) have been associated with a number of benefits for survivors of cancer including improvements in physical and pyscho-social well-being, fatigue and quality of life (Cheifetz et al., 2014; Knobf, Thompson, Fennie & Erdos, 2014; Santa Mina et al., 2017). These programmes also provide an opportunity for individuals to access advice and expertise regarding PA during their cancer journey (Santa Mina et al., 2017). MedEx is a CBERP located at Dublin City University in Ireland that offers supervised exercise classes to individuals living with different chronic conditions (e.g. cardiovascular disease, pulmonary disease, cancer). MedEx Move On (MMO), is the programme that provides such classes to individuals who have completed cancer treatment. MedEx IMPACT (Improve Physical Activity after Cancer Treatment) is a cancer-specific PA BC intervention which aims to increase cancer survivors' PA levels. It was developed for delivery within a community-based setting. This paper describes the protocol for a two arm non-randomised

comparison trial was that conducted to investigate the feasibility and clinical effectiveness of MedEx IMPACT versus MMO.

# Research Goals (Specific Aims and Hypotheses)

The primary aim of the trial was to compare the effects of MedEx IMPACT to MMO on short- and long- term PA levels among survivors of cancer. PA levels were assessed by both accelerometry and self-report at baseline and 3, 6 and 12 months. It was hypothesised that compared to MMO, participation in MedEx IMPACT would result in higher PA levels at 3, 6 and 12 months. A secondary aim of the study was to compare the effects of MedEx IMPACT, to MMO, on CRF, HRQoL and sedentary behaviour. Tertiary aims included comparing the effects of the intervention versus MMO on body composition, strength, flexibility and fatigue. It was hypothesised that compared to MMO, participation in MedEx IMPACT would result in greater improvements in CRF, HRQoL, sedentary behaviour, physical function and fatigue at 3, 6 and 12 months.

An exploratory analysis was conducted on psychosocial determinants of PA (i.e. barriers specific self-efficacy for exercise, self-regulatory self-efficacy for exercise, social support for PA (from family and friends) and intentions for PA) to examine the extent to which changes mediated PA BC.

## 6.1.3 Methods

#### 6.1.3.1 Study Design

The study utilised a two arm non-randomised comparison design consisting of an intervention group and a control group. Both groups attended twice weekly supervised exercise classes for 12 weeks which were delivered as part of a general chronic illness rehabilitation programme. In addition, the intervention group received materials developed specifically for survivors of cancer, namely: i) an independent PA programme (which consisted of a PA manual, PA logbook and a pedometer), ii) 4 PA information sessions and iii) a 1:1 exercise consultation. Participants were recruited at induction to the MMO programme following referral by healthcare professionals. Participants completed assessments of physical and psychological health at baseline and months 3, 6 and 12. Ethical approval was obtained from the Dublin City University Research Ethics Committee (DCUREC2014227; DCUREC2017128). The study algorithm is presented in Appendix K.

## 6.1.3.2 Participants - Selection criteria (eligibility)

Adults  $\geq$  18 years of age with an established diagnosis of cancer who had completed treatment, had been referred to MMO, and given medical approval to participate in an exercise programme by a healthcare professional were recruited to participate in the study. Exclusion criteria were: i) an uncontrolled cardiovascular condition, ii) a significant musculoskeletal or neurological condition,

or iii) a significant mental illness or intellectual disability that restricted participation in an exercise training programme.

MMO runs in cycles, with a new group of approximately 40-50 participants starting the programme every 12 weeks. Recruitment to the study occurred in cycles aligned with programme commencement dates. Individuals referred to 2 cycles of MMO between November 2015 and April 2016 were invited to participate in the control arm of the trial. Individuals referred to 2 cycles of the programme between September 2017 and January 2018 were invited to participate in the intervention arm of the trial. The programme is a user-pay model of communitybased exercise rehabilitation.

# 6.1.3.3 Recruitment

Individuals referred to MMO were contacted with an appointment for induction. During this appointment, participants were provided with a comprehensive oral explanation of the study and a written plain language statement. Participants provided written consent prior to participating in the study. Participants assigned to the intervention group were advised that declining to participate in the intervention arm of the trial did not preclude them from participating in the supervised exercise classes only (i.e. MMO). Participants were recruited between November 2015-April 2016 and September 2017-January 2018.

#### 6.1.3.4 Statistical power and sample size

G\*Power software (Faul, Erdfelder, Lang & Buchner, 2007) was used to perform the sample size calculation. A retention goal was set at 64 participants (or 32 per group) which allowed detection of a small to medium effect size = 0.40 (p<0.05, power of 0.80). Unpublished data indicated a MMO drop-out rate between 20-50%. Consequently, a minimum of 60 participants were recruited to each group.

## 6.1.3.5 Procedure

Assessments of physical and psychological health were undertaken at baseline (T1 – pre-intervention), 3 months (T2 – following completion of the 12-week programme), 6 months (T3 – 3 months post-intervention) and 12 months (T4 – 9 months post-intervention). Assessments were conducted over 2 days. An overview of the assessment procedures is presented in Appendix L.

Following referral to MMO, participants were invited to attend programme induction which occurred over 2 days. The control and intervention groups underwent the same induction process. On Day 1, participants were welcomed to the programme by the Medical Director and provided with information regarding programme logistics (i.e. car parking facilities, class times, access to the gym). Participants underwent a series of tests to measure height, weight, waist and hip circumference, lower and upper body strength and flexibility after which they completed a questionnaire that assessed self-reported PA, barriers specific self-efficacy for exercise, intentions for PA, social support for PA, fatigue and quality of life. Participants were given an accelerometer and asked to return it

when they attended for Day 2 of assessment, which was  $\geq 6$  days later. During this visit, participants completed an assessment of CRF and a second questionnaire which assessed psychological well-being, depression and self-regulatory self-efficacy for exercise.

Testing procedures were conducted by a team of experienced researchers. On occasions where participants were unable to attend the group-based assessments, individual appointments were scheduled and identical procedures and timeframes were adhered to.

## 6.1.3.6 Control Group

Following induction and assessment, participants in the control group were advised to attend two 60-minute supervised exercise classes each week for the 12week period. The classes were delivered by accredited exercise instructors who had experience in delivering exercise oncology rehabilitation programmes. At least 2 exercise instructors were present at each class. Participants were supervised at a ratio of 1:15. The delivery of the programme was overseen by the MedEx Medical Director. Classes focused on a combination of aerobic and resistance exercise as detailed in the exercise prescription presented in Table 6.1.

Table 6.1. Exercise prescription for the supervised exercise classes.

Frequency	2 supervised exercise classes each week for 12-weeks
Intensity	Moderate to vigorous intensity. Participants were instructed to exercise at an intensity at which they were moderately breathless, had a red face and sweat.
Time	60 minutes including a 15-minute warm up, 35-minute main phase and 10-minute cool-down.
Туре	<ul> <li>Warm up and cool down: Combination of aerobic exercise, range of motion exercises and stretches.</li> <li>The main phase for each class consisted of a combination of the below:</li> <li>Aerobic exercise: use of cardiorespiratory exercise equipment including treadmills, stationary bicycles, rowers and cross-trainers.</li> <li>Resistance exercise: Inclusion of 10-15 exercises focusing on lower and upper body strength including body weight exercises, weight machines and free weights.</li> <li>Instructor led exercise sessions: including step aerobics, circuits, total body resistance exercise (TRX) and spinning.</li> </ul>

Baseline assessments were completed over 2 visits and were repeated at 3 (T2), 6 (T3) and 12 (T4) months using identical procedures. In addition, participants attended a group-based exercise consultation on the second assessment day, where they received an individualized feedback report detailing changes in their fitness (i.e. body composition, CRF, strength, flexibility). The group-based exercise consultations were delivered by researchers with expertise in health BC. The sessions were 15 minutes in duration and focused on discussing: i) the results of the feedback report, including tables of normative values for each variable, ii) successes and challenges experienced in adhering to PA and iii) strategies to overcome challenges identified and optimise long-term PA adherence. This group-based exercise consultation was part of usual care and was therefore offered to participants in both arms of the trial.

## 6.1.3.7 Intervention Development

A novel approach to intervention development was adopted in the design of the MedEx IMPACT intervention and has been described in detail in Chapter 5. In summary, recommendations, generated by individuals living with and beyond cancer (n=41), for strategies to support long-term PA adherence were combined with statements of findings generated from a review of literature that assessed the determinants of PA behaviour, adherence or maintenance among survivors of cancer, and strategies that were associated with intervention success in PA BC interventions for this population. Behavioural theory, in the form of The Behaviour Change Wheel and Theoretical Domains Framework, was embedded within all intervention components. A detailed account of how theoretical constructs and BCTs were embedded within the intervention has been described in Chapter 5. The Medical Research Council's framework for the development and evaluation of complex interventions guided the intervention development process. An overview of the resultant intervention is described below.

# 6.1.3.8 MedEx IMPACT Intervention

In addition to 12 weeks of twice-weekly supervised exercise classes and assessments of physical and psychological health at baseline and months 3, 6 and 12) participants received an independent PA programme, 4 information sessions regarding PA and a 1:1 exercise consultation, which were specifically developed for survivors of cancer.

## Independent physical activity programme

This consisted of a PA manual, an SW-200 Yamax Digiwalker Pedometer (Yamax UK, Shropshire, United Kingdom), and a PA logbook. Participants were given the independent PA programme in week 4 of the 12-week supervised exercise programme.

### Physical activity manual

The 43-page PA manual contained 3 chapters. Chapter 1 (entitled "MedEx and the Role of Physical Activity") outlined the benefits of PA for individuals with a cancer diagnosis, the PA guidelines for individuals living with and beyond cancer and information on how to set PA goals. This chapter also described how the PA manual could support attendance at the supervised exercise classes and continued PA participation upon completion of the 12-week programme.

Chapter 2 (entitled "Let's Get Started!") presented 3 exercise programmes. Programme A was an aerobic exercise programme, which outlined targets for aerobic PA across 3 categories (beginner, intermediate and long-term exerciser). The targets progressed the intensity and duration of PA over 12 weeks and worked towards achieving the recommended aerobic component of the PA guidelines (i.e. at least 150 minutes of moderate intensity PA each week). Programmes B and C were exercise sessions that could be completed at home without equipment. Both programmes included a warm-up, main phase and cool-down. The warm-up and cool-down focused on aerobic and range of motion exercises and stretches. The main phase consisted of i) a circuit (that included alternating aerobic (e.g. half jacks,

side steps) and resistance exercises (e.g. wall press, upright row), ii) aerobics (e.g. marching on the spot with lateral raises, high knees with chest press) and iii) balance exercises (standing on one leg, bridge). Programme C was a progression of the exercise session presented in Programme B.

Each exercise included in the manual was accompanied by pictures of an individual completing the action and teaching points to direct performance of the movement. All exercises included in the manual were performed within the supervised classes to provide participants with the opportunity to complete the exercises under supervision, receive feedback on technique where necessary, and ask questions. This chapter also discussed the interaction between cancertreatment related side-effects and PA (e.g. lymphoedema, peripheral neuropathy, bone health) and advice regarding the structure, intensity and duration of an exercise session.

Chapter 3 (entitled "Let's Keep Going!") described solutions for overcoming barriers to PA participation and strategies that could be implemented (e.g. goal setting, action planning, enlisting social support) to support long-term PA adherence. To foster use of the PA manual and support initiation/continuation of independent PA, participants were encouraged to supplement their attendance at the supervised exercise classes, where appropriate, with at least one independent exercise session during weeks 4-8 of the programme. This recommendation was increased to  $\geq$ 2 independent exercise sessions, where appropriate, during weeks 9-12. At the end of the 12-week programme, participants were encouraged to use

the components from the independent PA programme to transition from the supervised classes to autonomous PA.

## SW-200 Yamax Digiwalker Pedometer

Each participant received an SW-200 Yamax Digiwalker pedometer (Yamax UK, Shropshire, United Kingdom) which they were encouraged to wear daily and to continue wearing following completion of the 12-week supervised exercise programme.

## Physical Activity Logbook

The PA logbook contained weekly templates for recording PA participation. The templates included prompts for the recording of the frequency, intensity, duration and type of PA performed as well as daily step count (as recorded by the pedometer). The template prompted participants to calculate their total weekly minutes of PA, record successes and challenges to PA participation experienced each week and develop a plan to address these challenges. The logbook also contained templates for setting and reviewing short-, medium- and long-term PA goals (at weeks 6, 10 and 20 of the intervention).

## Physical Activity Information Sessions

Participants were invited to attend four 30-minute PA information sessions, after a supervised exercise class, in week 0 (on Day 2 of assessment), 4, 6 and 10 of the 12-week programme. Sessions were delivered by an individual with expertise in chronic illness rehabilitation and motivational interviewing. Session 1 discussed the

benefits of PA for health, and issues and concerns for being physically active after cancer treatment. An overview of the MedEx IMPACT intervention was also presented and participants were given a welcome pack which included print materials from a National Cancer Charity regarding other health behaviours associated with reducing cancer risk, namely smoking cessation, reduced alcohol consumption, healthy eating and sun safety. During session 2 the participants were introduced to the PA manual, pedometer and PA log book. Session 3 focused on setting individualised PA goals, discussing challenges to PA participation and identifying solutions to overcome barriers that were identified. Finally, session 4 involved a review the PA goals set during session 3 and discussed strategies to support habitual PA and lapses in PA participation.

#### Exercise Consultation

Participants were invited to attend a 15 minute 1:1 exercise consultation during week 10, 11 or 12 of the 12-week programme. The consultation focused on developing an individualised action plan for PA to guide PA participation upon completion of the supervised exercise classes. Consultations were delivered by a team of 5 trained researchers with expertise in exercise consultation/prescription and oncology rehabilitation. In addition,  $\geq$ 2 of the consultations conducted by each researcher were audio recorded and reviewed to ensure protocol adherence.

All researchers adopted a motivational interviewing style. Prior to the consultation, participants were asked to complete a short investigator-developed questionnaire regarding PA preferences and interests (see Appendix M). Questions included "What times in your week would you like to do physical activity (e.g. walk

after work/on lunch break, structured classes 3 times a week, exercise at the weekends)?" and "Are there commitments in your weekly routine that would be important to consider when planning your physical activity?"

The consultations included discussion of:

- The responses given by participants to the investigator-developed questionnaire,
- Challenges to PA participation,
- Strategies to overcome barriers to PA participation,
- Setting a daily step count goal,
- The independent PA programme,
- Reviewing PA goals and amending where required,
- Development of a weekly plan for PA.

Following the consultations, individualized action plans were typed, laminated and distributed during the last supervised exercise class. A timeline of the components of the MedEx IMPACT intervention is presented in Table 6.2.

Table 6.2. The MedEx IMPACT intervention components and timeline
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	Twice-weekly supervised exercise classes	Physical activity manual (Used to supplement attendance at supervised exercise classes)†*	Pedometer (Worn daily)*	Physical activity logbook (Records kept daily)*	Physical activity information sessions	1:1 Exercise consultation††	Assessments of physical and psychological health
Week							
0					$\checkmark$		$\checkmark$
1	$\checkmark$						
2	$\checkmark$						
3	$\checkmark$						
4	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$		
5	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$			
6	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$		
7	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$			
8	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$			
9	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$			
10	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	
11	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$		$\checkmark$	
12	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$		$\checkmark$	$\checkmark$
24							$\checkmark$
52							$\checkmark$

<sup>†</sup> Participants were encouraged to supplement attendance at the supervised exercise classes with i)  $\geq$  1 independent exercise session(s) from week 4-8 (where appropriate), ii)  $\geq$  2 independent exercise sessions from week 9-12 (where appropriate).

<sup>++</sup> The exercise consultation took place in either week 10, 11 or 12.

\*Participants were encouraged to continue use of this component of the intervention following completion of the 12-week supervised exercise programme.

# 6.1.3.9 Outcomes

Table 6.3 provides a tabulated summary of the study flow including the study schedule, assessments and primary, secondary and tertiary outcomes.

# Table 6.3. Study flow

	Study Period						
Timeline	Enrolment	Baseline	3 mth	6 mth	12 mth		
Timepoint	Т0	T1	Т2	Т3	T4		
Enrolment:							
Eligibility screen	x						
Informed consent	x						
Demographic data	X						
Intervention:							
MedEx IMPACT Intervention							
Group		<b>♦</b>	<b></b>				
MedEx Move On Control		<b>♦</b>	•				
Group							
Assessments:							
Primary outcome:							
Physical activity							
Accelerometry		х	х	Х	х		
IPAQ		Х	х	х	х		
Secondary outcomes:							
Cardiorespiratory Fitness							
6-minute time trial		Х	Х	х	х		
Health-related quality of life							
FACT		Х	Х	х	х		
PHQ-8		х	х	х	х		
SWLS		х	Х	х	х		
SWEMWBS		х	х	х	х		
Sedentary behaviour		х	х	х	х		
Tertiary outcomes:							
Other components of							
physical fitness							
Body composition		Х	Х	х	х		
Strength		Х	Х	х	х		
Flexibility		Х	Х	х	х		
Fatigue		Х	Х	х	Х		

Timeline	Enrolment	Baseline	3 mth	6 mth	12 mth
Timepoint	Т0	T1	T2	Т3	T4
Exploratory outcomes					
Psychosocial determinants					
of physical activity					
Barriers specific self-		х	х	х	х
efficacy					
Self-regulatory self-					
efficacy for exercise					
Social support for		х	Х	х	Х
physical activity					
Intentions for physical		Х	Х	х	х
activity					
Process evaluation					
Attendance data		Х	Х	х	х
Intervention debrief				х	
questionnaire					
Intervention debrief focus				х	
groups					

Abbreviations: MedEx (Medical Exercise); IMPACT (Improve Physical Activity after Cancer Treatment); IPAQ (International Physical Activity Questionnaire) FACT (Functional Assessment of Cancer Therapy questionnaire); PHQ-8 (Patient Health Questionnaire); SWLS (Satisfaction with Life Scale); SWEMWBS (Short Warwick-Edinburgh Mental Well-being Scale)

## 6.1.3.9.1 Primary study outcome

# Physical activity levels

PA was objectively measured using six-day accelerometry (ActivPAL<sup>3</sup> Micro (PAL Technologies Ltd. Glasgow, Scotland)). The ActivPAL<sup>3</sup> Micro is a triaxial accelerometer that samples at 10 Hz for 15 second epochs. The device was covered with a water-resistant nitrile sleeve and attached to the midpoint of the anterior aspect of the right thigh using a 3M Tegaderm<sup>TM</sup> (Kooperationspartner Wundversorgung, Germany) film adhesive dressing. Participants wore the ActivPAL<sup>3</sup> Micro 24 hours a day from the time they received the device until they attended for Day 2 ( $\geq$  6 days later). Participants were instructed to perform their

usual activity and to remove the device only during full water immersion activities (i.e. swimming, bathing). Participants were given written and oral instructions regarding how to apply the monitor and contact information for the research team. On Day 2 of induction, the accelerometer data was downloaded and reviewed to ensure the wear-time criteria had been met (i.e.  $\geq$  4 valid days (incl. 1 weekend day)) (Trost, McIver & Pate, 2005). A valid day was defined as  $\geq$  600mins of recording during daytime hours (7am-11pm)) (Harrington, Dowd, Bourke & Donnelly, 2011). Non-wear time was defined as  $\geq$  60 minutes of consecutive zero accelerometer counts (Dowd, Harrington, Bourke, Nelson & Donnelly, 2012).

The ActivPAL<sup>TM</sup> proprietary software (ActivPAL<sup>TM</sup> Professionals VX) was used for the analysis, where algorithms classify activities into sitting/lying time, standing time, stepping time, step count and activity counts. Data was exported to Microsoft Excel (Microsoft Excel 2010, Microsoft Corporation, WA, USA) where data from each category (i.e. standing, stepping, etc.) was presented in 15 second epochs. The total time spent sitting/lying, standing and stepping was calculated by summing the values for each 24-hour period that the device was worn. Average values for each behaviour category were calculated. Moderate to vigorous PA was defined as  $\geq$  25 steps per 15 second epoch (Aoyagi & Shephard, 2010). Light-intensity PA was defined as activity performed <25 steps per 15 second epoch excluding sitting, lying and standing.

Where possible, participants were asked to wear the device on a second occasion if wear-time criteria were not met. The primary outcome measure was

indices of PA including weekly minutes of moderate-to-vigorous-, and lightintensity PA, and daily step count.

To facilitate comparison with the objective accelerometer data, participants were asked to complete the 7-day short International Physical Activity Questionnaire (IPAQ) (Ekelund et al., 2006). The results from the IPAQ are reported in categories of PA (i.e. low, moderate and high levels of PA) and as a continuous variable (MET-minutes-per-week).

#### 6.1.3.9.2 Secondary Outcomes

#### Cardiorespiratory Fitness (secondary study outcome #1)

CRF was assessed using the 6-minute time trial (6MTT) (Ayán-Pérez, Martínez-Lemos & Cancela-Carral, 2017; Bergmann et al., 2014). Participants were instructed to cover the greatest distance possible in 6 minutes while walking, running or a combination, between 2 cones on a flat indoor 20 m course. No warmup was permitted. Instructions for test participation were given to participants that were adapted from the American Thoracic Society guidelines for the 6-minute walk test (American Thoracic Society, 2002). The point on the course where the participant stopped was marked with a cone and the distance covered in the final partial lap was measured to the nearest metre. The total distance covered was calculated and recorded.

#### *Health-related Quality of life (secondary study outcome #2)*

HRQoL was measured using the Functional Assessment of Cancer Therapy-General (FACT-G) questionnaire (Cella et al., 1993). The 27-item instrument includes sub-scales of physical well-being (PWB), social well-being (SWB), emotional wellbeing (EWB) and functional well-being (FWB). Sub-scales scores are calculated by multiplying the sum of responses given to each item on a 5-point Likert scale, by the total number of items in the subscale. This score is divided by the number of items answered to yield the final score. Overall HRQoL is measured by calculating the sum of scores to the sub-scales. Individuals with a breast, prostate or colorectal cancer diagnosis also completed the additional scales from the relevant FACT questionnaires (i.e. FACT-B (breast), FACT-P (prostate), FACT-C (colorectal)) (Brady et al., 1997; Esper et al., 1997; Ward et al., 1999). Higher scores indicate greater quality of life.

In addition to the cancer-specific measure of HRQoL, global satisfaction with life was assessed using the Satisfaction with Life scale (SWLS) (Diener, Emmons, Larsen & Griffin, 1985) and mental well-being, focusing entirely on positive aspects of mental health, was assessed using the short Warwick-Edinburgh Mental Wellbeing scale (SWEMWBS) (Haver Akerjordet, Caputi, Furunes & Magee, 2015). The SWLS score is the product of the summed responses given by participants to 5 items on a 7-point Likert scale (1=strongly disagree, 7=strongly agree). The SWEMWBS is scored by first summing the score for each of the seven items and then transforming the total raw scores to metric scores using a conversion table. The Patient Health Questionnaire depression scale (PHQ-8) was used to assess

levels of depression (Kroenke et al., 2009). The score is the sum of the 8 items, where a score > 10 indicates major depression and a score  $\geq$ 20 indicates severe major depression.

#### Sedentary behaviour (secondary study outcome #3)

Sedentary behaviour characteristics were examined using a customized MATLAB<sup>®</sup> (version 7.0.1, The Mathworks Inc, Natick, MA, USA) software programme (Dowd, Harrington, Bourke, Nelson & Donnelly, 2012). The programme has been described elsewhere (Dowd, Harrington, Bourke, Nelson & Donnelly, 2012). In short, the programme analyses the ActivPAL data output file epoch by epoch and categorises bouts as sedentary or non-sedentary. Sedentary epochs are classified as a full epoch spent sitting/lying. Non-sedentary epochs are classified as <15 seconds of sitting/lying. The number and duration of total sedentary bouts per day was calculated.

## 6.1.3.9.3 Tertiary Outcomes

#### Body Composition

Height and weight were measured using a stadiometer and electronic scale (model 707 balance scales: Seca GmbH, Hamburg, Germany). BMI was calculated using the equation body mass in kilograms divided by squared height in metres. Waist and hip circumference measurements were taken by the same trained researcher at all time points. The waist circumference measurement was taken at approximately the midpoint between the last palpable rib and the top of the iliac

crest. The hip measurement was taken around the widest portion of the buttocks. Waist-to-hip ratio was calculated.

## Muscular strength

The 10-repetition sit-to-stand test was used to assess lower body strength (Csuka & McCarty, 1985). Participants completed the test twice and the fastest time taken to complete 10 sit-to-stands was recorded. A hand-held dynamometer was used to assess hand-grip strength in the dominant arm (Takei 5401 digital hand grip dynamometer, Takei Scientific Instruments Co. Ltd., Japan). The average of 3 attempts was recorded.

#### Flexibility

Flexibility was measured using a modified sit and reach test (Baumgartner, Jackson, Mahar & Rowe, 1995). Participants were asked to sit on a bench with their legs fully extended and feet flat against the sit and reach box (Eveque Leisure Equipment Ltd, Cheshire, UK). Participants were asked to flex forward to reach their fingertips as far as possible along the measurement scale. The best of 3 attempts was recorded.

# Fatigue

Fatigue was measured using the 13-item Functional Assessment of Chronic Illness Therapy – Fatigue scale (FACIT-F) (Yellen, Cella, Webster, Blendowski & Kaplan, 1997). Fatigue scores are calculated by summing the responses given to each item on a 5-point Likert scale. This number is multiplied by the total number of

items in the scale and divided by the number of items answered to yield the final score. Higher scores indicate higher HRQoL.

### 6.1.3.9.4 Exploratory outcomes

# Self-efficacy

Barriers specific self-efficacy for exercise was assessed using a validated 13item scale (McAuley, 1992). Participants rated their confidence regarding their capability to be physically active in the presence of common barriers (e.g. bad weather, exercising alone) on a Likert scale from 0 (not confident at all) to 100 (very confident). The mean score was calculated.

Self-regulatory self-efficacy for exercise was assessed using a modified 11item scale (Luszczynska & Sutton, 2006; Shields & Brawley, 2006). Questions focus on task, scheduling and recovery self-efficacy. Participants rated their confidence to be physically active on a Likert scale from 0 (not confident at all) to 100 (very confident). The mean score was calculated.

### Social support

Social support from family and friends for PA was assessed using a 10-item validated tool (Sallis, Grossman, Pinski, Patterson, & Nader, 1987). On a 1-5 Likert scale, participants rated the degree of social support for PA that they receive from family and friends. The mean score was reported with higher values indicating greater social support for PA.

#### Intentions

To assess intentions for PA and intentions to attend the community-based exercise programme, a modified 6-item measure was used (Sniehotta, Schwarzer, Scholz, & Schüz, 2005). Participants recorded their responses on a Likert scale ranging from 1 (completely disagree) to 4 (totally agree). A higher score indicated greater intentions for PA/attendance at the community-based exercise programme.

# 6.1.3.9.5 Process evaluation

### Attendance Data & Reflective Log

Objective attendance records were kept by one of the authors (MC) for all components of the intervention. A reflective log, maintained by MC throughout intervention delivery, documented logistical challenges regarding intervention implementation and evaluation.

### Intervention debrief questionnaire

All participants were asked to complete an intervention debrief questionnaire at 6-month follow-up (T3). The debrief questionnaire was used to develop an understanding of the participants' experiences and opinions regarding the intervention, and their independent PA participation, upon completion of the 12-week programme. The 25-item investigator-developed questionnaire aimed to explore participants' attitudes towards, and experiences of, each intervention component (e.g. participants are asked to rate their enjoyment of the programme and its overall effectiveness in increasing levels of PA on a 5-point Likert scale

(1=not at all, 5=extremely). Participants were also asked to complete a 26-item user experience questionnaire as described by Schrepp and colleagues (2017) which focused on the PA manual only. Each item on the questionnaire consists of a pair of opposite terms (e.g. not understandable, understandable; efficient, inefficient) which participants were asked to apply to the PA manual and rate on a 7-point scale. Participants expressed their agreement with the attributes by ticking the number that most closely reflected their impression. The questionnaire included 6 subscales that assess attractiveness, perspicuity, efficiency, dependability, stimulation and novelty of the PA manual. Raw data was entered into a data analysis tool in Microsoft Excel (Microsoft Excel 2010, Microsoft Corporation, WA, USA) and means and standard deviations per item were calculated.

# Intervention debrief focus groups

To further explore the feedback received from participants regarding their experiences of the intervention, 4 intervention debrief focus groups were conducted by a trained qualitative researcher (LL). The purpose of the focus groups was to gain an in-depth understanding of participants' experiences of each intervention component and how the programme could be optimised for future implementation. Purposive sampling was undertaken to recruit at least 16 male and female survivors of cancer across all ages.

### 6.1.3.10 Statistical methods

### Quantitative Analysis

Data was entered into SPSS statistics software (version 24) (IBM, New York, United States). Demographic and baseline characteristics of all participants will be summarized. Continuous variables will be reported as estimated marginal means ± standard error. Categorical variables will be reported as n and percentages. To investigate treatment effects (i.e. CG vs. IG) on dependent variables across the 3 time points, adjusted linear mixed model analyses of variance will be conducted. The Akaike Information Criterion (AIC) and the Bayesian Information Criterion (BIC) will be used as metrics to determine which covariance and model structure are most appropriate. Contrast estimates will be conducted as a post-hoc analysis. A two sided p value <0.05 will be used to determine statistical significance.

In an analysis of the exploratory outcomes, adjusted linear mixed model analyses of variance will be conducted that include social support- (from family and friends), intentions- and self-efficacy- (barrier and self-regulatory) for PA as covariates to investigate their effect on indices of PA, CRF and HRQoL.

# Qualitative Analysis

Audio material from the focus groups was transcribed verbatim. A thematic analysis as outlined by Braun and Clarke (2006) was conducted using NVivo qualitative data analysis software (version 10 for Windows) (QSR International UK Ltd., Cheshire, United Kingdom).

# 6.1.4 Discussion

In a recently published agenda for translating PA, nutrition and weight management interventions for survivors of cancer into clinical and community practice, Basen-Engquist and colleagues (2017) highlighted the need to expand D&I research to test models for service delivery of evidence-based interventions. Previous research had focused primarily on internal validity, with little attention to translation to real-world settings (Basen-Engquist et al., 2017). Indeed, a recent review of the National Cancer Institute's research portfolio of lifestyle interventions for individuals living with and beyond cancer highlighted the dearth of D&I research that is currently being conducted in this area (Alfano et al., 2015). This study aims to address this gap by evaluating the feasibility and effectiveness of delivering a PA BC intervention for survivors of cancer within a community-based setting. Findings from this research have the ability to have an immediate impact on programme delivery and therefore minimise the delay in optimising patient outcomes.

A limitation of previous research has been the use of subjective measures of PA, which are subject to multifarious bias, and short-term follow-up procedures, which inhibit assessment of intervention effectiveness on long-term PA adherence (Bourke et al., 2013; Turner et al., 2018). The significance of this research is further strengthened by the use of an objective measure of PA and the inclusion of long-term follow-up procedures.

To the authors knowledge, MedEx IMPACT is the first PA BC intervention for individuals living with and beyond cancer to be developed using the BCW and TDF, coupled with recommendations generated by survivors of cancer and statements of

findings distilled from a review of the literature. This unique approach to intervention development aims to ensure that the intervention is relevant and meaningful to the intended population, while also building upon findings from previous scientific literature to further advance our understanding of long-term adherence to PA for individuals living with and beyond cancer.

The inclusion of BC theory within exercise interventions is often viewed as essential (Turner et al., 2018) and has been proposed as a mechanism for optimising the effectiveness of BC interventions (Bluethmann, Bartholomew, Murphy & Vernon, 2017; Michie et al., 2005). BC theory can link relevant causal factors of the target behaviour to mechanisms of change, and can provide valuable insight into how theory integration within intervention design, implementation and evaluation may contribute to desired changes in the target behaviour (Bluethmann, Bartholomew, Murphy & Vernon, 2017; Keller, Fleury, Sidani & Ainsworth, 2009). Despite this, the application of BC theory is often poor, ambiguous and seldom analysed in the context of intervention effectiveness (Turner et al., 2018). A detailed analysis of how theoretical constructs and BCTs have been embedded within MedEx IMPACT has been documented and described in Chapter 5. An examination of the theoretical constructs will provide an insight into how changes in PA behaviour are mediated, and may provide valuable information for intervention designers by highlighting key constructs that should, or should not, be targeted within PA BC interventions for individuals living with and beyond cancer.

MedEx IMPACT aims to empower individuals living with and beyond cancer to become habitually physically active through the delivery of individual- and group-

based components that taper to self-directed PA. Intervention sustainability and cost-effectiveness were important considerations in the intervention development process and further work to conduct formal assessments of both is planned. Maximising intervention quality and effectiveness with a low-tech and moderatelyresource intensive community-based programme has been an important goal in designing this intervention.

The authors acknowledge that a limitation of this study is the absence of a non-exercise control group and randomisation procedures. As the study is being conducted within an existing exercise rehabilitation programme, withholding access to the service to facilitate a more rigorous study design would raise ethical concerns.

### 6.1.5 Conclusion

As the number of individuals living with and beyond cancer continues to grow, the need to identify effective PA BC interventions for this population and translate them into community settings has never been greater. Conducting intervention studies in this setting can provide actionable information that can be implemented with immediate effect and minimise the delay in optimising patient outcomes. The results of this study will provide such information and can inform the planning and provision of community-based exercise oncology rehabilitation programmes for survivors of cancer.

Chapter 7 Study 5

### 7.1 Study 5

Cantwell, M., Moyna, N., McCaffrey, N., Skelly, F., Loughney, L., Woods, C., Walsh, D., Dowd, K., McCarren, A., & & Furlong B., (2019). The feasibility and clinical effectiveness of a physical activity behaviour change intervention for individuals living with and beyond cancer.

**Statement of Contribution:** Prof. Niall Moyna, Dr. Bróna Furlong, Dr. Deirdre Walsh, Dr. Noel McCaffrey and Prof. Catherine Woods supervised this project, and were involved in the development of the study concept and research design, and in reviewing the manuscript. Dr. Lisa Loughney and Ms. Fiona Skelly assisted with data collection. Dr. Kieran Dowd and Dr. Andrew McCarren provided guidance on the statistical analysis of the data.

## 7.1.1 Abstract

Exercise has been advocated as an adjunct treatment for individuals living with and beyond cancer to support the optimisation of health and well-being and maximise HRQoL. However, most survivors of cancer are not sufficiently active to achieve the health benefits associated with regular PA. Few effective PA BC interventions for this population have been identified. This study reports the effects of the MedEx IMprove Physical Activity after Cancer Treatment (IMPACT) BC intervention on PA levels, CRF and HRQoL. One-hundred and ninety-one cancer survivors referred to a community-based exercise programme were recruited (control group (CG), n=87, intervention group (IG), n=104, mean age (± SD) 56 ± 10y, 73% female). CG and IG both received twice-weekly supervised exercise classes for 12 weeks. IG group also received an independent PA programme, 4 PA

information sessions and a 1:1 exercise consultation during the 12 week programme. Assessments of physical and psycho-social health, including 6-day accelerometry, the 6 minute time trial and the Functional Assessment of Cancer Therapy-General Quality of Life questionnaire, were conducted at baseline (T1), post-intervention (T2) and 3 months following programme completion (T3). The trial completion rate was 51%. Linear mixed-model analyses of variance demonstrated significant main effects for time for both groups from T1 to T2 with increases in self-report (p<0.01) and objectively measured PA (daily steps, LIPA, p<0.05), CRF (p<.001) and HRQoL (p<.01), which were maintained for self-report PA levels (p<.01) and CRF (p<.001) at T3. MedEx IMPACT augmented improvements by also maintaining increases achieved at T2 in steps, LIPA and HRQoL, at T3 (p<0.01). The results provide preliminary evidence of intervention effectiveness in increasing and maintaining improvements in cancer survivors' objectively measured PA levels, CRF and HRQoL. Further work is required before valid conclusions can be drawn.

# 7.1.2 Introduction

Treatment for cancer has been shown to negatively impact patients' physical and psycho-social well-being via decrements in a number of parameters including CRF and HRQoL (Ganz et al., 2002; Koch et al., 2013; Loughney & Grocott, 2016; Loughney et al., 2016; Loughney, West, Kemp, Grocott & Jack, 2018; Nayak et al., 2017; Peters, Mendoza Schulz & Reuss-Borst, 2016). These reductions, in conjunction with poor nutritional status, are associated with prolonged hospitalisation, greater levels of treatment-related toxicity and poorer prognosis (Loughney & Grocott, 2016; Loughney et al., 2016; Loughney et al., 2016; Loughney et al., 2016; Loughney, West, Kemp, Grocott

& Jack, 2018). Cardiotoxicity is an important complication of cancer treatment (Florescu, Cinteza & Vinereanu, 2013; Mehta et al., 2018) and is associated with increased morbidity and mortality (Harris, 2008). Recent data suggests that mortality among survivors of breast and prostate cancer is most likely to be attributable to CVD that occurs as a consequence of cancer treatment, infection following treatment or patients' general risk factor profile (Zaorsky et al., 2017).

PA has been advocated as an adjunct to cancer treatment to assist in the management of treatment related side-effects and support the optimisation of patient outcomes (Cormie et al., 2018). Indeed, exercise interventions have resulted in improvements in body composition, CRF, depression and HRQoL and reductions in the risk of cancer recurrence and mortality (Meneses-Echávez, González-Jiménez & Ramírez-Vélez, 2015; Rock et al., 2012; Schmitz et al., 2010; Spence, Heesch & Brown, 2010; Turner et al., 2018). It is recommended that survivors of cancer aim to engage in at least 150 minutes of moderate intensity PA each week in addition to 2 strength training sessions (Rock et al., 2012). The majority of individuals living with and beyond cancer do not meet these recommendations (Bourke et al., 2013; LeMasters, Madhavan, Sambamoorthi & Kurian, 2014; Liu et al., 2016; Rock et al., 2012; Turner et al., 2018). Findings from a recent systematic review indicate that few interventions have been effective in maintaining improvements in cancer survivors' objectively assessed, long-term PA levels (Turner et al., 2018). In addition, little is known about the factors that mediate changes in PA behaviour in this population (Bluethmann, Bartholomew, Murphy & Vernon, 2017; Finlay, Wittert & Short, 2018). As a result, the question of

how to support habitual PA participation in this population remains largely unanswered (Bluethmann, Vernon, Gabriel, Murphy & Bartholomew, 2015).

The need to develop and evaluate more effective PA BC interventions to increase PA levels in individuals living with and beyond cancer has recently been identified as a priority (Courneya, Rogers, Campbell, Vallance & Friedenreich, 2015). Research efforts in this area to date have focused on the recruitment of predominantly older survivors of breast cancer, employed self-report measures and conducted very little long-term follow-up (Bluethmann, Vernon, Gabriel, Murphy & Bartholomew, 2015; Haberlin et al., 2018; Stacey, James, Chapman, Courneya & Lubans, 2015). In addition, the translation of effective interventions from controlled research environments to real world settings has received limited attention within the scientific literature (Courneya, Rogers, Campbell, Vallance & Friedenreich, 2015). PA programmes are not routinely available as part of standard cancer care (Basen-Enquist et al., 2017), and it is likely that the lack of D&I research in this area has contributed to this absence. Indeed, the need for D&I research has also been highlighted as a research priority (Courneya, Rogers, Campbell, Vallance & Friedenreich, 2015)

The primary aim of this study was to investigate the effects of a patientcentred, evidence-based and theoretically-informed PA BC intervention (MedEx IMproved Physical Activity after Cancer Treatment (IMPACT)) for survivors of cancer. The MedEx IMPACT PA BC intervention was delivered within an existing community-based exercise rehabilitation programme called MedEx Move On (MMO). The study compared the effect of the MedEx IMPACT intervention to

MMO, on PA levels, CRF and HRQoL among survivors of cancer. It was hypothesised that the MedEx IMPACT intervention, when compared to MMO, would result in significantly greater increases in PA levels, CRF and HRQoL post-intervention (T2), and 3-months following intervention completion (T3). A secondary aim was to conduct an exploratory analysis to identify factors that influence changes in PA BC (e.g. social support-, intentions- and self-efficacy- for PA).

## 7.1.3 Methods

### 7.1.3.1 Study Design

The study protocol was presented in Chapter 6. In summary, this investigation utilised a two arm non-randomised comparison design consisting of an intervention group (IG) and a control group (CG). Survivors of cancer who had been referred to MMO were recruited at induction to the programme. As new groups of approximately 40-50 participants start the programme every 12 weeks, recruitment to the trial occurred in cycles aligned with programme commencement dates. Individuals referred to four separate 12-week cycles of the programme were invited to participate in the study (CG=2 cycles; IG=2 cycles). All participants provided written informed consent before study procedures were initiated.

# 7.1.3.2 Setting and participants

The study was conducted in the leisure centre on the Dublin City University (DCU) campus. To be included in the study, participants had to: i) be  $\geq$ 18 years of age, ii) have received a diagnosis of cancer and completed active treatment (e.g. chemotherapy, radiation therapy, surgery), iii) have received medical approval to

participate in an exercise programme by a healthcare professional and iv) have been referred to MMO. Exclusion criteria included: i) an uncontrolled cardiovascular condition, ii) a significant musculoskeletal or neurological condition, or iii) significant mental illness or intellectual disability that restricted participation in an exercise training programme. Ethical approval for the study was granted by the DCU Research Ethics Committee (DCUREC2014227; DCUREC2017128).

### 7.1.3.3 Control Group

Participants in the CG received 12 weeks of twice-weekly supervised exercise classes and assessments of physical and psycho-social health at baseline, post-intervention (T2) and 3 months following completion of the 12 week programme (T3). Classes were led by accredited exercise instructors who had experience in delivering exercise rehabilitation programmes. The classes were 60 minutes in duration and focused on a combination of aerobic and resistance exercise. Participants were instructed to exercise at moderate-to-vigorous intensity, where appropriate. The verbal descriptors associated with this prescription were to exercise at an intensity at which participants' felt moderately breathless, had a red face and were sweating. Assessments of physical and psycho-social health were conducted during 2 visits, that were separated by 6 days, and included measurement of indices of physical function (e.g. hRQoL, depression).

7.1.3.4 MedEx Improved Physical Activity after Cancer Treatment (IMPACT) intervention

The MedEx IMPACT intervention is a PA BC intervention designed to increase PA levels among cancer survivors. The development process and content of the intervention has been presented in Chapter 5. In brief, the intervention development process was guided and informed by: i) the MRC framework for the development, evaluation and implementation of complex interventions, ii) BCW, iii) the TDF, iv) findings from a review of the literature and v) recommendations generated by survivors of cancer.

In addition to 12 weeks of twice-weekly supervised exercise classes and assessments of physical and psycho-social health, participants in the MedEx IMPACT IG also received an independent PA programme which consisted of a PA manual, PA logbook and a pedometer (SW-200 Yamax Digiwalker Pedometer, Yamax UK, Shropshire, United Kingdom), 4 PA information sessions and a 1:1 exercise consultation. The PA information sessions were held during weeks 0, 4, 6 and 10 of the programme. The sessions focused on the benefits of PA for health and issues/concerns for PA participation following cancer treatment, an overview of the independent PA programme, PA goal setting and challenges to PA participation, and strategies to support long-term PA adherence. Upon receipt of the independent PA programme in week 4, participants were encouraged to supplement their attendance at the supervised exercise classes with independent PA and to progressively increase their levels of PA participation over the remaining 8 weeks of the programme. Participants were invited to attend a 15 minute 1:1

exercise consultation in week 10, 11 or 12 of the programme. The purpose of the consultation was to develop an individualised action plan for PA to support continued PA participation upon completion of the supervised exercise classes.

#### 7.1.3.5 Outcome Measures

Outcome measures were assessed at T1, T2 and T3. A detailed overview of the outcomes measures has been presented in Chapter 6. A summary is presented below.

# Primary Outcome Variable

The primary outcome measure was indices of PA, namely minutes of lightintensity PA (LIPA), minutes of moderate-to-vigorous PA (MVPA) and daily step count as measured by the ActivPAL<sup>3</sup> Micro accelerometer (PAL Technologies Ltd. Glasgow, Scotland). Total time spent in sedentary behaviour during waking hours (defined as 7am-11pm) was also assessed using data collected by the accelerometer. Self-reported PA was measured using the 7-day short International Physical Activity Questionnaire (IPAQ) (Ekelund et al., 2006).

## Secondary Outcome Variables

CRF was assessed using the 6-minute time trial (6MTT) (Bergmann et al., 2014; Ayán-Pérez et al., 2017). HRQoL was measured using the Functional Assessment of Cancer Therapy-General (FACT-G) questionnaire which includes subscales for the assessment of physical, social, functional and emotional well-being (Cella et al., 1993). Global satisfaction with life, mental well-being (focusing entirely on positive aspects of mental health) and levels of depression were assessed using

the Satisfaction with Life scale (SWLS), the short Warwick-Edinburgh Mental Wellbeing scale (SWEMWBS) and Patient Health Questionnaire depression scale (PHQ-8) respectively (Diener et al., 1985; Haver et al., 2015; Kroenke et al., 2009).

# **Exploratory Outcomes**

Barrier self-efficacy for PA was assessed using a 13-item scale as outlined by McAuley (1992). Self-regulatory self-efficacy for PA was assessed using a modified 11-item scale (Luszczynska & Sutton, 2006; Shields & Brawley, 2006). A modified 6-item measure was used to assess intentions for PA (Sniehotta, Schwarzer, Scholz, & Schüz, 2005). Social support from family and friends for PA was assessed using a validated 10-item tool (Sallis, Grossman, Pinski, Patterson, & Nader, 1987).

# Intervention Debrief Questionnaire

Participants' attitudes towards, and experiences of, each intervention component were assessed using a 25-item investigator-developed questionnaire. Participants were also asked to complete a 26-item user experience questionnaire as described by Schrepp and colleagues (2017) which focused on the PA manual only.

### 7.1.3.6 Sample size calculation and statistical analyses

G\*Power software (Faul, Erdfelder, Lang & Buchner, 2007) was used to perform the sample size calculation. A retention goal of 64 participants (or 32 per group) was set to facilitate detection of a small to medium effect size = 0.40 (p<0.05, power of 0.80).

The statistical analysis of the data was conducted using SPSS statistics software (version 24) (IBM, New York, United States). Descriptive statistics were conducted to summarize participants' demographic information and baseline characteristics. To investigate treatment effects (i.e. CG vs. IG) on dependent variables across the 3 time points, adjusted linear mixed model analyses of variance incorporating a diagonal or first-order autoregressive (AR1) covariance structure, and random intercept of within subject, were conducted. A vast array of covariance structures, from first-order ante-dependence (AD1) to variance components (VC), were implemented and the Akaike Information Criterion (AIC) and the Bayesian Information Criterion (BIC) were used as metrics to determine which covariance and model structure was most appropriate. The random intercept was removed if a non-significant value was reported by the estimates of covariance parameters (p>0.05). Parameter estimates were used to identify where differences occurred following a significant fixed effects value. Main and interaction effects were assessed. Contrast estimates were conducted as a post-hoc analysis to identify where significant main and/or interaction effects occurred. A two sided p value <0.05 was used to determine statistical significance. Where applicable, analyses were adjusted for covariates identified using univariate analyses. To test the hypothesised model, data were analysed using restricted maximum likelihood (REML).

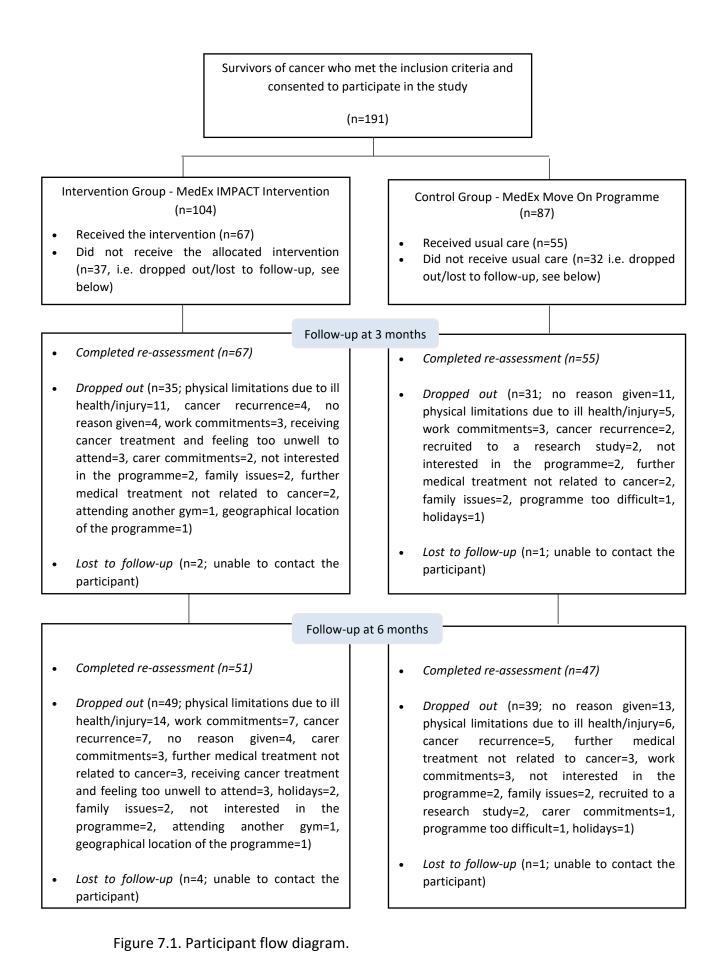
In an analysis of the exploratory outcomes, social support- (from family and friends), intentions- and self-efficacy- (barrier and self-regulatory) for PA were included as covariates in adjusted linear mixed model analyses of variance to

investigate their effect on indices of PA, CRF and HRQoL. Correlation analysis was first conducted to determine the strength of the relationship between these covariates. All variables were included as covariates within the model where results from the correlation analysis indicated that there was no strong correlation between the variables (i.e. correlation coefficient <0.7).

# 7.1.4 Results

#### 7.1.4.1 Participants

One-hundred and ninety-one survivors of cancer were referred to MMO between November 2015-April 2016 and September 2017-January 2018. All participants consented to participate in the study. Figure 7.1 presents the participant flow diagram. 51% of participants (n=98) completed the trial (CG, n=47; IG, n=51). Trial completion was defined by completion of the 6 month reassessment. Participant baseline characteristics are presented in Table 7.1. Participants' mean age was  $56 \pm 10.5$  years (CG =  $57 \pm 10.5$  yrs; IG =  $56 \pm 10.6$  yrs) and mean BMI was  $28.3 \pm 5.7 \text{ kg/m}^2$  (CG =  $28.2 \pm 5.2 \text{ kg/m}^2$ ; IG =  $28.4 \pm 6.0 \text{ kg/m}^2$ ). 73% of participants were female (CG = 70%; IG = 75%). Sixty per cent, 16%, 13% and 11% of participants had had a breast, colorectal, prostate or other cancer diagnosis respectively (CG = 57, 16, 16, 11%; IG = 63, 15, 10, 12%). CG and IG were from similar socioeconomic backgrounds. At baseline, CG had a statistically significant lower 6MTT score (mean difference = -33m), higher HRQoL (i.e., FACT-G (mean difference = +3.34), functional well-being (mean difference = +1.43) and emotional well-being (mean difference = +1.15) and spent less time in engaging in sedentary behaviour during waking hours (mean difference= -0.56h) when compared to IG.



Variable	Full Sample	MedEx IMPACT	Usual Care Control
	(n = 191)	Intervention	Group
		(n = 104)	(n = 87)
Age (years)	56 ± 10.5 (29-82)	56 ± 10.6 (36-79)	57 ± 10.5 (29-82)
Gender			
Male	52 (27.2)	26 (25)	26 (30)
Female	139 (72.8)	78 (75)	61 (70)
Weight (kgs)	78.7 ±17.6	78.3 ±17.8	79.1 ±17.4
BMI (kg/m2)	28.3 ±5.7	28.4 ±6.0	28.2 ±5.2
Waist to hip ratio	0.90 ±.09	0.9 ±.08	0.88 ±0.1
Education			
No education	1 (0.6)	0 (0)	1 (1.1)
Some primary (not completed)	4 (2.2)	3 (3.0)	1 (1.1)
Junior certificate or equivalent	12 (6.5)	8 (8.0)	4 (4.8)
Leaving certificate or equivalent	38 (20.5)	16 (16.0)	22 (25.8)
Diploma/certificate	57 (30.8)	30 (30.0)	27 (31.8)
Primary degree	24 (13.0)	13 (13.0)	11 (13.0)
Postgraduate/higher degree	48 (25.9)	29 (29.0)	19 (22.4)
Don't know	1 (0.5)	1 (1.0)	0 (0)
Present Principle status			
Working for payment or profit	78 (42.6)	46 (46.0)	32 (38.6)
Looking for first regular job	1 (0.5)	1 (1.0)	0 (0)
Unemployed	9 (4.9)	5 (5.0)	4 (4.8)
Student or pupil	1 (0.5)	0 (0)	1 (1.2)
Looking after home or family	14 (7.7)	7 (7.0)	7 (8.4)
Retired from employment	47 (25.7)	23 (23.0)	24 (28.9)

Table 7.1. Baseline participant characteristics for the full sample and by study group.

Unable to work due to permanent sickness	13 (7.1)	7 (7.0)	6 (7.2)
or disability			
Other	20 (10.9)	11 (11.0)	9 (10.8)
Distance from the CBERP (kms)	13.7 ±14.2	13.45 ±14.87	14.03 ±13.43
Marital status			
Married	124 (67.0)	68 (68.0)	56 (65.8)
Living with partner	9 (4.9)	4 (4.0)	5 (5.9)
Single (never	31 (16.8)	17 (17.0)	14 (16.5)
married)			
Separated	6 (3.2)	4 (4.0)	2 (2.4)
Divorced	8 (4.3)	5 (5.0)	3 (3.5)
Widowed	7 (3.8)	2 (2.0)	5 (5.9)
Cancer Diagnoses			
Breast	114 (60.3)	65 (63.1)	49 (57.0)
Colorectal	30 (15.9)	16 (15.5)	14 (16.2)
Prostate	24 (12.7)	10 (9.7)	14 (16.2)
Other	21 (11.1)	12 (11.7)	9 (10.6)
Presence of Other Chronic Conditions			
Heart disease	12 (6.4)	7 (6.7)	5 (5.7)
Chronic bronchitis, emphysema or chronic obstructive pulmonary disease	3 (1.6)	2 (2.0)	1 (1.1)
Other lung disease	3 (1.6)	1 (1.0)	2 (2.2)
Asthma	9 (4.8)	4 (3.9)	5 (5.7)
Type 2 diabetes	5 (2.7)	4 (3.9)	1 (1.1)
Type 1 diabetes	1 (0.5)	0 (0)	1 (1.1)
Depression	11 (5.9)	6 (5.9)	5 (5.7)
Anxiety or other emotional mental health condition	14 (7.5)	8 (7.8)	6 (6.9)

21 (11.3)	14 (13.7)	7 (8.0)
30 (16.0)	18 (17.6)	12 (13.8)
7 (4.0)	4 (4.2)	3 (1.2)
127 (66.5)	70 (67.3)	57 (65.5)
2 ±2	2 ±1	2 ±2
3.2 ±2.7	3.2 ±2.8	3.2 ±2.6
4 ±1	4 ±1	4 ±1
2 ±1	2 ±1	2 ±1
	30 (16.0) 7 (4.0) 127 (66.5) 2 ±2 3.2 ±2.7 4 ±1	$30 (16.0)$ $18 (17.6)$ $7 (4.0)$ $4 (4.2)$ $127 (66.5)$ $70 (67.3)$ $2 \pm 2$ $2 \pm 1$ $3.2 \pm 2.7$ $3.2 \pm 2.8$ $4 \pm 1$ $4 \pm 1$

Note: Continuous variables are displayed as mean ± standard deviation; age is displayed as mean± standard deviation (range); Categorical variables are presented as n (%); CBERP=community-based exercise rehabilitation programme

# 7.1.4.2 Adherence

Adherence to the supervised exercise classes, defined as the mean percentage of classes attended (from a maximum of twice-weekly classes for 12 weeks), was 66% (±25%) (CG=67±22%; IG=66±27%). Eighty-seven per cent of IG participants received the independent PA programme and 68% attended the 1:1 exercise consultation. On average, participants attended 3 of out 4 (75%) of the PA information sessions. A little over one third (36%, n=37) of IG participants were classified as not having received the allocated intervention according to the following criteria:

- did not attend ≥50% of the supervised exercise classes, and/or
- did not attend ≥50% PA information sessions, and/or
- did not receive the independent PA programme, and/or
- did not attend the 1:1 exercise consultation.

Table 7.2 presents an overview of the results for physical and psycho-social outcomes at T1, T2 and T3.

Variable	Time Point	Estimate	Standard Error	df	t value	P value
Steps	T1-T3	-1125.94	411.40	98.41	-2.74	.007*
	T2-T3	-345.09	404.57	91.71	-0.85	.396
LIPA	T1-T3	-0.17	0.06	103.90	-2.99	.003*
	T2-T3	-0.07	0.06	71.98	-1.37	.176
MVPA	T1-T3	-3.61	2.36	92.99	-1.53	.130
	T2-T3	-0.49	2.38	107.13	-0.21	.837
IPAQ Met-min per week	T1-T3	-1497.89	364.39	91.13	-4.11	.000*
	T2-T3	-8.14	455.63	123.53	-0.02	.986
Total sedentary behaviour <sup>+</sup>	T1-T3	-0.04	0.22	91.62	-0.19	.848
	T2-T3	-0.06	0.22	96.33	-0.27	.788
6 minute time trial score	T1-T3	-93.48	10.64	155.91	-8.79	.000*
	T2-T3	-15.75	9.22	64.06	-1.71	.092
FACT-G	T1-T3	-6.00	1.58	113.924	-3.79	.000*
	T2-T3	0.63	1.50	74.38	0.422	.674
Physical well-being	T1-T3	-2.94	0.50	153.91	-5.86	.000*
	T2-T3	-0.43	0.46	85.16	-0.94	.352
Emotional well-being	T1-T3	-1.69	0.43	144.26	-3.92	.000*
	T2-T3	0.11	0.34	94.76	0.32	.752
Functional well-being	T1-T3	-2.29	0.57	97.69	-4.01	.000*
	T2-T3	-0.03	0.67	88.52	-0.06	.954
Social well-being	T1-T3	0.02	0.48	113.36	0.05	.964
	T2-T3	0.14	0.47	97.63	0.30	.763

- rapic 7.2. Jummary of parameter countails, standard ciror, and t and p values for physical and povent outcomes across t	Table 7.2. Summary of parameter	r estimates. standard error.	df. and t and p values for ph	physical and psycho-social outcomes across tim
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Note: T1=baseline; T2= 3 month follow-up; T3= 6 month follow-up

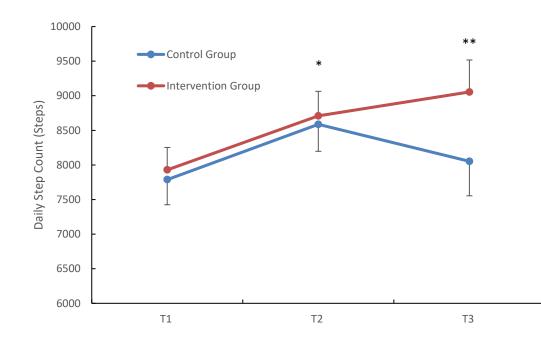
<sup>+</sup> Indicates total sedentary time during the waking hours of 7 am-11 pm

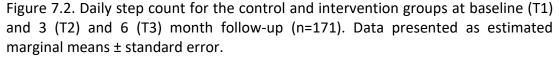
\*Denotes statistically significant results

### 7.1.4.3 Primary Outcome Variable: Physical Activity Levels

There was no statistically significant difference for any of the objectively (i.e. steps, LIPA, MVPA) or subjectively (i.e. IPAQ MET-minutes per week score) measured PA variables (p>0.05) between CG and IG across the 3 time points.

Statistically significant main effects for time were found for CG and IG for both steps (Figure 7.2) and LIPA (Figure 7.3), with improvements occurring from T1 to T2 for both CG and IG (CG: steps, p=0.015, LIPA, p=0.020; IG: steps, p=0.007, LIPA, p=0.008), and for IG from T1 to T3 (steps, p=0.007; LIPA, p=0.003). There was no significant change in step count or LIPA between T2-T3 in IG. No significant main effects or interactions were found for MVPA in both CG and IG. Estimated marginal means (± standard error) for all PA variables are presented in Appendix N.





\*Denotes a statistically significant main effect for time for both groups from T1-T2

\*\*Denotes a statistically significant main effect for time for the IG only from T1-T3

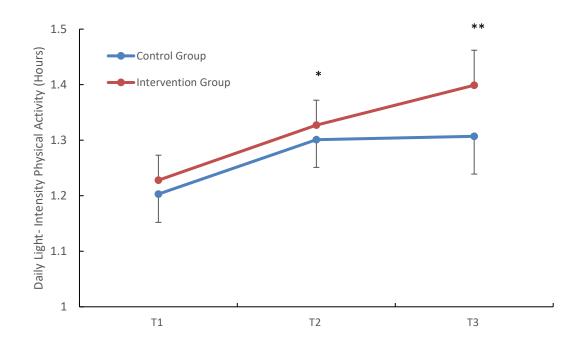


Figure 7.3. Daily hours of light-intensity physical activity for the control and intervention groups at baseline (T1), and 3 (T2) and 6 (T3) month follow-up (n=171). Data presented as estimated marginal means ± standard error. \*Denotes a statistically significant main effect for time for both groups from T1-T2 \*\*Denotes a statistically significant main effect for time for the IG only from T1-T3

IPAQ MET-min per week score was significantly elevated for the CG and IG from T1 to T2 (CG, p=0.003; IG, p=0.000), and T1 to T3 (CG, p=0.001; IG, p=0.000) (Figure 7.4). Estimated marginal means (± standard error) for IPAQ MET-min per week scores are presented in Appendix N.

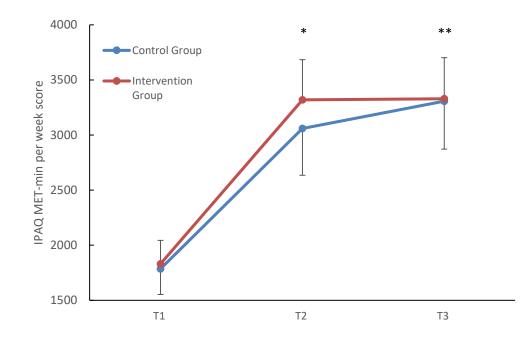


Figure 7.4. IPAQ-MET min per week score for the control and interventions groups at baseline (T1) and 3 (T2) and 6 (T3) month follow-up (n=176). Data presented as estimated marginal means ± standard error.

\*Denotes a statistically significant main effect for time for both groups from T1-T2

\*\*Denotes a statistically significant main effect for time for both groups from T1-T3

The percentage of participants classified as insufficiently active, minimally active and HEPA active at T1, T2 and T3, according to IPAQ categorical scores, are presented in Table 7.3. The percentage of participants classified as insufficiently active decreased in both CG and IG from T1 to T3 (CG, T1=27.0%, T3=14.7%; IG, T1=34.0%, T2=2.1%). The percentage of participants classified as minimally active decreased in both CG and IG from T1 to T3 (CG, T1=57.0%, T3=41.2%; IG, T1=47.9%, T3=42.6%). The percentage of participants classified as HEPA active increased in both CG and IG from T1 to T3 (CG, T1=57.0%, T3=41.2%; IG, T1=47.9%, T3=42.6%). The percentage of participants classified as HEPA active increased in both CG and IG from T1 to T3 (CG, T1=57.0%, T3=41.2%; IG, T1=47.9%, T3=42.6%).

	Т	1	Т2		Т3		
	CG (n=79)	IG (n=94)	CG (n=43)	IG (n=59)	CG (n=34)	IG (n=47)	
Insufficiently Active†	27.0 (21)	34.0 (32)	4.7 (2)	3.4 (2)	14.7 (5)	2.1 (1)	
Minimally Active <sup>++</sup>	57.0 (45)	47.9 (45)	58.1 (25)	45.8 (27)	41.2 (14)	42.6 (20)	
HEPA Active +++	16.0 (13)	18.1 (17)	37.2 (16)	50.8 (30)	44.1 (15)	55.3 (26)	

Table 7.3. IPAQ Categorical Scores for the control and intervention groups at baseline (T1) and months 3 (T2) and 6 (T3).

Variables presented as % (n).

CG= Control Group; IG=Intervention Group

*†* Individuals who do not meet the criteria listed below for 'minimally active' and 'HEPA active' are considered insufficiently active

*††* Minimally active is defined as 3 or more days of vigorous activity of at least 20 minutes per day, or 5 or more days of moderate-intensity activity or walking of at least 30 minutes per day, or 5 or more days of any combination of walking, moderate-intensity or vigorous intensity activities achieving a minimum of at least 600 MET-min/week.

*t+t* HEPA (health-enhancing physical activity) active is defined as 'vigorous-intensity activity on at least 3 days achieving a minimum of at least 1500'MET-minutes/week, or '7 or more days of any combination of walking, moderate-intensity or vigorous intensity activities achieving a minimum of at least 3000 MET-minutes/week'

### 7.1.4.4 Sedentary Behaviour

There was no statistically significant interaction (p=0.772) or main effects

(time, p=0.579; treatment, p=0.118) found for time spent engaging in sedentary

behaviour during the waking hours. Estimated marginal means (± standard error)

for time spent in sedentary behaviour are presented in Appendix N.

### 7.1.4.5 Secondary Outcome Variables

## Cardiorespiratory Fitness

There was no statistically significant difference between CG and IG for 6MTT score at any time. Performance in the 6MTT increased significantly from T1 to T2

(p<0.001), and T1 to T3 (p<0.001) for both CG and IG (Figure 7.5). There was no significant difference in 6MTT in CG and IG between T2 and T3.

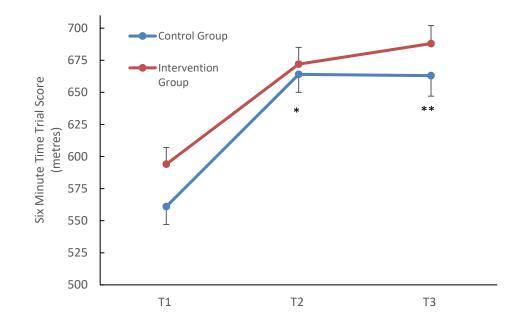


Figure 7.5. Six minute time trial score for the control and intervention groups at baseline (T1) and 3 (T2) and 6 (T3) month follow-up (n=182). Data presented as estimated marginal means  $\pm$  standard error.

\*Denotes a statistically significant main effect for time for both groups from T1-T2

\*\*Denotes a statistically significant main effect for time for both groups from T1-T3

Health-related Quality of Life

There was no significant difference between CG and IG for total FACT-G or physical-, emotional- or functional- well-being subscales across the 3 time points. FACT-G score increased significantly from T1 to T2 for both groups (p<0.001) and from T1 to T3 for IG (p<0.001) (Figure 7.6).

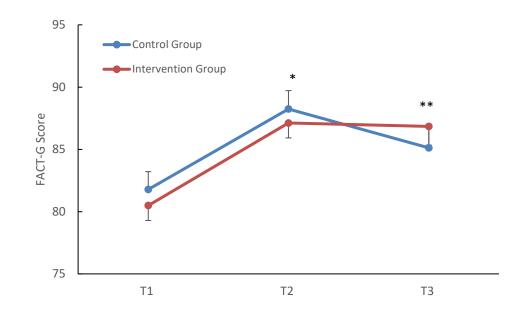


Figure 7.6. FACT-G score for the control and intervention groups at baseline (T1) and 3 (T2) and 6 (T3) month follow-up (n=158). Data presented as estimated marginal means  $\pm$  standard error.

Note: Higher scores indicate a greater quality of life.

\*Denotes a statistically significant main effect for time for both groups from T1-T2

\*\*Denotes a statistically significant main effect for time for the intervention group from T1-T3

Statistically significant main effects for time were identified from T1 to T2 (p<0.01), and T1 to T3 (p<0.01) for physical- and emotional- well-being for both CG and IG. A statistically significant main effect for time for functional well-being was observed from T1 to T2 for both groups (p<0.01), and from T1 to T3 for IG (p<0.001). Functional well-being was not significantly different between T2-T3 for IG. Social well-being scores increased significantly in CG from T1 to T2 (p<.05). Estimated marginal means (± standard error) for CG and IG for FACT-G and associated subscales are presented in Appendix N.

# 7.1.4.6 Other Secondary Outcome Variables

A summary of the results for satisfaction with life, positive mental wellbeing and depression scores are presented in Table 7.4. Main effects for time were observed for both groups from T1 to T2, and T1 to T3 with improvements occurring across all measures. No significant interaction or main effects for treatment were found.

Table 7.4. Results from adjusted linear mixed models analyses of variance that assessed changes in satisfaction with life, mental wellbeing and depression scores for the control and intervention groups across the 3 time points (i.e. baseline (T1) and 3 (T2) and 6 (T3) month follow-up).

	Time Point	Estimate	Standard Error	Df	t value	p value	CG: T1	CG: T2	CG:T3	IG: T1	IG: T2	IG:T3
			-						++++			
SWLS†	T1-	-2.27	0.66	126.61	-3.42	.001*						
	Т2						_ 24±.08	25±0.8	26±0.9	23±0.7	26±0.7	25±0.7
	T2-	0.94	0.58	95.66	1.61	.111*	- 24±.08	2510.8	2010.9	2310.7	2010.7	2510.7
	T3	1.00	0.54	100.25	2.11	002*						
SWEMWBS++	T1- T2	-1.69	0.54	106.25	-3.11	.002*	26±0.5	28±0.6	28±0.7	25±0.5	28±0.5	27±0.6
	T2- T3	0.72	0.56	106.70	1.29	.202*	_					
PHQ-8+++	T1- T2	2.35	0.61	106.41	3.853	.000*	6±0.6	4±0.5	4±0.6	6±0.5	3±0.5	4±0.6
	T2- T3	-4.90	0.53	97.98	-0.92	.358*	_					

Abbreviations: SWLS= Satisfaction with Life Scale Score; SWEMWBS= Short Warwick-Edinburgh Mental Well-being Scale Score; PHQ-8= Patient Health Questionnaire Depression Score

\*Results from contrasts tests showed a main effect for time for both groups from T1 to T2, and T1 to T3.

*†Scores of 20-24 indicate average life satisfaction; scores of 25-29 indicates high satisfaction with life;* 

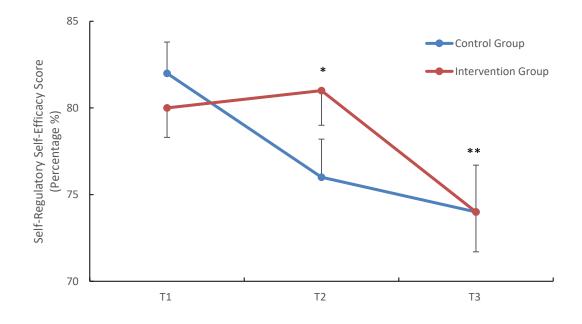
*tt* Higher scores indicate higher positive mental well-being;

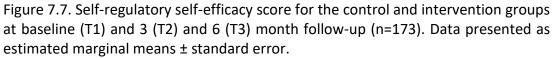
*t+t* Score of  $\geq$ 10 indicates major depression,  $\geq$ 20 indicates severe major depression.

*++++* Values for the CG and IG across the 3 time points are presented as estimated marginal means *±* standard error.

# Self-regulatory self-efficacy

A statistically significant interaction effect was observed for self-regulatory self-efficacy for PA (p=0.018). IG participants' self-regulatory self-efficacy increased from T1 to T2, while CG participants' self-regulatory self-efficacy decreased during this time. Both groups' scores had decreased to lower than baseline levels at T3 (Figure 7.7).





Note: Scale: 0% - not at all confident, 50%-moderately confident, 100% - highly confident \*Denotes a statistically significant main effect for time for the CG only from T1-T2 \*\*Denotes a statistically significant main effect for time for both groups from T1-T3

# Barrier self-efficacy

No statistically significant interaction or main effects were observed for CG

or IG across the 3 time points (p>0.05) (Table 7.5).

# Social Support

No significant interaction or main effects were identified for social support from family for PA (Table 7.5). Participants rated their perceived social support from family for PA as low, with family 'rarely' to 'a few times' providing support for PA within the last 3 months.

Social support from friends for PA increased significantly (p<0.05; Table 7.5) in both CG and IG from T1 to T2. Participants rated their perceived social support from friends for PA as low, with friends 'rarely' to 'a few times' providing support for PA within the last 3 months.

### Intentions

Intentions to be physically active decreased in both groups from T1 to T3 (p<0.05), and from T1 to T2 for IG (p=0.042) (Table 7.5). Mean intentions for PA score indicates that participants in both groups had intentions to be physically active.

Table 7.5. Results from the linear mixed models of analyses of variance that assessed changes in intentions for PA and indices of selfefficacy and social support for PA for the control and intervention groups across all 3 time points (i.e. baseline (T1) and 3 (T2) and 6 (T3) month follow-up).

	Interaction Effect	Main Effect	Main Effect Time	CG: T1	CG: T2	CG:T3	IG: T1	IG: T2	IG:T3
	(p value)	Treatment (p value)	(p value)			+++-	ŧ		
Self- regulatory self-efficacy for PA†	p<.05	-	p<.01*	82.1±1.8	75.5±2.2	73.7±2.7	79.7±1.7	81.1±2.0	73.9±2.3
Barrier self- efficacy for PA†	-	-	-	60.3±2.3	58.5±2.6	56.6±3.0	60.0±2.1	57.7±2.3	62.7±2.6
Social Support for PA - Family††	-	-	-	2.5±0.127	2.7±0.142	2.5±0.166	2.7±0.117	2.7±0.128	2.7±0.141
Social Support for PA - Friends <sup>++</sup>	-	-	p<.05**	2.2±0.127	2.6±0.143	2.3±0.161	2.3±0.114	2.6±0.128	2.5±0.139
Intentions for PA+++	-	-	p<.05**/***	3.6±.05	3.5±0.06	3.2±0.07	3.5±0.05	3.4±0.06	3.3±0.06

<sup>†</sup>Scale: 0% - not at all confident, 50%-moderately confident, 100% - highly confident

*tt* Scale: 1=none, 2=rarely, 3=a few times, 4=often, 5=very often

*ttt* Scale: 1=completely disagree, 2=disagree, 3=agree, 4=totally agree

*++++Values for the CG and IG across the 3 time points are presented as estimated marginal means ± standard error.* 

\*A main effect for time for the CG from T1 and T2, and for the IG from T1 to T3 was observed; \*\*A main effect for time for both groups from T1 to T2 was

observed; \*\*\*A main effect for time for the intervention group from T1 to T3 was observed.

Influence of exploratory outcomes on changes in PA levels, CRF and HRQoL

No strong correlations (i.e. >0.7) were identified between social support from family or friends, intentions, or barrier- or self-regulatory- self-efficacy for PA. Results from linear mixed model analyses of variance found that none of these exploratory variables influenced the change in LIPA or steps that occurred from baseline to 3 and 6 month follow-up. The change in self-regulatory self-efficacy for PA was shown to significantly influence minutes of MVPA (p=0.014), 6MTT (p=0.038) and FACT-G score (p=0.003) over time.

#### 7.1.4.8 Intervention Debrief Questionnaire

The intervention debrief questionnaire was completed by all IG participants who completed 6 month re-assessment (n=51). Eighty-four percent of participants reported that they extremely enjoyed taking part in the MedEx IMPACT intervention. Findings regarding participants' self-reported use/non-use of intervention components are reported in Table 7.6. The pedometer was the intervention component that was used most by participants with 42.2% of participants reporting daily use. The PA action plan and PA manual were the intervention components used least by participants. Twenty percent of participants reported never using the PA manual.

	Yes	% (n)		No % (n)		
Did you use the:						
Pedometer	84.0	(42)	16.0 (8)			
Physical	82.4	(42)	17.6 (9)			
activity						
logbook						
Physical	74.5	(38)	25.5 (13)			
activity						
manual						
Physical	67.3	(33)	32.7 (16)			
activity						
action plan						
In a typical	Never	Once	Sometimes	Almost	Everyday	
week, how				everyday		
often did you						
use the: % (n)						
Physical	20.0 (9)	24.4 (11)	48.9 (22)	6.7 (3)	0.0 (0)	
activity				. ,	( )	
manual						
Physical	8.5 (4)	6.4 (3)	12.8 (6)	38.3 (18)	34.0 (16)	
activity	. ,			. ,	. ,	
logbook						
Pedometer	6.7 (3)	2.2 (1)	6.7 (3)	42.2 (19)	42.2 (19)	

Table 7.6. Participants self-reported use of intervention components (n=51).

Fifty-eight percent of participants stated that the intervention was extremely helpful in supporting them to be regularly physically active. This was followed by 30%, 8% and 4% of participants who rated the intervention as 'quite a bit', 'moderately' and 'a little bit' helpful in supporting regular PA participation respectively. The supervised exercise classes, assessments at months 3 and 6 and the pedometer were reported as the most helpful in supporting regular PA participation (Table 7.7).

	Extremely helpful	Very helpful	Moderately helpful	A little bit	Not at all
				helpful	helpful
			% (n)		
Supervised exercise	84.0 (42)	16.0 (8)	0.0 (0)	0.0 (0)	0.0 (0)
classes					
Re-Assessments at 3	68.0 (34)	26.0 (13)	4.0 (2)	2.0 (1)	0.0 (0)
and 6 months					
Pedometer	52.0 (26)	30.0 (15)	12.0 (6)	0.0 (0)	6.0 (3)
1:1 Exercise	42.9 (21)	32.7 (16)	12.2 (6)	6.1 (3)	6.1 (3)
Consultation					
Physical activity	34.0 (17)	32.0 (16)	16.0 (8)	12.0 (6)	6.0 (3)
logbook					
Physical Activity	30.6 (15)	49.0 (24)	14.3 (7)	4.1 (2)	2.0 (1)
Information					
Sessions					
Physical activity	16.3 (8)	30.6 (15)	32.7 (16)	14.3 (7)	6.1 (3)
manual					

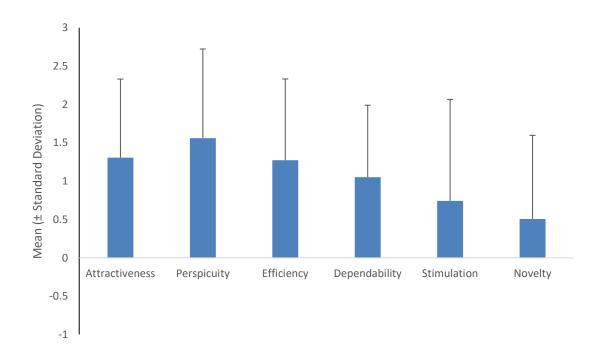
Table 7.7. Participant rating of how helpful each intervention component was in supporting regular physical activity participation (n=51).

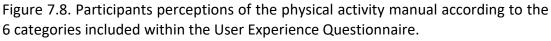
# Participants' experiences of the intervention components

# Participant feedback regarding the PA manual

Participants were asked, via an open-ended question, what they liked and disliked about the PA manual. Participants stated that the manual was a good resource that was easy to follow and included helpful illustrations. Participants said it was: i) a good reminder of the different exercises that were completed in the structured exercise classes, including the correct technique for each exercise, ii) provided a useful alternative for PA on days of poor weather, iii) helped to keep participants focused and 'stay on track', particularly after periods of reduced PA, and iv) provided a good home-based solution for PA participation.

The most commonly reported challenge by participants in using the PA manual was having to keep referring to it while completing the exercises. Respondents found it difficult to record the timing of each exercise. This interrupted the momentum of the session. Participants reported finding it difficult to motivate themselves to use the manual. Figure 7.8 presents the findings from the User Experience Questionnaire (UEQ) for the PA manual. Participants reported positive evaluations of the PA manual for the categories of attractiveness, perspicuity, efficiency and dependability. Neutral evaluations were reported for the manual under the categories of stimulation and novelty.





\*Note: Values between -0.8 and 0.8 represent a more or less neural evaluation of the corresponding scale, values > 0.8 represent a positive evaluation, values <-0.8 represent a negative evaluation.

Participants gave a positive evaluation of the manual with regard to its pragmatic quality which describes task-related quality aspects (score=1.30, which

was calculated using mean values from the scales of perspicuity, efficiency and

dependability). The manual received a neutral hedonic quality score (score=0.63, which was calculated using mean values from the scales of stimulation and novelty), which refers to non-task related quality.

# Participant feedback regarding the physical activity logbook

Participants reported that the PA logbook helped participants to keep focused and 'on track' with regard to their PA participation. Participants stated that it was a helpful, motivational tool that provided information on progress achieved and gave participants a feeling of accountability.

Regarding the challenges involved in using the PA logbook, participants reported that it became tedious and felt like 'a chore' at times. Some participants found it challenging to remember to fill it in and did not find it motivating.

## Participant feedback regarding the pedometer

Participants reported that the pedometer was a beneficial motivational tool which was helpful in providing feedback regarding PA levels and acted as a prompt for when PA levels were low. Participants disliked that the pedometer was not always practical to wear (e.g. could not be worn with dresses) and the accuracy of the readings was sometimes questioned.

## Participant feedback regarding the physical activity information sessions

Participants reported that the PA information sessions were educational and informative and delivered within a supportive, reassuring and encouraging environment. Participants found the sessions motivational as they helped to keep the focus on and reinforce why PA is important for health. They also assisted in focusing PA goals. One participant felt that the sessions were not relevant to them as they were already regularly physically active. When asked how the sessions could be optimised for future delivery, the number one recommendation was the inclusion of a nutrition element within the programme.

# Participant feedback regarding the 1:1 exercise consultation

Participants found that the 1:1 exercise consultation and the action plan that was developed as part of this session provided a helpful goal and maintained focus on PA. The participants liked the individualised, realistic and achievable nature of the action plans that were set in these sessions. Two participants reported that their expectation with regard to PA was unrealistic due to work and other commitments and that this influenced the action plans they had set during this session.

### Participant feedback regarding the re-assessments

Participants reported that the re-assessments at 3 and 6 months motivated them to increase/maintain their efforts with regard to PA and to keep going to try to maintain/improve their fitness results. Participants found that the reassessments kept them focused on PA upon completion of the supervised exercise classes. Ten percent of participants (n=5) said that the re-assessments had little-tono-impact on their PA levels.

## Recommendations to optimise future intervention delivery

Participants offered suggestions via an open-ended question regarding how the intervention could have been optimised for them or for other individuals who may take part in the future. The top three recommendations were, in order of popularity (i.e. most commonly cited by participants), i) provide participants with a DVD of the structured exercise classes, ii) share videos of the structured exercise classes with participants via an online platform (e.g. Youtube) and iii) provide more individualised exercise prescription within the group-exercise classes.

# 7.1.5 Discussion

The MedEx IMPACT intervention is novel in its development in that it was based on the integration of findings, generated from a synthesis of recommendations from survivors of cancer and a review of the scientific literature. In addition, it was underpinned by the MRC framework, the BCW and the TDF. This approach ensured that the intervention was patient-centred, evidenced-based and theoretically-informed. MedEx IMPACT is also the first PA BC intervention for survivors of cancer to be developed using this approach and subsequently implemented and evaluated in a real world setting among a diverse cohort of individuals living with and beyond cancer.

The similar increases in daily step counts, LIPA, self-report PA levels, CRF and HRQoL in both CG and IG at week 12 indicates that the identified improvements were attributable to participation in the twice-weekly supervised exercise classes. The improvements achieved in self-report PA levels and CRF at the end of the 12

week programme were maintained for both groups at the 6 month follow-up. The inclusion of the BC intervention components maintained improvements in daily step counts, LIPA and HRQoL, in IG at 6 months. While no statistically significant differences in the primary and secondary outcome variables were identified between CG and IG at either of the follow-up time points, the findings presented provide preliminary evidence of the effectiveness of the MedEx IMPACT intervention in augmenting improvements achieved following participation in an exercise rehabilitation programme, through the additional maintenance of improvements in objectively measured levels of PA and HRQoL among survivors of cancer. While no statistically significant differences were observed between CG and IG for MVPA, IG participants on average were closer to achieving the recommended 30 minutes of MVPA per day at 6 months than the CG (CG, T3=23.8±2.7 min; IG=T3=28.5±2.5).

### 7.1.5.1 Intervention adherence

On average, participants attended  $66(\pm 25)\%$  of the supervised exercise classes during the 12 week programme, with similar rates of adherence being reported for the additional intervention components. Similar rates of adherence to supervised exercise classes delivered within community-based settings have also been reported (Santa Mina et al., 2017). Higher rates of adherence to supervised PA sessions ( $\geq$ 80%) have been reported for PA interventions delivered within controlled research environments (Al-Majid, Wilson, Rakovski & Coburn, 2015; Cantarero-Villanueva et al., 2012; Kampshoff et al., 2016).

Levels of PA participation can be influenced by cancer type, cancer treatment received, presence of treatment-related side-effects and stage of the cancer journey (Chung et al., 2013; Coups et al., 2009; Hefferon, Murphy, McLeod, Mutrie, & Campbell, 2013; Irwin et al., 2003). As such, heterogeneity among survivors of cancer who were referred to the CBERP, and subsequently recruited to this study, may have contributed to the observed differences in adherence rates between this investigation and interventions undertaken on more homogenous groups of cancer survivors in controlled research settings.

# 7.1.5.2 Indices of physical activity

## Light-intensity physical activity

The maintenance of improvements in objectively measured LIPA at 6 month follow-up in IG is a notable finding. LIPA is defined as activity performed >1.5 but <3 metabolic equivalents (METs) (Chastin et al., 2019). The replacement of sedentary behaviour with LIPA can assist in lowering the incidence of CVD and T2DM and the risk of cardiovascular and all-cause mortality among individuals who engage in little-to-no MVPA (Office of Disease Prevention and Health Promotion, 2018). While the evidence regarding the benefits of LIPA for health and well-being have yet to be fully elucidated, recent research suggests that LIPA may provide an important therapeutic target within PA interventions, particularly for sedentary/insufficiently active populations (Chastin et al., 2019; Füzéki, Engeroff & Banzer, 2017).

Given the low rates of adherence to the PA guidelines that have been previously reported among individuals living with and beyond cancer (17-47%)

(Blanchard, Courneya & Stein, 2008; Courneya, Katzmarzyk & Bacon, 2008; Forbes, Blanchard, Mummery & Courneya, 2014; Nayak, Holmes, Nguyen & Elting, 2014; Speed-Andrews et al., 2012), and the challenges that limit PA participation throughout the different stages of the cancer journey, including ill health, fatigue and fear of PA (Blaney, Lowe-Strong, Rankin-Watt, Campbell & Gracey, 2013; Hefferon, Murphy, McLeod, Mutrie, & Campbell, 2013), interventions like MedEx IMPACT that increase and maintain improvements in LIPA may provide a promising solution to achieve benefits associated with regular PA in this population.

Sedentary time and LIPA have been shown to be significantly associated with psychosocial health outcomes among lung cancer survivors (Vallance et al., 2018). In light of this cohort's older age, reduced functional status and decreased pulmonary capacity, recommendations to engage in LIPA may be more appropriate for this population (Vallance et al., 2018). Increased LIPA, and MVPA, have been associated with reduced depressive symptoms among survivors of breast cancer in the 12 months following treatment completion, suggesting that either light or moderate intensity PA may be effective in this capacity during this time (Sylvester, Ahmed, Amireault & Sabiston, 2017). LIPA has also been shown to attenuate functional decline in older ( $\geq$ 65 years) breast, prostate and colorectal cancer survivors who were  $\geq$ 5 years post-cancer diagnosis (Blair et al., 2014).

Exercise prescription for individuals living with and beyond cancer should be tailored to each individual, taking into account a number of factors including individuals' current level of physical functioning and stage of the cancer journey (Cormie et al., 2018). While attainment of the recommended PA guidelines for

survivors of cancer may be optimal in terms of maximising the therapeutic value of PA for this population, significant benefits are associated with LIPA. It should therefore be considered as a meaningful option for PA prescription by all members of the multidisciplinary oncology team, and for PA participation by individuals living with and beyond cancer.

## Steps

At 6 month follow-up, mean daily step count for IG was 9,055 steps compared to 8,053 steps among CG participants. Cancer survivors are at an increased risk for developing CVD (Siegel, Naishadham & Jemal, 2012). Sugiura et al. (2002) reported that attainment of 9,000 steps per day was associated with significant improvements in blood lipid parameters including reducing circulating levels of total cholesterol and increasing high-density lipoprotein cholesterol, in middle-aged women without cancer. While the difference between CG and IG for daily mean step count was not statistically significant, it could be clinically meaningful and play an important role in reducing cancer survivors' risk for CVD.

### 7.1.5.3 Cardiorespiratory fitness

Improvements in 6MTT score from baseline to 6 month follow-up were similar in CG and IG. The majority of previous studies that used a field-based measure to estimate CRF in cancer survivors used a 6-minute walk test, making it difficult to compare results with a 6MTT.

Estimates for minimal clinically important differences in 6-minute walk test distance of 17-86m have been reported among older adults and individuals with

heart failure or chronic obstructive pulmonary disease (Kwok, Pua, Mamun & Wong, 2013; Shoemaker, Curtis, Vangsnes & Dickinson, 2013; Wise & Brown, 2005). Although a 6MTT was used in the present study, the results indicate that community-based exercise rehabilitation is effective in eliciting a clinically meaningful change in CRF among survivors of cancer. Given the similar rates of improvement observed across both CG and IG, participation in the supervised exercise classes may have been the greatest contributor to the improvements observed.

# 7.1.5.4 Constructs related to physical activity behaviour change

The exploratory analysis provided important insight into the theoretical constructs that were targeted within the intervention (i.e. social support from family and friends, intentions and barrier- and self-regulatory- self efficacy for PA). Social support from friends for PA increased at 3 month follow-up for both CG and IG. It is possible that participation in the group-based supervised exercise classes may have been a significant contributor to the increase in social support. Further evidence of this hypothesis is that there was no significant difference in social support from friends in CG and IG at 6 months, suggesting the improvements achieved at 3 months were lost at T3 following cessation of the supervised exercise classes.

Intentions for PA decreased in CG and IG from baseline to 6-month followup. However, this result may have been influenced by 2 items in the scale that was used to measure intentions. Participants were asked to indicate their level of agreement with statements regarding whether they intended to continue attending the community-based exercise rehabilitation centre and to stick to these classes following completion of the programme. Participants were encouraged to commit to the 12 week programme and were offered continued access to classes following programme completion. Data was not collected regarding the level of uptake by participants to continue attending the classes, however anecdotal evidence suggested that many participants were returning to work, were living too far away or had other family commitments that inhibited continued engagement with the programme. As such, low scores on these 2 statements may have contributed significantly to the decrease in intentions observed from baseline to 6 months as an average score from 8 items was used to assess intentions for PA overall.

Self-regulatory self-efficacy appears to hold the most promise in terms of theoretical constructs that may have influenced PA behaviour as it was shown to significantly influence changes in minutes of MVPA, and 6MTT and FACT-G scores over time. While the use of linear mixed models is a strength of the current investigation, as it assists in maximising the retention of data in cases where some values may be missing and enables post-hoc testing, it was not able to provide detail regarding the percentage of variance in indices of PA that was attributable to the exploratory variables. Therefore, this finding should be interpreted with caution.

## 7.1.5.5 The effectiveness of community-based exercise oncology rehabilitation

The results from the current investigation are the first to report the benefits of community-based exercise rehabilitation on physical and psycho-social wellbeing among a diverse cohort of individuals living with and beyond cancer within

Ireland, and are supported by similar findings from previous studies conducted in Canada and the United States of America (Cheifetz et al., 2014; Foley, Hasson & Kendall, 2018; Knobf, Thompson, Fennie & Erdos, 2014; Santa Mina et al., 2017).

#### 7.1.5.6 Physical activity behaviour change interventions for survivors of cancer

The results of the MedEx IMPACT trial are supported by findings from previous RCTs that investigated the efficacy of combined supervised- and homebased- exercise programmes for sedentary survivors of cancer, where improvements in PA levels, CRF and HRQoL from baseline to post-intervention were also reported (Bourke et al., 2011; Bourke et al., 2014; Rogers et al., 2015). Two of these studies reported results from long-term follow-up conducted at 3- (Rogers et al., 2015), and 6- (Bourke et al., 2014) months post-intervention. Both studies reported statistically significant differences between the control and intervention groups for self-reported PA and CRF at follow-up assessment. However, in contrast to the results of MedEx IMPACT, the increase in self-reported PA levels identified at 3 month follow-up by Rogers et al. (2015) was not supported by the results from objective data collected.

This study demonstrates the feasibility and acceptability of delivering a PA BC intervention for survivors of cancer within an existing community-based exercise programme. Relatively few published studies have assessed the feasibility and effectiveness of delivering such interventions within non-research settings (Courneya, Rogers, Campbell, Vallance & Friedenreich, 2015). In addition, the extent to which successful PA BC interventions conducted within controlled research environments can be effectively disseminated to sustainable PA services

for survivors of cancer is unclear (White, McAuley, Estabrooks & Courneya, 2009). Beidas et al. (2014), investigated whether an evidenced-based exercise intervention for survivors of breast cancer, whose success had been established within an efficacy trial, could retain its effectiveness and safety when translated into a community-based physical therapy setting. The trial demonstrated that the intervention was successfully delivered in this new setting as was evident by improvements in lymphedema symptoms, muscular strength and body image. The magnitude of improvements in strength were greater in the efficacy trial compared to the effectiveness trial, however few other differences between the 2 studies were identified. The authors identified a number of implementation barriers, including the identification of feasible payment options and the need for active engagement with referring healthcare professionals (e.g. follow-up phone calls). The reporting of such information provides important insight into barriers to implementation which can be easily addressed to optimise future intervention delivery (Beidas et al., 2014).

### 7.1.5.7 Strengths and limitations

This investigation had a number of strengths including the use of an objective measure of PA and the recruitment of a diverse cohort of individuals living with and beyond cancer. The inclusion of follow-up assessment at 6 months also provides important information regarding the effectiveness of the MedEx IMPACT intervention on PA levels, aerobic capacity and HRQoL. A 12 month follow-up assessment has also been conducted as part of the present investigation. This data

will be analysed to evaluate the long-term impact of the intervention on the reported outcome variables.

This study demonstrates the feasibility of delivering a PA BC intervention within an existing community-based exercise rehabilitation programme and provides valuable insights and recommendations from participants to optimise service delivery. The fact that recommendations could be implemented within existing services with immediate effect increases the external validity of the study.

Participants mean daily number of steps and minutes of MVPA at baseline were 7859 steps and 25 minutes, respectively, suggesting that while, on average, participants may not have been sufficiently active to achieve the recommended PA guidelines, they were engaged in moderate levels of PA participation. A ceiling effect in terms of upper limits for improvement may have occurred. Therefore, implementing and evaluating the MedEx IMPACT intervention among less active cohorts of survivors of cancer is warranted to assess its effectiveness for such populations.

Similarly, individuals were referred to the community-based exercise programme by a member of their healthcare team and there is a strong possibility that only individuals with an interest in PA or motivation to become more physically active attended the programme. The recruitment of participants from sources other than referral to exercise programmes may assist in identifying a larger proportion of participants who are sedentary or insufficiently PA who may benefit from increasing PA levels. Studies investigating other delivery modalities for PA interventions (e.g.

e-Health and home-based PA interventions) in non-research environments are also needed.

Information regarding participants' stage of the cancer journey was not collected (i.e. how far post-treatment completion participants were). This may have been a significant contributing factor to the heterogeneity of the cohort and may have influenced the study findings. Future research should collect more detailed participant information in order to facilitate sub-group analyses to determine if time since treatment completion and/or treatment modality itself (e.g. chemotherapy and surgery vs. surgery only groups) significantly influenced PA levels and intervention effectiveness.

# 7.1.6 Conclusion

Participation in the 12-week community-based exercise rehabilitation programme significantly increased cancer survivors' objectively (daily step count and LIPA) and subjectively (IPAQ MET-min per week score) measured PA levels, CRF and HRQoL. The improvements in self-report PA and CRF were maintained at 6 months. The addition of the BC intervention components within MedEx IMPACT assisted in maintaining improvements in objectively measured daily steps, LIPA and HRQoL at 6 months. Further work evaluating 12 month follow-up data is planned and will provide valuable information regarding the long-term impact of the intervention on physical and psycho-social well-being for individuals living with and beyond cancer. The findings presented provide preliminary evidence of intervention effectiveness in increasing, and maintaining improvements, in cancer survivors' objectively measured PA levels, CRF and HRQoL. However, due to the

absence of significant interaction effects, further work, particularly in relation to the mechanisms of behaviour change, is required before valid conclusions can be drawn. Chapter 8 Discussion

## 8.1 Overview of the Research

Discussions for each individual study have been included in the preceding chapters. This purpose of this chapter is to contextualise the overall research findings within the existing scientific literature by examining themes identified within each study. This discussion of findings from the work in its entirety will be used to inform the overall conclusions and future recommendations presented in Chapter 9.

This research aimed to explore PA across the cancer journey from the perspective of both patients and OHPs, and to develop, implement and evaluate a PA BC intervention for survivors of cancer in a community-based setting. The results indicated that the PA promotion practices of the majority of healthcare professionals did not align with the recommended PA guidelines for individuals living with and beyond cancer. PA was not promoted routinely to every patient. Survivors of cancer reported a number of challenges to PA participation, including experiencing a period of isolation following treatment completion. Exercise was viewed as a vehicle for recovery by many as it empowered ownership of health to enhance physical and psycho-social well-being. The intervention development process produced a PA BC intervention, namely the MedEx IMPACT intervention, which consisted of 7 components including an independent PA programme, PA information sessions and a 1:1 exercise consultation. The intervention was implemented and evaluated within a two-arm non-randomised trial that was conducted within an existing community-based exercise programme. Results from the trial provide preliminary evidence to support the effectiveness of the MedEx

IMPACT intervention in increasing cancer survivors' objectively measured PA levels, CRF and HRQoL from baseline to post-intervention and successful maintenance of these improvements 3 months following programme completion. Further research investigating the long-term impact of the intervention on these outcomes is warranted.

## 8.1.1 Physical activity promotion throughout the cancer journey

Study 1, a Delphi study, explored OHPs' knowledge, barriers and practices in relation to PA promotion for cancer survivors and aimed to generate guidance regarding the optimisation of the referral process to CBERPs. The study found that less than 1 in 5 OHPs provided recommendations that align with the current PA guidelines for individuals living with and beyond cancer. While the majority of OHPs believed that discussing PA with patients was part of their role, it was not a feature of usual care for every patient, and was most commonly recommended to survivors of breast cancer who had completed treatment. A number of barriers which limited PA promotion, including limited time with patients, a lack of CBERPs to refer to and a lack of resources regarding PA for cancer survivors, were reported by OHPs.

These key themes were reflected in the experiences shared by individuals living with and beyond cancer during focus groups completed in Study 2, which aimed to explore individuals' experiences of PA behaviour across the cancer journey, and obtain recommendations for strategies to support habitual PA. OHPs were identified as credible and important sources of information whose recommendations had a significant impact on levels of PA engagement. However, participants reported a lack of suitable advice and/or conflicting information from

their cancer care team regarding PA which led to a fear of PA for some individuals. Issues related to immune compromise and safety, particularly during treatment, underpinned OHPs' concerns for PA participation. Participants reported receiving a lack of direction regarding recovery following cancer treatment, and experiencing a period of isolation at this time. The period of isolation was characterised by a decrease in physical and psycho-social well-being. For participants who engaged in a CBERP during the post-treatment period they expressed an "if I knew then, what I know now" attitude towards PA where they felt they would have made a greater effort to engage in PA, both during and after treatment, had they been made aware of its importance at the time.

One cross-sectional study had previously explored the extent of exercise prescription among oncology nurses and physiotherapists working in Ireland (O'Hanlon & Kennedy, 2014). They found that three quarters of physiotherapists working in oncology recommended exercise to greater than 80% of patients with cancer. These rates of PA promotion are higher than those reported in the current investigation. Study 1 is unique from an Irish perspective in that it is the first to report the PA promotion practices of a diverse sample of multi-disciplinary healthcare professionals involved in the delivery of cancer. In contrast to the findings from Study 1, O'Hanlon & Kennedy, (2014) reported that patient-related barriers including patients' family and/or friends advising patients to rest and avoid activity and poor exercise compliance among patients with cancer were the primary challenge to PA promotion by physiotherapists. Oncology nurses cited a lack of exercise guidelines for patients with cancer as their primary barrier to PA

promotion for this population (O'Hanlon & Kennedy, 2014). Similar findings were reported from Study 1, and from a number of other investigations that explored the barriers to PA promotion among physicians, oncology nurses, oncologists and surgeons in Spain, the United States of America, Australia and the United Kingdom (Karvinen, McGourty, Parent & Walker, 2012; Puig Ribera, McKenna & Riddoch, 2005; Spellman et al., 2013; Williams, Beeken, Fisher & Wardle, 2015). Rates of PA promotion varied from less than 45 to 67% among nurses, surgeons, oncologists and physicians working in oncology (Karvinen, McGourty, Parent & Walker, 2012; Williams, Beeken, Fisher & Wardle, 2015) to 88% among nurses and physicians working in primary practice (Puig Ribera, McKenna & Riddoch, 2005). However, the quality and detail of the recommendations provided, including their alignment with the recommended PA guidelines for this population, varied across studies. Consequently, the value of such advice to patients remains unclear.

To our knowledge, Study 2 is the first to document the experiences of PA across the cancer journey among individuals living with and beyond cancer in the Republic of Ireland. The lack of support and PA services during the post-treatment phase of the cancer journey and the associated decrease in physical and psychosocial well-being reported by participants is supported by findings from previous investigations (Fernandez et al., 2015; Irwin et al., 2003; Jefford et al., 2008). The need for, and absence of, PA promotion from cancer care reported by participants has also been highlighted by survivors of breast cancer (Binkley et al., 2012).

When viewed concurrently, the findings from studies 1 and 2 indicate that individuals living with and beyond cancer experience a lack of guidance regarding

post-treatment recovery and an unmet need for holistic rehabilitation during this time. For some, this is mediated in part by a lack of PA promotion from OHPs throughout the cancer journey and presents a lost opportunity to support those motivated to adopt positive lifestyle behaviours and optimise patients' HRQoL. This research provides valuable information, directly related to the OHP and patient experience in Ireland, to advocate for i) improved support for OHPs in the promotion of PA to patients, ii) PA advice and services to be integrated within usual care for individuals living with and beyond cancer, and iii) a holistic approach to rehabilitation during survivorship to support individuals to achieve the best possible health outcomes.

# 8.1.2 Referral to community-based exercise rehabilitation programmes for survivors of cancer

Referring individuals living with and beyond cancer to external PA services may, at least in theory, provide a feasible and pragmatic solution to address the barriers reported by OHPs in the promotion of PA, and the lack of support services in the post-treatment phase highlighted by survivors of cancer. However, the findings from Study 1 indicate that less than 50% of OHPs use referral to exercise specialists as a method to provide PA advice to patients and less than one-third use referral to CBERPs. The low levels of referral presented are likely to be attributable, at least in part, to the lack of CBERPs available, which was reported by more than 50% of OHPs as a barrier to PA promotion.

Lack of engagement in referral processes to PA services could be an additional factor that contributed to the low rates observed. OHPs highlighted a

number of barriers to referral including insufficient time with patients to discuss referral, referral forms taking too long to complete and a lack of knowledge regarding the referral processes to PA services. Bridging the gap between the promotion of PA in cancer care and engagement with PA services for this population is a complex issue that may extend beyond the need for increased service provision and engagement by OHPs. Importantly, Study 1 was the first investigation, to our knowledge, to generate a consensus agreement among OHPs regarding strategies to optimise the referral process to CBERPs for this population. The implementation of these recommendations could provide promising solutions to assist in addressing the disjoint between PA promotion in cancer care and access to PA services by individuals living with and beyond cancer.

## 8.1.3 Barriers to physical activity participation among survivors of cancer

PA adherence for individuals living with and beyond cancer is complex. The findings from Study 2 reported on the PA experiences of a large, diverse group of survivors of cancer. In addition, the findings added to existing scientific literature by providing an understanding of the challenges to PA participation facing this population, including those who have had a previous prostate, colorectal, breast or lung cancer diagnosis. The barriers identified by participants focused on environmental, patient and treatment related barriers. In particular, an individual's stage of the cancer journey (i.e. treatment vs. survivorship) and the treatment modality received (e.g. chemotherapy/radiotherapy and surgery vs. surgery) were highlighted as significant factors that influenced participants' levels of PA participation throughout the cancer journey. Results from previous quantitative

investigations support these findings (Blanchard et al., 2003; Bluethmann, Vernon, Gabriel, Murphy & Bartholomew, 2015; Chung et al., 2013; Courneya, Karvinen & Vallance, 2007; Irwin et al., 2003; Lee et al., 2012; Phillips & McAuley, 2015).

It could be argued that one of the fundamental steps in the promotion and prescription of PA to this population is the identification of barriers that are salient to each individual at different stages of the cancer journey. While research investigating barriers to habitual PA for survivors of cancer has been conducted (Blaney, Lowe-Strong, Rankin-Watt, Campbell & Gracey, 2013; Blaney et al., 2010; Fisher et al., 2016; Gho, Munro, Jones & Steele, 2014; Hefferon, Murphy, McLeod, Mutrie, & Campbell, 2013; Maxwell-Smith, Zeps, Hagger, Platell & Hardcastle, 2017), important methodological limitations and considerations have been identified that may limit inferences regarding the barriers experienced (Brawley, Culos-Reed, Angove & Hoffman-Goetz, 2002).

One issue is the conceptualisation of barriers and how they are defined where reasons, excuses and attributions are often measured as opposed to 'true barriers' (Brawley, Culos-Reed, Angove & Hoffman-Goetz, 2002). Interventions designed to target barriers that do not represent 'true' barriers may not improve exercise behaviour. The use of a variety of methods and scales to assess barriers to PA among cancer survivors has made it difficult to compare findings and to draw conclusions. Indeed, some studies have borrowed barrier scales that were developed for different populations or behaviours and applied them to the oncology context. Such an approach may lead to the measurement of irrelevant barriers and a failure to identify and measure important cancer-specific barriers to

PA. The use of recall measures to assess barriers encountered, and a failure to collect information regarding the frequency with which a barrier is experienced, have also been identified as limitations of the research in this area (Brawley, Culos-Reed, Angove & Hoffman-Goetz, 2002). Investigations that address these methodological concerns would provide valuable information regarding potential targets within future PA BC interventions for individuals living with and beyond cancer and support the identification of the most suitable BCTs to embed within appropriate interventions. This approach could contribute to greater likelihood of intervention success.

# 8.1.4 Recommendations from survivors of cancer for strategies to support habitual physical activity

To date, few effective, sustainable interventions to support individuals with and beyond cancer to be habitually physically active have been identified (Bluethmann, Vernon, Gabriel, Murphy & Bartholomew, 2015; Bourke et al., 2013; Turner et al., 2018). The inclusion of patients as active partners in all stages of the research process to assist in the identification of meaningful research questions and the optimisation of research methods, implementation and evaluation has been recommended (INVOLVE, 2013). A recent systematic review that sought to determine the impact of patient and public involvement (PPI) in health and social care research concluded that PPI can have a positive impact through the enhancement of research quality and ensuring relevance and appropriateness of studies (Brett et al., 2014). The impact of PPI in the development of research questions and agendas has been shown to assist in the identification of relevant

topics for investigations that were grounded in the intended end-users' experiences (Brett et al., 2014). It is possible that the initial stage of a research project is when PPI is most critical given the potential to influence all aspects of a research project at an early stage (Brett et al., 2014; Oliver & Buchanan, 1997).

It is however, important to note that the evidence base for PPI remains weak as a result of a number of methodological concerns including insufficiently detailed reporting of PPI, and its impact within studies, and an absence of quantitative measurement of PPI (Brett et al., 2014). Further enhancement of research to advance understanding in this area is needed (Brett et al., 2014).

Given the complex nature of PA adherence for individuals living with and beyond cancer, using recommendations generated by this population to direct research efforts in the identification of effective PA interventions represents a pragmatic, worthy and logical approach that could contribute to an increased likelihood of intervention success. Despite these postulated benefits, to the best of our knowledge, no published studies have described the inclusion of patients in the formulation of PA BC interventions for cancer survivors or grounded their intervention development in recommendations obtained from individuals living with and beyond cancer. This present study sought to address some of these issues.

In conjunction with findings from a review of the literature, the recommendations obtained from survivors of cancer in Study 2 formed the foundation for intervention content development. The resultant patient-centred, theoretically-informed and evidenced-based PA BC intervention was reviewed by a SEP (which included individuals living with and beyond cancer), prior to

implementation to determine intervention acceptability and obtain stakeholder feedback to inform intervention optimisation. This approach ensured that relevant information was obtained directly from the intended intervention end-users, and viewed within the social context in which the intervention would be delivered. While elements of a process evaluation were conducted, information regarding the impact of PPI within the project was not formally collected. Future research that incorporates PPI should include comprehensive reporting of the specific role of PPI, and its subsequent impact, within projects (Brett et al., 2014).

# 8.1.5 The development process for physical activity behaviour change interventions for survivors of cancer

Study 3 details the intervention development process for the MedEx IMPACT PA BC intervention which, as previously highlighted, was guided by the MRC framework for the development, implementation and evaluation of complex interventions, the BCW and the TDF (Cane, O'Connor & Michie, 2012; Craig et al., 2008; French et al., 2012; Michie, Atkins & West, 2014). Recommendations generated by survivors of cancer in Study 2 regarding strategies to support habitual PA and adherence to CBERPs were synthesised with findings distilled from a review of the literature that investigated the determinants of PA behaviour, adherence and maintenance for survivors of cancer, and existing PA BC interventions for this population. These findings formed the foundation for intervention content development and were operationalised into intervention components. The BCW and TDF provided the theoretical frameworks for this process and detailed mapping exercises were completed which outlined the links between intervention

components, COM-B and TDF constructs, BCW intervention functions and BCTs. As discussed, acceptability of the resultant intervention, which included an independent PA programme, 4 PA information sessions and a 1:1 exercise consultation in addition to 12 weeks of supervised exercise classes, was determined following review by a multidisciplinary SEP. This review also provided the opportunity to obtain recommendations and feedback from the SEP to support intervention optimisation. This process led to the development of the MedEx IMPACT intervention, a novel PA BC intervention which aims to increase cancer survivors' PA levels, CRF and HRQoL.

Theory application within PA BC interventions for survivors of cancer varies greatly and is generally poorly reported, with many investigations failing to outline in sufficient detail the links between intervention development, implementation and evaluation, and components of the theoretical framework cited (Bluethmann, Bartholomew, Murphy & Vernon, 2017; Wallace, Brown & Hilton, 2014). The absence of such evidence may have contributed to the dearth of effective PA BC interventions currently available for survivors of cancer. This research aims to contribute to the existing scientific literature by addressing this gap and providing a detailed, transparent overview, in the form of mapping exercises, which explicitly outline the links between theoretical constructs, recommendations generated from intervention end-users and the review of literature, intervention components and BCTs. In addition, to ensure completeness of reporting and to assist in intervention replicability, the TIDieR (Template for Intervention Description and Replication) checklist (Hoffman et al., 2014) was completed which provides a detailed

description of the intervention including the rationale for intervention development and intervention procedures.

To our knowledge, MedEX IMPACT is the first PA BC intervention for survivors of cancer to be guided by the BCW, the TDF and MRC framework, and grounded in findings generated from a synthesis of recommendations from the target population and a review of literature. The BCW has been used previously to develop PA BC interventions for other clinical conditions (e.g. multiple sclerosis) and the general population (e.g. adolescent girls) (Casey, Coote & Byrne, 2018; Murtagh, Barnes, McMullen & Morgan, 2018), with preliminary findings from a feasibility study suggesting that a BCW-guided, 6 week mother-daughter walking programme was effective in increasing participants' daily step count (Corr, Morgan, McMullen, Barnes & Murtagh, 2018).

While the intervention development process for the MedEx IMPACT intervention was time-consuming and resource intensive, it provided a clear rationale for our choice of intervention components and a means to dis-assemble the intervention following completion of the trial to assess and explain the factors associated with intervention success, or lack thereof, and to gain an understanding of how the intervention could be optimised for future implementation. If advances are to be made with regard to the integration of PA within usual care for individuals living with and beyond cancer, effective, scalable and cost-efficient PA interventions that can be translated into clinical and community-based settings urgently need to be identified. A similar approach to intervention development adopted within the current investigation could be used by intervention designers as a means to

understand the mechanisms that underpin intervention success, and could therefore expedite efforts to identify suitable interventions to be included within cancer care.

In a bid to assist researchers in the process of intervention development, O'Cathain and colleagues (2019) identified 8 categories of approaches for intervention development (e.g. implementation-based, evidence and theory-based, target population-centred, combination) which were associated with 18 actions for consideration for intervention conception, planning, design, creation and refinement for future evaluation (e.g. identify that there is a problem in need for a new intervention, understand the problems or issues to be addressed, generate ideas about solutions, components and features of an intervention). This systematic methods overview can help intervention designers to understand the variety of approaches that are available and to identify potential actions that should be considered based on the context of the intervention to be developed. Consideration of these approaches and actions by intervention designers could assist in minimising research waste, maximising resources and successfully developing effective interventions for target populations (Hawe, 2015; MacLeod et al., 2014; O'Cathain et al., 2019).

# 8.1.6 Physical activity behaviour change interventions for individuals living with and beyond cancer

Studies 4 and 5 report the methods and results of a two-arm nonrandomised comparison trial that was conducted to determine the feasibility and clinical effectiveness of MedEX IMPACT among survivors of cancer who were referred to an existing CBERP, namely MMO. MMO is a 12 week programme that consists of twice-weekly supervised exercise for individuals who have completed cancer treatment. Participation in the MMO programme was used as the control/comparative condition within the two-arm non-randomised trial. Results from the post-intervention assessment of physical and psycho-social health indicated that significant improvements in objectively measured daily mean steps and LIPA, self-report PA levels, CRF and HRQoL were observed for both the control and intervention groups. The control group maintained improvements in self-report PA and CRF at 6 months. In addition to maintenance of these improvements, the inclusion of BC components within MedEx IMPACT also resulted in maintenance of improvements in daily mean steps, LIPA and HRQoL for the intervention group at 6 months.

The results presented in Chapter 7 provide preliminary evidence of the effectiveness of the MedEx IMPACT intervention in increasing and maintaining improvements in the objectively measured PA levels, CRF and HRQoL of individuals living with and beyond cancer. However, as no significant interaction effects were identified among the primary or secondary outcome variables measured, further

work assessing the long term impact of the intervention is warranted before valid conclusions regarding its effectiveness can be drawn.

In an attempt to assess the extent to which findings from PA interventions evaluated within RCTs for survivors of breast cancer could be translated into practice, a review was undertaken to generate a quantitative estimate of the reporting of both internal and external validity (White, McAuley, Estabrooks & Courneya, 2009). While most studies reported on aspects of internal validity, information related to external validity was rarely reported and thus the potential to generalise findings from RCTs was limited.

Given the dearth of D&I research regarding PA BC interventions for survivors of cancer, the ability to further contextualise findings within the existing scientific literature is limited. The findings from the present study indicate that the benefits of PA for survivors of cancer that have previously been identified (Rock et al., 2012; Schmitz et al., 2010) in controlled research environments extend to a real world setting.

The absence of D&I research within the existing scientific literature is likely to have contributed to few effective programmes to support the adoption and longterm adherence to healthy-lifestyle behaviours for survivors of cancer being currently available within cancer care and community-based settings (Basen-Enquist et al., 2017). The findings from this investigation provide an important first step in understanding the mechanisms underpinning PA BC in community-based settings and challenges associated with the real-world implementation of such interventions. A process evaluation, which included intervention debrief

questionnaires and focus groups with intervention participants, was conducted as part of the current investigation. Future work aims to conduct an in-depth analysis of the focus group data to gain further insight into the strengths and limitations of the MedEx IMPACT intervention to inform its optimisation for future implementation.

Findings from an analysis of the intervention debrief questionnaires presented in Chapter 7 suggest that while the majority of participants enjoyed taking part in the intervention and found it helpful in supporting regular PA participation, a number of factors were highlighted which may have limited the potential for further improvement in indices of PA, CRF and HRQoL to occur, and influenced the absence of improvements within participants' levels of MVPA. For example, the PA manual did not offer participants the same motivational potential as the supervised exercise classes and its use was associated with a number of logistical limitations (e.g. the momentum of the session being interrupted by having to time exercises and continuously refer to the PA manual for instruction) which may have limited the intensity of exercise undertaken by participants. To overcome these issues, the primary recommendation from participants to support intervention optimisation was to provide participants with a DVD of the supervised exercise classes or access to such material via an online platform. Such resources may have greater potential to reflect the supportive and motivational environment created by staff and participants within the supervised exercise classes, which was valued by participants, and therefore contribute to performance of PA that is moderate-to-vigorous in nature.

### 8.2 Summary

Physical inactivity is a serious and prevalent issue among individuals living with and beyond cancer. PA promotion and prescription do not currently feature as part of usual care for all individuals on the cancer journey and this represents an important missed opportunity to maximise patients' quality of life and healthrelated outcomes. The findings from the current research provide meaningful evidence that is specific to the Irish context that can be used to advocate for: i) increased support for healthcare professionals working in oncology to embed PA promotion practices within usual care for every patient, ii) the inclusion of holistic rehabilitation following cancer treatment completion to optimise patient health and well-being, and iii) increased provision of PA services to facilitate access to support and expertise to empower individuals living with and beyond cancer to engage in habitual PA. The novel approach to intervention development enabled the development of a PA BC intervention that was patient-centred, evidencedbased and theoretically-informed. Detailed reporting of this development process generated a transparent overview of how recommendations generated from survivors of cancer and the review of the literature, theoretical constructs and BCTs were embedded within the intervention, and thereby extends behavioural science methodology. Preliminary findings from the two-arm non-randomised trial offer promise and warrant further investigation.

### Chapter 9 Conclusions and Future Recommendations

#### 9.1 Strengths and limitations

This mixed-methods research design employed both objective and subjective data collection methods in order to explore PA across the cancer journey from the perspective of both OHPs and patients, and develop, implement and evaluate a PA BC intervention for survivors of cancer in a community-based setting.

Study 1, which employed the Delphi method, is the first study to generate a consensus agreement from OHPs regarding the optimisation of referral processes to CBERPs for survivors of cancer. It is also the first study to investigate the knowledge and practice of PA promotion for individuals living with and beyond cancer among a diverse sample of multi-disciplinary OHPs in Ireland. The findings from this study highlight the need to provide more support (e.g., increased provision of formal training opportunities in PA promotion and prescription) to OHPs to enable the integration of PA promotion into usual care for every patient. The consensus statements presented provide pragmatic, actionable strategies that could aid new and existing PA services in maximising engagement from OHPs in the referral process and therefore increase the number of individuals living with and beyond cancer accessing such services. Study 1 was limited by the low response rate observed and the potential response bias that may have occurred where only OHPs who were physically active and/or interested in PA may have participated. Both of these limitations have been reported previously (Hsu & Sandford, 2007; Keogh et al., 2017).

Study 2 extends our current understanding of PA across the cancer journey by reporting the experiences of a large, diverse group of survivors of cancer, of all

ages, with varying cancer diagnoses, at different levels and stages of PA participation. Previous qualitative research in this area has predominantly focused on the experiences of PA among post-treatment survivors of breast cancer (Burke et al., 2017) with limited research being conducted among other cohorts of individuals living with and beyond cancer. Study 2 addresses this gap within the existing scientific literature.

The findings from this study regarding the barriers to PA participation experienced by participants and recommendations for strategies to support habitual PA and adherence to CBERPs provided a valuable foundation for intervention development in Study 3. The data collected facilitated an in-depth understanding of the PA experiences of the intended intervention end-users, that was specific to the context in which the intervention would be delivered. This ensured that intervention development was grounded in addressing issues that were highlighted as relevant and meaningful by the intended users of the intervention. This approach may have contributed to an increased likelihood of intervention success as the inclusion of PPI enhances research quality and ensures the relevance and appropriateness of studies (Brett et al., 2014).

Experiences of PA throughout the cancer journey have been shown to be affected by a number of factors including cancer type, stage of the cancer journey and cancer treatment modality (Blanchard et al., 2003; Bluethmann, Vernon, Gabriel, Murphy & Bartholomew, 2015; Chung et al., 2013; Courneya, Karvinen & Vallance, 2007; Irwin et al., 2003; Lee et al., 2012; Phillips & McAuley, 2015). Therefore, the findings from Study 2 may not reflect the experiences of individuals

diagnosed with cancers that were not represented. Similarly, the strategies recommended by participants to support habitual PA and adherence to CBERPs may not be generalizable to cohorts of cancer survivors with cancer types that were not represented.

Study 3 provides a detailed overview of the intervention development process for the MedEx IMPACT PA BC intervention. This process was documented and reported in line with best practice procedures to ensure completeness of reporting and support intervention replicability (Hoffman et al., 2014). The intervention development process was iterative and sought guidance from both the intended intervention end-users (i.e., survivors of cancer) and other key stakeholders, including exercise instructors involved in the delivery of a CBERP for survivors of cancer and representatives from a national cancer charity. The potential for intervention scalability, as well as sustainability and cost-effectiveness, were important considerations central to the intervention development process. The aim was to develop an intervention that maximised quality and effectiveness while also being low-tech and moderately-resource intensive, in order to generate a potentially pragmatic, affordable solution for community-based exercise rehabilitation that is suitable for delivery within usual cancer care.

The recommendations generated by focus group participants in Study 2 were synthesised with results from a review of the literature which focused on the determinants of PA behaviour, adherence and maintenance among survivors of cancer and PA BC interventions for this population. Many of the studies included in the review of literature were conducted among survivors of breast cancer. As such,

other salient determinants of PA behaviour, adherence and maintenance for nonbreast cancer cohorts may not have been considered during the intervention design process.

Studies 4 and 5 report the methods and results of a two-arm nonrandomised comparison trial that was undertaken to determine the effectiveness of the MedEx IMPACT intervention on cancer survivors' PA levels, CRF and HRQoL. The use of the comparative research design, which sought to compare a general community-based exercise rehabilitation programme with an exercise rehabilitation programme developed specifically for survivors of cancer, is a strength of the current investigation given that, to our knowledge, no published studies have adopted such an approach. In addition, previous PA BC interventions for this population have been limited by the use of self-report measures of PA, short term follow-up procedures and a narrow scope of investigation with a primary focus on post-treatment survivors of breast cancer (Turner et al., 2018). This research endeavoured to address these limitations through the use of objective assessment of PA levels using accelerometry, the inclusion of 6 and 12 month follow-up assessments and the recruitment of a diverse cohort of individuals living with and beyond cancer. Extensive efforts were made to collect data that assessed intervention feasibility and effectiveness. This research also provided an insight into the mechanisms underpinning the success of the intervention, and its effectiveness in supporting PA BC among individuals living with and beyond cancer. While this was a significant undertaking given the time and resources available for the project,

this information was essential to inform future delivery and replication of the MedEx IMPACT intervention.

While the implementation and evaluation of Study 5 within a real world setting was a major strength of the study, it also contributed to a number of the study's limitations. Firstly, it was not possible to recruit only individuals who were sedentary or had low levels of PA participation at baseline as withholding access to the CBERP would have raised ethical concerns. The mean levels of PA participation among participants at baseline suggested that participants were not sedentary and did engage in some PA. Therefore, a ceiling effect in terms of the potential of the intervention to result in further improvements in the outcome variables assessed may have occurred. Secondly, bias may have occurred within the sample of participants recruited where only individuals who were interested in or motivated to become more physically active that had been referred by a member of their healthcare team to the CBERP had attended for assessment.

Preliminary findings presented in Study 5 suggest that the intervention led to clinically meaningful increases in PA levels, CRF and HRQoL. However, no significant interaction effects were identified and therefore further research assessing the long term impact of the intervention on the outcomes of interest is warranted before valid conclusion regarding its effectiveness can be drawn.

#### 9.2 Directions for future research

#### 9.2.1 Optimisation of physical activity promotion throughout the cancer journey

The inclusion of PA within cancer care offers an attractive solution to the issues highlighted by participants in Studies 1 and 2. PA can support improvement and maintenance of physical and psycho-social well-being for individuals throughout the cancer journey and thereby assist in addressing the period of isolation experienced by many following treatment completion. PA promotion can also support OHPs to deliver the holistic care they believe is needed to support patients to live a healthy life, as was highlighted in the results of the second round of the Delphi study. However, the results of this research suggest that OHPs need more support to develop their skills and confidence to prescribe individualised exercise regimes to cancer survivors and embed PA promotion practices within usual care for every patient. A number of strategies could be implemented to achieve this aim including:

- increasing awareness of the benefits and safety of PA among OHPs for all cohorts of cancer survivors at all stages of the cancer journey,
- including PA promotion and prescription as part of undergraduate training for OHPs,
- providing continuous professional development opportunities in the form of in-service training days or work-place seminars. Such sessions could be delivered by physical activity specialists with expertise in oncology (e.g. clinical exercise physiologists, physiotherapists),

- iv) including clinical exercise physiologists and other PA specialists as members of the multi-disciplinary teams delivering cancer care,
- v) increasing the number of hospital-based, community-based and remotely accessed PA programmes (e.g. online PA services) that can provide PA support to individuals living with and beyond cancer at all stages of the cancer journey,
- vi) establishing, and/or strengthening, referral pathways to oncology specific and non-specific PA services for survivors of cancer,
- vii) exploring the application of models of rehabilitation, adapted from other clinical conditions, to the oncology setting (e.g. cardiac and pulmonary rehabilitation).

Future investigations that implement and evaluate these recommendations would provide valuable insight regarding how the promotion of PA by OHPs to survivors of cancer can be maximised and the teachable moment associated with a cancer diagnosis capitalised.

# 9.2.2 Optimisation of referral processes to community-based exercise programmes

Implementation and evaluation of the strategies that achieved consensus among OHPs in Study 1 is warranted. The identified strategies focused on the optimisation of the referral process under 4 central themes:

1. Optimising the logistics of the referral process (e.g. making it standardised, electronic),

- Improving access and awareness for patients and healthcare professionals with regard to information about the benefits of PA, information about existing exercise programmes and increasing access to programmes,
- Providing education to both healthcare professionals and patients regarding the benefits of PA and the logistics and quality of programmes, and
- 4. Providing feedback to OHPs regarding patients progress in a programme.

The recently published National Cancer Strategy for Ireland (Department of Health, 2017) includes a number of recommendations to optimise cancer care, including conducting a needs assessment to identify the most suitable model of survivorship care and developing and implementing survivorship programmes that emphasise physical and psycho-social well-being. A number of studies investigating the implementation and evaluation of the strategies presented in Study 1 are needed as a research priority to inform the development of survivorship programmes and support their optimisation from the outset. Maximising OHPs engagement in referral to such services, that aim to enhance patient well-being, would be an important initial step worthy of exploring. Indeed, the strategies to optimise referral identified within this research may also be generalisable to referral processes to CBERPs for other clinical conditions (e.g. CVD, pulmonary disease) and warrant investigation in such settings.

### 9.2.3 Identification of barriers to physical activity among individuals living with and beyond cancer

An important first step in the development of PA interventions for survivors of cancer is the identification of salient barriers that limit or inhibit PA participation. This information would assist in ensuring that interventions were tailored to address the specific challenges identified by the intended intervention end-users and could therefore contribute to an increased likelihood of intervention success. To address the methodological limitations identified within previous investigations conducted to assess barriers to PA participation, the implementation of a number of guidelines has been recommended to improve the detection, measurement and understanding of barriers to PA that can be applied to the oncology setting (Brawley, Culos-Reed, Angove & Hoffman-Goetz, 2002; Brawley, Martin & Gyurcsik, 1998). These recommendations include:

- Identifying salient barriers to PA participation through consultation with survivors of cancer to inform the development of scales to establish the unique challenges facing this population,
- ii) Implementing prospective research designs may eliminate recall bias and assist in more accurate detection of relevant barriers. In addition, prospective studies may provide important information regarding whether barriers are transient or constant,
- iii) Collecting information regarding the frequency and perceived strength of barriers to PA behaviour to provide sufficiently detailed information

to inform intervention development (Brawley, Culos-Reed, Angove & Hoffman-Goetz, 2002).

Research that evaluates the identified recommendations is needed in order to provide a better understanding of the barriers experienced by individuals living with and beyond cancer at different stages of the cancer journey in varying socioeconomic environments and psycho-social contexts in order to inform the development of relevant and meaning PA BC interventions.

## 9.2.4 Patient public involvement: Recommendations for reporting and evaluation within PA interventions for survivors of cancer

According to Pain et al., (2015) the conceptualisation and measurement of impact within research settings tends to be very narrow and often does not align or reflect novel approaches that are used to create knowledge and affect change. Impact is becoming an increasingly important metric that governs how research is funded and evaluated (Pain et al., 2015) and the inclusion of PPI in the research setting is now commonly advocated (INVOLVE, 2013). This is because PPI "can facilitate the co-production of research and knowledge by a community, organisation or group in collaboration with academic researchers" (Pain et al., 2015, p4). Such an approach could potentially result in enhanced research quality and appropriateness (Brett et al., 2014). However, the quality of reporting of PPI within the scientific literature is inconsistent (Staniszewska et al., 2017). This has limited the understanding and impact of PPI and therefore, its advancement in research (Staniszewska et al., 2017). To improve the quality, transparency and consistency of PPI research and ensure its practice is evidenced-based,

Staniszewska and colleagues (2017) developed the Guidance for Reporting Involvement of Patient and the Public (GRIPP2) checklist. Developed in both short-(SF) and long-(LF) forms, the GRIPP2 checklist (LF) includes 34 items including aims, definitions, stages and nature of involvement, context and reflections and is suitable for use in studies concerned with PPI. PA BC interventions that include PPI should use the GRIPP2 checklist to increase the standard of reporting in this area, in order to develop the evidence base and in time, enable meaningful comparison of PPI across studies. The identification of appropriate ways to measure the impact of PPI, both qualitatively and quantitatively, is needed. Current published literature is flawed by the lack of consistency in the reporting of PPI impact (Brett et al., 2014). Robust tools with the specific intention of measuring the impact of PPI in the research setting are needed (Brett et al., 2014). Such tools would enable an assessment of quality of PPI in the research setting and advance the evidence base in this area.

# 9.2.5 Recommendations to improve dissemination and implementation research within the oncology context

To address the limitations of existing research and support the identification of effective PA BC interventions for individuals living with and beyond cancer, a number of recommendations are proposed:

 Theoretical frameworks should be used to guide intervention development in order to link relevant causal factors of the target behaviour with appropriate BCTs, which may increase the likelihood of intervention success (Bartholomew & Mullen, 2011; Bluethmann, Bartholomew, Murphy & Vernon, 2017). Theory also provides a framework to understand mechanisms of BC and therefore provides valuable insight regarding the effectiveness of an intervention (Bluethmann, Bartholomew, Murphy & Vernon, 2017; McEwan et al., 2019). This information is essential to inform intervention replicability and could expedite efforts to identify effective PA BC interventions that could be translated for delivery within clinical- and community-based settings for survivors of cancer.

- ii) Greater quality of reporting of intervention development processes that link theoretical constructs with intervention components, and where applicable intervention functions and BCTs, is urgently needed. The absence of such reporting has significantly impeded efforts to assess the impact and value of theoretically informed interventions and the mechanisms associated intervention effectiveness. Interventions that embed BCTs within intervention content should use the BCT v1 taxonomy for reporting (Michie et al., 2013). Use of the TIDieR (Template for Intervention Description and Replication) checklist (Hoffman et al., 2014) should also be advocated among intervention designers to facilitate the standardised reporting of interventions and subsequently enable their replication. Such information also permits greater comparison across studies.
- iii) Researchers should consider the 8 categories of approaches for intervention development and the associated actions proposed by O'Cathain and colleagues (2019) at the start of the intervention development process.
   These approaches provide intervention designers with a means to systematically i) identify the most suitable approach to intervention

development given the social-, environmental- and financial- context specific to the intervention to be developed, and ii) consider all potential actions that may be necessary to complete. Consideration of these approaches and their associated actions could assist in maximising available resources, minimising research waste and ultimately support the development of successful interventions for the chosen target populations (Hawe, 2015; MacLeod et al., 2014; O'Cathain et al., 2019).

- iv) The inclusion of objective methods for the assessment of indices of PA is advised (Turner et al., 2018).
- v) Long term (i.e., 12+ months) follow-up procedures should be included to provide insight into the effectiveness of interventions to support sustained engagement in PA behaviour by individuals living with and beyond cancer.
- vi) The goal of PA integration into usual care for all individuals living with and beyond cancer will only be achieved when a significant body of evidence is available that demonstrates the effectiveness of PA BC interventions delivered within a 'real-world' context. Despite efforts to advance this field (Basen-Engquist et al., 2017; Phillips, Alfano, Perna & Glasgow, 2014; Pollack, Hawkins, Peaker, Buchanan & Risendal, 2011), little progress has been achieved. D&I research is urgently needed to address this gap and support the identification of effective PA programmes suitable for delivery in clinical- and community-based settings for survivors of cancer (Brownson, Jacobs, Tabak, Hoehner & Stamatakis, 2013; Courneya, Rogers, Campbell, Vallance & Friedenreich, 2015; Santa Mina et al., 2017).

#### 9.3 Conclusion

PA represents an important therapeutic target for individuals living with and beyond cancer given its ability to enhance physical and psycho-social well-being, and reduce the risk of cancer recurrence, cancer mortality and all-cause mortality. However, PA participation in this population is suboptimal and efforts are urgently needed to increase PA levels among cancer survivors in order to optimise health outcomes and quality of life.

The identification of OHPs as important sources of information and the fact that their recommendations influence cancer survivor's levels of PA participation is an important finding. However, the inclusion of PA promotion and prescription within cancer care is limited by a number of challenges experienced by OHPs, including limited time with patients and a lack of resources for PA for survivors of cancer. As such, PA promotion and prescription do not currently feature as part of usual care for every patient. Referring patients to CBERPs may provide a solution to overcome some of the barriers highlighted by OHPs and provide patients with access to the necessary advice and expertise to enable the adoption of habitual PA. Consensus statements regarding the motivators and barriers to the referral process and strategies to support its optimisation are presented. If implemented, these recommendations could support greater engagement by OHPs in the referral process to CBERPs and therefore maximise the number of individuals living with and beyond cancer experiencing the benefits of regular PA.

Results from the qualitative study completed highlighted that while exercise was viewed by many survivors of cancer as a vehicle for recovery as it enabled 'self-

power' (defined as a means for individuals to take ownership and control of PA to increase well-being), many environmental-, patient- and treatment- related barriers were encountered which limited/inhibited participants' PA engagement. Participants highlighted the lack of support services available for patients, particularly during the post-treatment phase of the cancer journey, and the need for holistic rehabilitation to be embedded within routine cancer care. Recommendations to support habitual PA and adherence to CBERPs generated by focus group participants are presented. Their implementation could assist in addressing many of the challenges to PA cited by participants and increase PA participation among individuals living with and beyond cancer.

The MedEx IMPACT PA BC intervention development process was aligned with the MRC framework for the development, implementation and evaluation of complex interventions (Craig et al., 2008), guided by theoretical frameworks (Cane, O'Connor & Michie, 2012; French et al., 2012; Michie, Atkins & West, 2014) and informed by a synthesis of recommendations distilled from the scientific literature and intervention end-users. Reporting of the intervention development process sought to adhere to best practice (Hoffman et al., 2014; Staniszewska et al., 2017) and address limitations identified within previous investigations with regard to intervention development reporting.

A two-arm non-randomised comparison trial, conducted to evaluate the feasibility and effectiveness of the MedEx IMPACT PA BC intervention for survivors of cancer within a community-based setting, demonstrated that participation in 12 weeks of twice-weekly supervised exercise was associated with significant increases

in participants' PA levels and CRF at 3 and 6-month follow-up. Inclusion of additional BC intervention components within the MedEx IMPACT intervention contributed to additional improvements for cancer survivors' by maintaining increases in objectively measured daily steps and LIPA, and HRQoL achieved from baseline to 3 month follow-up, at 6-months. As no significant interaction effects were identified for these variables within the statistical analysis of the data, further work is required to fully elucidate the potential impact of the intervention before valid conclusions regarding its effectiveness can be drawn. The maintenance of improvements in daily step count and LIPA at the 6-month follow-up were not mediated by social support from family or friends, intentions or self-efficacy for PA. Results from the analysis of the intervention debrief questionnaire completed by participants at the 6-month follow-up indicated that the majority of participants enjoyed taking part in the intervention and found it helpful in supporting regular PA participation. A number of recommendations from participants to optimise the MedEx IMPACT intervention for future implementation are outlined, including incorporation of a DVD or online platform containing videos of structured exercise classes.

### 9.4 Impact of the research

Cancer care needs to adapt to address the challenges facing individuals living with, and recovering from, the impact and burden of cancer and its treatment. Patient care needs to better reflect the unique needs of this population at all stages of the cancer journey and support cancer survivors to optimise their health and quality of life, both acutely and in the long-term. The findings from this

research suggest that PA is an under-utilised therapeutic intervention among OHPs and individuals living with and beyond cancer. Its integration into usual care for all individuals on the cancer journey should be advocated.

The PA prescription given, and adhered to, by patients needs to reflect individuals' current functional capacity, stage of the cancer journey and preferences for PA. The promotion of PA should also be tailored to the individual to enable the provision of achievable, realistic PA goals. This approach may help to build patients' self-efficacy for PA and support continued motivation and PA engagement. The recently updated PA guidelines for the general population (Office of Disease Prevention and Health Promotion, 2018) recommend that individuals who engage in little to no PA, replace sedentary behaviour with LIPA and aim to gradually include some or more moderate-intensity PA. The translation of such recommendations into the oncology setting could provide more meaningful, realistic PA targets for survivors of cancer and foster habitual PA participation. While attainment of the recommended PA guidelines for survivors of cancer may be optimal for PA participation in order to maximise its therapeutic value, the updated guidelines highlight that "there is no threshold that must be exceeded before benefits begin to occur" (Office of Disease Prevention and Health Promotion, 2018, pA-5). Therefore, where appropriate, PA recommendations given to patients should emphasise this message and encourage patients to move more in order to confer some health benefits from PA.

The PA guidelines for survivors of cancer should be further developed and refined to provide a more detailed overview of PA recommendations for different cohorts of cancer survivors at different stages of the cancer journey. Such detailed

recommendations could assist those promoting PA in healthcare settings by enabling them to provide more meaningful and relevant guidance to patients.

The Department of Health (2017) has made a commitment to invest in cancer survivorship programmes to address short falls identified within the Irish National Cancer Strategy. This body of research provides valuable evidence, that is specific to the Irish context, that could inform the development of such cancer survivorship programmes. MedEx IMPACT demonstrates future promise that transcends this research project as it is scalable, and could be implemented across hospital and community-based settings at a National level. Participation in such programmes by individuals living with and beyond cancer could also have economic implications. Return to work for survivors of cancer has been shown to be influenced by a number of factors, including fatigue, depression and emotional distress (Islam et al., 2014). PA has been shown to have a positive effect on such factors (Rock et al., 2012) and engagement in regular PA could enhance individuals' rate of recovery and subsequently, return to work.

Multi-sectoral action, ranging from the inclusion of PA with curriculums for healthcare professionals working in oncology, to advocacy by cancer charities and Governing bodies, to changes within the healthcare system, is needed to support, and enable, the integration of PA into usual cancer care. This action must be driven and guided by relevant policy.

As this study was conducted at the interface where research meets service delivery, it maximized the potential for the translation of knowledge into

immediate societal benefits. It is hoped that the findings from this research can assist in advocating for the inclusion of PA within cancer care to support those living with and beyond cancer to live healthier, better quality lives.

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# Appendices

Appendix A. List of strategies that focus group participants were asked to rate (within the investigator developed questionnaire) regarding the top 3 strategies to support increased physical activity participation.

Strategy	Accompanying Text
Fitness Assessments	Fitness assessments would consist of exercise testing at the start and 3, 6 and 12 months after commencing a community-based exercise programme. Exercise testing involves completing tests that measure different aspects of your fitness such as your strength and flexibility. This information could be used to monitor progress and give feedback.
Exercise 'how-to' guide	An exercise 'how-to' guide would include a home-based exercise programme to supplement attendance at a community- based exercise programme
Tapering to a home-based programme by week 12	Tapering from supervised exercise classes to a home-based programme would mean attending 2 exercise classes per week for 8 weeks, then 1 class per week for 4 weeks (where the other supervised session is replaced by at least one other independent physical activity session), and moving to solely a home-based exercise programme from week 12 onwards.
Face-to-face counselling regarding physical activity from knowledgeable staff	
Group discussion sessions	Group discussions every 2 weeks to discuss topics like time management, stress management and goal setting.
Mobile Phone Application	A mobile phone app regarding physical activity. Examples of commercially available applications for physical activity were included as examples.
Website	A website to find information regarding physical activity, interact with other users, get ideas and tips for physical activity.

Phone-based support	Receive a follow-up call from a member of the exercise team member to discuss physical activity, challenges you may have encountered and goal setting
Text messaging support	Receive reminder texts to encourage you to be physically active and to give you tips and ideas for exercise

Appendix B. Examples of focus group questions developed using the COM-B model (Michie, van Stralen & West, 2011)

COM-B Model Component	Question
Capability (physical and psychological	Do you feel you are physically able to be
capability)	active?
	When do you think you were ready (in
	terms of your health) to be physically
	active?
Opportunity (physical and social)	Are there opportunities for you to be
	physically active at home/within your
	local community?
	What do your friends and family think
	about you being physically active?
Motivation (reflective)	What motivates you to be physically
	active?
	What would make exercising more
	appealing to you?

#### Appendix C. Additional Results from Study 2 - Section 4.1.4

## 4.1.4 Results

Forty-one individuals living with and beyond cancer were recruited and 7 focus groups consisting of 4-8 participants were conducted. Two participants were receiving on-going treatment for advanced prostate cancer. All other participants were in the survivorship phase of the cancer journey. Focus group characteristics are presented in Table 4.1. Participants' demographic information is presented in Table 4.2.

	% (n)
Gender	
Male	44 (18)
Female	56 (23)
Cancer Diagnosis	
Breast	41 (17)
Prostate	27 (11)
Colorectal	20 (8)
Lung	5 (2)
Cervical	2 (1)
Melanoma	2 (1)
Leukaemia	2 (1)
Age (yr)	
31-40	2 (1)
41-50	15 (6)
51-60	51 (21)
61-70	17 (7)
>71	15 (6)

Table 4.2. Participant demographic information.

Five main themes and a number of subthemes were identified within the data (Figure 4.1): 1) patterns of physical activity across the cancer journey, 2) benefits of physical activity participation, 3) challenges to physical activity

participation, 4) the role of the healthcare professional and 5) cancer survivors' recommendations for physical activity. Evidence of these themes is supported by illustrative quotes that are embedded within the findings presented below.

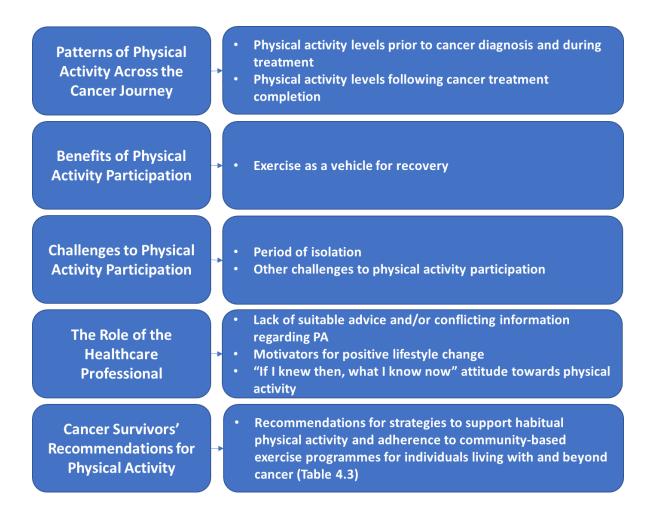


Figure 4.1. Themes and subthemes

## 4.1.4.1 Patterns of Physical Activity Across the Cancer Journey

4.1.4.1.1 Physical Activity Levels Prior to Cancer Diagnosis and During Treatment

Participants reported their PA level prior to their cancer diagnosis when responding to an open question phrased by the researcher conducting the focus group. Advancing age was recognised by some as a contributing factor to gradual declines in PA levels over time. During diagnosis and treatment individuals reported a decrease in their PA as a result of side effects from treatment and the emotional and mental stress of coping with cancer. Participants reported that it wasn't possible to be active as treatment procedures were aggressive and many felt too ill to consider being physically active.

"When I got the treatment I just couldn't do anything because my treatment was very aggressive, I had a lot of chemo and a lot of radiotherapy and it was just, it was not even up for discussion, I couldn't do anything" (FG1, ID04, 60 year old survivor of breast cancer).

"I think diagnosis you're in shock then its straight into surgery then obviously reduced physical activity straight away until you're well enough then its straight into chemo treatment again which is just, it was kind of bad chemo so it was hair loss, drastic reduced energy, etc., etc. And so it was dealing with all that emotional stuff too as well so you just weren't in the mood for exercising to be honest, em, you were just trying to get through each day...So physical activity was really the last thing on the list" (FG2, ID14, 47 year old survivor of breast cancer).

A minority of participants reported maintaining light-intensity activity, predominantly walking, during treatment.

#### 4.1.4.1.2 Physical Activity Levels following Cancer Treatment Completion

The importance of having a period of recuperation following treatment completion before engaging in an exercise rehabilitation programme was highlighted. Participants reported a number of different experiences of PA following completion of cancer treatment. Some individuals found it difficult to be active as a result of treatment-related side effects and pre-existing medical conditions.

"It doesn't just start with cancer, there's also multiple issues, like I got fibromyalgia and I've gotten arthritis because I had really high dosage chemo for leukaemia. So I was 9 months being dosed every 2 weeks you know...So my system just crashed like...So it's very difficult to even think in terms of physical exercise" (FG7, ID44, 52 year old female survivor of acute myeloid leukemia).

Other participants were motivated by their cancer diagnosis to improve their health and increased their PA levels. Two different experiences were identified by individuals who participated in an exercise rehabilitation programme following treatment. Many participants reported increases in their levels of PA as a result of participating in an exercise programme, which were maintained following programme completion.

"I bought a set of weights the last couple of weeks so I'm working at home one day a week on my own. I'm doing some walking, and like, regular exercise which I wasn't doing after my operation" (FG2, ID09, 50 year old survivor of prostate cancer).

Other participants reported increasing their PA levels while attending an exercise programme, which was followed by a return to previously lower levels of activity after completion of the programme.

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## 4.1.4.2 Benefits of Physical Activity Participation

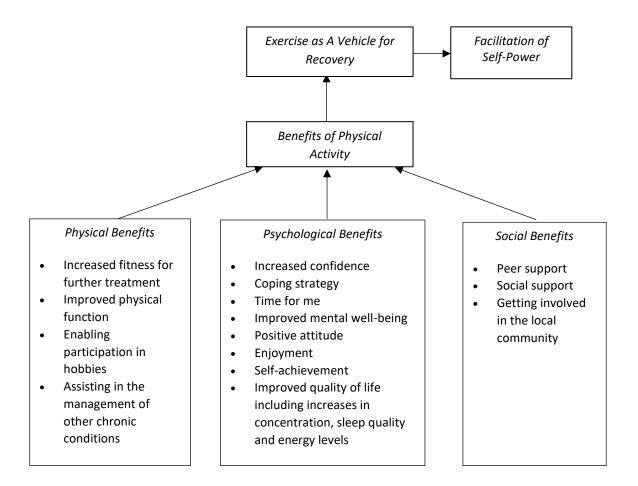


Figure 4.2 provides a summary of the benefits of PA reported by participants.

Figure 4.2. Benefits of physical activity reported by individuals living with or beyond cancer.

Benefits included improvements related to physical (e.g. physical function and quality of life) and psycho-social well-being (e.g. mental well-being and confidence, positive attitude and sense of self-achievement).

## 4.1.4.2.1 Exercise as a Vehicle for Recovery

The combined benefits resulted in many individuals viewing PA as a vehicle

for recovery as it facilitated 'self-power' - whereby participants took ownership and

control of their PA to increase well-being. For many individuals, this was associated with increases in self-confidence and belief in physical capabilities. PA assisted in the transition from 'cancer patient' to 'cancer survivor' and provided individuals with a medium through which they could learn what their physical capabilities were.

"It puts your brain back in, away from the hospital and back into the real world. And you're there and you can say, 'I can do this, I can do that" (FG2, ID13, 52 year old survivor of breast cancer).

"When you get into the cycle of exercise you think, well you've been fed a bit of information, information is power...I can do this for myself...You know, you're reclaiming a bit of yourself... and it does, it really motivates you" (FG1, ID01, 59 year old survivor of breast cancer).

"I've been saying to my surgeon all along, I'm going to be the lean, mean fighting machine when I come in here for the next phase of this. I'm not going to be a weak person like I was, when I had post-chemotherapy the first operation, so you know, it's there, in your head all the time, kind of like, how much exercise is beneficial to your body" (FG2, ID13, 52 year old survivor of breast cancer).

Individuals who had participated in a community-based exercise programme for survivors of cancer reported that the social and peer support they received by exercising within the group environment was very beneficial. Exercising with others who had shared similar experiences created an accepting and supportive environment for exercise where participants did not feel self-conscious.

"I love the support, I feel just the general, general support of being part of a group of people who you all understand. We all know what every one of us is going through" (FG2, ID07, 58 year old male survivor of colorectal cancer).

"You don't feel inadequate here [referring to a community-based exercise rehabilitation programme for survivors of cancer]. Whereas I've always felt inadequate" (FG2, ID12, 52 year old survivor of breast cancer).

"We motivate each other I think as part of a group. You might say a word to somebody you know 'keep going' or 'well done' or whatever, but, and you don't get that or I've never experienced that in another sort of gym session or format" (FG2, ID13, 52 year old survivor of breast cancer).

Other reported benefits of PA included that it: i) provided a strategy to cope with cancer, and time to focus on one's health and well-being, ii) increased fitness for further treatment, iii) assisted in the management of other chronic conditions (i.e. osteoporosis, depression and musculoskeletal conditions), and iv) provided opportunities to take part in hobbies and to engage with others in the community through PA.

### 4.1.4.3 Challenges to Physical Activity Participation

Figure 4.3 provides a summary of the challenges to PA participation reported by focus group participants that were categorised as environmental-, patient- and treatment-related barriers.

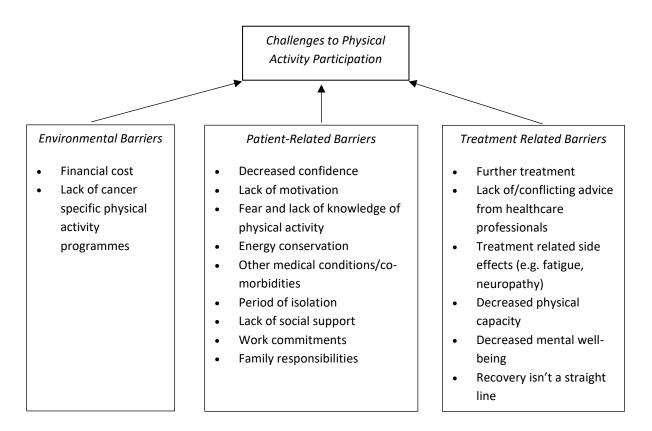


Figure 4.3. Challenges to physical activity participation reported by individuals living with or beyond cancer.

### 4.1.4.3.1 Period of Isolation

Many individuals reported experiencing a period of isolation following treatment completion. As a result of reduced contact with treatment centres and a lack of direction regarding how to recover following cancer treatment, many participants reported a decrease in their physical and psycho-social well-being. This was viewed as a gap in the cancer care pathway and many participants reported the lack of cancer-specific PA programmes available at this time, and voiced the need for a holistic approach to rehabilitation after treatment completion.

"Because you've had...the hamster wheel, you know, you're kind of going to the hospital today, and you've this tomorrow and you have all of that non-stop. And then all of a sudden, they say, 'That's it...and you can go now'. And you're like, 'What do I do next?' You've had all this time taken out of your life to deal with having cancer...and now all of a sudden, you've got nothing" (FG2, ID13, 52 year old survivor of breast cancer).

"Then suddenly you're discharged and you're out on your own. I was in absolute limbo. You know, I thought 'Well, what do I do now you know?' I don't have oncology, I don't have the breast clinic, I don't have the support group, I'd nothing, you know you're just in a very lonely place to cope with all this" (FG7, ID45, 61 year old survivor of breast cancer).

For many individuals, this period of isolation was compounded by decreased physical fitness following cancer treatment and reduced confidence in physical capabilities. For some participants, this led to a fear of PA. Many individuals were unsure what types of activity were safe for them to participate in and what intensity of activity was suitable.

"You don't know what you can do because you feel, you get an ache or I don't know, or you've a pain...and you're saying 'Aw dear God, what's the pain

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from...'" (FG3, ID15, 50 year old survivor of breast cancer).

"I was kind of stuck in neutral, because I didn't know where to go, I didn't know what was right, what was wrong" (FG2, ID12, 52 year old survivor of breast cancer).

4.1.4.3.2 Other Challenges to Physical Activity Participation

Participants felt that their expectations of the recovery journey and the reality of it did not align.

"Where I was after 2 years is where I thought I'd be after a year. I'm talking about every way – I'm talking about emotionally, physically, every way" (FG7, ID43, 53 year old survivor of breast cancer).

"It's not a straight line. You know you're up here and then you're down here and then you're building back up again" (FG1, ID06, 73 year old survivor of prostate cancer).

Fatigue dictated many participants' energy levels and was variable in its presentation. Individuals also reported the need to learn how to manage treatment related side effects (e.g. fatigue, neuropathy, bone pain). These factors impeded participants' recovery, quality of life and PA participation. Individuals found it challenging and frustrating to adapt to daily fluctuations in energy levels. "You've had to adapt to a new way of living, and coping, that's not the same as it was before. Because you can't, that's not going to work, it's a different formula, it won't fit. So the formula has changed...it's difficult to try and re-adjust then" (FG7, ID44, 52 year old female survivor of acute myeloid leukemia).

"It's just you don't know when the days that you're going to be really good and the days that you're going to be really bad, so you just kind of, every day's a day you know" (FG2, ID13, 52 year old survivor of breast cancer).

Many individuals felt that their physical capacity had changed as a result of their cancer treatment and that they, and their families, needed to adapt accordingly. The acceptance of the 'new' version of oneself was challenging.

"Do you know what, that's a big thing to accept that the old you isn't there any more...you have to learn to accept the new you for what you are and your limitations" (FG4, ID24, 53 year old survivor of breast cancer).

Work and family responsibilities as well as activities of daily life also presented challenges to PA participation. Some individuals referred to a need to conserve their energy for recovery and activities of daily living (e.g. cooking, cleaning).

"When I got the cancer...all my energies went into just trying to get well. You know, physical fitness wasn't, because you're mentally trying to stay ahead of life and living...the bills that come through the door and all the nasty stuff that happens, that life doesn't stop because you've had cancer, you know...So my energies would be on reserve all the time" (FG7, ID44, 52 year old female survivor of acute myeloid leukemia).

Other significant challenges to PA participation included: i) a lack of social support for PA, ii) prioritising family responsibilities over one's health and well-being, iii) treatment-related side effects, including fatigue, neuropathy, lymphedema, weight gain, poor balance and memory and concentration problems, iv) the financial cost associated with some forms of PA and v) further medical treatment.

## 4.1.4.4 The Role of the Healthcare Professional

Participants viewed healthcare professionals (e.g. medical oncologists, nurses, physiotherapists, psycho-oncologists) as credible and important sources of information. For some participants, recommendations from healthcare professionals had a significant impact on individuals' decision to be physically active.

#### 4.1.4.4.1 Lack of suitable advice and/or conflicting information regarding PA

However, the lack of suitable advice and/or conflicting information from healthcare professionals regarding PA was reported by many participants. It was reported that healthcare professionals' concerns for PA participation focused on issues relating to immune compromise and safety, particularly during treatment. This further compounded some individuals' fears for being active during their cancer journey.

"You were told what you couldn't do" (FG5, ID31, 67 year old male survivor of colorectal cancer).

"I used to ask them, I'd to say to them 'Is it ok, can I go swimming?' 'No, no, you're going through chemo'. Then when I was going through the radium I said 'Is it ok if I go to a gym?' 'No'. So you're just not allowed... do any of them things because swimming you could pick up an infection when you're going through chemo. And for the radium, it has you zonked. They said 'No, you'd be exhausted'" (FG5, ID34, 59 year old survivor of breast cancer).

"I don't think I was told, just how beneficial exercise was, so I actually, really did just vegetate and increase in size and girth" (FG1, ID01, 59 year old survivor of breast cancer).

#### 4.1.4.4.2 Motivators for positive lifestyle change

Some participants reported that advice and recommendations received from healthcare professionals acted as a motivator for the adoption of positive lifestyle changes with regard to PA and nutrition.

"My oncologist made me do this [referring to participating in an exercise rehabilitation programme], I had no choice...she said that it was part of my recovery and she gave me the letter and basically how to get there as soon as possible" (FG1, ID04, 60 year old survivor of breast cancer).

#### 4.1.4.4.3 "If I knew then, what I know now" attitude towards physical activity

For some individuals who attended an exercise rehabilitation programme after treatment completion, they expressed an "if I knew then, what I know now" attitude towards PA. Participants felt they would have made a greater effort to engage in PA, both during and after treatment, had they been made aware of its importance at the time.

"I probably wouldn't have felt well enough to do exercise until after the treatment...But I think had I been told in time, the benefit of it, I would have pushed myself further" (FG1, ID01, 59 year old survivor of breast cancer).

### 4.1.4.5 Cancer Survivors' Recommendations for Physical Activity

Appendix D provides a table of results from the questionnaire completed by participants regarding their preferences for PA. Aerobic, flexibility and strengthening exercises were the most popular (90, 68, 66%), followed by pilates, circuit training, swimming and step aerobics (37, 17, 15, 12%). Yoga, aqua aerobics and horse riding received limited support (<7%). Two participants reported having no preferences for PA.

The items reported by participants as being the most beneficial to include within an exercise rehabilitation programme and support habitual PA participation

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are summarised in Appendix E. Follow-up exercise testing was the most popular strategy to optimise PA participation (71%) and was defined as completing fieldbased tests that measure different components of fitness (e.g. CRF, lower body strength, flexibility) at the start of an exercise rehabilitation programme and after 3, 6 and 12 months. As part of this process, participants would receive feedback reports detailing changes in their fitness over time. An exercise-how-to guide, defined as the provision of a home-based exercise programme to supplement attendance at supervised exercise classes as part of an exercise rehabilitation programme, was the second most popular strategy (68%). The third most popular strategy was face-to-face counselling from exercise specialists regarding PA (44%), which was defined as attending educational sessions delivered by PA experts regarding the benefits of PA and strategies to incorporate PA into everyday life.

Participants identified other key components that are important to support habitual PA and adherence to community-based exercise programmes. Table 4.3 provides a summary of these recommendations. Table 4.3. Summary of recommendations from focus group participants for strategies to support habitual physical activity and adherence to community-based exercise programmes for individuals living with and beyond cancer.

Recommendation	Rationale
Individualised exercise	It is important to provide information to guide individualised exercise prescription within a group
prescription	setting. This enables individuals to learn how to tailor their physical activity to their personal
	exercise goals. For example: Survivors of prostate cancer are interested in learning more about
	core strength and pelvic floor exercises while survivors of breast cancer are interested in
	learning more about exercises to increase their upper body muscle strength and shoulder range
	of motion.
Exercising as part of a group of	Exercising with others who have shared similar experiences creates an accepting and supportive
individuals who have	environment for exercise where participants do not feel self-conscious. Exercising as part of a
completed treatment for	group provides comradery and generates increased motivation and confidence for physical
cancer	activity. Participants value the social and peer support they receive from the group.
Goal setting and action	Setting meaningful goals for physical activity is important. Developing an individualised action
planning	plan for physical activity is also fundamental to long term physical activity adherence.

Quantifying and measuring	Quantifying and measuring physical activity is important for feedback and to provide continued
physical activity	motivation for physical activity participation.
Information regarding	Receiving additional information about other health behaviours (e.g. healthy eating, smoking
additional health behaviours	cessation, alcohol consumption and stress management) is appealing to some participants. For
	those who were interested, nutrition and stress management are the two most popular topics.
Supervised exercise classes and	Participating in both supervised exercise classes and a home-based exercise programme is
a home-based exercise	appealing. The supervised classes increase confidence to be active while the home programme
programme	can guide independent physical activity.
Fitness Assessments	Intermittent fitness assessments can track progress and provide motivation for physical activity
Face-to-face counselling from	Individuals are interested in receiving face-to-face counselling from exercise specialists regarding
exercise specialists regarding	physical activity to learn about the benefits of physical activity and address concerns regarding
physical activity	physical activity participation following cancer treatment (e.g. advice for physical activity for
	individuals who have fatigue, neuropathy, lymphoedema, bone pain).

	% (n)
Aerobic Exercise	90 (37)
-lexibility Exercises	68 (28)
Strengthening Exercises	66 (27)
Pilates	37 (15)
Circuit Training	17 (7)
Swimming	15 (6)
Step Aerobics	12 (5)
Yoga	7 (3)
No Preferences	5 (2)
Aqua Aerobics	5 (2)
Horse Riding	2 (1)

Appendix D. Preferences for physical activity reported by individuals living with and beyond cancer.

	% (n)
	71 (20)
Exercise Testing	71 (29)
Exercise-How-To Guide	68 (28)
Face-to-face Counselling	44 (18)
Regarding Physical Activity	
Tapering to a Home-based	37 (15)
Programme	
Group Discussion Sessions	22 (9)
Phone Based Support	10 (4)
Mobile App	7 (3)
Website	7 (3)
Text-message support	2 (1)

Appendix E. Strategies rated by individuals living with and beyond cancer to support increased physical activity participation.

# Appendix F. Methodology for the review of the literature including key search terms and inclusion and exclusion criteria

## Purpose:

To understand the factors that influence physical activity behaviour, adherence and maintenance for survivors of cancer, and review physical activity behaviour change interventions for survivors of cancer, to inform the design of one such intervention to increase cancer survivors' levels of physical activity.

## **Research Questions:**

- Primary Research Questions
  - Searches 1-3: What are the determinants of physical activity i) behaviour, ii) adherence and iii) maintenance for survivors of cancer? Search 4: What behaviour change interventions have been conducted to increase cancer survivors' physical activity levels? What intervention components have been associated with intervention success?
- Secondary Research Questions:
  - 1. Do the predictors of physical activity behaviour, adherence and maintenance differ among male and female cancer survivors?
  - 2. Do the predictors of physical activity behaviour, adherence and maintenance differ among cancer diagnoses (e.g. breast vs. colorectal cancer)?
  - 3. Do the factors affecting physical activity behaviour, adherence and maintenance change during the cancer journey?
  - 4. What behaviour change strategies have been shown to be effective in increasing cancer survivors' physical activity levels?

# Search Strategy

- Stage 1: Exclude studies if not a meta-analysis, systematic review or review paper.
- Stage 2: Review and synthesize a sample of primary studies included within eligible meta-analyses, systematic reviews or review papers.
- Do not restrict search by year of publication
- Restrict search by language (English)
- Duplicates will be deleted
- Exclude studies if they are inaccessible at the time of data collection and analysis.

### Databases:

- The Cochrane Library
- EMBASE
- MEDLINE
- CINAHL
- PsycINFO
- SportDiscus

## Other Sources of Information:

- Grey Literature (no one source included Google scholar)
- Conference Proceedings (no one source included Web of Science and Scopus)

### Notes:

- In all databases, the searches were limited to the fields of abstract and title only.
- Functions to capture alternative spelling of the same word (e.g. behaviour, behavior) were included within all searches.
- All searches were run with and without the search terms included in the column labelled '\*Systematic Review'. This enabled the identification of meta-analyses, systematic reviews and review papers (if available) as well as original research articles.

## Key Search Terms

Search 1: What are the determinants of physical activity behaviour for survivors of cancer?

Keyword:	Determinants	Physical Activity	Behaviour	Cancer	*Systematic Review
Supplementary	Predictors	Exercise			OR
Terms:					
	OR	OR			Review
	Correlates	Physical Activities			OR
	OR	OR			Meta-Analysis
	Factors	Fitness			
	OR	OR			
	Variables	Sport			
	OR	OR			
	Barriers	Training			
	OR				
	Motivators				
	OR				
	Facilitators				

Search 2: What are the determinants of physical activity adherence for survivors of cancer?

Keyword:	Determinants	Physical Activity	Adherence	Cancer	*Systematic Review
Supplementary	Predictors	Exercise	Compliance		OR
Terms:					
	OR	OR	OR		Review
	Correlates	Physical	Attendance		OR
		Activities			
	OR	OR			Meta-Analysis
	Factors	Fitness			
	OR	OR			
	Variables	Sport			
	OR	OR			
	Barriers	Training			
	OR				
	Motivators				
	OR				
	Facilitators				

Search 3: What are the determinants of physical activity maintenance for survivors of cancer?

Keyword:	Determinants	Physical	Maintenance	Cancer	*Systematic
		Activity			Review
Supplementary	Predictors	Exercise			OR
Terms:					
	OR	OR			Review
	Correlates	Physical			OR
		Activities			
	OR	OR			Meta-Analysis
	Factors	Fitness			
	OR	OR			
	Variables	Sport			
	OR	OR			
	Barriers	Training			
	OR				
	Motivators				
	OR				
	Facilitators				

Search 4: What behaviour change interventions have been conducted to increase cancer survivors' physical activity levels?

Keyword:	Behaviour Change	Physical	Cancer	*Systematic
	Strategies	Activity		Review
Supplementary	Behaviour Change	Exercise		OR
Terms:	Intervention			
	OR	OR		Review
	Behaviour Change	Physical		OR
	Techniques	Activities		
	OR	OR		Meta-Analysis
	Behaviour Change	Fitness		
	Programmes/Programs			
	OR	OR		
	Behaviour Change Methods	Sport		
	OR	OR		
	Behaviour Change	Training		
	Approaches			
	OR	OR		
	Health Behaviour Change	Rehabilitation		
	Strategies			

## Inclusion and exclusion criteria

Searches 1-3:

Inclusion Criteria	Exclusion Criteria
Studies performed in adult cancer survivors	Lifestyle intervention that combined
(>18 years) before, during and/or after	physical activity with other behaviours (e.g.
primary cancer treatment	diet)
AND	OR
Primary studies reporting findings from	Studies not reporting analysis of physical
exercise intervention trials in cancer	activity i) behaviour, ii) adherence and/or
populations	iii) maintenance predictors
AND	
Focus on predictors physical activity i)	
behaviour, ii) adherence and/or iii)	
maintenance.	
AND	
Original full-text article was available in	
English	

## Search 4:

Inclusion Criteria	Exclusion Criteria
Studies performed in adult cancer	Lifestyle interventions that combined
survivors (≥18 years) before, during and/or	physical activity with other behaviours
after primary cancer treatment	(e.g. diet)
AND	OR
Focus on behaviour change strategies to	Exercise interventions consisting of a PA
support increased physical activity levels	recommendation only
for survivors of cancer	
AND	
Original full-text article was available in	
English	

Appendix G. Guidance for Reporting Involvement of Patients and the Public short form checklist (GRIPP2-SF) (Staniszewska et al., 2017)

Section and topic	Item
1. Aim	The aim of PPI within this study was to collaborate with individuals living with and beyond cancer to explore what the motivators and barriers to physical activity participation were, and to identify strategies that would address these challenges and support long-term physical activity adherence. This approach aimed to ensure that the intervention development process was meaningful, relevant and grounded in the recommendations received from intervention end-users (i.e. individuals living with and beyond cancer). The research team aimed to adopt an iterative approach to the intervention development process and sought guidance and feedback regarding intervention acceptability from the stakeholder expert panel prior to intervention implementation.
2. Methods	41 individuals living with and beyond cancer participated in 7 focus groups. Semi-structured interview scripts were used to guide the focus group discussions. Questions focused on exploring i) individuals' capability, opportunity and motivation to be regularly physically active and ii) strategies to support habitual physical activity and adherence to community-based exercise programmes.
	11 stakeholders, including individuals who were currently attending or had graduated from a community-based exercise programme for survivors of cancer (n=4) and representatives from a national cancer charity (n=3), were invited to participate in a 2-hour workshop to determine the acceptability of the proposed physical activity behaviour change intervention and provide feedback on the proposed intervention content. During the workshop, an overview of the proposed intervention was presented and stakeholders were asked to discuss questions that had been generated by the research team regarding intervention acceptability and effectiveness. Following this exercise, the discussion was opened to the floor and stakeholders asked questions of the research team and shared their comments and recommendations to inform the intervention design.
3. Study results	The focus group discussions provided valuable information regarding individuals' experiences of physical activity throughout the cancer journey and the factors that influence physical activity participation. 8 recommendations for strategies to support habitual physical activity and adherence to community-based exercise programmes were generated and used to inform intervention development. A detailed overview of the findings from this study are

	reported elsewhere (Cantwell et al., 2019) The range of experts deemed that the intervention was acceptable and would educate, motivate and encourage participants attending the 12-week programme to continue to be physically active upon completion of the supervised exercise classes. A number of recommendations to optimise intervention implementation and impact were proposed and are presented in additional file 3.
4. Discussion and conclusions	PPI within this study was effective and played an important role in influencing intervention content development and delivery. The recommendations obtained from individuals who participated in the focus groups formed the foundation for the intervention content development. This information informed a more appropriate selection of behaviour change techniques to support the desired behaviour change and could therefore contribute to an increased likelihood of intervention success.
	The stakeholder expert panel provided important feedback that assisted in further refining the proposed intervention. In particular, stakeholders highlighted important operational considerations including training for intervention delivery team members and ensuring continuity and communication between the exercise instructors delivering the supervised exercise classes and the researchers responsible for the delivery of other intervention components. This assisted in streamlining some aspects of intervention delivery and supported the research team to have protocols and procedures in place prior to intervention implementation. The feedback received from the stakeholder panel contributed significantly to the optimisation of the intervention.
5. Reflections/ critical perspective	The inclusion of PPI within this study ensured that the intervention addressed challenges that were pertinent to intervention end-users and focused on strategies that were feasible, of interest and considered effective by individuals living with and beyond cancer to support habitual physical activity. The next phase in this research is to test the acceptability and effectiveness of the intervention.
PPI=natient and pub	The research team did experience difficulties in recruiting individuals who were referred to a community-based exercise programme but did not attend, and those who began such a programme but subsequently dropped out, to participate in the focus groups. In addition, given the large sample size of participants recruited for the focus groups (n=41), the analysis of the data collected was significant and resource intensive. This should be considered by intervention designers who may be operating within time and financial constraints.

PPI=patient and public involvement

Appendix H. Identification of what needs to change using the COM-B Model and findings from the focus groups and the review of the literature.

COM-B Components	Findings from the Focus Groups	What needs to change for the target behaviour to occur?
Physical	- Physical capability is linked to the presence and severity	- Provide individualised exercise prescription
Capability	of treatment related side effects and ongoing treatment.	(e.g. if MSK problems are present, have a greater focus on non-weight bearing activity)
	<ul> <li>Many participants reported that 'recovery isn't a straight</li> </ul>	
	line'. Participants have to adapt to changes in energy	- Provide additional support to those who have
	levels. Some days, participants feel more fatigued than	been identified as needing it e.g. individuals
	others. There appears to be no pattern to predict this.	with a higher BMI, greater no. of co- morbidities, who have undergone
	<ul> <li>Regarding physical capability there were predominantly 3 reported experiences: i) Those who feel physically well</li> </ul>	chemotherapy or combination therapy
	enough to be active, ii) Those who feel physically unable	<ul> <li>Set goals using the SMARTER acronym</li> </ul>
	to be active (mainly due to treatment related side effects	
	or ongoing treatment) or iii) Those who are inactive and	<ul> <li>Provide supervised exercise classes and an</li> </ul>
	feel they have the physical capacity but report other	independent physical activity (PA) programme
	challenges (e.g. lack of motivation, other responsibilities)	
	- Some participants were also unsure about their physical	
	capabilities after cancer treatment. They had lost	
	confidence in their bodies and what they were physically able to do.	
Psychological	- With regard to monitoring PA, some participants felt that	- Provide group information sessions regarding:
Capability	this was guided by common sense whereas other	i) the benefits of PA for cancer survivors,

	participants felt unsure as to how far they could push	ii)	considerations for PA following cancer
	themselves.		treatment (e.g. lymphedema and resistance exercise),
	<ul> <li>Active participants had a greater awareness of PA</li> </ul>	iii)	goal setting, and
	intensity and engaged in higher intensity PA after cancer.	iv)	identifying strategies to overcome barriers to PA participation.
	- Decreased belief in physical capabilities was also linked		
	to decreased confidence following cancer treatment.		Provide opportunity for self-monitoring using a PA diary.
	<ul> <li>For some individuals who had participated in a community-based exercise programme, re-gaining confidence in physical capabilities was guided by feedback received from exercise instructors and participants "knowing their own limits".</li> </ul>	c s - P ir to p	Provide an individualised 1:1 exercise onsultation to facilitate action planning to upport maintenance of PA. Provide supervised exercise classes and an independent physical activity (PA) programme o assist in increasing self-efficacy and perceived behavioural control through mastery experiences.
Physical Opportunity	<ul> <li>Participants reported that there was a lack of cancer specific PA services.</li> </ul>	ir	Provide supervised exercise classes and an ndependent physical activity (PA) programme hat are specific to individuals who have
	<ul> <li>Most participants reported having access to non-cancer specific PA services within their community (i.e. local</li> </ul>		ompleted cancer treatment.
	gyms, parks, walks) but some were reluctant to engage with these facilities as a result of a number of different barriers (e.g. lack of motivation, feeling self-conscious, financial cost)		dentify opportunities for PA within participants' local communities

Social	- Some participants said that it was difficult to enlist social - Provide opportunity for group interaction
Opportunity	support from family and/or friends for PA. This was through group-based supervised exercise
	linked to the concept of 'you should rest when you're classes and information sessions
	sick' and also that family members may have stopped
	listening to participants if they had been complaining a - Encourage the enlistment of family and friends
	lot. to support independent PA
	- For individuals who had participated in a community-
	based exercise programme, participants said that family
	and friends were supportive of attendance at the
	programme.
	- Some participants reported that being part of a group
	made it easier to commit to being regularly physically
	active.
	- For some, exercising within the group setting made
	participants feel safe, supported, accepted, encouraged,
	and provided an understanding between participants of
	the journey they've been on and the side effects of
	treatment that they might be dealing with. As a result
	participants didn't feel self-conscious when exercising
	within the classes.
	- However, exercise in the group context was not for
	everyone and when discussing group-based PA
	programmes, some participants found groups were

	cliques. As a result, they preferred to exercise on their	
	own.	
Reflective & Automatic Motivation	community-based exercise programme and family support and encouragement were reported as motivators - Provide group-bas for PA. Participants were also motivated by achievements made when attending a community-based exercise of PA and address	e SMARTER acronym ed information sessions to ls' knowledge of the benefit concerns regarding PA wing cancer treatment.
	a community-based exercise programme. - Some participants reported feeling empowered through achievements mac	unity to reflect, during mation sessions and the 1:1 rcise consultation, on de during participation in the exercise programme.
	- Enjoyment of PA was important.	
	<ul> <li>The benefits of PA reported by participants included improved mental well-being, confidence and feeling good. Some participants highlighted the benefit of PA to positively impact the risk of cancer recurrence.</li> </ul>	

Description of Stakeholder	Illustrative Quote	Recommendation/how it is addressed within the MedEx
Feedback		IMPACT intervention
Stakeholders felt that there was a strong psychological component to the intervention and that there was the potential for participants to	psychological component to it, the idea of the one-to-one sessions with the participants and I suppose my concern is are you, and your team, equipped to deal with that?" (ID01, SEP, Cancer Charity	A patient support services co-ordinator from a National Cancer Charity provided training to the lead for intervention implementation [MC]. The training focused on identifying potential scenarios that could occur within the group-based information sessions and one- to-one exercise consultations and strategies that could be implemented to address these situations and concerns or queries raised by participants. The aims of these sessions were also clearly defined. A number of protocols were developed, in conjunction with the MedEx Director for a community-based exercise rehabilitation programme, which clearly outlined the process to be undertaken in the event of certain situations (e.g. someone becoming unwell during a one- to-one exercise consultation, a participant raising a concern regarding their well-being to a member of the research team). In the event of support, beyond the scope of the intervention being required, suitable external organisations were identified and information regarding such services and/or referral to such services was offered to participants. All research team members involved in intervention implementation received training from MC which discussed potential challenges and situations that could occur and the subsequent protocols that should be adhered to.

## Appendix I. Overview of key themes, illustrative quotes and recommendations from the Stakeholder Expert Panel.

Stakeholders suggested renaming the 'physical activity counselling session' as this title may create the wrong impression regarding the content of the session.	that's just knowing, that's just really putting it in a box, and knowing what your boundaries are. That it isn't a	The name of the group-based sessions was changed to 'physical activity information sessions'.
	"The counselling session, I think that you could change that to an information session or something like that" (ID04, SEP, Survivor of Cancer)	
Stakeholders wanted to clarify what the expertise were of those who would be delivering the intervention content, particularly the one-to-one exercise consultation sessions.	"Is there a need for [training in] motivational interview techniques [for research team members] as part of this?" (ID02, SEP, Medical Director for a Community-based Exercise Programme)	All research team members had completed a minimum of a B.Sc. in Sport Science and Health and as such wer competent in the field of health promotion. All researc team members also had prior experience working wit individuals living with and beyond cancer. Training wa delivered and standard operating procedures were pu in place to ensure that the delivery of the one-to-on exercise consultations was consistent and that the sam content was covered within each session.
options for physical activity behaviour to participants within the information	limitations after treatment, like for	The development of the content of the information sessions was informed by this comment where a wide variety of options for physical activity participation were

differences in individual preferences and abilities.	ok, I'm fixed, but I'm not going to be able to run again. So to have somebody who can say "You can try this instead" is actually very motivating" (ID04, SEP, Survivor of Cancer)	
Stakeholders highlighted the importance of creating a supportive environment for participants to discuss their levels of physical activity, particularly when returning for re-assessments. Participants may feel apprehensive about attending re-assessments if they have not continued to be physically active.	<i>"It's good motivation when there's follow- up, because at some stage you're going to have to admit, "Well actually I did nothing" (ID05, SEP, Survivor of Cancer)</i>	An accepting, supporting environment for discussion of challenges to physical activity adherence was created.
Stakeholders commented that the inclusion of a DVD of exercise classes could be a helpful resource for participants.	"Did you ever think of making a DVD, just of the warm up? Just with class on a Monday and Wednesday, maybe people could do that at home on a Friday and that would introduce the notion of self- motivated exercise" (ID05, SEP, Survivor of Cancer)	As the aim of this intervention was to develop a low- tech, low-cost and sustainable intervention with equal access, the research team chose to focus on a paper- based exercise manual. However, future development of this work would encompass development of a DVD or online platform for videos of exercise classes.
Stakeholders commented that it would be important to have continuity between the exercise instructors delivering the supervised exercise classes and the researchers involved in delivering the intervention,	"I think definitely if we're going through it [the home exercise programme] in the class they'll have some idea of what's going on and if they've any questions they can bring it into the programme and ask exactly what does this mean. So I think if you introduce that early on in the	The lead for intervention implementation [MC] met with the exercise instructor team to share the details of the proposed intervention and to discuss the potential implications for its delivery. Exercise instructors received copies of the home exercise programme and they delivered a minimum of 2 supervised exercise classes, during the 12-week programme, that focused on the

particularly in relation to the	programme you could be confident that	content from the home exercise programme. Exercise	
home exercise programme.	you could use it at the end" (ID06, SEP,	instructors also invited participants to ask questions	
	Exercise Instructor)	regarding its content and use.	

## Appendix J. The TIDieR (Template for Intervention Description and Replication) Checklist (Hoffman et al., 2014)

Information to include when describing an intervention and the location of the information

ltem number	Item	Where Located			
	BRIEF NAME				
1.	Provide the name or a phrase that describes the intervention.	MedEx IMPACT (IMprove Physical Activity after Cancer Treatment) intervention.			
	WHY				
2.	Describe any rationale, theory, or goal of the elements essential to the intervention.	The MedEx IMPACT intervention has been developed using the Behaviour Change Wheel and Theoretical Domains Framework The aim of the intervention is to increase the PA levels of individuals living with and beyond cancer who have been referred to a community-based exercise rehabilitation programme.			
	WHAT				
3.	Materials: Describe any physical or informational materials used in the intervention, including those provided to participants or used in intervention delivery or in training of intervention providers. Provide information on where the materials can be accessed (e.g. online appendix, URL).	<ul> <li>The MedEx IMPACT intervention includes:</li> <li>i) Supervised exercise classes: Participants attend a community-based exercise programme that consists of two 60-minute supervised exercise classes each week for 12 weeks.</li> <li>ii) Independent physical activity programme: Participants receive a physical activity manual, a pedometer and a physical activity logbook in week 4 of the programme.</li> <li>a. Physical Activity Manual: The manual includes exercise sessions that can be completed at home. Participants are encouraged to supplement</li> </ul>			

attendance at the supervised exercise classes with use of this manual.

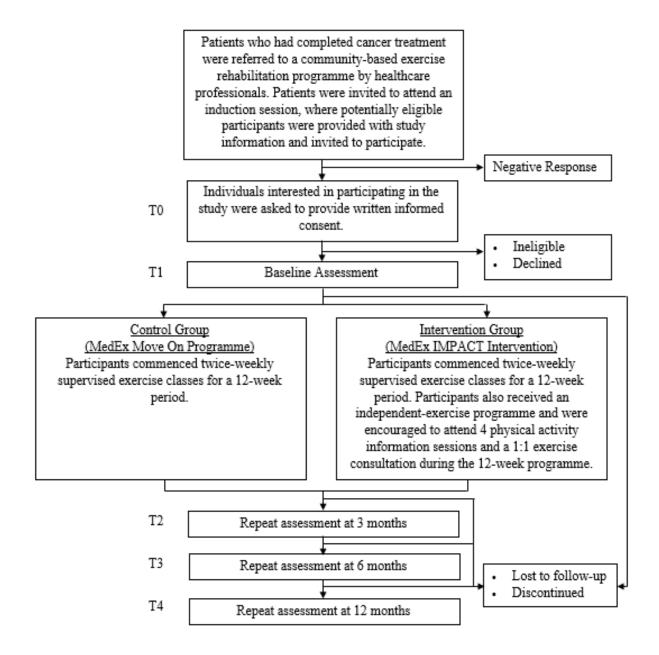
- b. Pedometer (Yamax Digi-Walker SW-200): Participants are encouraged to wear the pedometer daily.
- c. Physical activity logbook: Participants are encouraged to record their daily step count and minutes of physical activity.
- Physical activity information sessions: Participants iii) attend four 30-minute physical activity information sessions in weeks 0, 4, 6 and 10 of the intervention. Session 1 discusses the benefits of physical activity for health. Issues and concerns for being physically active after cancer treatment are also discussed. An overview of the MedEx IMPACT Intervention is presented. Session 2 focuses on introducing participants to the physical activity manual, pedometer and physical activity log book. Session 3 focuses on setting individualised physical activity goals. The group discusses challenges to physical activity participation and solutions to overcome these difficulties. Session 4 focuses on reviewing physical activity goals. Long- term strategies to support habitual PA and manage lapses in physical activity behaviour are discussed.
- iv) 1:1 exercise consultation: Participants attend a 15 minute 1:1 exercise consultation in week 10, 11 or 12 of the intervention which focuses on developing an individualised action plan to guide physical activity upon completion of the supervised exercise classes.

4.	Procedures: Describe each of the procedures, activities,	<ul> <li>v) Assessments of physical and psychological health: Participants complete assessments of physical function, physical activity levels and quality of life at baseline and months 3, 6 and 12. Participants attend a group exercise consultation at each assessment and receive feedback reports at months 3, 6 and 12.</li> <li>The MedEx IMPACT intervention consists of the potential</li> </ul>
4.	and/or processes used in the intervention, including any enabling or support activities.	delivery of 35 behaviour change techniques to participants (see Table 4).
	WHO PROVIDED	
5.	For each category of intervention provider (e.g. psychologist, nursing assistant), describe their expertise, background and any specific training given.	<ul> <li>Criteria for MedEx IMPACT intervention team members:</li> <li>1. Expertise in sport and exercise science.</li> <li>2. Experience working with individuals living with and beyond cancer in the promotion of and adherence to physical activity.</li> <li>3. Trained in the protocols and procedures of the MedEx IMPACT intervention.</li> <li>4. Ability to advise on acceptability or feasibility issues with the intervention and study protocol.</li> </ul>
6.	HOW Describe the modes of delivery (e.g. face-to-face or by some other mechanism, such as internet or telephone) of the intervention and whether it was provided individually or in a group.	The MedEx IMPACT intervention is a patient-centred, evidenced based and theoretically informed physical activity behaviour change intervention. It is delivered through face-to- face session. Participants are encouraged to use the independent physical activity programme at home. The supervised exercise classes, physical activity information sessions and assessments of physical and psychological health are delivered as group sessions. The 1:1 exercise consultations were provided to participants on an individual basis.

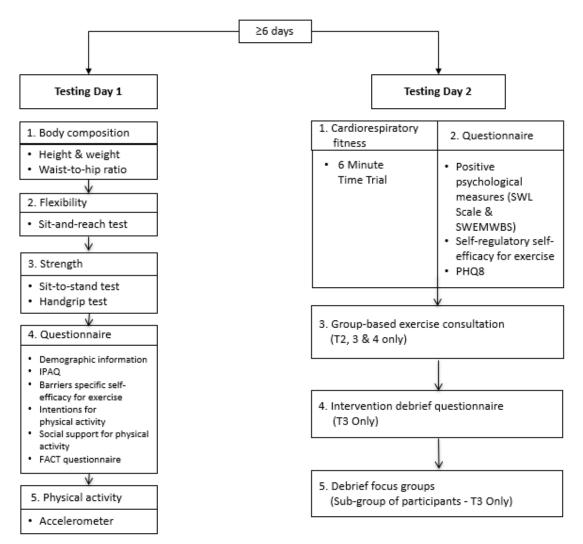
	WHERE	
7.	Describe the type(s) of location(s) where the intervention occurred, including any necessary infrastructure or relevant features.	The MedEx IMPACT intervention is delivered through a community-based exercise rehabilitation programme which is located in the gymnasium of a University. Participants use the independent physical activity programme at home. No equipment (e.g. weights) is required.
	WHEN and HOW MUCH	
8.	Describe the number of times the intervention was delivered and over what period of time including the number of sessions, their schedule, and their duration, intensity or dose. TAILORING	The MedEx IMPACT intervention is delivered through an existing community-based exercise rehabilitation programme which runs in 12 weeks cycles. The intervention was delivered to participants attending 2 cycles of the programme.
9.	If the intervention was planned to be personalised, titrated or adapted, then describe what, why, when, and how.	Supervised exercise sessions: While the exercise sessions are delivered in a group format, advice regarding individual adaptations to the exercise is given to individuals that require it. E.g. individuals with peripheral neuropathy are encouraged to use non-weight bearing CV equipment within the gym (i.e. avoid the treadmill and use a cycle ergometer); individuals with visual impairments are provided with 1:1 support and the exercise is adapted to the individual's ability accordingly. Physical activity information sessions: Group discussions are embedded within the content of the physical activity information sessions and provide opportunities for participants to discuss topics that important to them e.g. motivators and barriers to physical activity participation. Within these sessions, participants also set individualised goals.
		1:1 exercise consultations: Participants complete a short

		questionnaire that asks questions regarding participants' preferences for PA and their lifestyle (e.g. work and family commitments). This questionnaire forms the basis of the discussion within the exercise consultation and ensures that the physical activity action plan that is developed is tailored to each individual.
	MODIFICATIONS	
10.‡	If the intervention was modified during the course of the study, describe the changes (what, why, when, and how).	The intervention was delivered as intended.
11.	HOW WELL Planned: If intervention adherence or fidelity was	Attendance data, a reflective log maintained by the lead for
11.	assessed, describe how and by whom, and if any strategies were used to maintain or improve fidelity, describe them.	intervention delivery and intervention debrief questionnaires and focus groups will be used to assess intervention fidelity.
12. <sup>‡</sup>	Actual: If intervention adherence or fidelity was assessed, describe the extent to which the intervention was delivered as planned.	N/A (results of intervention fidelity not yet analysed).

#### Appendix K. Study algorithm for the two-arm non-randomised comparison trial



# Appendix L. Schedule for assessments of physical and psychological health at baseline and months 3, 6 and 12.



Note: Abbreviations: IPAQ: International Physical Activity Questionnaire; FACT: Functional Assessment of Cancer Therapy; SWL: Satisfaction with Life; SWEMWBS: Short Warwick-Edinburgh Mental Well-being Scale; PHQ8: Patient Health Questionnaire depression scale

# Appendix M. Investigator-developed questionnaire regarding physical activity preferences and interests

Please complete this questionnaire prior to attending your 1:1 exercise consultation. Please bring it and your physical activity logbook with you on the day.

- 1. What types of activity are you interested in (e.g. walking, gym-based exercise, exercise classes, home programme)?
- 2. How much physical activity is achievable for you each week?
- 3. What times in your week would you like to do exercise (e.g. walk after work/on lunch break, structured classes 3 times a week, exercise at the weekends)?
- 4. What opportunities for physical activity available within your local community are you interested in pursuing?
- 5. Are there any challenges that have stopped you from being active in the past (e.g. work commitments, family responsibilities, lack of motivation, being unwell)?
- 6. Are there commitments in your weekly routine that would be important to consider when planning your physical activity?

Variable	CG: T1	CG: T2	CG:T3	IG: T1	IG: T2	IG:T3
Steps	7788±363	8587±390	8053±499	7929±324	8710±354	9055±462
Light-intensity	1.203±0.05	1.301±0.05	1.307±0.07	1.228±0.05	1.327±0.05	1.399±0.06
PA (hrs)						
Moderate-to-	24 .8±2.2	27.4±2.4	23.8±2.7	24.9±1.9	28.0±2.2	28.5±2.5
vigorous						
intensity PA						
(mins)						
IPAQ MET-min	1786±233	3060±425	3307±435	1831±213	3320±364	3329±373
per week score						
Sedentary	9.0±0.2	9.0±0.3	9.3±0.3	9.6±0.2hrs	9.5±0.2	9.6±0.3
behaviour (hrs)						
6 minute time	561±14	664±14	663±16	594±13	672±13	688±14
trial (metres)						
FACT-G Score	82±1.4	88±1.5	85±1.8	80±1.2	87±1.2	87±1.5
Physical well-	21±0.5	23±0.5	23±0.5	21±0.4	24±0.5	24±0.5
being						
Functional well-	19±0.4	21±0.6	20±0.6	19±0.3	21±0.5	21±0.5
being						
Emotional well-	19±0.5	21±0.4	20±0.5	17.8±0.4	20±0.4	20±0.4
being						
Social well-being	22±0.6	24±0.7	22±0.7	22±0.5	22±0.6	22±0.6

Appendix N. Estimated marginal means (± standard error) for outcome variables for the control and intervention groups at baseline (T1) and 3 (T2) and 6 (T3) month follow-up.

Abbreviations: FACT-G=Functional assessment of cancer therapy – general questionnaire; IPAQ=International physical activity questionnaire; PA= physical activity