University of Southampton

Faculty of Environmental and Life Sciences

School of Health Sciences

An investigation of what influences exercise adherence in people with advanced cancer, and how to encourage lasting exercise behaviour after completion of supervised programmes.

by

Daniel David Aze

Thesis for the Degree of Doctor of Philosophy

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Abstract

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Evidence is accumulating to indicate exercise, for people with advanced cancer, can result in a range of benefits largely relating to the physical, psychological and social problems caused by the disease and treatment. However, most research has been in specialist settings with professional supervision, a context not possible to replicate for all who would benefit nor for an indefinite period of time. Studies which have investigated supervised exercise followed by a period of unsupervised exercise have found that typically participants do not continue to exercise once the supervised period ends.

This study aimed to answer the question: What is the experience of people with advanced cancer participating in supervised exercise programmes delivered in health care facilities, and how can exercise adherence be encouraged and facilitated as people transition to an unsupervised home-based approach?

A series of investigations, named here as ‘Elements’, were developed to explore and answer the research question. The study design was guided by the ‘Person-Based Approach’, a method of intervention design and development, proposed to encourage intervention acceptability and feasibility. The elements included: Element 1, a mixed method review exploring adherence in advanced cancer; Element 2, a qualitative review exploring how living with advance cancer may impact exercise adherence; Element 3, an empirical investigation of how participants with advanced cancer experience partaking in therapeutic exercise interventions; Element 4, the creation of a conceptual model to show what influences exercise adherence in advanced cancer.

Findings from each element generated an increasing understanding of exercise adherence. Element 1 suggests how components of an intervention might influence adherence. Element 2 proposes how factors identified in daily life of people with advanced cancer may impact upon exercise behaviour. Element 3 identifies the meta-theme of ‘moments of conscious decision’, and the related themes of ‘drivers of participation’ and ‘mitigation and accommodation of impediments’. Further sub themes explain and expand upon those two themes, and demonstrate the differences between the supervised and unsupervised periods. Element 4 demonstrates and explains how ‘pre-existing factors’, the ‘demands of the home exercise protocol’, ‘home exercise determinants’, and ‘theoretical mechanisms’ interact to influence a person’s decision to exercise, and their performance of exercise.

Recommendations are discussed in the form of guiding principles as per the person-based approach. These recommendations propose key objectives any intervention should aim to achieve to maximise adherence and key features an intervention should include to achieve those objectives.

This study has shown how in order to perform unsupervised home exercise, participants need the ‘motivation’ and ‘self-efficacy’ to perform the exercise or the ‘agency’ to respond positively to occasions when motivation and self-efficacy are inadequate. Attempts to maximise adherence during the supervised period may not have a positive influence upon adherence in the subsequent unsupervised period and may in fact undermine or prevent the development of factors necessary to adhere to an unsupervised home intervention. A stepped approach involving combinations of continuing support and sufficient preparation to exercise without that support, may enhance ‘motivation’, ‘self-efficacy’ and ‘agency’ and lead to enhanced exercise behaviour after completion of supervised programmes.

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Research Thesis: Declaration of Authorship

Print name: Daniel Aze

Title of thesis: An investigation of what influences exercise adherence in people with advanced cancer, and how to encourage lasting exercise behaviour after completion of supervised programmes.

I declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
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6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. None of this work has been published before submission

Signature: [Signature redacted] Date: 19/12/2021

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Definitions and Abbreviations

COM-B	The Capability, Opportunity, Motivation, Behaviour Model (COM-B). A model of behaviour which proposes that a person’s behaviour is a culmination of their capability, opportunity and motivation to enact that behaviour (Michie, van Stralen and West, 2011).
DA	Daniel Aze the author of this thesis.
Exercise	“A subset of physical activity that is planned, structured, and repetitive and has a final or an intermediate objective of the improvement or maintenance of physical fitness” (Caspersen, Powell and Christenson, 1985 p126).
HCP	Health care professional, in this research this included Doctors, Nurses, Physiotherapists, Occupational therapists, Exercise therapists, Assistant therapists, and Health researchers.
Home-based exercise	An exercise programme intended to be performed in a participants home environment, typically without any professional supervision.
Hospital-based exercise	An exercise programme intended to be performed in a specialist healthcare setting, typically with healthcare professionals providing supervision.
NHS	National Health Service.
PBA	The Person Based Approach, a multistage method of intervention design, intended to increase intervention acceptability and feasibility, through systematically addressing user experience (Yardley et al. 2015a; 2015b).

Definitions and Abbreviations

PETS	The Problematic Experience of Therapy Scale (Yardley and Kirby, 2006) and validated by Kirby, Donovan-Hall and Yardley, (2014). A 12-point, participant completed questionnaire, which establishes the extent to which an intervention user perceives something has prevented him or her from adhering to an intervention.
Physical activity	“Any bodily movement produced by skeletal muscles that requires energy expenditure” (Caspersen, Powell and Christenson, 1985 p126).
QoL	Quality of life.
RCT	Randomised Controlled Trial.
UK	The United Kingdom.

Chapter 1 Introduction

1.1 Background

The body of work presented here concerns the use of exercise as a form of palliative intervention or treatment for people with advanced cancer. The particular focus of the work investigated adherence to prescribed exercise programmes, initially undertaken for a period of weeks under supervision in specialist settings, that then progressed to exercise undertaken without supervision in a home-based environment. A mixed method study was designed to investigate what influences participant adherence to such interventions and continuing exercise behaviour after supervision ceases. The study was entitled; “FollowIng a person-based approach To supporT people with advanced cancer to cOntinue exercisinG at homE following an iniTial Hospital-based Exercise pRogramme” (FIT-TOGETHER). From here on the study will be referred to in short form as the FIT-TOGETHER study. The FIT-TOGETHER study involved the design and conduct of several different components. Two reviews of the literature were conducted, one that investigated what is known regarding adherence to exercise interventions in advanced cancer, and a second that investigated the experience of living with advanced cancer. These are referred to as Elements 1 and 2 and reported in Chapters 3 and 4 respectively. In addition, two empirical investigations were conducted to explore experiences of patients and professionals during and immediately following supervised exercise programmes, one hospital-based (EMBRACE) and one hospice-based (MOVEMENT study). These studies are collectively referred to as Element 3, the methods of which are presented in Chapter 5 and findings in Chapters 6 and 7. Thus the short title FIT-TOGETHER encompasses all this work, culminating in Element 4 the creation of a conceptual model, and conveys a sense of how the different elements were bought together, to address the study aims and attempt to solve the puzzle of exercise adherence in advanced cancer.

This chapter outlines the rationale for the chosen research topic and background information relating to exercise in the context of advanced cancer. Firstly, cancer, its treatment and the role of exercise in the developing field of exercise oncology will be introduced. The research question is presented, and study aims and objectives identified. An overview is given of chapters that comprise the thesis, and the research design briefly explained.

1.1.1 Cancer and its treatment

Cancer is a collection of different diseases that have the common feature of uncontrolled growth. It is distinguished from other benign growths by its ability to invade other locations distant from the original site (King and Robins, 2006). A combination of genetic, lifestyle, and environmental factors are thought to bring about an accumulation of errors in cell regulatory pathways which cause that cell to multiply and continue to grow to a greater extent than neighbouring cells (King and Robins, 2006). There were approximately 325,000 new cases, and 140,000 deaths from cancer in England each year (Baker, 2021). The most common forms of new cancers diagnosed in England in 2019 were: Breast 55,920 new cases, Prostate 47,497 new cases, Lung 40,168 new cases, and Colorectal 37,484 new cases (Baker, 2021). Management of cancer typically involves surgery, chemotherapy, radiotherapy, hormonal and immunotherapy. The exact combinations, approaches used, and intent of treatment is dependent on the type of cancer and its stage of development.

Tumours are classified in three main ways: Topographic site, Histological type, and anatomic extent (Greene and Sobin, 2008). This allows for comparison of patients with similar disease and forms the basis for decisions regarding prognoses and treatments. The level of a cancer's development or progressive spread is commonly referred to as staging. Once cancer has reached an advanced stage there is little chance of cure (World Health Organisation, 2015).

Various definitions for advanced cancer exist, however this study will employ the definition of Lowe et al. (2016a p2): a cancer is considered advanced if it is identified as a "progressive, incurable, locally recurrent, or metastatic malignancy". Advanced cancer involves abnormal cells invading adjoining parts of the body or metastasizing to other organs in the body. When cure is not possible, as with advanced stage cancers, the aim of treatment switches to a palliative approach with the aim of managing or slowing further disease progression and maintaining quality of life (Khan, Akhtar and Sheikh, 2005). Patients can encounter a range of physical, psychological and social problems as a result of the disease and treatment (Richardson et al. 2011; Wagland et al.,2016). Advances in treatment mean people can now live with advanced cancer for months or years before progressing to a terminal phase (Reed and Corner, 2015). Previously the trajectory of patients with cancer typically involved a relatively predictable decline in health followed by a rapid loss in performance status in the last few months of life (Lunney et al. 2003). Now the trajectory experienced by people with cancer can be more variable. This is due to advancement in treatment efficacy meaning people can now experience long periods of stability interspersed with multiple episodes of deterioration and subsequent improvement which may equal or even surpass pre-treatment levels of health (Reed and Corner, 2015).

1.1.2 Exercise in cancer

In 2007 a joint conference between the American Medical Association and the American College of Sports Medicine declared that if a pill could produce as many proven benefits as exercise, health care systems would ensure all patients had access to it (Berryman, 2010). It is now increasingly accepted that exercise should have an important role in the prevention and management of several diseases including cancer (Lobelo, Stoutenberg and Hutber, 2014; House of Commons Health Committee, 2015).

Physical activity can be defined as *"Any bodily movement produced by skeletal muscles that requires energy expenditure"* (Caspersen, Powell and Christenson, 1985 p126), and exercise as *"A subset of physical activity that is planned, structured, and repetitive and has a final or an intermediate objective of the improvement or maintenance of physical fitness"* (Caspersen, Powell and Christenson, 1985 p126). Pettee Gabriel, Morrow and Woolsey, (2012) expands on the definition of physical activity and identifies four categories of physical activity: 1) Leisure (which can include exercise), 2) occupation, 3) household domestic and self-care, 4) transport. Pettee Gabriel, Morrow and Woolsey, (2012) continues that exercise is a subset of, but not synonymous to physical activity and should not be used interchangeably. However, it is clear that much literature does not make explicit the distinctions between physical activity and exercise. Therefore throughout this study when reviewing published literature that referred to physical activity, consideration was given to whether or not the physical activity of focus was congruent with the definition of exercise used above. If the form of physical activity was determined to be incompatible with that definition of exercise, those sources were dismissed. Some research has suggested that people with cancer exhibit preferences for activities in which they engaged previously (Mikkelsen et al. 2019) or light activity relating to daily living (Wasley et al. 2018), often walking-based activity (Lowe et al. 2010; Maddocks, Armstrong and Wilcock, 2011; Lowe et al. 2016b). Evidence also suggests people with cancer are often advised to do 'light' activity by health care professionals (Wasley et al. 2018). However, such interventions involving gentle intensity leisure-type activities such as walking have been found to be less effective at achieving intended outcomes (Stuecher et al. 2019).

Observational research has indicated that exercise can impact on cancer development, spread, and, mortality. Moore et al. (2016) used self-reported levels of participant physical activity to compare the 10% most active against the 10% least active. Higher levels of physical activity were found to be associated with a greater than 20% reduction in risk of seven cancer types: oesophageal adenocarcinoma, cancers of the liver, lung, kidney, gastric cardia, endometrium, and myeloid leukaemia. In addition, a reduction in risk of between 10%-20% was found for myeloma, colon cancer, head and neck cancer, rectal cancer, bladder cancer, and breast cancer (Moore et al. 2016). A review by Li et al. (2016) found 71 prospective studies reporting on the association between physical activity and cancer mortality. Findings of that review showed people with the highest levels of physical activity, taken from a sample of general population, to have 17% reduction in cancer mortality. When findings were based on a sample of cancer survivors only, people who had the highest levels of activity displayed a 22% reduction in mortality. Such observational studies attempt to account for the possibility of confounding variables, particularly life style factors such as smoking, diet, and, body mass index. However, study authors admit possible residual confounding still exists and cannot be fully excluded (Moore et al. 2016). Therefore, although such observational findings are encouraging some caution is advised.

The exact mechanisms by which exercise impacts on development and spread of cancer, and on cancer-related mortality, are not known. It may be due to: modulation of metabolic and sex-steroid hormone levels; improved immune surveillance; reduced systemic inflammation and reduced oxidative damage (McTiernan, 2008).

Strategies to manage the consequences of cancer, symptoms and treatment side effects, have begun to reflect strategies employed to manage other long-term conditions. These include promoting changes in lifestyle and behaviour, including physical activity and exercise in order to improve quality of life (Independent Cancer Taskforce, 2015). Systematic reviews with meta-analysis have revealed a substantial amount of published empirical research investigating exercise in this patient group. Large, published reviews investigating exercise in either cancer survivors or mixed stage cancers include; Cramp and Byron-Daniel, (2012) (56 studies involving a total of 4068 participants), Fong et al. (2012) (34 randomised controlled trials 4113 participants), Mishra et al. (2012a) (40 trials involving a total of 3,694 participants), and (Mishra et al. 2012b) (56 trials involving a total of 4,826 participants). These reviews found exercise can improve physical functioning, psychological outcomes and quality of life both during and after cancer treatment. It is believed these improvements result from physiological adaptations, such as improved cardiovascular, respiratory, and musculoskeletal fitness brought about by exercise and physical activity (Cramp and Byron-Daniel, 2012; Fong et al. 2012; Mishra et al. 2012a; Mishra et al. 2012b). A more recent review of reviews (Stout et al. 2017) agreed that exercise can improve physical fitness and function as well as psychological outcomes and quality of life. In addition to this Stout et al. (2017) report improvements in immune and inflammatory markers during and after treatment, and further evidence from observational studies included in the review showed a positive association between self-reported physical activity and disease specific mortality. Morishita et al. (2020) synthesised the evidence of 18 Randomised Controlled Trials (RCTs) which had evaluated the effects of exercise on mortality, finding a positive effect on both recurrence and mortality. Reviews now typically focus upon investigating efficacy in single or small clusters of pre-determined outcomes which allows for confirmation or rejection of efficacy in specific areas of interest, providing stronger confidence in such finding. Confidence and specificity in findings for deliberate exercise has grown to the point that the American College of Sports Medicine now recommends specific exercise prescriptions of doses and type to target specific cancer-related health outcomes (Campbell et al. 2019).

1.1.3 Exercise in advanced cancer

In advanced cancer the evidence of the outcomes of exercise is less prolific, but increasing rapidly, and still indicates there is potential for improvements in patient outcomes and experience. Further investigation of the role of exercise in this patient group has been identified as a priority for exercise oncology (Courneya et al. 2015). Reviews investigating physical activity and exercise in advanced cancer found far less published evidence compared to the all stage cancer reviews described in the previous section. Beaton et al. (2009) reviewed studies investigating the effects of exercise on persons with metastatic cancer, finding only ten articles based on eight different studies. Lowe, Watanabe and Courneya, (2009) reviewed physical activity as a supportive care intervention in palliative cancer patients finding six studies involving a total of 84 patients. Albrecht and Taylor, (2012) examined the effectiveness of physical activity as an intervention for patients with cancer approaching end of life and found only six publications. Authors' conclusions from these reviews varied greatly. Beaton et al. (2009) suggested exercise increased quality of life and physical performance but advised caution as there appeared to be no agreement on exercise parameters and limited information on safety. Albrecht and Taylor, (2012) believed findings showed exercise to be safe and feasible in this patient group and could be used as a potential method to manage functional decline, symptom management, and health related quality of life for this unique group of patients. Although Lowe, Watanabe and Courneya, (2009) acknowledged studies generally reported positive findings, this team concluded there was insufficient evidence to evaluate the efficacy of physical activity as a supportive care intervention in this patient group.

A preliminary scan of published literature suggests exercise in advanced cancer is associated with many of the functional and health related quality of life benefits found in studies which investigated earlier cancer stages. Findings from recent intervention studies are accumulating that show exercise to be safe, and numerous benefits have been reported. Comparison of benefits across different studies is problematic due to differences in measures and terms used but findings indicate benefits can include: aspects relating to physical fitness and function (Nilsen et al. 2015; Murray and Bennett, 2020; Schink et al. 2020); Strength (Murray and Bennett, 2020; Quist et al. 2020; Storck et al. 2020); Body composition (Stuecher et al. 2019; Murray and Bennett, 2020;

Schink et al. 2020); Psychological and emotional wellbeing (Rief et al. 2014a; Quist et al. 2015; Quist et al. 2020); Fatigue (Litterini et al. 2013; Jensen et al. 2014; Rief et al. 2014a); Anxiety (Quist et al. 2015; Quist et al. 2020); Gait parameters (Stuecher et al. 2019; Schink et al. 2020); Sleep quality (Cheville et al. 2013); Global quality of life (Mouri et al. 2018); Emotional functioning (Schink et al. 2020); Bone density (Rief et al. 2014b); Completion of prescribed treatments and reduction in hospital admissions (Cheville et al. 2015); Augmented tumour regression (West et al. 2019).

More recent reviews have been conducted and the increased number of included studies and participants, compared to earlier reviews, highlights the growth in this area. For example, Dittus, Gramling and Ades, (2017) (26 studies involving a total of 2053) and Heywood, McCarthy and Skinner, (2018) (25 studies involving a total of 1118 participants). Dittus, Gramling and Ades, (2017) found exercise to be a useful intervention to prevent or delay decline in aerobic fitness, strength, and physical function, and improve quality of life (QoL). Dittus, Gramling and Ades, (2017) continued that although interpretation of outcomes was difficult due to inconsistent study design, population, and, programme characteristic, exercise was consistently beneficial in the context of advanced cancer. Heywood, McCarthy and Skinner, (2018) concluded exercise to be an 'effective adjunct therapy' due to significant improvements in physical function, quality of life, fatigue, body composition, psychosocial function, and sleep quality. Nadler et al. (2019) conducted a meta-analysis involving 16 randomised control trials to investigate QOL, fatigue, physical function and safety. This study found exercise to be associated with clinically meaningful improvements in both QoL and physical function but also found typically greatest improvements were found to be in those patients who at baseline had lower outcome measures.

Despite growing evidence of the benefits of exercise in this patient group the impact of exercise upon survival in advanced cancer is inconclusive. A recent review by Takemura et al. (2021) found physical activity and survival to be significantly associated with one another when performing analysis from only non-RCTs. But this association was not found from analysis of RCTs or when data of RCT and non-RCTs were pooled together. Furthermore, the review by Heywood, McCarthy and Skinner, (2018) found the outcome of survival to be unaffected.

1.1.4 Exercise and cancer treatment

Treatment for advanced cancer involves combinations of chemotherapy, radiotherapy, immunotherapy, hormonal treatments, steroidal therapy and surgical procedures. The intent of such treatments is management of the disease and relief from arising symptoms and complications. According to Stefani, Galanti and Klika, (2017), these treatments can result in several side effects which require consideration when designing exercise interventions including: pain, limited range of motion, infection, bleeding, thrombosis, radiation-induced heart disease, myelosuppression, immunosuppression, chemotherapy induced cardio-pathology, cancer related fatigue, and, cancer-induced peripheral neuropathy.

Jensen et al. (2014) explain that initially studies avoided the introduction of training programmes during palliative chemotherapy. Previous guidelines have recommended people receiving chemotherapy be advised not to exercise on days of intravenous chemotherapy or within 24 hours of treatment (Winningham, MacVicar and Burke, 1986). However, it is now thought exercise during periods of chemotherapy provides opportunity for further patient benefit. Exercise can increase tumour vascularisation allowing for better product delivery, which in animal models has been found to make chemotherapy in combination with exercise more effective in reducing tumour size than chemotherapy alone (Betof et al. 2015). Exercise has been shown to reduce some of the side effects of chemotherapy (Tofthagen et al. 2013; van Waart et al. 2015), reverse the decline in physical fitness that can occur during chemotherapy (West et al. 2015), and improve patient’s ability to tolerate chemotherapy to completion (van Waart et al. 2015). Both higher levels of physical fitness and ability to tolerate chemotherapies are associated with more favourable survival outcomes in people with metastatic colorectal cancer (Zacharakis et al. 2010).

1.1.5 Exercise setting

Exercise interventions for people with advanced cancer have till now been delivered predominantly in specialist facilities, like hospitals. Limited healthcare resources coupled with increasing demand do however necessitate services move away from acute hospitals and closer to people’s home (National Health Service (NHS), 2014). Home-based exercise interventions in other diseases are indicated to be more cost effective than supervised hospital-based interventions, but with slightly lower efficacy, which has been attributed to lower adherence in the home-based programmes (Cowie and Moseley, 2014).

Research has shown patients with advanced cancer often have a strong preference for unsupervised home-based exercise rather than supervised hospital-based programmes when asked about future intervention design (Lowe et al. 2010). Research into other chronic conditions indicates home-based interventions may actually lead to improved long-term physical activity (Blair et al. 2011), whereas in cancer a general trend for improved outcomes in supervised settings has been reported (Stout et al. 2017).

Ultimately, delivery of these types of interventions in a hospital-type setting will remain expensive. Resources and facilities will never be sufficiently plentiful to provide hospital-based exercise interventions for every patient that might benefit. Therefore, exercise interventions that are purely hospital based are unlikely to be widely adopted. Unless there are specific safety reasons for exercising patients in hospital, models that incorporate home-based protocols should be developed and implemented.
A team of researchers based at University Hospital Southampton has investigated the effects of exercise interventions delivered in hospital outpatient settings, to patients with locally advanced rectal cancer, prior to surgery (Burke et al. 2013; Burke et al. 2015; West et al. 2014; West et al. 2015; West et al. 2019). The same research team has also conducted an RCT to investigate a hospital to home exercise programme involving interval training and resistance exercise in advanced lung cancer patients undergoing palliative chemotherapy, titled – 'Exercise regiMens Before and duRing Advanced Cancer thErapy: (EMBRACE)' The EMBRACE trial, (Chief Investigator, [Name redacted]). Data collected during the EMBRACE trial, support the notion that exercise can provide several benefits, with the intervention group having experienced fewer toxicities and hospital admissions (Angharad-Long, 2016). However, participant adherence dropped below 10% when participants progressed from the hospital-based stage to the home-based exercise (S. Jack 2016 personal communication).

1.1.6 Exercise adherence considerations

Despite growing knowledge about the benefit of exercise in cancer, there remains a significant gap in implementing this knowledge into clinical practice. Survey data suggests approximately 30% of people living with and beyond cancer in the United Kingdom (UK) are completely inactive, just 20% exercising in line with physical activity recommendations (Glaser et al. 2013). To reduce this gap, the Moving Through Cancer initiative is aiming to make exercise standard practice in oncology by 2029 and strongly argued that research will be needed to study a variety of existing, and new, delivery models for exercise and rehabilitation (Schmitz et al. 2021).

The body of work contained in this thesis is focused on how people with advanced cancer follow prescribed guidance about exercise. There are a number of terms in healthcare and medicine to describe the extent to which people follow advised recommendations or instructions, the three most commonly used being 'compliance', 'adherence' and 'concordance'. These terms are often used interchangeably however they differ greatly in their meaning, tone, and the attitude they portray regarding the relationship, and balance of power, between those who set the recommendations and those who attempt to follow them (Randall and Neubeck 2016). The term which been most commonly used historically, 'compliance', has been defined as *"the extent to* *which the patient's behaviour matches the prescribers recommendations"* (Horne et al 2005p 12). The term compliance, which implies a paternalistic approach and expectation of obedience (Gray et al 2002) is now generally agreed to be inappropriate for all behaviours other than those involved in following matters relating to laws or professional standards (Rae 2021). A widely accepted definition of 'adherence' is that of the World Health Organisation (2003 p 3) *"the extent to which a person's behaviour – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider"*. In reference to this definition the fundamental difference between adherence and compliance being that adherence involves an 'agreement' to follow the recommendations, whereas compliance involves recommendations from professionals to patients with no consideration of whether or not any agreement to those recommendations is established. Lastly the term 'concordance', rather than indicating a power imbalance between the creators and the followers of recommendations, involves a mutual partnership with equal input. A commonly agreed definition is that suggested by Snowden and Marland (2012p 3) *"The process of developing a mutually agreed treatment plan"*. Concordance shares many of the principles of a co-creation approach to intervention development as both involve collaboration between experts and target users (Popp et al 2021), rather than a one directional delivery of knowledge from expert to lay person, as with the terms compliance and adherence. In this thesis the term 'adherence' is used because the interventions at issue here are typically designed initially by professionals then 'agreement' between professional and participant is sought later as part of a discussion when a person is invited to participate in said exercise programmes.

Adherence levels to the interventions in the studies mentioned earlier in this introduction varied greatly with little investigation or explanation of the reasons why. Considering the physiological mechanisms through which exercise brings about benefit it seems reasonable to propose that participants who do not adhere to the interventions are less likely to receive benefit. This view is supported by Mouri et al. (2018) who found far better improvement in QoL in those who followed the exercise intervention and increased their levels of physical activity compared to those who did not. However, it is known exercise interventions can be burdensome to the individual (Eton et al. 2012) and the difficulty of achieving adherence with prescribed therapeutic exercise in healthcare is a well-known phenomenon (Dishman, 1982). Reviews into treatment adherence for a variety of conditions have found exercise to be more problematic to adhere to than pharmacological interventions (DiMatteo, 2004; Martin et al. 2005). A participant of a qualitative study investigating the burden of treatment for people with chronic conditions described receiving medical advice to exercise on top of other medical and life demands as "pathetically unrealistic" (Tran et al. 2015 additional file 3 p2). In cancer-specific exercise studies, it has been suggested that less intensive or less physically demanding exercise interventions may result in higher adherence (Courneya et al. 2014). However, exercise has been shown to have a dose effect so higher intensities and combinations of aerobic and resistance exercise may result in better outcomes (Allgayer, Nicolaus and Schreiber, 2004; Courneya et al. 2013; Li et al. 2016; Stout et al. 2017). Therefore, if the intensity of an intervention is reduced in an attempt to improve adherence it may also impact upon the degree of benefit and potentially abate any reasons for doing the exercise. Typically, exercise interventions attempt to change the behaviour of people who do not undertake exercise, to exercise regularly. However, large Cochrane reviews into promoting habitual exercise in people with cancer found that studies rarely report whether interventions have been informed by a behaviour change theory and that published intervention protocols often consist of instruction to exercise with no consideration of the psychological elements required to change behaviour (Bourke et al. 2013) updated by Turner et al. (2018).

Previously researchers have recommended future study protocols consider moving exercise to home-based settings, in order to reduce the number of visits to hospital and make the intervention more acceptable and reasonable to participants (Temel et al. 2009). Research has also found that when asked participants express a preference for home-based exercise rather than in hospital or at a fitness centre. These views are expressed consistently whether patients were asked to inform hypothetical future interventions (Lowe et al. 2010; Maddocks, Armstrong and Wilcock, 2011; Lowe et al. 2016b), or asked about their current physical activity and exercise habits (Wasley et al. 2018). However, despite this preference to exercise at home, studies involving hospital and home-based exercise sessions for people with advanced cancer have since found less adherence to home-based sessions when compared to hospital-based sessions (Quist et al. 2012; Kuehr et al. 2014; Winters-Stone et al. 2014; 2015).

A recent review by (Sheill et al. 2019) found variation in recruitment, adherence, and attrition between studies. Although reasons were reported for not recruiting, not adhering, or withdrawing from the studies, no conclusions were put forward to explain reasons for the variation between studies. Although an ever increasing body of research is finding benefits to exercise in patients with advanced cancer, adherence to exercise interventions appears to be highly variable, not well understood and requires further investigation.

1.2 Research questions, aims and objectives.

1.2.1 Research Question

What is the experience of people with advanced cancer participating in supervised exercise programmes delivered in health care facilities, and how can exercise adherence be encouraged and facilitated as people transition to an unsupervised home-based approach?

1.2.2 Aim

The overall aim of this study was to develop a conceptual model to describe, characterise, and explain factors influencing adherence to exercise programmes for people with advanced cancer. Specifically those interventions that begin under professional supervision in specialist healthcare settings then progress to unsupervised home-based sessions. Then with reference to the model develop a series of recommendations to increase the likelihood of continued exercise behaviour in this patient group.

1.2.3 Objectives

- Investigate the structural characteristics of exercise interventions developed for people with advanced cancer that may explain reduced adherence to home-based protocols
- Investigate what living with advanced cancer entails and explore the consequences of this for the design of home-based exercise programmes
- Explore how patients with advanced cancer and healthcare professionals experience such exercise programmes
- Using the sources of data above and with reference to theory and literature, develop a conceptual model to explain adherence to home-based exercise in people with advanced cancer
- Present recommendations, in the form of guiding principles, for clinicians and researchers to assist in the design of interventions that encourage adherence

1.3 Overview of thesis

This thesis represents work carried out to meet the requirements for the award of a PhD. A mixed method investigation was designed that can be best described as qualitatively driven, mixed methods, multi component research. The research followed a pragmatic approach seeking to maximise the relevant ways in which the research question could be approached (Johnson et al.

2017), with the intention to produce new knowledge to inform real world decisions (Treweek and Zwarenstein, 2009). It comprised four different elements designed to explore: 1) components of intervention design; 2) the experience of general life whilst living with advanced cancer; 3) how patients' interact with, and experience, exercise interventions and how this can influence adherence; 4) how the findings from the earlier elements relate to known theory and the development of a conceptual model.

The first three elements were explored using secondary and empirical research to collect and analyse data, which were then combined with theory in Element 4 in the final phase to address the aim of the study. In summary:

> Element 1) a systematic review of literature investigating what is known regarding adherence to exercise interventions in advanced cancer.
>
> Element 2) a qualitative review of literature that sought to investigate the experience of living with advanced cancer and extrapolate from this ways that experience might influence a person's likely exercise behaviour.
>
> Element 3) an investigation of patient and professional experiences of supervised exercise programmes for people with advanced cancer, including exercise behaviour when supervision ceases.
>
> Element 4) a conceptual model to describe, characterise and explain what might encourage, facilitate, or impede adherence to exercise for people with advanced cancer having completed a supervised exercise programme.

Knowledge generated through these different elements then informed the development of guiding principles, and was applied through two exemplar case studies to propose how these might influence exercise behaviour once supervision ceases. An overview of the elements and how they 'FIT-TOGETHER' is depicted in Figure 1.

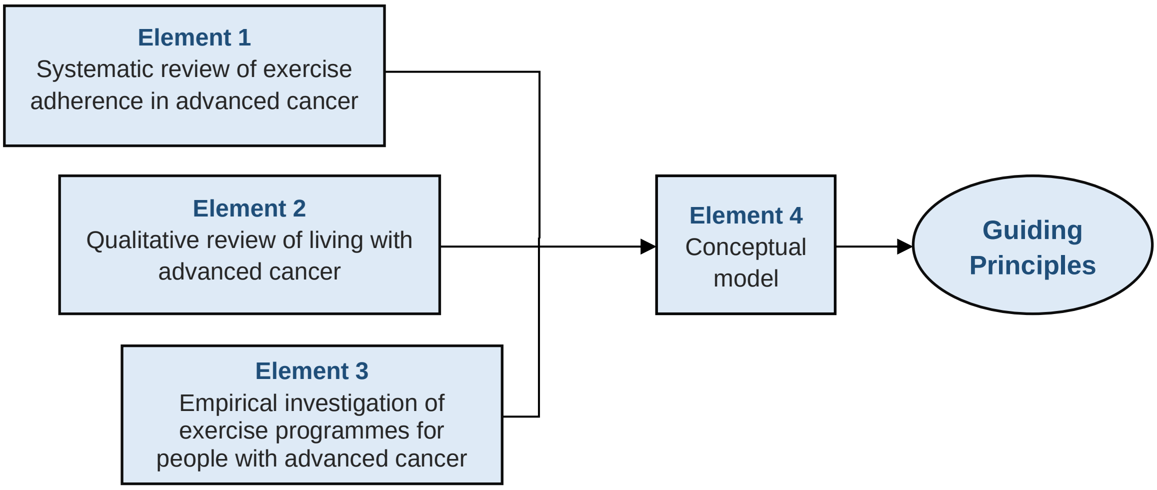


Figure 1: Schematic representation of the FIT-TOGETHER study

The thesis is set out in a series of nine chapters.

Chapter 1 introduces the background to the study, including the condition being investigated, the use of exercise as a therapeutic tool, and sets out the remainder of the thesis.

Chapter 2 will introduce the methodology and approach which guided the design of the research. It will then briefly outline the methods employed to collect and analyse data in Elements 1-3, and how in Element 4 findings were synthesised with theory to construct a conceptual model.

Chapter 3 presents Element 1, a review conducted to investigate what was previously known about adherence to exercise interventions in advanced cancer. A particular focus was the investigation of exercise interventions performed in specialist outpatient settings compared to those performed at home, and what might be done to support participants performing exercise as they transition from one setting to the other. The mixed method design and processes of analysis are discussed and justified. Findings are presented and discussed and explanation is given into how this informed the additional Elements 2-4.

Chapter 4 reports findings from Element 2, a qualitative review which aimed to identify how living with advanced cancer might influence exercise behaviour.

Chapter 5 presents the method used to conduct the empirical research in Element 3, a mixed method investigation of exercise programmes for people with advanced cancer.

Chapter 6 reports findings from Element 3, identifying factors that influenced adherence during the supervised exercise period.

Chapter 7 reports findings from Element 3 with a focus on factors that influenced adherence during the unsupervised exercise period.

Chapter 8 describes the development of a conceptual model, to demonstrate what influences home-based exercise patterns following a supervised exercise programme.

Lastly, Chapter 9 discusses these findings in relation to other theory and literature, outlines recommendations in the form of guiding principles for practice and research settings, and finally presents conclusions from this body of work.

Chapter 2 Overview of methodology and methods

2.1 Chapter Introduction

The purpose of this chapter is to present an overview of the research methodology underpinning the FIT-TOGETHER study, including the discrete elements designed to address the research question and the study's aims.

2.2 Philosophical underpinnings

Creswell and Plano Clark, (2011) explain the importance of researchers explicitly identifying the paradigms to which their research aligns. However, Morgan, (2007) argues that there is much conflict and confusion in literature as to what a paradigm is, and puts forward four commonly used meanings when the concept of paradigms are discussed. Morgan, (2007) grouped those common meaning of paradigms into a hierarchy from general to more specific concepts. These were: worldviews, epistemological stances, shared beliefs among members of a speciality area, and model examples of research. Morgan, (2007) suggests these meanings are not exclusive of one another and can be nested within each other as the level of specificity develops, but emphasises that no one meaning is more correct than the others.

The worldview most influential on this research is that of pragmatism, in that it has involved a series of linked investigations, incorporating mixed methods of data collection, with each investigation intended to answer specific aspects of the research question rather than attempting to strictly adhere to any one philosophical view. Johnson et al. (2017), claims pragmatism to be the most popular, and arguably the most useful, paradigm in the field of mixed methods research. A key concept of pragmatism is the view that the best way to proceed in research is to maximise the various relevant ways in which a question can be approached. This is because, as Johnson et al. (2017) continue, it is believed that the unjustified exclusion of certain methods, or the one-sided favouring of others could block the way of inquiry, and so is unscientific. Such views are apparent within the FIT-TOGETHER design by the way it incorporated both primary and secondary research utilising qualitative and quantitative methods, to best address the issues identified.

Johnson et al. (2017) assert that another aspect of the pragmatic paradigm, is that people can only experience a fleeting component of reality, and therefore no single observer can perceive all possible perceptions of a phenomenon. The acknowledgement of this aspect is evident in the FIT-TOGETHER study through the inclusion of patient and professional perspectives in the empirical research. It is further evident through the recruitment of clinicians from several different health professions as well as the perspectives of people with advanced cancer onto the advisory panel. According to Seale, (1999), research should attempt to match the most appropriate methods to address important research questions rather than focusing on following specific philosophical positions. However, as argued by Morgan, (2007), certain questions are not inherently most important nor are certain methods inherently most appropriate, but are determined by researchers' opinion, which in turn are formulated from factors such as personal history, social background and cultural assumptions. Therefore, the background to the researcher and research are presented here as well as brief discussion of philosophical positions relating to ontology, epistemology, and axiology, as these will have influenced decisions which informed the design and conduct of this research.

My own background is that I am an English male nurse who is forty years old, who prior to this study had no experience of conducting qualitative research and very limited experience of quantitative research. I have worked in a palliative setting in both the English NHS and a charity funded care provider for the past six years since graduating as a nurse, alongside completing the PhD enabled by a clinical academic PhD fellowship. I have a previous background in the education of children excluded from mainstream education, and, before that, sports science. My background in education, behaviour, and sports science is longer established than my experience of healthcare and this may have influenced my approach to the research design, data collection and analysis. The fellowship that supported my PhD was originally advertised in response to exercise in advanced cancer being identified as an important area for further research. The PhD opportunity aligned with concepts I found of most interest and placed most value on during my nurse training, such as self-management, health promotion, and health-related behaviour change. In my view these areas of healthcare seemed to be underpinned by several of the concepts and theories I had previously learnt of in sports psychology, as they both concern non-pharmacological methods to improve human performance and/or patient health.

Axiology concerns the study of values (Pole, 1961) and the role of values in research (Creswell, 2014). It can involve researchers reflecting on the intrinsic value of their research (Kelly et al. 2018) and reflecting upon the extent to which researchers' values and/or biases are thought to be inhibited, or believed to be inevitable and acknowledged (Polit and Beck, 2021). Fundamental values of the clinical doctoral research fellowship that support this PhD, includes the belief that research should be for patient benefit, grounded in day-to-day issues, practice relevant, and involve the translation of findings into practice (Westwood et al. 2018). The principal value of Daniel Aze (DA) when designing the research was that it should be useful and beneficial. Ultimately beneficial to people with advanced cancer, but also useful to others who were involved in the project, because if it was useful to everyone involved it would further enhance patient benefit through the related work of those others. These principle values, that the research ought to be beneficial to patients, useful for all involved, and facilitate translation of the findings into practice, directed the design of this study.

Ontology concerns beliefs about the nature of reality and its characteristics (Creswell, 2014). The ontological position of ‘subtle realism’ involves a belief that social phenomena can exist independently of people's representations of them but can only be accessed through those representations (Hammersley, 1992). This view aligns closely with the view held by the study author and is apparent in the design of this study; seeking to investigate the reality of adherence to an exercise intervention through the representation of those who had participated in or who had helped to design and deliver such interventions.

Epistemology concerns thoughts around knowledge, what counts as knowledge, how knowledge is constructed, and how claims of knowledge are justified (Creswell, 2014). According to Ormston, Spencer and Snape, (2014), there are three main areas for debate: 1) how knowledge is acquired, whether through a ‘deductive’ method involving top down processes to compare previously devised conclusions against what is being observed, or ‘inductive’ methods involving a bottom up process of pattern identification; 2) the relationship between a researcher and what is being researched, including the influence the researcher may exert over what is being researched; 3) Issues around truth and how something can be accepted as accurate or true.

In relation to those areas of debate, the FIT-TOGETHER study involved a combination of both deductive and inductive processes. Deductive processes looked to identify known concepts reported from conclusions of research that had investigated exercise adherence in other populations, but now in the context of advanced cancer. On the other hand, inductive processes were used to form further knowledge regarding the previously identified concepts and where possible to identify new concepts not included in the conclusions of previous research. Research processes such as this involving the back-and-forth movement between deductive and inductive approaches can be considered ‘abductive’ and is a common approach in pragmatism (Morgan, 2007). The study was developed with the acceptance that the author will have in some way influenced the findings through pre-held biases. Those biases may have influenced interpretation during analysis of each element and through the brief interaction and relationship that forms with the participants in Element 3. Although this influence was accepted as inevitable and unavoidable, steps were taken in an attempt to minimise it. Examples of these steps include attempting to curtail the extent to which any relationship may form between researcher and participant, and the involvement of an advisory panel to test findings against opinions of people external to the researcher-participant relationship. Finally, with regard to issues of truth, this research aligned, to some extent, with the ‘coherence’ theory of truth, as described in Ormston, Spencer and Snape, (2014), in that the extent to which something was viewed as true was increased when multiple accounts and perspectives cohered with each other and were further validated by advisory panel members. However, in keeping with the ideas of pragmatism as described in Feilzer, (2010), this was secondary to the extent to which something could be practically useful, and so therefore aligns with the ‘pragmatic’ theory of truth, whereby beliefs are considered true if they have practical utility Ormston, Spencer and Snape, (2014).

2.3 Design

2.3.1 Research Question

What is the experience of people with advanced cancer participating in supervised exercise programmes delivered in health care facilities, and how can exercise adherence be encouraged and facilitated as people transition to an unsupervised home-based approach?

2.3.2 Aim

The overall aim of this study was to develop a conceptual model to describe, characterise, and explain factors influencing adherence to exercise programmes for people with advanced cancer. Specifically, those interventions that begin under professional supervision in specialist healthcare settings then progress to unsupervised home-based sessions. Then, with reference to that model, develop a series of recommendations to increase the likelihood of continued exercise behaviour in this population.

2.3.3 Objectives

- Investigate the structural characteristics of exercise interventions developed for people with advanced cancer that may explain reduced adherence to home-based protocols
- Investigate what living with advanced cancer entails and explore the consequences of this for the design of home-based exercise programmes
- Explore how patients with advanced cancer and healthcare professionals experience such exercise programmes
- Using the sources of data above and with reference to theory and literature, develop a conceptual model to characterise and explain how to promote adherence to home-based exercise in people with advanced cancer
- Present recommendations, in the form of guiding principles, for clinicians and researchers to facilitate the design of interventions that encourage adherence

2.3.4 Person-based approach

The PBA (Yardley et al. 2015a; 2015b) was selected to inform and guide the research process to meet the aims and objectives of the project. The research was conducted in accordance with a pragmatic view which prioritises matching appropriate methods with the research questions. PBA was used to guide and inform the process of selecting which methods were most suitable to be used to achieve the study objectives. PBA is highly suited for this purpose as the process described in PBA has been used successfully in the development of interventions that involve a large behavioural component in several health contexts including: weight management (Smith et al. 2017), physical activity in older adults (Pollet et al. 2021), management of blood pressure (McManus et al. 2021). PBA is a multistage method of intervention design, intended to increase intervention acceptability and feasibility, through systematically addressing user experience (Yardley et al. 2015a; 2015b). PBA focusses on understanding and accommodating the perspectives of the intended population involved in the intervention. It then combines these perspectives with the knowledge and experience of skilled researchers, to improve intervention uptake, adherence and outcomes (Muller and Tonkin-Crine, 2016). It can be used alongside and complement more traditional theory based or evidence-based methods of intervention design (Yardley et al. 2015b).

PBA was selected as a suitable method to guide the research in this project for several reasons. Firstly, it advocates the incorporation of several different methods of conducting research. This is intended to go beyond, but can be used to complement, a theory and evidence-based approach such as advocated by the Medical Research Council (Craig et al. 2008). It is hoped that by better incorporating user perspectives a better understanding can be formed of the issues which need to be addressed (Yardley et al. 2015b). The suggestion to incorporate different approaches and methods widens the possible ways in which a problem can be investigated and aligns with the pragmatic values underpinning this project that sought to understand the issues relating to exercise adherence using the methods deemed most appropriate. Secondly, the PBA is rooted in health psychology and aims to ground the development of interventions in the psychological context of the people who will use them (Yardley et al. 2015b). Such psychological considerations were highlighted, in a large Cochrane review performed by Bourke et al. (2013) and updated by Turner et al. (2018), as often missing in exercise interventions for people with cancer.

PBA comprises four stages: ‘Planning’; ‘Design’; ‘Development and evaluation of acceptability and feasibility’; and finally, ‘Implementation and trialling’ (Yardley et al. 2015b). Each stage contains activities and processes specific to the PBA method, but also recognises that other actions can be undertaken which complement PBA activities. The purpose of the ‘Planning’ stage of PBA is to identify the key behavioural issues, needs, and challenges that an intervention must address. Two PBA specific processes are stipulated, the ‘Synthesis of previous qualitative research into user experiences of similar interventions’, and ‘Conducting primary qualitative research to elicit users' views of planned behaviour changes' (including relevant previous experience, barriers and facilitators). In addition to this, three complementary activities are suggested which can be undertaken as part of wider development, these are: 'Consultation with key stakeholders', 'Examination of theory and evidence from relevant previous trials' and 'Observation of real-life context of anticipated health care products' (Yardley et al. 2015a; 2015b).

The PBA 'Design' stage focusses on the development of 'guiding principles' which are considered to be an essential or core constituent of the approach. The purpose of these guiding principles are to achieve a coherent focus to underpin the intervention and summarise what the intervention must seek to address and contain (Yardley et al. 2015b). Guiding principles are not intended to be exhaustive, nor intended to replace more comprehensive techniques like theoretical modelling. They are developed through synthesis of knowledge generated from the planning stage to identify behavioural issues, needs, and challenges the 'key objectives' of an intervention must address. Then 'key features' the intervention should contain to achieve those objectives are developed. In addition to the PBA specific activity of developing guiding principles the PBA recognises other activities which can be taken to complement the approach, including theoretical modelling, intervention mapping of behavioural determinants against behavioural change techniques, and the creation of personas and scenarios (Yardley et al. 2015b).

The third PBA stage 'Development and evaluation of acceptability and feasibility' is intended to evaluate and optimize intervention components from the user's perspective. PBA specific activities at this stage include using 'think aloud' techniques to observe and analyse user reactions to every element of the intervention before iterative modification to optimise the intervention to the user's perspective. Additional PBA specific activity proposed for this stage is longitudinal mixed method case studies for the purpose of further evaluation and optimisation of independent usage. Additional broader non-PBA specific activities which could complement the PBA approach include: the development of detailed procedures for the intervention plus development of any supporting materials or additional training which would be required, creation of a prototype product, and mixed method acceptability and feasibility evaluations (Yardley et al. 2015b).

The final stage according to the PBA 'Implementation and trialling' aims to evaluate the intervention in real-life contexts to modify and improve implementation in future usage. The stipulated PBA activity involves the use of mixed methods process analyses to identify ways to improve acceptability, feasibility, and effectiveness in future implementation, or in different contexts. Complementary activities can include methods such as RCT and audit to evaluate efficacy and cost effectiveness, and, mixed methods process analyses of implementation, as well as investigation of mediators and moderators of effectiveness (Yardley et al. 2015b).

The FIT-TOGETHER study comprised two stages, a data collection and analysis stage (Elements 1-3), followed by a stage involving further synthesis, interpretation and application to practice (Element 4 and thesis discussion). These stages corresponded to and were guided by the first two stages of PBA ‘Planning’ and ‘Design’. Table 1 lists the activities stipulated by Yardley et al. (2015b) as specific person-based processes or as complementary activities and shows which FIT-TOGETHER elements were developed in response to those stipulated and complementary activities. One complementary activity ‘Observation of real-life context of intended product’ was not incorporated into the FIT-TOGETHER study, this was to avoid any possible disruption to the exercise sessions. Elements were conducted in a largely sequential manor progressing through 1-4, with earlier elements contributing to the development of the later elements.

Table 1: Person-based approach activities and resultant FIT-TOGETHER elements

PBA stage	PBA target output	Specific PBA processes	Complementary activities	FIT-TOGETHER process in response to PBA specific and complementary activities
Planning	Identification of issues which need to be addressed	Synthesis of previous qualitative studies of similar interventions Primary qualitative research to elicit user views	Consultation with stakeholders such as experts and user groups Examination of theory and evidence from previous trials Observation of real-life context of intended product	Conduct a systematic mixed method review of adherence to exercise intervention in advanced cancer - Element 1 Conduct a qualitative review investigating living with advanced cancer - Element 2 Conduct empirical mixed method research investigating experience of exercise programmes for people with advanced cancer - Element 3 Formation and consultation with an advisory panel - Element 3
Design	Creation of guiding principles to summarize features of the intervention crucial to achieving intervention objectives	Create guiding principles to demonstrate key objectives, and key features the intervention must contain to achieve those objectives	Theoretical modelling such as logic models, and/or intervention mapping of behavioural determinants and behaviour change techniques Creation of personas and scenarios	Develop a conceptual model of adherence to home-based unsupervised exercise, following a supervised exercise programme - Element 4 Develop recommendations in the form of guiding principles – Presented in discussion Creation of persons to hypothetically demonstrate relevance of proposed guiding principles – Presented in Appendix HH and II

2.3.4.1 Element 1) Systematic review of exercise adherence in advanced cancer

Element 1 was aligned with the PBA complementary activity of ‘Examination of theory and evidence from relevant previous trials’. A brief exploration of literature investigating exercise in advanced cancer, performed as an introduction to the topic, and reported in the background section in Chapter 1, revealed that the benefits of exercise in this patient group are plentiful. It is established that if participants undertake the prescribed exercise there will be, at the very least, a physiological adaptation in response to exercise, resulting in improvements in the functioning of musculoskeletal and cardiovascular systems. This alone, coupled with the resultant improvements in quality of life, make exercise beneficial and worthwhile in this patient group. What appeared less well researched, and most in need of further investigation, was the issue of intervention adherence.

A mixed method systematic review of literature was undertaken to investigate factors that influence adherence to exercise interventions in advanced cancer. The aims and objectives of Element 1 were to establish:

- Adherence rates to exercise interventions for people with advanced cancer
- Characteristics of interventions associated with more favourable levels of adherence
- How future studies might maximise adherence
- What was known about the reasons for decline in adherence as people transition from specialist to home-based settings
- How participants might be supported to perform exercise as they transition from one setting to another

The aims of this element primarily aligned with the first overall PhD objective to ‘Investigate the structural characteristics of exercise interventions developed for people with advanced cancer that may explain reduced adherence to home-based protocols’. Data reported in included studies was analysed using a framework approach as described by (Gale et al. 2013). The Conceptual Framework of Implementation Fidelity designed by Carroll et al. (2007), modified by Hasson, (2010), was used to evaluate systematically the implementation fidelity of complex interventions. The framework proposes that implementation fidelity is a measure of adherence, and that there are seven factors which may moderate this: Participant responsiveness; Intervention complexity; Comprehensiveness of policy description; Strategies to facilitate implementation; Quality of delivery; Recruitment; Context.

This review generated deeper understanding of the adherence to exercise in advanced cancer including revealing areas which were still poorly understood. Findings were used to inform the aims, design, and process of analyses of subsequent elements, and, to a lesser extent, to inform later model development. Further details of the methods and findings of this review are presented in Chapter 3.

2.3.4.2 Element 2) Qualitative review of living with advanced cancer: contextual factors which may influence exercise behaviour

Element 2 aligned with the specific PBA activity of the ‘Synthesis of previous qualitative research into user experiences of similar interventions’. A deficiency of qualitative research in similar interventions had already been identified as part of findings from Element 1. Consequently, this systematic search and review adopted a broader scope and investigated the general day-to-day experiences of people living with advanced cancer. This was done as a means to establishing the contextual and personal environment in which an intervention will operate and to identify what should be taken into account when designing an intervention to enable it to fit successfully into the day-to-day context. This was intended to find out what living day-to-day for people with advanced cancer involves and how this experience might impact on their ability to adhere to an exercise intervention at home.

The aim of the review was to identify how living with advanced cancer might influence exercise behaviour. The objective was to establish what factors in daily life potentially inhibit or promote the likelihood of adopting and adhering to a hospital to home-based exercise intervention in this population, then use this information to inform emergent principles for a new exercise intervention. This aligns with the specific PhD objective to ‘Investigate what living with advanced cancer entails and explore the consequences of this for the design of home-based exercise programmes’.

A framework approach to analysis was adopted for this review using a framework matrix primarily developed from the capability, opportunity, motivation, behaviour model (COM-B) (Michie, van Stralen and West, 2011). The COM-B model was developed following the synthesis of over 90 theories of behaviour change. According to the COM-B model, a person’s behaviour is a culmination of their capabilities, their opportunities, and their motivations, whereby capability involves the individual’s psychological and physical capacity to perform the behaviour, opportunity is considered to be factors that lie outside the individual that make the behaviour possible or prompt it, and motivation is considered to be brain processes that energize and direct the persons behaviour (Michie, van Stralen and West, 2011).

Text passages from findings discussion and conclusions of relevant studies were plotted into the constructed framework and interpreted to indicate how daily life with advanced cancer may influence those factors of capability, opportunity, and motivation, in relation to exercise behaviour. The findings of this review contributed to identifying areas needing further investigation, helped inform the aims and method of analysis of Element 3, and contributed to the conceptual model development. Further details of the methods and findings of this element are presented in Chapter 4.

2.3.4.3 Element 3) Mixed method empirical research

Element 3 involved the conduct and synthesis of two pieces of mixed method multi-perspective empirical research. This element aligned with the specific PBA activity of 'Conducting primary qualitative research to elicit users' views of planned behaviour changes' (including relevant previous experience, barriers and facilitators), and, the complementary activity of 'Consultation with key stakeholders'.

The aim of Element 3 was to establish the experience of participants exposed to prescribed exercise programmes and determine factors effecting adherence as those participants transitioned from a supervised programme in specialist settings to a home-based programme without supervision. This aligns with the overall PhD objective of 'Explore how patients with advanced cancer and healthcare professionals experience such exercise programmes'.

The objectives were to investigate:

- Why participants chose to join the exercise programmes, what they feel they might gain and the value they placed on the programmes
- The acceptability of different aspects of content and delivery of the interventions
- What difficulties participants encountered when trying to adhere to the supervised exercise programmes, and what helped or encouraged participants to adhere
- Whether participants continued exercising once the series of sessions had been completed, in what ways they continued to exercise, and why
- What difficulties participants encountered when trying to exercise after the supervised exercise programmes had been completed, and what helped or encouraged participants to adhere
- The thoughts, views and experiences of therapists delivering the classes with regard to class adherence, and continued exercise behaviour post class completion

Initially, a mixed method evaluation was developed to be nested within an ongoing RCT investigating hospital to home exercise for people with advanced non-small cell lung cancer receiving chemotherapy in two local hospital trusts, the EMBRACE trial, full name ‘Exercise regiMens Before and duRing Advanced Cancer thErapy’. Funded by the National Institute of Academic Anaesthesia “Fit 4 Surgery” program, the British Lung Foundation and Boehringer Ingelheim. The nested evaluation conducted as part of this PhD was titled ‘Empirical multi-perspective exploration of the EMBRACE trial, an ongoing hospital to home exercise intervention’. The 12 week EMBRACE exercise intervention consisted of: weeks 1-4 supervised hospital-based training, weeks 5-6 a transition period involving both supervised hospital-based and unsupervised home-based exercise, weeks 7-12 home-based unsupervised sessions only. Hospital-based sessions involved a combination of high intensity aerobic interval training, and resistance exercises. Interval training was conducted on cycle ergometers with training intensities determined by baseline cardiopulmonary exercise testing (CPET). Home-based training involved a tailored stair climbing, brisk walking program and resistance exercises.

Due to a change in the treatment of people with non-small cell lung cancer, chemotherapy to immunotherapy, recruitment to the EMBRACE trial sharply declined during the period of my data collection. Inclusion criteria for the EMBRACE RCT stipulated that participants had to be treated with first line gemcitabine and platinum-based chemotherapy, therefore following NICE approval of a new treatment for advanced lung cancer, pembrolizumab, fewer patients were eligible for inclusion and recruitment slowed. To compensate for this decline in recruitment the nested investigation was amended to also collect data from family or carers of the trial participants, participants in the control group, and healthcare professionals (HCPs) involved in the design or delivery of the trial. Shortly after this amendment however, a decision was made by the Chief Investigator to close the EMBRACE trial early due to continued slow recruitment. This closure occurred before any family or carers could be interviewed.

In response to the closure of the EMBRACE trial, a further study was developed, by the author of this thesis, DA, to explore what influenced adherence of participants to supervised exercise classes in a local hospice day centre and their continued exercise behaviour after the programmes finished, the MOVEMENT study. This study investigated the experience of patients with any advanced cancer diagnosis. MOVEMENT was a pragmatic, single centre, mixed method, multi-perspective study using an opportunistic population to identify factors which enhance or impede exercise adherence and continuing exercise behaviour. The study was conducted at a local palliative day care centre. The centre offered two exercise programmes, delivered as a series of supervised exercise classes, for patients with incurable / palliative conditions including advanced cancer. Classes were designed and overseen by a senior palliative physiotherapist, with assistance from other less senior therapists. The classes, of two different intensities, were intended to help patients increase their general fitness, and maintain independence and wellbeing. Class one, titled ‘Chairs Class’, was a four-week, sixty-minute seated exercise class, for people who want to be active but have limited mobility. Chairs class involved a variety of activities including seated circuits, chair bingo, tai chi and seated Olympics. The second class, titled ‘Circuits Class’, was a six-week, 30 minute dynamic exercise class for the more able patient. Circuits class was performed in the therapy gym and involved seven exercise stations to improve: upper limb strength, core stability, endurance, balance, agility, step climbing and slope walking. Upon completion of the programme, all participants were given advice to continue exercising either at home following printed information leaflets or at recommended local leisure centres. Discussion with the therapist who designed the programmes revealed that service evaluation forms, previously administered to participants upon completion of the programmes, indicated all attendees found the programme to be a positive experience. However, it was not known what the longer-term exercise behaviour of those completing the classes had been, or what continuing to exercise after class completion involved for participants.

Qualitative data collection for Element 3 across both investigations involved semi-structured interviews with patients and healthcare professionals at six and 12 weeks after the first session. Quantitative data collection involved exercise participants completing a questionnaire at those same time points to enquire about any perceived difficulties participants had performing the exercise. The Problematic Experience of Therapy Scale (PETS) was developed by Yardley and Kirby, (2006) and validated by Kirby, Donovan-Hall and Yardley, (2014). PETS is a 12-point, participant completed questionnaire, which establishes the extent to which an intervention user perceives something has prevented him or her from adhering to an intervention. Every attempt was made to ensure consistency in terms of data collection across the different contexts. In both the EMBRACE trial and MOVEMENT hospice classes context, HCPs were interviewed at one time point, whereas patients were interviewed and completed the same questionnaire at two time points. Interviews were scheduled once during the supervised period and with a further interview six weeks after the supervised period had finished.

Data from both investigations were synthesised together during analysis, following a framework approach (Gale et al. 2013). An initial coding matrix was developed from published literature which demonstrated factors believed to influence intervention adherence and exercise behaviour (Carroll et al. 2007, Hasson, 2010, Michie, van Stralen and West, 2011), and findings from earlier elements. This framework was applied to the first few transcripts, modifications and changes were made before reapplying to those transcripts again and continuing. As part of the analysis process an advisory panel of key stakeholders was formed and consulted to validate emergent findings. The findings from this synthesis formed the main source of evidence used to develop the conceptual model and guiding principles.

This element collected data from a broader sample than the originally intended EMBRACE lung cancer evaluation. The synthesised data in this element thus involved multiple settings, multiple exercise interventions, multiple types of advanced cancer, and contained the perspectives of both patients and health care professionals (HCPs). This heterogeneity enabled findings to be more generalizable to a wider context. Further details and justification of the methods employed including considerations such as recruitment, data collection, and analysis, as well as the common areas and differences for each study will be discussed together in Chapter 5. Findings from this investigation are presented in Chapters 6 and 7 for the supervised and unsupervised periods respectively.

2.3.4.4 Element 4) Development of conceptual model

The purpose of the PBA 'Design' stage is to help summarize and easily refer to features of an intervention identified as central to achieving the intervention objectives (Yardley et al. 2015a; 2015b). 'Theoretical modelling', is considered to be a complementary activity to the PBA during the design stage. The aim of this element, was to form a conceptual model to explain what happens and why, with regards to exercise adherence when participants' with advanced cancer progress from supervised programmes in specialist settings to home-based unsupervised exercise. This aligns with general PhD objectives of – 'Using the sources of data above and with reference to theory and literature, develop a conceptual model to characterise, explain, and inform about adherence to home-based exercise in people with advanced cancer'.

Findings from Elements 1-3 were interpreted and synthesised with known theory and arranged to depict what occurs to a participant as they undertake a supervised to unsupervised exercise programme. Model development was guided by the method described by Hunt and May, (2017) and modified by Lippiett-Chapple, (2019). Steps of this process included: 1) Identification and characterisation of sensitizing concepts; 2) Identification and characterisation of theoretical concepts; 3) Integration and refinements of sensitizing and theoretical concepts; 4) Modelling constructs.

The model was then used to develop recommendations to help professionals in practice and research settings to maximise the likelihood of adherence to exercise interventions in this patient group. The recommendations are presented later in the thesis and discussed in the form of 'Guiding principles' considered to be a fundamental aspect of the PBA (Yardley et al. 2015a; 2015b). It was intended that the guiding principles developed in this thesis should be used by researchers to identify behavioural issues that would likely needed to be addressed in the design of interventions and offer possible ways to address those issues, providing a coherent focus to underpin intervention design through the later stages of the PBA. In a practice context, clinicians should use the guiding principles presented to evaluate any programmes offered and identify where adjustments might be more or less likely to promote adherence.

Finally, another recognised PBA complementary activity, ‘Creation of personas and scenarios’, was used to create two exemplar case studies from data collected during Element 3. These case studies are presented in Appendix HH and II to illustrate how the proposed guiding principles might encourage adherence in this population.

2.4 Chapter summary

This chapter has given an overview of the methodology and methods of the FIT-TOGETHER study. The philosophical underpinnings have been discussed and the research question and aims have been introduced. The PBA, which informed the design of the study, and the individual elements have been presented. Explanations have been given as to how each element contributed to achieving the overall study aims and objectives. The next chapter presents Element 1, a mixed method review investigating adherence to exercise interventions in people with advanced cancer.

Chapter 3 Element 1 Review of adherence to exercise interventions in people with advanced cancer

3.1 Introduction

This chapter presents the first element of the FIT-TOGETHER study, a mixed method review to establish what was already known regarding adherence to exercise in advanced cancer.

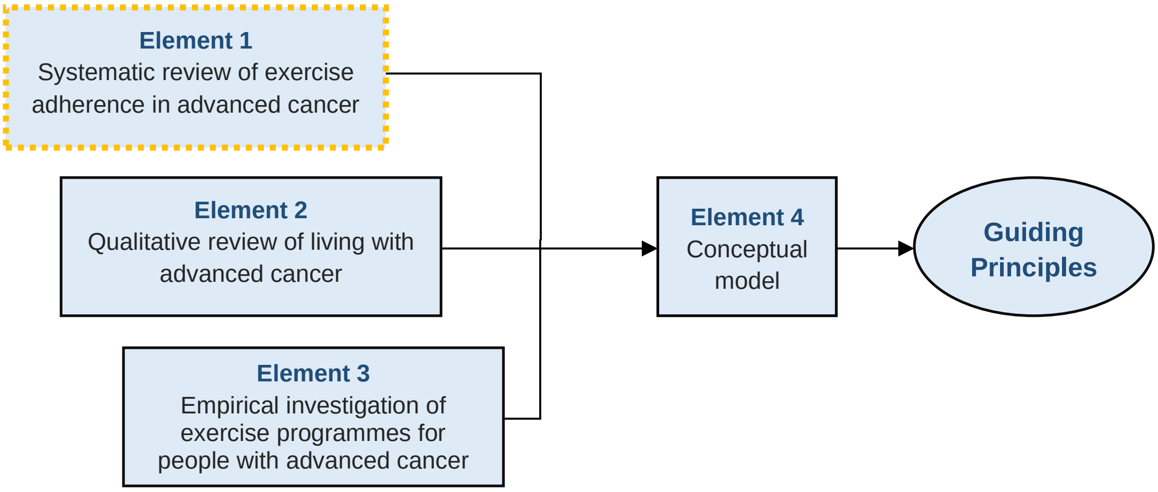


Figure 2: Element 1 schematic representation of the FIT-TOGETHER study

3.2 Aims.

The aims of this element were to establish: 1) the adherence rates to exercise interventions for people with advanced cancer, 2) the characteristics of interventions associated with higher levels of adherence, and how might they be incorporated into future interventions, 3) what is already known regarding exercise interventions performed in hospital settings compared to those performed at home, and what might be done to support participants performing exercise as they transition from one setting to the other.

3.3 Method

3.3.1 Information sources and search strategy

Systematic reviews of quantitative research are considered the best approach for generating evidence regarding the effectiveness of an intervention. However, Pearson et al. (2015) explain the incorporation of qualitative research alongside quantitative research can elaborate on issues of practicality and appropriateness of interventions by producing evidence about the personal experience of participants. Therefore, this review will incorporate both quantitative and qualitative research studies in order to understand the complex issue of exercise adherence in people with advanced cancer to establish what works when and for whom, and what might be done in situations where adherence to an intervention is problematic.

Databases: MEDLINE, EMBASE, CENTRAL, as identified by the Cochrane Handbook for Systematic Reviews (Lefebvre et al. 2021), were searched separately for quantitative and qualitative studies. A MEDLINE search strategy was developed from key words identified in previous reviews into exercise and advanced cancer (Beaton et al. 2009; Lowe, Watanabe and Courneya, 2009; Albrecht and Taylor, 2012), the published protocol for an upcoming review (Lowe et al. 2016a) and publicly available search filters (University of Texas health sciences centre 2016), then modified for the other databases. For MEDLINE quantitative and qualitative database search strategies see Appendix A and B respectively. Searches were carried out in one week in July 2016. Additional search strategies included reference list searches of identified studies and networking with other researchers.

3.3.2 Eligibility criteria and study selection

Over 13,000 studies were initially returned. This number was consistent with an initial scoping search performed first using the Lowe et al. (2016a) search strategy. The high number of returned studies resulted in a pragmatic decision to perform an initial screening of titles to remove irrelevant studies. This strategy has been shown to be more efficient than a traditional title and abstract search (Mateen et al. 2013). The remaining studies were entered into the bibliographic software Endnote, duplicates removed, and abstracts screened against inclusion and exclusion criteria (Table 2). Full texts were obtained for studies deemed eligible or that could not be confidently excluded at this stage. Multiple publications for the same studies were grouped together and the full papers read to check eligibility. Any uncertainty regarding study eligibility was discussed at PhD supervisory meetings.

Table 2: Element 1 inclusion criteria and justification

Inclusion criteria	**Justification / rationale**
Human	The intended population for which this thesis was focused, and therefore it was needed to avoid introducing studies which had involved laboratory-based in vitro, or animal-based research
18 years of age or over	The intended population for which this thesis was focused, and so needed to avoid introducing studies which had involved children
The study population is people with advanced cancer* or people with mixed stage cancers but with advanced cancer subgroup analysis	The intended population for which this thesis was focused, and therefore needed to avoid introducing bias through studies which had involved people with earlier stages of cancer
Any study that investigated the outcomes of a 'prescribed'** physical activity¥ or exercise¥¥ intervention. And / or any study which involved a qualitative evaluation of the experience of 'prescribed' exercise interventions	This thesis is focused upon adherence to prescribed therapeutic exercise therefore any study which investigated general or day to day activity or previous exercise habits is not relevant and so not included
Study population is either participants involved in the exercise / physical activity intervention or the family and carers of the participants	This review is concerned with perspectives of those who performed the interventions not those who designed or delivered them
Only those interventions which investigate exercise in isolation from other health related interventions. ie those which involve exercise combined with other health related interventions such as diet will be excluded	This review is focused upon exercise interventions and the inclusion of studies which investigated other non exercise components to supplement the exercise interventions could introduce bias
Written in English language	Time and resource constraints of the study would not allow for accurate translation from other languages
*Advanced Cancer: For the purposes of this review, advanced cancer is defined as progressive, incurable, locally recurrent, or metastatic malignancy	
**Prescribed: For the purpose of this review prescribed will mean guidance or directions specifying how the exercise or physical activity should be performed.	
¥Physical Activity: Any bodily movement produced by skeletal muscles that requires energy expenditure (Caspersen et al. 1985). For the purposes of this systematic review, basic self-care activities, such as bathing, dressing, and position transfers, which produce only minimal changes in energy expenditure are not included in this definition.	
¥¥Exercise: A subset of physical activity that is planned, structured, and repetitive and has a final or an intermediate objective of the improvement or maintenance of physical fitness (Caspersen et al. 1985).	

3.3.3 Data extraction and analysis

Data extraction forms were modified from the Cochrane Collaboration Data Extraction and Assessment Form (Hannes, 2011) to fit the aims of the review and differentiated for quantitative and qualitative study designs. Data were arranged into comparative charts, tabulating characteristics of the intervention and levels of adherence. The Conceptual Framework of Implementation Fidelity (Carroll et al. 2007; Hasson, 2010) was selected as a suitable way to consider the findings and enable synthesis across different types of studies. This Framework splits adherence into four components, which can be affected/informed by seven moderating factors. Definitions of each component of adherence and the moderating factors according to Carroll et al. (2007) and Hasson, (2010) with additional definitions for the purpose of this review are set out in Table 3.

Table 3: Conceptual Framework of Implementation Fidelity definition of terms

Components of adherence	
Content	Concerns whether each component of the intervention was delivered as planned (Carroll et al. 2007)
Coverage	Concerns whether all the people who should be participating in an intervention actually do so (Carroll et al. 2007)
Frequency	Concerns whether the intervention was delivered as often as planned (Carroll et al. 2007)
Duration	Concerns whether the intervention was delivered for as long as planned (Carroll et al. 2007)
Moderating Factors	
Intervention Complexity	The number of components to the intervention and how they interact, the behaviours required to by those receiving the intervention, and the degree of flexibility or tailoring permitted to the intervention (Craig et al. 2008)
Comprehensiveness of policy description	How specific the interventions description is (Hasson, 2010). Interventions described with detail are more likely to be followed with accuracy than interventions with only a vague description (Carroll et al. 2007)
Strategies to facilitate implementation	Strategies or components of the intervention deliberately put in place for the purpose of optimising the level of fidelity achieved (Carroll et al. 2007)
Quality of delivery	Whether an intervention is delivered in a way appropriate to achieving what was intended, involves the person delivering the intervention as well as any supporting materials used. If the content of an intervention is delivered badly, then this may affect the degree to which full implementation is realised (Carroll et al. 2007)
Participant Responsiveness	Involves a participant’s views, opinions and judgements about an intervention’s relevance and the processes involved in its implementation. It is believed participants’ enthusiasm towards an intervention influences how well that intervention is enacted (Carroll et al. 2007)
Recruitment	Procedures used to attract potential program participants (Hasson, 2010), and covers aspects such as the consistency of recruitment procedures reasons for nonparticipation among potential participants, and subgroups that are less likely to participate (Hasson, 2010)
Context	Larger social systems, political, and economic environment, as well as historical and concurrent events that may influence implementation (Hasson, 2010). For this review context involves any factors external to the intervention which may influence the intervention (Moore et al. 2015) and the setting in which it is to be implemented (McCormack et al. 2002)

Implementation science originated from a need to address difficulties experienced when attempting to apply research findings into practice (Nilsen, 2015). Implementation fidelity, and several similar terms such as fidelity of implementation, fidelity, treatment fidelity, treatment integrity, and intervention fidelity, used for the same purpose, concerns the extent to which an intervention is being delivered as intended by the program developers, and in line with the program model (Breitenstein et al. 2010). It is believed to be a moderator between an intervention and the outcomes it achieves (Carroll et al. 2007). Glasgow, Lichenstein and Marcus, (2003) explain that the importance of understanding fidelity is increased if something is to be delivered by different practitioners with different levels of expertise. This seems particularly relevant to exercise interventions where due to the nature of exercise the participant has to take a much more active role in the implementation of the intervention than in other forms of care and treatment.

The Conceptual Framework of Implementation Fidelity (Carroll et al. 2007) was designed following a critical review of previous implementation literature and was intended to help researchers monitor and evaluate an intervention, and to guide practitioners when implementing research into practice. Carroll et al. (2007) proposed that adherence was the bottom-line measurement of implementation fidelity stating that if the implemented intervention adheres completely to the content, frequency, duration and coverage intended by the designers then the fidelity is high. It was found that adherence was moderated by five factors: ‘Intervention complexity’, ‘Facilitation strategies’, ‘Quality of delivery’, ‘Participant responsiveness’, and ‘Comprehensiveness of policy description’.

Hasson, (2010) recognised the Conceptual framework of Implementation Fidelity as the most complete framework for implementation fidelity available. But chose to modify it with the addition of two extra moderating factors, ‘Context’ and ‘Recruitment’, which Hasson, (2010) believed was supported by enough empirical evidence, suggesting the importance of these factors on programme implementation, to warrant inclusion. Published literature now demonstrates the framework to have been successfully used to evaluate implementation fidelity, and the associated moderating factors in the continuation of care of frail elderly when transitioning from hospital to home care (Hasson, Blomberg and Dunér, 2012), and to investigate local adaptations to the fidelity of a work-based exercise programme (von Thiele Schwarz, Hasson and Lindfors, 2015). There are many other theories, models and frameworks which investigate intervention implementation, and Moullin et al. (2015) conducted a systematic review to assess the comprehensiveness of current existing implementation frameworks. Some 49 different frameworks were identified that were intended to facilitate implement of innovation in health care. From those frameworks core implementation concepts were identified and were synthesised into what was termed the Generic Implementation Framework (Moullin et al. 2015). The authors stressed this was not intended to be used as a new standalone framework but as a composite of what other frameworks offer, providing the opportunity for researchers to check a framework or combination of frameworks incorporated the core concepts necessary for the implementation of a given innovation. Such concepts were identified as those relating to the process of implementation (the stages and steps), the innovation to be implemented, the context in which the implementation is to occur (divided into various numbers of domains), and the influencing factors, strategies, and evaluations. Comparison between the Conceptual Framework of Implementation Fidelity modified by Hasson, (2010) and the General Implementation Framework (Moullin et al. 2015) suggest the former adequately addressed the core requirements for implementation. Therefore, the chosen framework was appropriate for this review as it documents adherence in a comprehensive and detailed manner, and identifies factors likely to influence adherence that are applicable to the intervention itself, the people delivering the intervention and the people receiving the intervention. The framework has also been tested empirically in interventions and settings that have a relevance to the focus of this PhD study (Hasson, Blomberg and Dunér, 2012, von Thiele Schwarz, Hasson and Lindfors, 2015).

3.3.4 Assessment of risk of bias in included studies.

The Downs and Black, (1998) checklist was used to assess quantitative papers. Often used in contemporary healthcare research, it creates a profile of the methodological strengths of a paper including risk of bias (Latter et al. 2016).

The Cochrane Collaboration explain that the biggest risk to qualitative research is researcher bias (Hannes, 2011). The Critical Appraisal Skills Programme (2013) produce a checklist for qualitative research which specifically considers researcher bias and was used to assess the qualitative papers. Three quantitative papers and three qualitative papers were assessed jointly by DA and a member of the PhD supervisory team, before DA assessed the remainder of the papers.

3.4 Findings.

The combined search strategies found 26 papers, derived from 20 studies, that were identified as being suitable for inclusion in the review. A summary of the selection process can be seen in Figure 3. There were 22 papers that utilised a quantitative design ranging in sample size from n=101 to n=9. Quantitative study designs included 13 randomised controlled trials (RCT), two non-randomised trials and four single group pre-test post-test trials. Two of the interventions (Uth et al. 2014; 2016, West et al. 2015) were further evaluated in three qualitative papers (Bruun et al.

2014, Burke et al. 2013; 2015). One mixed methods study was found (Siemens et al. 2015). However, after data extraction and quality assessment, this was excluded as only one participant was recruited, who subsequently dropped out before baseline testing after being notified of upcoming surgery. Siemens et al. (2015) attributed the overall poor recruitment to this study to what they concluded to be overly tight inclusion criteria regarding participant physical function.

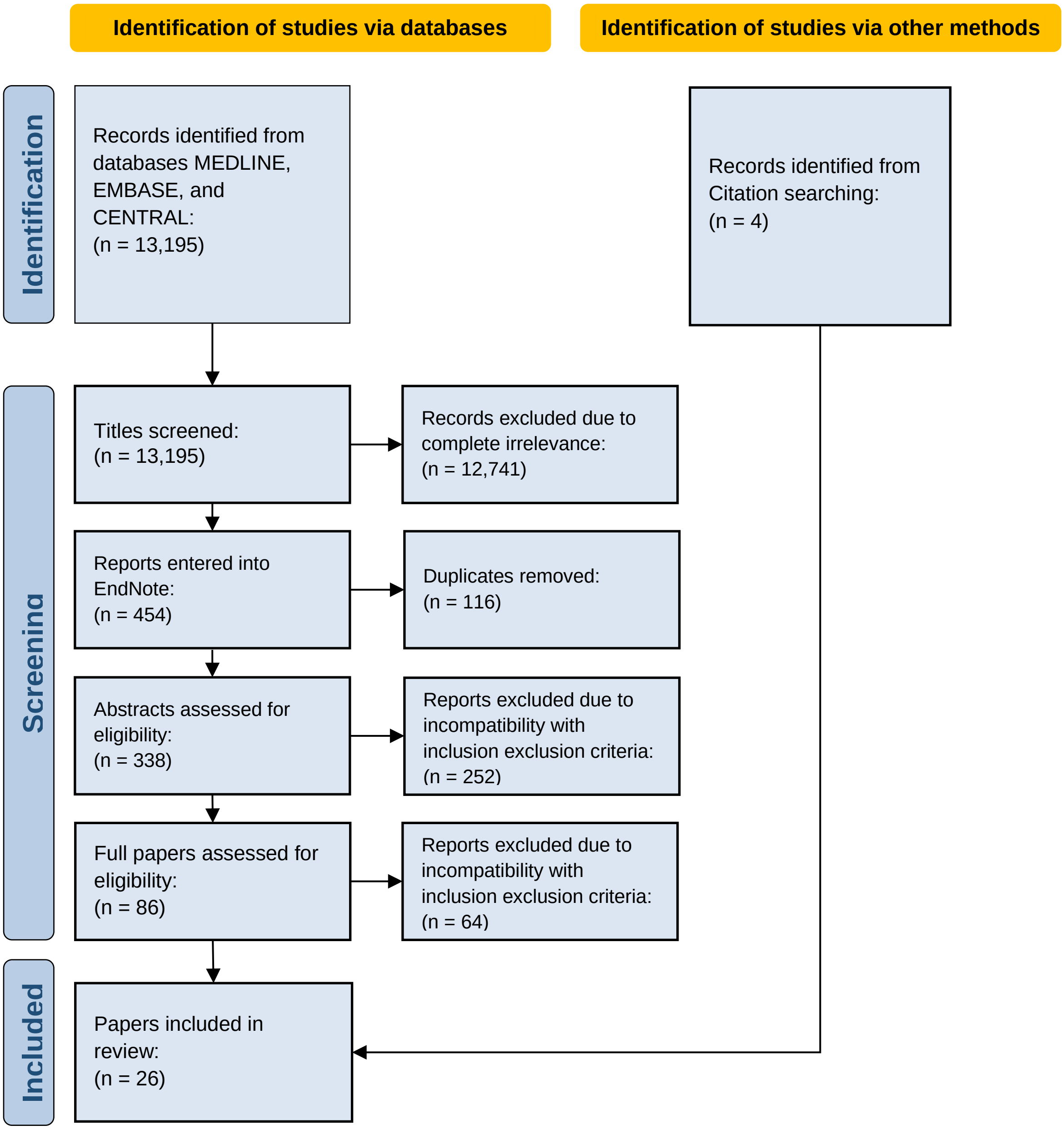


Figure 3: PRISMA diagram showing identification and selection of papers for Element 1

3.4.1 Recording and Reporting of Adherence

Of the quantitative studies included in this review, seven of the 26 papers did not report intervention adherence (Segal et al. 2003; Mayo et al. 2014; Porock et al. 2000; Rief et al. 2014a; 2014b; 2014c; Ligibel et al. 2016) and so were not included in the analysis. Therefore in addition to Siemens et al (2015), which was excluded because no participant had started the intervention, eight of the originally selected papers were excluded leaving a total of 18 to be analysed against the conceptual framework of implementation fidelity. In the papers which measured adherence the heterogeneity of methods used and variabilities in the characteristics of the interventions mean a meta-synthesis was not possible. Instead, this section will first describe the methods used to measure adherence, then investigate how components of the interventions may have influenced adherence rates. The majority of studies recorded adherence by logging attendance at supervised sessions. Adherence to unsupervised sessions were recorded using self-report exercise diaries or calendars. In the study by Headley, Ownby and John, (2004) participants were required to document the type, duration and intensity of activities performed, however insufficient data was recorded to allow report on these. Cheville et al. (2013) provided participants with pocket pedometers to attempt better recording of unsupervised exercise. Inaccuracy of self-report measures of adherence is well known. Interventions by Lowe et al. (2013), Cormie et al. (2013) and van den Dungen et al. (2014) involved supervised and unsupervised components but only recorded adherence to the supervised sessions.

Levels of adherence reported by studies included in this review are grouped together according to the component of adherence reported and how it was calculated, this is reported in Table 4. Using the modified Conceptual Framework of Implementation Fidelity, the most commonly reported component of adherence was ‘Frequency’**,** which was reported in three different ways. Nine studies (11 papers) reported the mean number of sessions participated in compared to the maximum number of sessions which were prescribed. Of these, five papers used data from all participants who started the intervention (West et al. 2015; Winters-Stone et al. 2014; 2015; Cormie et al. 2013; Litterini et al. 2013), four papers calculated the rate of adherence using data only from those who completed the intervention (Lowe et al. 2013; Uth et al. 2014; 2016; Hwang et al. 2012) and one paper reported both (Jensen et al. 2014): all participants, 65%, and from only those who completed the intervention, 75%. This distinction and the resulting variations demonstrate the potential risks of comparing adherence if it is not clear from which participants the data are drawn. Cheville et al. (2013) reported their own definition of adherence which fits most closely with the component ‘Frequency’, but was the only study to include an element of progression. As well as exercising and logging step counts four or more times a week, participants also had to increase step counts by 10% at least every four weeks. Six studies reported adherence in a way that could be considered to involve ‘Frequency’ and ‘Duration’. Four studies reported the percentage of participants who participated in every session, receiving the maximum dose of the intervention (Cormie et al. 2013; van den Dungen et al. 2014; Hwang et al. 2012; Temel et al. 2009). The study by van den Dungen et al. (2014) further highlights the importance of reporting which participants were included in the calculations of adherence because, although 65% of those who started the intervention completed every session, 100% of participants who finished the intervention completed all the sessions. Van den Dungen et al. (2014) also reported adherence as a measure of ‘Frequency’ and ‘Duration’ reporting how many participants completed eight out of the 12 sessions but did not explain the rational for this unique measurement. Kuehr et al. (2014) reported adherence using two definitions unique to that study, which combined elements of Frequency and Duration together. One definition, which was termed feasibility, was the primary endpoint of that study and defined as participating in two out of five sessions a week for a minimum of six out of the eight weeks, meeting this was deemed adequate adherence; the other definition, termed overall adherence, was defined as the ability to train according to the study guidelines by performing five sessions in the in-patient and three sessions in the home-based setting each week. Only one study, Cormie et al. (2013), included a measure of ‘Content’, which was termed compliance, and found 93% of all sessions completed the number of exercises, sets and repetitions as intended in the prescription. Only Cormie et al. (2013) assessed adherence in relation to the Content, Frequency and Duration of the intervention.

Table 4: Type and rate of adherence

Author	**Type of adherence**	**Rate of adherence**
West et al. (2015)	Frequency adherence. Percentage of sessions participated in including all participants	**96%**
Winters-Stone et al. (2014,2015)	Frequency adherence. Percentage of sessions participated in including all participants	**83%** supervised (2014) **43%** home (2014) **84%** supervised (2015) **49%** home (2015) (Reasons for differences in adherence between 2014 and 2015 papers not reported)
Cormie et al. (2013)	Frequency adherence. Percentage of sessions participated in including all participants	**83%**
Hwang et al. (2012)	Frequency adherence. Percentage of sessions participated in including all participants	**71%**
Litterini et al. (2013)	Frequency adherence. Percentage of sessions participated in including all participants	**70%**
Jensen et al. (2014)	Frequency adherence. Percentage of sessions participated in using data from all participants	**65%** overall **72%** resistance exercise **59%** aerobic exercise
Lowe et al. (2013)	Frequency adherence. Percentage of sessions participated in using data from participants who completed the study	**87%**
Uth et al. (2014,2016)	Frequency adherence. Percentage of sessions participated in using data from participants who completed the study	**76.5%** Week 0-12 **46.2%** Weeks 13-32
Jensen et al. (2014)	Frequency adherence. Percentage of sessions participated in using data from participants who completed the study	**75%**
Cheville et al. (2013)	Unique definition of frequency adherence	**76%** of participants perform the exercise 4 or more times a week, logged step counts 4 or more times a week and increased step count by at least 10% every 4 weeks or less

Author	Type of adherence	Rate of adherence
Cormie et al. (2013)	Frequency and duration. Participants who completed every session, percentage of total who started the intervention	**70%**
van den Dungen et al. (2014)	Frequency and duration. Participants who completed every session, percentage of total who started the intervention	**65%**
Temel et al. (2009)	Frequency and duration. Participants who completed every session, percentage of total who started the intervention	**58%**
Hwang et al. (2012)	Frequency and duration. Participants who completed every session, percentage of total who started the intervention	**23%**
van den Dungen et al. (2014)	Frequency and duration specified dose unique to that intervention	**85%** of participants completed 2/3rds of the intervention
Kuehr et al. (2014)	Frequency and duration specified dose unique to that intervention	**55%** of participants completed 2 out of 5 sessions for minimum 6 out of 8 weeks **82%** overall adherence of the of the participants who were able to train in accordance with the study guidelines each week. Hospital based =**95%** Home-based =**77%**
Cormie et al. (2013)	Content adherence. Number of participated sessions which conformed exactly to the prescription in terms of number of exercises repetitions and sets performed	93%
Headley, Ownby and John, (2004)	Reported as overall adherence without an explanation	75%

3.4.2 Factors that influence adherence

The following sections outline the ways in which previous studies address the seven moderating factors that influence adherence, according to the modified Conceptual Framework of Implementation Fidelity (Carroll et al. 2007); Hasson, (2010) as set out previously in Table 3.

3.4.2.1 Recruitment

‘Recruitment’ involves the procedures used to attract program participants and is important with regard to the generalisation of findings to clinical population (Hasson, 2010). In this review it will include any procedures involved in the identification of participants for the study, as well as any reasons given for or against participants consenting to the study. Inclusion and exclusion criteria determine the population of a study, and therefore have the potential to produce a study population more or less likely to adhere to the intervention. For example, one study showed that approximately half of participants would miss the first exercise session immediately after chemotherapy treatment (van den Dungen et al. 2014), therefore studies that exclude participants receiving chemotherapy may have higher adherence than those who do not. All of the inclusion/exclusion criteria in the studies in question involved elements to select participants with advanced cancer, the population of interest. Several studies also included criteria that may influence adherence to the intervention such as severity of symptoms or physical function of selected participants. Most noticeably, Cheville et al. (2013) deliberately recruited participants within a functional range that previous research suggested would be most likely to result in adherence**.** Litterini et al. (2013) and Headley, Ownby and John, (2004) provided no information regarding recruitment rates. From studies included in this review that did report recruitment rates, findings show 1014 otherwise eligible participants declined consent, 531 with no reason reported. Of those that did give reasons for not consenting, common reasons included lack of interest, already being active enough, and travel/time commitments. The inclusion of qualitative papers in this review allows for the investigation of reasons for participation, something the quantitative papers did not report. Bruun et al. (2014) questioned participants about their motives for enrolment which involved: viewing the intervention as an opportunity to restart exercise, which they had previously participated in but currently felt unable to perform; interest in the activity; enthusiasm for exercise supervision, as this meant it would be safe and beneficial; and interest in the testing, which would give objective information about their health.

Some issues were also highlighted in the group allocation process in two studies which may have impacted on adherence. West et al. (2015), who achieved the highest frequency adherence of any study, purposely assigned participants living over 15 miles from the hospital, and any participants who felt unable to commit to the intervention, to the control group. Following randomisation Hwang et al. (2012), moved two participants, at their own requests, from the control group into the exercise group and one from the exercise group into the control group.

3.4.2.2 Context

Hasson, (2010) explains ‘Context’ involves social systems, and the political, and economic environment, as well as historical and concurrent events that may influence implementation. For this review ‘Context’ is described as involving factors external to the intervention that may influence the intervention (Moore et al. 2015) and the setting in which it is to be implemented (McCormack et al. 2002). Supervision could be included in, and certainly influences, several other moderating factors, but is included here as it is so closely associated with the setting. All home-based sessions were unsupervised except the resistance exercise sessions by Lowe et al. (2013) and all hospital-based sessions were supervised except for a small proportion of sessions by Kuehr et al. (2014) as a deliberate strategy to aid progression to home-based exercise. The intervention context and participant characteristics of the studies included in this review can be seen in Appendix C. Participants in the studies comprised a variety of different tumour type. Four studies (encompassing eight papers) investigated prostate cancer, two studies (comprising three papers) investigated rectal cancer. Three studies investigated lung cancer. Breast and Gastrointestinal cancer were investigated in one study each. One study investigated lung and colorectal cancer together. Six studies involved mixed populations of a range of cancer sites. The studies which involved one cancer type reported precise staging of the disease whereas the studies involving multiple cancers used vaguer descriptions to summarize across the cancer types. The general health of participants at the start of the trial was relatively high, the homogeneity of this allowed for little comparison of findings. Only two studies involved solely home-based unsupervised exercise. Chevilli et al. (2013) used a unique definition of adherence, and Headley, Ownby and John, (2004) did not specify how adherence was measured, preventing direct comparison with hospital supervised interventions. Two interventions measured adherence to supervised clinical sessions and unsupervised home-based sessions allowing a comparison between the two settings. Both reported lower adherence to the home sessions than hospital sessions. Kuehr et al. (2014) reported a drop in adherence from 95% for inpatient exercise to 77% when the intervention progressed to unsupervised home-based sessions. Winters-Stone et al. (2014; 2015) found attendance to the supervised hospital sessions to be 83% and the home sessions 49%. Possible reasons for this decline in adherence when transitioning from a supervised hospital-based setting will be discussed in sections that follow.

3.4.2.3 Intervention Complexity

‘Intervention Complexity’ refers to the fact an intervention may be simple or complex, detailed or vague. Simple interventions are more likely to be implemented with high fidelity than overly complex ones (Carroll et al. 2007). Complexity can include the number of components to an intervention, the degree of difficulty in terms of behaviours required by those being asked to engage with the intervention, and the degree of flexibility or tailoring permitted to the intervention (Craig et al. 2008). Appendix D contains a table detailing the factors which contribute to the complexity of each intervention. Least complex intervention was that of Headley, Ownby and John, (2004) which involved following a seated exercise video for 30 minutes three times a week. The intervention was only performed in the participant’s home, required no additional equipment other than a chair and video player. The video contained no element of adjustment or tailoring which although increased simplicity, did cause some dissatisfaction with the participants. In contrast, the most complex intervention was perhaps deployed by Kuehr et al. (2014) which involved a number of components to follow, across two different settings, involving a large number of different equipment and could allow a high amount of tailoring. This involved participants with advanced non-small cell lung cancer performing eight weeks of aerobic and resistance exercise, initially whilst an inpatient then later becoming home-based sessions. During the in-patient period, sessions were conducted five times a week, three of which were supervised.

During the home-based period, sessions were unsupervised. The intervention was highly flexible during its implementation based on participants' health and wellbeing. At the start of each session participants self-rated their current health on a traffic light colour system which then selected exercise intensity for the session: Green for relative good or normal health resulted in the highest intensity exercise, yellow and red for medium and poor health respectively resulting in lower intensities. Adherence for the whole duration of the Kuehr et al. (2014) study was 82%, 95% during the inpatient setting and dropping to 77% during the home-based sessions. One possible explanation for this decline in adherence was the differences in behaviours demanded of participants in each setting. The hospital sessions were largely supervised in a specialist facility. Any equipment needed was already in place prior to the start of each setting whereas at home participants were responsible for setting up and storage when not in use. In addition, during supervised sessions, participants may simply have been following instructions of which exercise to do and how. While in the home-based setting this information would have to be established by reading and understanding the exercise manual, then matching the exercises in the manual with the appropriate level in traffic light self-assessment system. All of which would have increased the physical and cognitive work needed to be done by the participant. Further sub-analysis revealed a preference for resistance training during the hospital sessions, 50% of sessions involved only resistance training, 27% involved only aerobic training, and 23% a combination of both. However, this trend was reversed during the home-based period with 47% of sessions involving only aerobic training, 29% only resistance training and 24% involving a combination of both. As resistance training involves substantially more components than an aerobic intervention this points to the importance of simplicity in home-based situations. However, despite Kuehr et al. (2014) being the most complex intervention, the decline in adherence from 95% to 77% when moving to unsupervised home-based settings does compare favourably with other studies which recorded higher declines in adherence when moving from supervised hospital based to unsupervised home-based settings. Winters-Stone et al. (2014; 2015) reported a decline from 84-44%. The traffic light self-rating system and the two sessions a week hospital based but unsupervised may have led participants to feel more comfortable to exercise once they had gone home. Both these elements to the intervention, although adding significant complexity, could help alleviate any concerns participants may have regarding safety when progressing to a home-based situation. Safety was a key theme identified in the qualitative studies (Bruun et al. 2014, Burke et al. 2013; 2015), and therefore any element of an intervention which increases perceived safety is likely to impact on 'Participant Responsiveness' and have a positive impact on adherence.

3.4.2.4 Quality of Delivery and Comprehensiveness

'Quality of Delivery', concerns whether the content of an intervention has been delivered in a way appropriate to achieving what was intended. It involves the person delivering the intervention and any supporting materials used (Carroll et al. 2007). For the purpose of this review supporting material include anything shown or given to the participant to enable understanding or performance of the exercise. Appendix E contains a table showing the factors which indicate the 'Quality of delivery' of each intervention. **'**Quality of Delivery' overlaps somewhat with both 'Intervention Complexity' and 'Comprehensiveness'**.** Supporting material added to an intervention can improve the 'Quality of Delivery' but can also increase 'Intervention complexity' because each item added may require extra action of some sort by the participant. The moderating factor 'Comprehensiveness'**,** described by Carroll et al. (2007) as the level of detail given in the delivery of the intervention, is influenced by the 'Quality of Delivery'**,** in that who or what delivers the intervention moderates the level of specificity that can be achieved. 'Quality of Delivery' in turn seems to be heavily influenced by the intervention setting, previously discussed as part of the moderating factor of 'Context'. Sessions delivered in hospital-based exercise facilities are able to access expensive high tech supporting materials allowing the intervention to be performed and monitored in ways not possible in other settings. For example, West et al. (2015), used pre-programmed chip and pin cards to control the intensity and duration of a cycle based aerobic interval training program whist additional equipment was used to continuously monitor vital signs. This allowed the intervention to be individualised and executed exactly as the designer intended for each participant based on baseline cardiopulmonary exercise testing and ensured participant safety. Adherence to the intervention was particularly high, all participants who started the intervention completed the six-week program and frequency adherence, measured as a percentage of the total sessions which were planned, was 96% the highest in the review. Furthermore, Litterini et al. (2013) provided a choice of eight different cardiovascular exercise machines and obtained a prescription so that oxygen could be delivered or increased to any patient whose saturation levels fell below 90%.

Most interventions involving unsupervised sessions provided a range of supporting material. Three studies involving some unsupervised aerobic exercise sessions provided no additional supporting material for the unsupervised sessions, but as they did not measure or report adherence to this part of the intervention impact on adherence is not known (Lowe et al. 2013; Cormie et al. 2013; van den Dungen et al. 2014). Supporting material provided whilst moving to home-based sessions, replicated or replaced components of what is provided during a supervised sessions, and can be categorised into four purposes; A) Supporting material intended to guide or demonstrate the activities such as videos (Headley, Ownby and John, 2004), and illustrated exercise manuals (Cheville et al. 2013; Kuehr et al. 2014); B) Supporting material for use in performing exercise such as resistance bands (Cheville et al. 2013; Kuehr et al. 2014; Winters-Stone et al. 2014; 2015), and dumbbells (Kuehr et al. 2014); C) Supporting material to record session information such as diaries (Kuehr et al. 2014), and calendars (Cheville et al. 2013; Headley, Ownby and John, 2004); and D) supporting material or methods to enable intervention adjustment such as phone call (Cheville et al. 2013, Kuehr et al. 2014), or visual analogue scale to assess relative health which then determined exercise intensity (Kuehr et al. 2014). Methods such as phone calls provided more individualised approach and also allowed for additional safety monitoring and advice when needed. Although supporting material in home-based sessions is unlikely to provoke the same 'Quality of Delivery' as hospital sessions, there is evidence to suggest supporting material can be somewhat successful when transitioning to a home-based setting. Out of the two studies which measured adherence in both hospital and home-based settings the intervention which provided a more comprehensive array of supporting materials (Kuehr et al. 2014) reported a far smaller drop in adherence than the intervention which merely provided participants with exercise equipment (Winters-Stone et al. 2014; 2015).

3.4.2.5 Facilitation Strategies

'Facilitation Strategies' encompass components of an intervention put in place with the intention of optimising the level of fidelity achieved. The more that is done to support implementation, through monitoring, feedback, training and guidance, the higher the potential level of implementation fidelity (Carroll et al. 2007). Few studies stated they put in place strategies or components with the intention of improving adherence, although it could be argued many of the supporting materials discussed as part of 'Quality of Delivery' were 'Facilitation Strategies', even if that was not their primary purpose. West et al. (2015) and Uth et al. (2014; 2016) both deliberately included training with peers with the intention of generating support and encouragement. The qualitative evaluations of these studies found this to be a valued aspect of the sessions (Bruun et al. 2014, Burke et al. 2013; 2015). Additional strategies deliberately incorporated to improve or facilitate adherence, included unsupervised sessions whilst still in a hospital setting to get participants used to training independently before transition to a home-based setting, and extra education on overcoming barriers to exercise (Kuehr et al. 2014). Winters-Stone et al. (2014; 2015) included an extra home-based session each week in an attempt to increase the amount of exercise being performed whilst minimizing the additional burden to the participant, and deliberately used equipment in the home-based sessions which mimicked the movements in the hospital sessions.

3.4.2.6 Participant Responsiveness

‘Participant Responsiveness’ involves judgements about an intervention’s relevance and processes involved in implementation, assuming participants’ enthusiasm towards an intervention influences how well that intervention is enacted (Carroll et al. 2007). Findings regarding the ‘Participant Responsiveness’ were variable, and dependent on study methodology**.** Every study reported reasons for dropout or attrition, which could potentially indicate how participants view an intervention’s relevance to their needs or enthusiasm for partaking in the intervention. However, the vast majority of reasons reported related to disease progression and changes in treatment which without additional information is difficult to determine if and how it relates to ‘Participant Responsiveness’. Only two examples were given of participants withdrawing from the intervention due to not liking it, and having no interest (Uth et al. 2014; 2016; Winters-Stone et al. 2014; 2015). Four studies reported reasons for non-attendance to sessions, with personal, or treatment related side effects reported as the most common reasons. Two studies assessed interest in future exercise, both finding participants wished to continue exercising after the study finished. In the study by Lowe et al. (2013), all three cases presented expressed high levels of satisfaction with the intervention particularly the supervised sessions, however participants expressed dissatisfaction with the unsupervised sessions. One expressed dissatisfaction with lack of intervention effect and his continued physical decline and therefore did not wish to continue exercising in the future. One study used a post intervention survey to evaluate participants’ experience. Although complete findings were not made available, participants reported feeling stronger, valuing staff, finding the program enjoyable, with some participants reporting they would have liked to exercise more. Additional evidence regarding ‘Participant Responsiveness’ included a scale for participants to rate how tolerable each session was (Cormie et al. 2013), and anecdotal evidence expressed to the research team that the intervention guidance video was not physically challenging enough and the subjects in the video did not reflect how the participants viewed themselves (Headley, Ownby and John, 2004). Two interventions, Uth et al. (2014; 2016) and West et al. (2015) were evaluated in subsequent qualitative studies by Burke et al. (2013; 2015) and Bruun et al. (2014). Participants expressed the view that the intervention had noticeably improved their quality of life through increasing feelings of strength and vitality, and reducing feelings of tiredness. The participants liked having the opportunity to do something purposeful and constructive for their own health and liked the social interaction with staff and being able to talk with their peers (Burke et al. 2013; Bruun et al. 2014). Burke et al. (2015) found the intervention increased participants’ motivation or desire to participate in exercise, compared with before the intervention. Again reasons given for this were the camaraderie and social interaction developed between other participants and the sense of control they felt from completing the sessions. A strong motivating factor to attend sessions was an obligation towards their exercise peers (Burke et al. 2013; 2015; Bruun et al. 2014). All three papers stressed the importance of a sense of safety created by supervisors ensuring they felt secure even when exerting themselves. This sense of perceived safety even saw participants return to the training after sustaining serious injuries, such as a broken fibular and sprained ankle (Bruun et al. 2014). Participants were enthusiastic about completing outcome measures, in that feedback provided quantifiable information about their health and they enjoyed being able to tell family members about their training (Bruun et al. 2014).

3.5 Discussion

This review is the most comprehensive study of adherence to exercise interventions for people with advanced cancer to date. The review comprised 26 papers, of which 15 quantitative studies reported adherence, compared to four studies measuring adherence reported in a previous review (Beaton et al. 2009). In that review suggestions were made that individualized programming, group participation, and noticeable improvements may have motivated adherence to the interventions. However, Beaton et al. (2009) continue that this suggestion was speculation due to the limited information reported in the included studies and needs investigation in further research. Limited information and heterogeneity of intervention, population and outcomes is commonly reported in several other reviews (Lowe et al. 2009; Heywood, McCarthy and Skinner, 2018; Nadler et al. 2019; Sheill et al. 2019). The use of the conceptual framework presented in this chapter helped organise the heterogeneity of the studies, and with the addition of the qualitative studies (n=3), can offer deeper more robust explanations. Albrecht and Taylor, (2012) highlighted the importance of taking into account the interests and needs of the specific population. The review presented here offers further explanation of what the needs and preferences might be through the moderating factor of ‘Participant responsiveness’ and identifies factors in ‘Facilitation strategies’ which have been successful in meeting such needs.

Since completion of this review other published reviews into exercise in advanced cancer have been conducted and give further support to what has been reported here. Dittus, Gramling and Ades, (2017) and Sheill et al. (2019) both give support to the finding of inconsistency in how adherence is measured and reported. Dittus, Gramling and Ades, (2017) also highlighting the difficulty and potential misleading accounts caused by some studies reporting adherence in all participants while others only report adherence in participants who were deemed to have participated for a long enough period of time. However, adherence to exercise in this patient group remains largely unexplained. Dittus, Gramling and Ades, (2019) reported that participant recruitment and adherence rates varied considerably between studies but suggests no reasons for that variation. Dittus, Gramling and Ades, (2017) supports the assertion that supervision enhances adherence and continues that regular contact may to some extent abate the decline in adherence which is encountered if supervision is removed. Takemura et al. (2021) considered low adherence and the inappropriate analysis to calculate the effect of low adherence to cause high risk of bias. The review by Nadler et al. (2019) into the benefits and safety of exercise in advanced solid tumours concludes that the understanding of how exercise prescriptions can be optimised for participant adherence is very limited. The review presented in this chapter suggests how the Conceptual Framework of Implementation Fidelity (Carroll et al. 2007; Hasson, 2010) could be an appropriate method of improving such optimisation.

3.5.1 Limitations

The exclusion of interventions which involved exercise and additional lifestyle components such as diet or relaxation, as recommended by Beaton et al. (2009), could be seen as a strength of this review. However, this decision excluded several qualitative papers of interest which may have added further understanding of participant experience. Further limitations of this review include a limited number of databases searched, the minimum recommended by the Cochrane Collaboration, only one person selecting studies, and only a proportion of the studies being assessed for quality by two researchers. Although this review included greater input from qualitative methods than previous reviews it still provides relatively few examples of this and relatively limited understanding of participants perspective. In part due to the limited evidence available of participants’ perspective this review therefore provides limited understanding as to why characteristics of interventions and their association with the factors of the Conceptual Framework of Implementation Fidelity may impact theoretical behavioural considerations. The way in which factors such as advanced cancer and the different components of exercise interventions influence such behavioural considerations will be investigated further in Elements 2, 3, and, 4.

3.5.2 Adherence rates to exercise interventions for people with advanced cancer

The ‘Context’ in which exercise interventions have been designed for people with advanced cancer can be divided into four basic forms: those performed solely in specialist facilities such as hospitals or exercise clinics (Temel et al. 2009; Hwang et al. 2012; Litterini et al. 2013; Jensen et al. 2014; Uth et al. 2014; 2016; West et al. 2015,); those performed solely in participants’ homes (Headley, Ownby and John, 2004; Cheville et al. 2013; Lowe et al. 2013); those which involve hospital based exercise and home-based exercise each week (Cormie et al. 2013; van den Dungen et al. 2014; Winters-Stone et al. 2014; 2015); and finally, those which progress from hospital sessions to home-based sessions (Kuehr et al. 2014). Adherence rates ranged from 23% (Hwang et al. 2012) to 96% (West et al. 2015). However, heterogeneity between how adherence is defined and measured in each study can make comparisons between studies misleading. Standardisation of how adherence is reported using the four components of the Conceptual Framework of Implementation Fidelity would allow better comparison between interventions.

3.5.3 Characteristics of interventions associated with improved adherence.

Evidence suggests that when exercise sessions move from a hospital setting to a home-based setting adherence declines. This reduction in adherence occurs whether the exercise is performed in both settings each week (Winters-Stone et al. 2014; 2015) or when sessions transition from hospital settings into home settings as the intervention progresses (Kuehr et al. 2014). Reduced adherence to home-based sessions when moving from hospital was found previously in a study into exercise in advanced cancer excluded from this review (Quist et al. 2012), and in the active control group performing flexibility training of an included study (Winters-Stone et al. 2014). This contradicts previous research which found potential participants thought they would prefer home-based exercise (Lowe et al. 2010; Maddocks, Armstrong and Wilcock, 2011) and recommendations that home-based exercise may improve adherence rates (Temel et al. 2009). The findings of this review suggest that once participants have experienced the intervention they highly value the input of supervision, specialist facilities, monitoring equipment, social interaction and scheduled appointments (Litterini et al. 2013; Lowe et al. 2013; Bruun et al. 2014; Burke et al. 2013; 2015). It could be that prior to participants having experienced hospital based supervised interventions, they do not appreciate the difference between the two settings.

3.5.4 What can be done in future studies to maximise adherence?

The evidence from the qualitative studies and case studies presented by Lowe et al. (2013) seems to suggest high levels of participant satisfaction and enthusiasm for exercise interventions. This included belief in the benefits to exercise, feeling reassured that the intervention would be safe, experiencing noticeable physical, psychological, and, social benefits during and after the interventions. Very little is known about what participants do not like about the interventions. The only suggestions of dissatisfaction with the interventions included anecdotal evidence regarding the level of intensity and image of disability portrayed in a training video (Headley, Ownby and John, 2004), dissatisfaction with an unsupervised component of a predominantly supervised intervention, and one participant not wanting to continue exercising because he felt he had declined physically despite the intervention (Lowe et al. 2013). Only one participant was reported as dropping out due to lack of interest in an intervention (Uth et al. 2014; 2016). Without detailed knowledge of what participants do not like it may be difficult to design interventions that participants will adhere to. Some studies recruited only participants they felt would be most able to adhere to the interventions, most notably, Cheville et al. (2013) who used findings from previous research to identify participants within a functional range most likely to adhere to the intervention. Whist this would enhance the apparent feasibility of the intervention within a study, it raises questions of any subsequent application to practice and what would be provided for those individuals not within that functional range.

The use of the Conceptual Framework of Implementation Fidelity (Carroll et al. 2007; Hasson, 2010) in this review to categorise components of an intervention into factors that may moderate adherence helped suggest explanations as to why some interventions were adhered to better than others although the heterogeneity of the included studies allowed for little confirmation of this. However, examples of facilitation strategies identified which appear to have been successful included: involving training with peers to generate support and encouragement (West et al. 2015; Uth et al. 2014; 2016); including some training sessions without supervision to encourage independence before transition to the home period (Kuehr et al. 2014); including education on overcoming barriers to exercise (Kuehr et al. 2014).

Findings in this review indicate perceived safety can be an important influence upon adherence. Recent reviews by Nadler et al. (2019) and Sheill et al. (2019) concluded exercise in advanced cancer to be safe. The moderating factor of ‘Recruitment’ highlighted that studies often have narrow inclusion criteria which may limit recruitment numbers and bias adherence in research settings compared to clinical practice. Sheill et al. (2019) continued that due to the increasing evidence of safety, studies could move away from the narrow inclusion criteria often used, and now recruit participants more representative the general advanced cancer population. However this was largely based upon supervised interventions, and qualitative finding presented in this chapter indicate the importance of perceived safety which was generated through the use of professionally trained supervisors and use of monitoring equipment, both of which are less prevalent in home-based interventions. Therefore, it is possible the decline in adherence when moving away from this setting may be due to a decline in the extent to which the participants feel safe performing the exercise.

3.5.5 Conclusion

Participants of exercise interventions greatly value the perceived safety, purposeful social interaction, and legitimacy or perceived validity of exercise performed in specialist facilities with trained supervisors. A decline in adherence occurs when exercise moves away from these supervised specialist settings into unsupervised home-based conditions. However, this decline maybe be moderated to some extent if steps are taken to facilitate the continuation of exercise adherence when participants move between the two exercise settings. One possible approach for future intervention design could be to use the Conceptual Framework of Implementation Fidelity as a tool to identify moderating factors which have not been accounted for and need to be considered, or require compensating for with additional facilitation strategies.

Chapter 4 Element 2: Qualitative review of how life with advanced cancer may impact exercise behaviour

4.1 Introduction and background

This review comprises the second of three elements, designed in accordance with the PBA (Yardley et al. 2015a; 2015b). The way in which this review fits with the other elements that together form the FIT-TOGETHER study is illustrated in Figure 4.

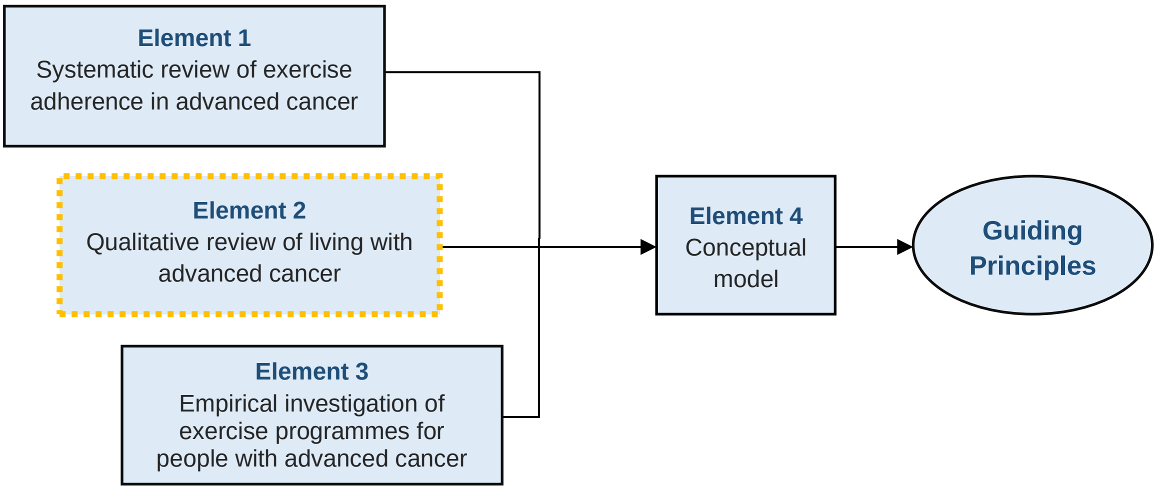


Figure 4: Element 2 schematic representation of the FIT-TOGETHER study

The purpose of this review was to investigate what living day-to-day for people with advanced cancer involves and how this experience might impact on their ability to adhere to an exercise intervention at home. This review adopted a broad scope to investigate the general day-to-day experiences of people living with advanced cancer as a means to establish the context in which any intervention would operate and the likely responsiveness of intended participants; factors identified as important considerations in implementation (Hasson, 2010). Later in the chapter, the findings are used to consider how these experiences might influence exercise intervention design in this population.

4.2 Aim

The aim of Element 2 was to identify how living with advanced cancer might influence exercise behaviour, and therefore what should be taken into account when designing an intervention to enable it to fit successfully into the day-to-day context of people with advanced cancer.

The objective was to establish what factors in daily living potentially inhibit or promote the likelihood of adopting and adhering to a hospital to home-based exercise intervention in this population, then use this information to inform emergent principles for potential new exercise interventions.

4.3 Method

4.3.1 Information sources and search strategy

This review concerns the daily life of people with advanced cancer, how it affects them, but also what they do, how they feel, and what is important to them. It was intended to develop a better understanding of the context of living with advanced cancer from the perspective of participants. Qualitative methods are best suited to answer questions regarding experience, meaning and perspective (Hammarberg, Kirkman and de Lacey, 2016), and so a strategy was developed in consultation with a University of Southampton Research Engagement Librarian to identify qualitative data that would best meet the aims of the review. Following discussion between DA and the research engagement librarian the databases: MEDLINE, SCOPUS, PsycINFO, were identified as those most likely to contain relevant qualitative research.

An initial MEDLINE search strategy was developed using the SPIDER search tool; Sample, Phenomenon of Interest, Design, Evaluation, Research Type (Table 5). The SPIDER tool was designed by Cooke, Smith and Booth, (2012) and is appropriate for use in qualitative and mixed method literature as it facilitates the development a search strategy that returns fewer irrelevant results than comparative searches using the PICO tool (Methley et al. 2014). The final MEDLINE search strategy can be seen in Appendix F.

Search terms were identified from several sources: terms used previously to identify advanced cancer in the pre-stage systematic review; published studies which investigated daily living with chronic conditions (May et al. 2016) and with advanced cancer (García-Rueda et al. 2016); general considerations which may influence behaviour (Michie and West, 2013); and a publically available search filter to identify qualitative studies (DeJean et al. 2016). The MEDLINE search strategy was tested by cross referencing results with key papers already identified, and once considered suitable, modified as necessary for the other databases. All final database searches were conducted in one week in September 2017. Additional search strategies included reference list searches of eligible studies and of relevant reviews identified through the search process. Searches were limited to only involve studies published in the previous 10 years so locating findings in contemporary practice. No geographical restrictions were set.

Table 5: Element 2 SPIDER search tool

Sample	People with advanced cancer* receiving treatment. Not those whose death was deemed imminent**
Phenomenon of Interest	Experience of day-to-day life
Design	Qualitative study designs e.g. questionnaires, surveys, interviews
Evaluation	Terms relevant to COM-B framework structure
Research type	Qualitative / Mixed Methods
*Advanced cancer: for the purposes of this review advanced cancer is defined as progressive incurable, locally recurrent, or metastatic malignancy	
**Imminent death: expected within hours or days, as defined by Leadership Alliance for the Care of Dying People, (2014)	

4.3.2 Eligibility criteria and study selection

Studies identified through the search process were entered into the bibliographic software Endnote, and duplicates removed. A high number of studies were returned, therefore an initial screening of titles to remove clearly irrelevant studies was performed before abstract screening using inclusion / exclusion criteria (Table 6). Full texts were obtained for studies deemed eligible or that could not be confidently excluded at any earlier stage. Multiple publications for the same studies were grouped together. The full papers, and where possible interview guides, were read to confirm eligibility.

Table 6: Element 2 Inclusion criteria and justification

Inclusion criteria	**Justification / Rationale**
People over 18 years of age with advanced cancer* or a population of people with mixed stages of cancer but findings of advanced cancer sub-group clearly separated	The intended population for which this thesis was focused, without introducing potential bias from studies that included perspectives of children or those diagnosed with earlier stage cancer that was therefore curable
Published primary qualitative research	To ensure high quality reliable sources
Focus on a specific issue rather than day to day experience and challenges	To allow the issues that are important to people with cancer to emerge rather than introducing bias through selection studies which investigated specific issues
Evidence of sample in receipt of chemotherapy, radiotherapy or both	Background reading and conversation with clinicians and researchers suggested this to be a key consideration requiring further investigation
No evidence to suggest participants were dying Imminently**, unless there was subgroup analysis of those with longer prognosis	Those dying imminently are less likely to be enrolled onto exercise interventions and so their perspective is of less relevance to the aims of this thesis
No evidence to indicate participants have previously taken part in a research intervention intended to impact on daily life	To ensure participant are reflective of general population and have not been biased by participation in non-standard interventions
Written in English language	Time and resource constraints of the study would not allow for accurate translation from other languages
*Advanced Cancer, For the purposes of this review, advanced cancer is defined as progressive incurable, locally recurrent, or metastatic malignancy	
** Dying Imminently- in the next hours or days, as defined by Leadership Alliance for the Care of Dying People, (2014)	

4.3.3 Data extraction and analysis

Analysis was guided by the framework approach (Ritchie and Spencer, 1994). Framework approach is a method of data management and analysis used to answer focused aims and objectives demonstrating transparency and rigor whilst allowing for in-depth data exploration (Smith and Firth, 2011). Several interpretations of the process are available which provide step by step explanations of the technique to direct researcher as to how it can best be carried out (Ritchie and Spencer, 1994; Barnett-Page and Thomas, 2008; Smith and Firth, 2011; Gale et al. 2013; Spencer et al. 2014). The step by step nature in which it can be carried out is thought to enhance its suitability for qualitative researchers of all levels of experience (Smith and Firth, 2011). All interpretations of framework were read as well as empirical research which had used similar approaches (Gallacher et al. 2013; Cummings et al. 2017) to generate an understanding of the techniques. The analysis performed in this review followed the five step process advised by

Ritchie and Spencer, (1994): 1) Familiarisation; 2) Identifying a thematic framework; 3) Indexing; 4) Charting; 5) Mapping and interpretation.

Familiarisation should involve immersion in the data to gain an overview and become familiar with the range and diversity of what has been gathered (Ritchie and Spencer, 1994). In this review papers were first read in full as part of the selection process, then read again. Data to be analysed included results and findings, themes and categories, patient primary data extracts, and interpretation of patient responses'. Data extracts and interpretation of data from study participants who were not patients were excluded. The was extracted using a template modified from that used by Kavanagh et al. (2012). Data were managed using NVivo data management system.

Identifying a thematic framework involves the researcher using what was learnt during the familiarisation stage, and a priori issues, to identify a suitable framework to allow the data to be sifted and sorted (Ritchie and Spencer, 1994). Barnett-Page and Thomas, (2008) consider the framework approach to be distinct from other forms of qualitative research synthesis as it specifies use of an a priori framework constructed from literature, experience and discussion. The main structure of the initial framework for this review was based around the COM-B model (Michie, van Stralen and West, 2011) described in the previous chapter. Additional division pertaining to the component of motivation was achieved using PRIME theory (West, 2006). PRIME, with the acronym standing for Plans, Responses, Impulses/inhibition, Motives and Evaluations, is a comprehensive theory of motivation intended to represent the structure of human motivation at multiple levels. According to PRIME theory, people act in pursuit of what we most 'want' or 'need' at that moment, where by wants involve anticipated pleasure or satisfaction and needs involve anticipated relief from mental or physical discomfort.

Further elements were introduced into the framework from other sources of literature that described previously identified barriers and facilitators to exercise using cohorts of mixed stages of cancer. A brief scoping search was conducted, using the University of Southampton, Delphis, resource, to identify factors shown to influence exercise behaviour. Delphis is a single interface that allows searches of the University of Southampton library collection and other resources without having to search databases individually. A simple search for "Barriers and Facilitators" and "Exercise" and "Cancer" was performed and results arranged in order of relevance. Six papers were identified and deemed relevant: three empirical qualitative studies (Blaney et al. 2010; Henriksson et al. 2016; Mas, Quantin and Ninot, 2015); one empirical quantitative study (Blaney et al. 2013); one empirical mixed method research (Fernandez et al. 2015); and a mixed method systematic review (Clifford et al. 2018). Studies included exercise in both randomised control trials and recreational settings, as research indicates the same barriers to be pertinent across both settings (Courneya et al. 2005). An additional paper (Ormel et al. 2018), a systematic review investigating predictors of adherence to exercise interventions in mixed stages of cancer, was not retrieved in the search but known previously and deemed relevant for inclusion. It was likely not retrieved as it did not use the terms barriers and facilitators, but was known to contain useful information so was included. Using these different sources of information a framework was devised (Table 7). Barriers and facilitators relating to specific components of an exercise intervention, for example equipment used or number of exercises, were not incorporated as they were not the focus of this particular review, and were previously investigated in Element 1.

Indexing involves applying the devised framework to the data (Ritchie and Spencer, 1994). The extracted data were read line by line. Factors likely to influence exercise behaviour and adherence, related to the person, their care or their environment were identified, and then catalogued according to the appropriate component of the framework. The framework enabled known exercise barriers and facilitators to exercise in other populations to be confirmed or refuted, as well as identifying what motivated people with advanced cancer in their daily lives. Gale et al. (2013) explains that although framework often involves a largely deductive process, in many cases space is left ‘open’ for unexpected aspects to be identified. This was the case in this review which deliberately allowed prospect for any factors unique to this context, or unexpected to emerge.

Charting involves building up a picture of the data as a whole by considering the range of attitudes and experiences for each issue, lifting data from its original context and rearranging it into new thematic references (Ritchie and Spencer, 1994). To direct this process data catalogued using the framework presented in Table 7, were scrutinised further regarding issues such as cause, severity, variability over time, and impact on participants. Common matters were identified and combined. As part of this process evidence was arranged to, where possible, answer the following eight questions:

1. What were the most common/prevalent factors which may influence Capability/Opportunity/Motivation?
2. How variable was this factor between the participants?
3. What were the causes of this factor?
4. Did this factor change longitudinally with time?
5. How was this factor controlled or managed?
6. How did this factor impact the participants?

7. Did this interact with the other factors?
8. What are the implications for exercise behaviour?

Mapping and interpretation involves pulling together key characteristics of the data with the aim to provide outcomes such as: definitions of concepts; identification of the range and nature of phenomena, creation of typologies, associations, explanations and development of strategies (Ritchie and Spencer, 1994). Mapping and interpretation in this review involved compiling extensive detailed accounts to present answers to the questions asked in charting, then again these accounts were synthesised and re arranged where necessary to devise summaries to represent and explain how advanced cancer might influence components of capability opportunity and motivation in peoples daily lives and the implications of this for exercise behaviour. These summaries were presented, discussed and refined during supervision meetings.

Table 7: Element 2 data analysis framework matrix based upon the COM-B model (Michie, van Stralen and West, 2011)

Capability		Motivation	Opportunity
Physical	Psychological		
Fatigue/low energy/tiredness	Emotional distress	Motivational support	Support from family
Pain / myalgia / arthralgia	Depression	Obligation to health providers	Support from friends
Compromised immunity and infection	Anxiety / anticipation of physical disorder	Other positive health related behaviour	Support from health professionals
Joint stiffness / limited joint movement	Period of withdraw after diagnosis	Other stated wants and needs	Inhibiting care
Numbness and tingling	Managing emotions	Strategies to maintain motivation	Social isolation
other health problems / co morbidities / aging	Ability to project self into future.	Awareness of benefits of exercise	Social support
Deconditioning, muscle weakness	Ability to invest self in projects	Stated intention to exercise	Time / lack of time / more free time
Other physical challenges / symptoms / limitations	Expectation of being unable to establish a routine	Specific to current or previous exercise	Environmental factors
Other negative effects of treatment	Improved mental well-being		Financial impact upon opportunities

Capability		Motivation	Opportunity
Physical	Psychological		
Changes in appearance	Fear of moving		Lack of information
Skin sensitivity	Fear of falling		Practical issues
Bowel / bladder issues	Self-image		Teachable moments
Nausea/vomiting	Kinesiophobia		Location of the healthcare centre
Lymphedema	Other potential influences upon psychological capacity		Other emergent sources of support
Extent of surgery	Strategies to improve psychological capability		Strategies to maximise opportunities
Improved physical health	Specific to current or previous exercise		Specific to current or previous exercise
Other potential influences upon physical capacity			Supervision
Strategies to improve physical capability			
Specific to current or previous exercise			

4.4 Results

4.4.1 Description of studies

The screening process resulted in 32 papers being identified for inclusion in the review, this process is depicted in the PRISMA diagram presented in Figure 5, representing the views of 469 people living with advanced cancer. Demographic data and study characteristic are summarised in Table 8.

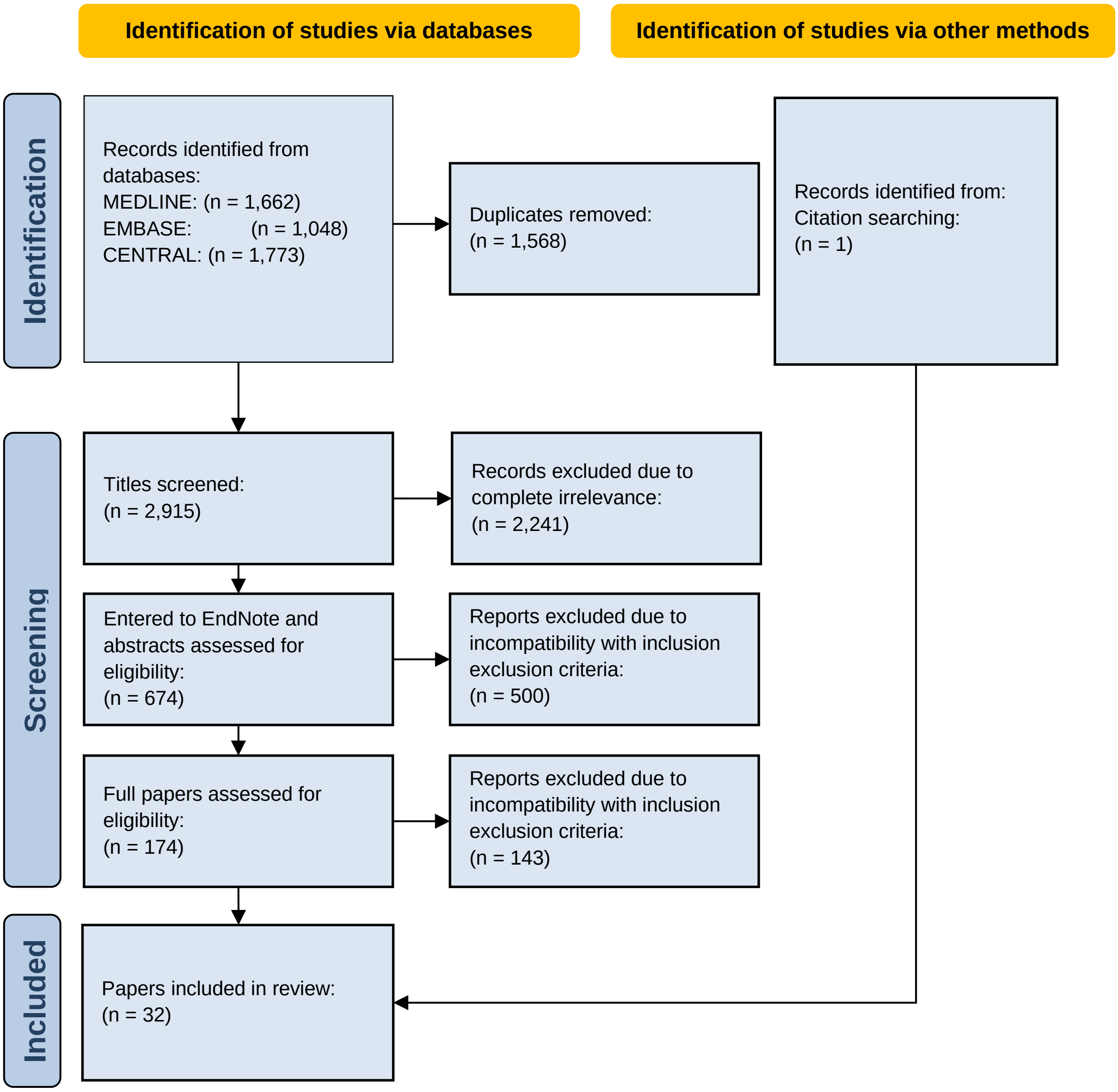


Figure 5: PRISMA diagram showing identification and selection of papers for Element 2

Study methodology was not always disclosed, however phenomenology (n=8) and grounded theory (n=7) were the most commonly reported methods. All studies, except one, involved interviewing as the primary method of data collection. Eight studies supplemented interview data with other methods such as: diary writing, observation, medical and nursing documentation, quantitative physical functioning assessment, and object elicitation. Findings were generally presented as themes, categories, or key constituents. Some studies however, presented findings as meta narratives, meta stories, multiple case studies, and one described as an interwoven exemplary paradigm case. Eleven papers stated they had recruited a purposive sample, three a convenience sample. Twenty-five papers confined data collection to people with advanced cancer, the remainder collected from other sources including, partners or relatives, professional or informal caregivers.

Table 8: Element 2 characteristics of included studies

Author, Year, Country	**Type of cancer**	**Aim/Purpose**	**Method of data collection**	**Sex**	**n**	**age**
Single condition studies						
Banning and Tanzeem, (2013)	Breast	Explore illness trajectory, psychological impact and how women coped with diagnosis of advanced breast cancer	Semi-structured interviews.	F	21	33-83
Krigel et al. (2014) USA	Breast	Further explore lived experiences of women with metastatic breast cancer (MBC), to inform development of interventions to enhance survivorship care	Semi-structured focus groups	F	15	32-75
Maree and Mulonda, (2015) Zambia	Breast	Explore experiences of Zambian women living with advanced breast cancer	In-depth interviews	F	10	29-66
Reed and Corner, (2015) UK	Breast	Explore illness trajectory of progressive breast cancer, and examine women's experiences	Narrative interviews, clinical documentation, assessment of functional ability	F	10	40-78
Sarenmalm et al. (2009) Sweden	Breast	Explore main concerns of women with recurrent breast cancer, and how they deal with their situations	In-depth interviews	F	20	55-81
Willig, (2015) UK	Breast	Demonstrate how application of qualitative methodology generated novel insights into the experience of living with advanced cancer	Interviews using object elicitation	F	3	Mid 30s – late 50s

Author, Year, Country	Type of cancer	Aim/Purpose	Method of data collection	Sex	n	age
Adorno and Brownell, (2014) USA	Lung	Examine perception of QOL from older veterans living with late-stage lung cancer	Semi-structured interviews	M	12	55-87
McCarthy and Dowling, (2009) Ireland	Lung	Explore patients' experience of living with non-small cell lung cancer	Unstructured interviews	M&F	6	52-74
Sparla et al. (2016) Germany	Lung	Explore and compare individual difficulties and resources for lung cancer patients and their relatives within the palliative care context	Semi-structured	M&F	9	55-79
Sparla et al. (2017) Germany	Lung	Explore and compare reflections that arise out of context of diagnosis and compare how patients and their relatives try to handle advanced lung cancer	Qualitative interviews	M&F	9	55-79
Carduff, Kendall and Murray, (2018) Scotland	Colorectal	Report longitudinal experiences, perceptions and service use of patients with metastatic colorectal cancer	Serial in-depth interviews	M&F	16	48-80
Sjövall et al. (2011) Sweden	Colorectal	Investigate how life situation by persons with advanced colorectal cancer and their partners is affected by living with disease and its treatment	Semi-structured interviews	M&F	12	40-78

Author, Year, Country	**Type of cancer**	**Aim/Purpose**	**Method of data collection**	**Sex**	**n**	**age**
Ekwall, Ternestedt and Sorbe, (2007) Sweden	Ovarian	Deepen understanding of how women having a recurrence of ovarian cancer experience living with this knowledge, and what it means in their daily lives	Open ended interviews	F	12	50-74
Ekwall et al. (2014) Sweden	Ovarian	Illuminate phenomenon of living with recurring ovarian cancer as lived and experienced by women in that condition	Open ended interviews	F	4	46-69
Arber and Spencer, (2013) England	Mesothelioma	Explore patient's experience during first 3 months following a diagnosis of mesothelioma	Semi-structured interviews	M&F	10	61-82
Hansen et al. (2015) USA	Hepatocellular carcinoma	Explore illness experiences of patients with terminal hepatocellular carcinoma as they approached the end of life	Semi-structured interviews	M&F	14	54-68
Missel and Birkelund, (2011) Sweden	Oesophageal	Contribute to literature with knowledge about circumstances and phenomena of particular significance for these patients	Narrative interviews	M&F	5	43-76
Richardson et al. (2015) UK	Cancer of unknown primary	Explore experiences of patients, informal and professional carers to improve understanding of the needs of those affected by cancer of unknown primary	Interviews matched with medical record data	M&F	17	41-78
Mixed Condition studies						

Author, Year, Country	**Type of cancer**	**Aim/Purpose**	**Method of data collection**	**Sex**	**n**	**age**
Dehghan et al. (2012) Bangladesh	Breast, bone	Describe needs, experiences and care of patients and families in receipt of palliative care in Bangladesh, and those of their providing clinicians, in order to identify gaps, strengths and weaknesses, and inform service development	Semi-structured interviews	M&F	3	20-52
Devik et al. (2013) Norway	Stomach, intestinal, uterine/brain	Explore and understand the lived experience of older people living alone and suffering from incurable cancer in rural Norway	Narrative interviews	M&F	5	70-79
Haug et al. (2014) Norway	Colon Prostate Female breast Lung Lymph/blood Urinary tract, Skin	Describe how people experience daily living while receiving palliative care in specialized healthcare contexts	Semi-structured interviews	M&F	21	70-88
la Cour, Nordell and Josephsson, (2009) Denmark	Lung, colon, breast	Describe and explore everyday activities of people with advanced cancer in relation to time, location, social engagement, and experience	Diary writing and qualitative interviews	M&F	45	39-80
la Cour, Johannessen and Josephsson, (2009) Denmark	Lung, colon, breast	Explore and understand how people with advanced cancer create meaning and handle everyday life through activity	Qualitative interviews and observations	M&F	7	39-67
la Cour and Hansen, (2012) Denmark	Lung, colon, breast	Illuminate how persons with advanced cancer reflect upon and use engagement in ordinary daily activities	Diaries, interviews, and participant observation	M&F	7	39-67

Author, Year, Country	**Type of cancer**	**Aim/Purpose**	**Method of data collection**	**Sex**	**n**	**age**
Lin, (2008) USA	Lung, nasopharyngeal, ovarian, leukaemia, colon, breast, and brain	Explore experiences of searching for meaning in life among US resident Chinese immigrants with metastatic cancer	Life story and in-depth interviews	M&F	12	37-70
Lobb et al. (2015) Australia	Bowel, breast. lung prostate, other	Explored how patients diagnosed with advanced cancer cope with an uncertain disease trajectory	Semi-structured interviews	M&F	27	21-88
Nilmanat et al. (2010)	Cervical, urogenital, lung, head and neck, breast, colon	To describe suffering patients with terminal advanced cancer experience in their everyday life	Interviews and observation	M&F	15	30-72
Nilmanat et al. (2015).	Cervical, urogenital, lung, head and neck, breast, colon	Explore how Thai persons with advanced cancer move beyond suffering at the end of their life	Interviews and observation	M&F	15	30-72
Nissim et al. (2012) Canada	Lung and GI	Provide an understanding of a prolonged experience of advanced cancer	Open ended interviews	M&F	27	45-82
Peoples et al. (2017) Denmark	Lung, Colon/rectum, prostate, cervix, breast	Describe and explore how people with advanced cancer manage occupations in their everyday lives	Qualitative interviews	M&F	77	59-89
Schapmire Head and Faul, (2012) USA	Breast, colon, brain, vulvar, cervical, liver, peripheral nerve sheath	Describe lived experiences of persons diagnosed with advanced cancer who receive Medicaid	Open ended interviews	M&F	10	23-59
Shilling et al. (2017) UK	Ovarian, melanoma, lung	Explore impact of extended cancer survival on broader aspects of life and wellbeing	In-depth interviews	M&F	24	39-84

4.4.2 Findings

This section will summarise findings generated through the process of analysis. With reference to the COM-B model the themes arising from the data will be described and discussed in terms of their hypothesised influence on exercise behaviour. A pictorial representation of this can be seen in Figure 6. Michie and West, (2013) explain that motivation lies at the heart of the COM-B model as it is central to the generation of health-related behaviour. Michie and West, (2013) argue given all the variety of things a person is capable of doing and has the opportunity to do, that it is motivation which determines what that person actually does. However, the findings of this review indicate that for people with advanced cancer motivation was more commonly the starting point for their behaviour rather than the deciding factor. This review found intended behaviour was directed by motivation, then regulated by the components of capability and opportunity. In acknowledgement of this, and because motivation would be the first possible deciding factor when patients are approached about an exercise programme, findings will be presented sequentially starting with motivation.

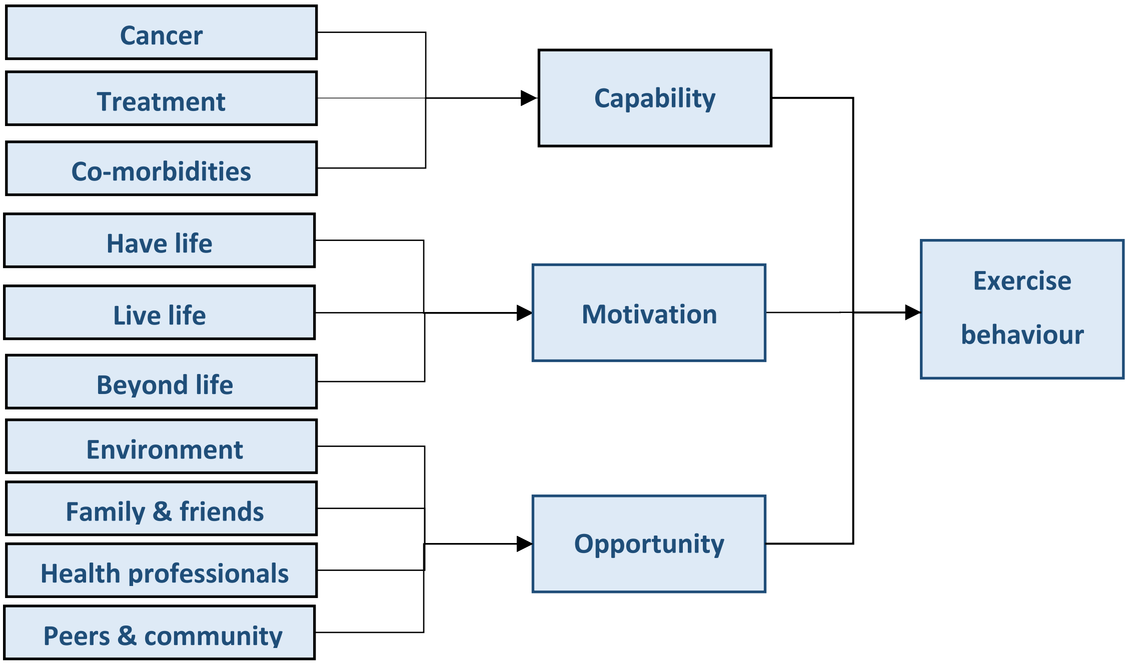


Figure 6: How living with advanced cancer might influence components of the COM-B model and influence exercise behaviour

4.4.2.1 Motivation

Motivation is defined in the COM-B model as brain processes that energise and direct behaviour, including conscious decisions, habitual processes and emotional responses (Michie, van Stralen and West, 2011).

4.4.2.1.1 Motivation in daily life

During analysis, three motivational themes were identified which summarise the motives present in participants in daily lives, 'Have life', 'Live life', and 'Beyond life'. Subthemes operated within each theme and further characterised that motive. These themes are first summarised below before later discussion of instances of when those motives were found to relate directly to exercise. Appendix G, shows each theme and the associated subthemes that characterised them in daily life, providing a quote from the literature for each subtheme and giving evidence as to which studies contained the data that led to their identification.

'Have life' concerned the importance of being alive. Subthemes operated which characterised This involved the desire for cure and/or prolongation of life, and attempts to fight the illness. It was often felt because of thoughts of their family. It was typically actioned by engagement with professional health care and involved decisions around treatments, and to a lesser extent by alternative therapies and engaging in a healthy lifestyle. It was often the predominant focus initially after being diagnosed with advanced cancer. However, the 'Have life' motive could diminish, when repeated treatment cycles brought about a deterioration in physical condition, increased suffering and reduced quality of life. Following a reduction in perceived quality of life this was often accompanied by a reduction in desire to remain alive.

'Live Life' involved living the remainder of their life how they wished it to be, doing what was important to them, what they liked, what gave them pleasure, making the most of the time remaining. It commonly involved keeping the cancer and the negative consequences of both the disease and the treatments out of their lives as best as possible, often involving use of and decisions around treatment. This led to participants striving to lead their lives as they had before to maintain or reclaim normality. Participants wanted to be active and healthy, maintaining regular routines, maintaining their independence, and carrying out their daily activities. Combined with the desire to live their life as they had before was an increased desire to pursue exceptional events. Thoughts of family featured strongly in this theme, participant wanted to spent time with family but also wanted to avoid becoming a burden to others. Having both control and a purpose in their lives was also important. Participants changed priorities in their lives due to the cancer but also had to change their expectations as well. Participants also expressed preferences as to how they wished to die which to some extent mirrored their preferences for how to live, without pain, without burdening others and with as much control as possible. If participants were unable to ‘Live life’ as they wished the desire to ‘Have life’ reduced also.

Finally, ‘Beyond life’ involved consideration of, and concerns about, how they might be remembered after they had died, what their legacy would be, and concerns for family and loved ones after death. It involved making gifts and memories for people who were important to them, steps to benefit people with similar diseases in the future, and measures to ensure family members physical, psychological, and financial wellbeing after death.

Michie, van Stralen and West, (2011), explain that in the COM-B system there is potential for each component to influence another and gave examples demonstrating how opportunity and capability could influence motivation as well as behaviour, and that behaviour could influence the other three components. Interaction between the different components of capability, opportunity, motivation and behaviour were apparent in the findings of the included papers. Findings also showed the three themes within motivation could, and did, interact with each other. When participants carried out actions to help meet one motive this could increase or decrease the likelihood of successfully meeting other motives. For example, treatment received in an attempt to ‘Have life’ caused a number of negative physical and psychological consequences. In turn these consequences greatly impeded capability to do many of the things participants wished to do and so made it harder to ‘Live life’. Conversely, actions taken to ‘Live life’ such as trips to the beach and other periods of pleasant time with family, helped to accomplish the motive of ‘Live life’, but also created strong memories which would persist for those they cared about after they had died so helping to realise the ‘Beyond life’ motive.

4.4.2.1.2 Reported motivation to exercise.

There were only a few studies in which participants spoke of exercise or physical activity habits. Exercise and physical activity mentioned included, physically demanding jobs (Devik et al. 2013; Peoples et al. 2017), housework / gardening (Haug et al. 2014; Peoples et al. 2017), non-specific hobbies (Haug et al. 2014), walking (la Cour, Johannessen and Josephsson, 2009; Peoples et al.

2017), cycling (Peoples et al. 2017), tennis (Peoples et al. 2017), running (Sjövall et al. 2011), swimming, (Sparla et al. 2016), attending sports clubs (Sparla et al. 2016), and playing with family members (Nissim et al. 2012). Although the motives behind performing exercise and physical activity were not always discussed there was some suggestion exercise was being performed for reasons that aligned with the themes 'Have life', 'Live life', and 'Beyond life'.

Levels of physical activity were reported to generally decline as people's cancers progressed. However, some participants deliberately increased exercise and physical activity as part of their response to the illness. Studies by Ekwall, Ternestedt and Sorbe, (2007), Sjövall et al. (2011), Ekwall et al. (2014), revealed interviewees used exercise and physical activity, in combination with healthy diets and deliberately positive attitudes, as part of a holistic approach to their health. The holistic approach to their health was intended to aid recovery between chemotherapy treatments, improve chances of good treatment outcomes and protect from further disease recurrence. All reasons which closely align with the 'Have life' motivational theme.

> They strived to live in accordance with their beliefs of how to keep the body strong and resistant. Living "right" by, for example, eating healthy food and exercising increased the chances of good treatment outcomes and protected them from further recurrence.
>
> **(Ekwall et al. 2014)**

The most common reasons for which participants reported performing exercise all align closely with the 'Live life' theme. Many participants expressed that for them performing exercise was to keep their condition out of their lives, either because it was used to achieve distraction from the cancer (Sarenmalm et al. 2009; McCarthy and Dowling, 2009), or more commonly they had exercised previously and now wished to continue to perform the same exercise as they had pre-diagnosis. The types of exercise and physical activity performed after a diagnosis of advanced cancer largely mirrored the same activities performed before diagnosis (Ekwall, Ternestedt and Sorbe, 2007; Haug et al. 2014; la Cour, Nordell and Josephsson, 2009; la Cour, Johannessen and Josephsson, 2009; la Cour and Hansen, 2012; Lobb et al. 2015; McCarthy and Dowling, 2009; Missel and Birkelund, 2011; Sarenmalm et al. 2009; Sjövall et al. 2011; Sparla et al. 2016). To continue with the things they used to do before, maintaining what was normal, was a recurring theme across several aspects of participants' lives, including exercise:

> The main thing [about being] sick is to live as I used to, to be physically active, and to be with family and friends.

> **(Haug et al. 2014) (woman, 71)**

Of those who were exercising for reasons related to the ‘Live life’ theme, few participants who took part in physical activity expressed reasons relating to physiological benefits. Some participants used walking, swimming, cycling, and spinning classes to gain general health benefits as a way to “get back into shape” (Sarenmalm et al. 2009 p1122). Another study found participants actively sought complementary methods including physical activity to palliate disease symptoms (Sjövall et al. 2011). Conversely, some participants avoided exercise as they felt it may make their quality of life worse due to risk of injury (la Cour, Nordell and Josephsson, 2009) or may worsen symptoms (la Cour and Hansen, 2012). Participants performed physical activity and exercise because of the perceived emotional benefits they gained from doing it (la Cour, Johannessen and Josephsson, 2009; Lobb et al. 2015; Missel and Birkelund, 2011). Some performed physical activity if it was anticipated it would bring emotional benefit, even though it was also anticipated it might bring further physical discomfort (la Cour, Johannessen and Josephsson, 2009). There was evidence some participants were performing physical activity and exercise for its own enjoyment, and those that did this took deliberate steps to make the activity more pleasurable:

> “she enjoyed walking….sometimes complemented by a drink in a cafe. This can be understood as the enjoyment of basic sensory experiences….along with other kinds of sensory experiences such as taste and smell”
>
> **(La cour and Hansen 2012)**

Participants also reported partaking in physical activity and exercise due to the therapeutic effect garnered from social interaction as a result of exercise and physical activity routines (McCarthy and Dowling, 2009; la Cour, Johannessen and Josephsson; 2009, Sparla et al. 2016).

Rarely was exercise or physical activity reported for reasons relating to the ‘Beyond life’ motive. However, on the occasions it was, for example a mother playing sports with her son to create happy memories for the future, proved to be a strong enough motive to overcome considerable physical difficulties:

> Will he remember that I played baseball with him or that I was lying in bed? So even when I don’t feel like it and even when I’m too tired I’ll play baseball with him cause that’s what

> he'll remember…. I don't want him at 20 to say, ''Oh, yeah. My mom died when I was four. I don't remember her.'' ….it's not what I want for him. Not at all.
>
> **(Nissim et al. 2012)**

4.4.2.2 Capability.

4.4.2.2.1 Introduction

Capability was explained by Michie, van Stralen and West, (2011) to pertain to an individual's psychological and physical capacity. Capability can involve physical skills/physical strength or psychological resources, psychological skills, knowledge, and capacity for understanding. Based on the number of studies in which they were reported, the five most common physical factors which may impede capability to exercise, were: Pain; Fatigue; General deterioration; Changes to appearance; Nausea and/or vomiting. The five most common psychological factors identified were: Uncertainty; Depression; Lowered view of self; Anxiety; Fear. Complete lists of all physical and psychological factors reported that are likely to influence exercise capability, and the studies the factor was reported in, can be seen in Appendix H and I respectively. Some participants reported difficulty in verbalising the physical and psychological issues they experienced, reporting it was impossible for verbal descriptions to accurately represent what they experienced. Descriptions of the factors experienced varied greatly, some participants gave detailed descriptions of the physical and psychological factors experienced, others simply gave a label with little additional description. All physical factors identified were either negative, or at best neutral, in their nature. For example, pain or absence of pain, fatigue or absence of fatigue. However, psychological factors identified although predominantly negative could also occasionally be positive. For example, the negative psychological factor of depression was often identified by participants, but in contrast, other participants reported a euphoric appreciation of life (Willig, 2015). Other examples of positive psychological factors included optimism (Schapmire, Head and Faul, 2012), gratitude for extra time lived (Ekwall et al. 2014; Sarenmalm et al. 2009; Sjövall et al. 2011), and an enhanced appreciation of life in the present (Nissim et al. 2012; Sarenmalm et al. 2009). Hope was the most common positive factor, identified in 12 studies.

4.4.2.2.2 Cause

Identifying the exact cause of factors which influenced capability was problematic. Often the exact cause of factors was not reported, additionally participants would sometimes report to not know, or to be confused, as to what the cause was. However, based on what was reported, physical factors were found to have been caused by four main issues: the cancer and its progressive nature; from treatments received; from co-morbid conditions and aging; and finally developed secondary to other physical or psychological negative factors, for example increased pain could cause or worsen nausea, increased anxiety could worsen feelings of pain.

Psychological factors were found to be caused and influenced by a broad range of issues, including: the cancer's influence on participants' bodies; concerns participants felt about future deterioration; association with death; losses cancer caused in other areas of their life; side effects from treatments; disease response to treatment; decisions regarding future treatments; interactions with others such as healthcare friends and family; previous life experiences.

4.4.2.2.3 Contrasting trajectory

Longitudinal trajectories of physical and psychological factors differed greatly. Physical factors, whilst being highly changeable day to day or even hour to hour, tended to begin relatively mildly at the time of diagnosis. In many cases gentle or nagging tell tail signs such as mild ache were first signs that indicated a possible disease recurrence. However, over time, disease progression combined with repeated treatment cycles led to increases in the severity and number of negative factors experienced concurrently. In contrast to this, psychological factors appeared most pronounced shortly after diagnosis when participants were first confronted with a threat to their existence. Then over time, for many, the psychological factors identified would lessen as an acceptance developed. However, potential for development of new psychological factors and acute fluctuation of the severity of psychological factors experienced was still possible during this period of gradual acceptance. Reasons for fluctuation included events such as suspected or confirmed worsening of condition, clinical appointments and diagnostic results, exacerbations of physical issues, loss of things important to them such as independence and social interaction.

4.4.2.2.4 Participants' methods to lessen or accommodate negative factors

Participants reported a number of techniques to lessen the severity of the impact of the physical and psychological factors upon them. The techniques fell into two different strategies: attempts to reduce the negative factors which impacted capability and attempts to accommodate the negative factors into their lives. Attempts to reduce the negative factors included actions such as receiving standard and nonstandard therapies, attempts to hide or conceal changes in their bodies, actively pursuing knowledge of their condition, deliberate attempts to maintain positivity, and resting.

Often attempts to reduce the negative factors would not be successful or created further negative consequences of their own. Therefore, participants adapted and employed strategies to compensate for and accommodate the negative factors they experienced. This adaption allowed the participant to still do what they wanted in their daily life, despite the limitations upon their capability. The most common adaptions involved getting support from others or making the most of good days when they were free from negative influences. Other methods to adapt or accommodate the negative factors involved, attempts to create a spilt between what their body and mind experienced, distraction or ignoring the negative factors, avoidance of others, being selective with how they used their limited physical capability, adoption of short-term goals, and an adjustment of what was important given their new situation.

Physical factors were typically alleviated to some extent through healthcare treatments and medicines. Psychological factors were largely alleviated through adaptation which allowed them to still achieve what they wanted to. If participants were able to still do the things important to them, less negative emotion was experienced.

4.4.2.2.5 Impact

Although some of the identified factors were far more common than others the severity of these varied. Across the studies, 13 different physical factors were identified by participants as being the most debilitating to their daily life.

Physical and psychological factors impacted upon participants in similar ways. They caused distress directly. They also increased the sensitivity with which participants monitored their own bodies, becoming barometers to measure perceived disease progression irrespective of whether or not they were related to the cancer. The factors also interacted with one another, worsening or causing additional negative consequences. For example, new pain could heighten anxiety which in turn could reduce sleep and lead to higher levels of depression and fatigue. These factors prevented participants from being able to plan longer term or even short term events, and reduced environmental and social interaction. Whilst the physical and psychological factors experienced by participants may be experienced differently, the ultimate impact of those factors upon participants was that they often made them less able to achieve whatever it was they wanted to accomplish.

4.4.2.3 Opportunity

4.4.2.3.1 Identified examples showing opportunity to exercise

According to the COM-B model, opportunity involves factors outside an individual which may make a behaviour possible. Little was found reporting directly about factors influencing opportunity to exercise. Examples included: a participant who deliberately found a place to walk where she felt help would be readily available if she were to become unwell (la Cour and Hansen, 2012); a participant provided with access to a neighbour’s field to go for daily walks (la Cour, Johannessen and Josephsson, 2009); and a participant with bone metastases who would only exercise under professional supervision (la Cour, Nordell and Josephsson, 2009).

4.4.2.3.2 External factors likely to inhibit exercise

The studies which informed the analysis framework identified several factors which impeded a person’s opportunity to exercise in a way congruent with the COM-B component of opportunity. Many of these factors were found to be present in the studies included in the review, and, although there was no evidence to indicate their influence upon exercise behaviour, they were reported to have inhibited participants’ enactment of other behaviours. Factors identified in this review included: constraints of time largely due to healthcare commitments, such as hospital appointments (Devik et al. 2013; la Cour, Nordell and Josephsson, 2009; McCarthy and Dowling, 2009; Nissim et al. 2012; Richardson et al. 2015; Sparla et al. 2016); financial constraints (Arber and Spencer 2013; Dehghan et al. 2012; Sjöval et al. 2011; Sparla et al. 2016); and distance to local resources (la Cour and Hansen, 2012).

4.4.2.3.3 External factors likely to facilitate exercise behaviour

In this review the most frequently reported influence upon a persons’ opportunity to enact their desired behaviour or accomplish what they were trying to achieve was support from others. In the context of the exercise studies which informed the analysis framework, support was identified to facilitate exercise in four of the six papers (Blaney et al. 2010; Fernandez et al. 2015; Mas, Quantin and Ninot; 2015, Henriksson et al. 2016). In these studies types of support found to facilitate exercise included professional education, guidance, and supervision, shared experiences and subjective norms with peers, and encouragement and active participation of friends and family.

Valued support was always closely aligned with one of the three motives identified earlier, ‘Have life’, ‘Live life’, ‘Beyond life’. Support either aided the participant to achieve what was important to them or eliminated things that were making it harder to achieve what they wanted to do. The intensity and comprehensiveness of the support given to participants varied greatly, dependant on the participants’ own abilities and the complexity of what needed to be done. This could range from highly specialist healthcare interventions that relied almost entirely on an external source with little input needed from participants. For example, the authorisation, provision, and administration of cancer treatment. Other examples of support involved greater levels of shared activity involving more equal input from both participants and external sources, complementing a participant’s own strengths to enable them to achieve what was required. Examples of this included health care professionals who ensured participants were informed and involved in decisions regarding their treatment, and family who would arrange all the provisions the participant may need overnight within easy reach of them before going to bed for the night. A specific example of this was a neighbour who provided a participant with land to exercise on and accompanied the participant as they performed their daily walk. Finally, the least intensive form of support, but still highly valued, involved simply being with others they cared about, maintaining the usual roles people had with one and other, empowering participants, and sharing experiences together. This did not require any special input from those providing the support but participants reported experiencing reduced emotional distress, and derived great pleasure and enjoyment from merely being with those they cared about.

Support received was provided by three groups; health professional teams and services, family and friends, peers and community. Although each group performed their own characteristic forms of support, overlap would occur.

4.4.2.3.3.1 Health and care professionals, teams and services.

Support from health professionals was identified in all 32 studies. It involved standard healthcare such as general practitioners, hospitals, nurses, doctors, palliative care services and social services, as well as complementary and alternative therapies. This most often aligned with the ‘Have life’ motive in the form of diagnostic tests, treatments and information intended to prolong life. Health professional support also aligned with the ‘Live life’ motive in the form of treatments, medications, and advice, intended to alleviate negative physical factors which were causing suffering in the participants’ lives. Elimination of physical factors causing suffering in turn reduced psychological distress. Good interactions with professional healthcare services in which participants were treated with dignity and respect, and felt cared for, reduced depression and generated a more hopeful attitude. Participants also reported healthcare professionals would provide their social interaction in the later stages of the disease when interactions with friends became less frequent. Healthcare also provided participants with opportunity to be involved with new treatment trials. Being involved in clinical trials provided hope of prolonging life and also generated feeling of being able to help future patients and thus aligned with the ‘Beyond life’ motive.

4.4.2.3.3.2 Family and friends*.*

Support from family and friends was identified in all 32 studies. It involved mostly psychological benefits but was difficult to identify exactly what this involved. “Being there”, or being together, was often identified as important, but specific tasks or activities were not generally reported. Sharing time and experiences and participating in activities together with family and friends meant participants did not feel they had to face the situation alone. Family and friends brought happiness, joy and encouragement to participants. Family and friends being as they were before the diagnosis meant participants could maintain their usual role as much as possible. Maintaining their usual role was identified as an important part of maintaining normality and living their life how they wished. Having someone to talk to about their illness and other life situations was an important form of support given by family and friends. However, the extent to which participants wished to talk varied greatly and participants would often have different layers of relationship to which they would convey differing levels of detail. Sometimes giving all the information to those closest to them and sharing less detailed information with those less close. Conversely, some participants would not talk openly with those they were closest, to avoid placing psychological burden upon them, and instead would talk most openly with people who are less close. Another important source of support from family and friends was simply knowing they mattered to another valued person.

Family and friends also provided physical support in the form of assistance with shopping, lifts in cars, household tasks and care activities. However, this form of support was not viewed entirely positively. Practical help from family and friends generated a sense of comfort that these people cared about them, but also often generated negative emotions as it conflicted with the desire to live normally and generated feelings of burden. Feeling of being a burden to family and friends was reported by participants as the worst part of living with their disease.

4.4.2.3.3.3 Peers and community.

Peer and community support involved official organisations, unofficial groups and people with whom participants came into contact with but were outside close friends and family group. Common examples included: religion and religious organisations; work and work colleagues; others with cancer; neighbours. Support from these sources was highly varied and involved help with emotional and practical issues. And whilst often similar in nature to the practical support from family and friends, did not generate feelings of being burdensome.

Several sources, including neighbours, religious organisations, work colleagues, social clubs, and others with cancer, were all valued for providing social interaction. Strangers were identified as both a source of social interaction and also provided reassurance to participants that help would be available in the event of acute illness. Support from work, and work colleagues, was important to participants because it provided financial reward but also because it was an opportunity for structure, generated purpose, maintained identity and a sense of normality. Colleagues were also a valuable source of psychological support particularly if they acknowledged a participant’s situation, but also treated them as they had previously. Commonly neighbours provided support with practical tasks such as shopping, cleaning, transportation to appointments and providing care for pets. Other people with advanced cancer, either in formal support groups or met whilst attending clinical appointments, were found to provide an opportunity to talk to others with a greater understanding of their situation. They were reported to create a reassurance that they were not alone and helped participants to cope. Religion and religious groups provided a wide range of support to participants. Some participants felt religion helped relieve distressing physical symptoms and stopped the spread of the disease. More commonly, religion and religious organisations provided an opportunity for participants to interact with others, and collect their thoughts. Religion helped participants gain psychological and emotional comfort, with participants reporting feelings such as hope, strength, and finding meaning and acceptance of their illness. Religion was also reported to ease concerns about death.

4.4.2.3.3.4 Inhibitory support

In the framework constructed for the analysis in this review, support intended to be helpful, but which in fact hindered participants exercise behaviour, was referred to as “inhibiting care” based on a term used by (Henriksson et al. 2016). There was much evidence that all three of the identified categories of support provided could, at times, be inhibitory. Therefore this section will report examples of support given intended to help participants, but which could at times make it harder for participants to accomplish the things they wished to achieve.

Examples of support provided by health professional teams and services which had an inhibitory effect upon participants included: treatments and surgeries which caused additional negative consequences; clinical interactions which left participants feeling disrespected and took away their dignity; inability to provide participants with accurate information about their illness and likely treatment efficacy**;** support groups being organised at times that take participants away from their families.

Regarding support from family and friends, although highly valued, there was a sense that they did not and could not really understand what it was like for the participant and so would often give misguided support. For example, wanting to talk about the illness at a time that participants did not wish to, which caused an unwanted reminder of the disease and also caused increased feelings of fatigue. Family and friends would also suggest remedies that were unproven and unlikely to be effective against the disease. Giving physical support with daily care needs was reported to worsen the sense of burden the participants felt they were placing upon their family. Examples also existed of friends judging participants to be too ill to be involved in normal routines and activities and so stopped inviting them to social events.

Peer and community support was also found to be, at times, inhibitory. Examples of this included interactions with others with advanced cancer which increased negative emotions such as sadness, uncertainty and jealousy. People in the community who stigmatised participants, provided unqualified incorrect advice regarding the condition, and inconsiderately reminded participants of their condition and likely future death.

4.4.2.4 Summary of impact upon exercise behaviour

According to the COM-B model a person’s behaviour is a culmination of their motivations, their capabilities and their opportunities. The previous sections have shown what motivates people, what physical and psychological factors influence their capability and what influences opportunity (or what support was available) in the context of advanced cancer.

Evidence of exercise behaviour was limited in the studies retrieved. Where exercise behaviour was mentioned this included people trying to impact on their disease and recover between chemotherapy cycles, people trying to improve their general health, distraction from the disease, social interaction, two examples of regular walks largely for enjoyment and psychological benefit, and one example of playing sports with children. The most common reason for exercise was to try and keep the cancer out of their life, particularly when exercise had been a part of their pre cancer life to continue with things they had done before. Participants reported physical factors that made it harder to exercise such as pain, fatigue and general deterioration. Support to exercise came in the form of one participant being provided with a convenient area to walk by a neighbour, and another participant feeling reassured that strangers would assist her if she became ill and a participant being a member of a sports club. Attempts to eliminate the physical factors affecting a person's capabilities were only partially effective, or ineffective. Therefore, if participants wanted to do the things they wished they would have to adapt how they did those activities, to accommodate their diminished capability. Methods of adaptation included maximising "good days" when capability was highest, prioritisation how energy was used, careful use of help and support, ignoring negative factors and doing what they wanted regardless of negative factors experienced.

4.5 Conclusions

The findings of this review point to various considerations that exercise intervention designers and clinical teams, might usefully consider, to develop exercise programmes that are well suited to this population, and sympathetic to their particular needs and motivations. These considerations are set out below and arranged into potential early guiding principles.

4.5.1 Any intervention must align with what is important to the participant.

Time for participants is precious due to the progressive nature of their condition. Participants' behaviour was largely driven by one or more of the three motivational themes of 'Have life', 'Live life', or 'Beyond life'. Unless an intervention aligns closely with motives important to participants, they will be unlikely to commit time and energy to first start, and then continue to follow, an exercise programme.

4.5.2 Any intervention must make clear to participants how it can align with what is important to them.

Many of the known benefits of exercise can help participants achieve things important to them, and align with the motivational themes identified. However, interventions must make this alignment explicit to participants.

Previous research has shown exercise has the capacity to improve the number of people who are able to receive a full course of treatment (Cheville et al. 2015). Receiving treatment, intended to slow disease progression, was identified in this review as one of the central aspects of the 'Have life' theme. Exercise also has the potential to help participants achieve aspects related to the 'Live life' theme. Reducing negative physical and psychological disease symptoms and treatment side effects, was reported to be important for participants' day to day quality of life, and something that previous research has found to be a benefit of exercise (Bourke et al. 2011; Burke et al. 2013; Cheville et al. 2013; Jensen et al. 2014; Litterini et al. 2013; Quist et al. 2012; Quist et al. 2015; Rief et al. 2014a; Rief et al. 2014b; Temel et al. 2009). Exercise has also been found to reduce hospital admissions (Cheville et al. 2015), and improve physical function (Bourke et al. 2011; Cheville et al. 2013; Cormie et al. 2013; Oldervoll et al. 2011; Quist et al. 2012; Quist et al. 2015; Jensen et al. 2014; Litterini et al. 2013; Rief et al. 2014a; Temel et al. 2009), both benefits likely to enable participants to do more of the things they want to do. One of the common concerns reported by participants with regard to how they wanted to spend their lives was they did not want to become a burden to their loved ones. Again, this is something which can be ameliorated through exercise. Participants in exercise groups report significantly lower concerns regarding their loss of mobility and worries of becoming dependent on others compared to a control group (Rief et al. 2014a). If participants can be persuaded that exercise can help them to achieve what they want in the context of advanced cancer they may be more likely to start and continue with a prescribed exercise intervention.

4.5.3 Any intervention must be able to accommodate changes in capability.

The participants capability to do the things they wanted to do was inhibited by a variety of physical and psychological factors. Physical factors effecting capability generally accumulated and worsened longitudinally with time. Psychological factors were perhaps worst at the point of diagnosis and eased as time passed. Both had potential to vary in number and severity acutely over short periods of time. Complete relief of these factors was rare, and so participants had to adapt either what they did or how they did it to accommodate the factors being experienced. For participants to be able to continue with an exercise intervention over a period of time any intervention must be designed in a way that it can accommodate any changes in capability without individuals having to cease exercising.

4.5.4 Any intervention is likely to require an element of external support to aid participants in following an exercise programme.

Finally, the review found participants received much support from three different sources, health professional teams and services, family and friends, peers and community, to achieve the things important to them. Little was reported to have been achieved by the participant in isolation, without some level of aid or assistance from others. For support to be valued by participants it typically aligned with the three motivational themes of ‘Have life’, ‘Live life’ and ‘Beyond life’. However, support could have both intended and unintended consequences and if care was not taken it could prove to be negative. Any intervention protocol should have capacity to provide support, but accompanied by an awareness that any support provided might influence participants’ behaviours in multiple ways and can have unintended consequences.

The findings of this review have shown that little of what is important to participants is likely achieved without some form of support. At this stage the characteristics of this support and the best source(s) to help participants participate in an exercise intervention in the context of the advanced cancer remains unclear. This is investigated further in Element 3.

These emergent guiding principles, when combined with what is known about the components of exercise programmes as explored in Chapter 2 together suggest what may encourage sustained exercise behaviour on discharge from a hospital initiated programme. The following chapter will further investigate the concept of adherence to exercise in advanced cancer through the conduct of empirical research which explores adherence to supervise hospital-based and unsupervised home-based exercise programmes.

Chapter 5 Element 3: Empirical research methods

5.1 Introduction

This chapter outlines the methods used to carry out Element 3 data collection and analysis. Element 3 involved the conduct and synthesis of two mixed method multi-perspective empirical studies exploring exercise programmes for people with advanced cancer from the perspective of those who participated in, and those who designed or delivered, the programmes.

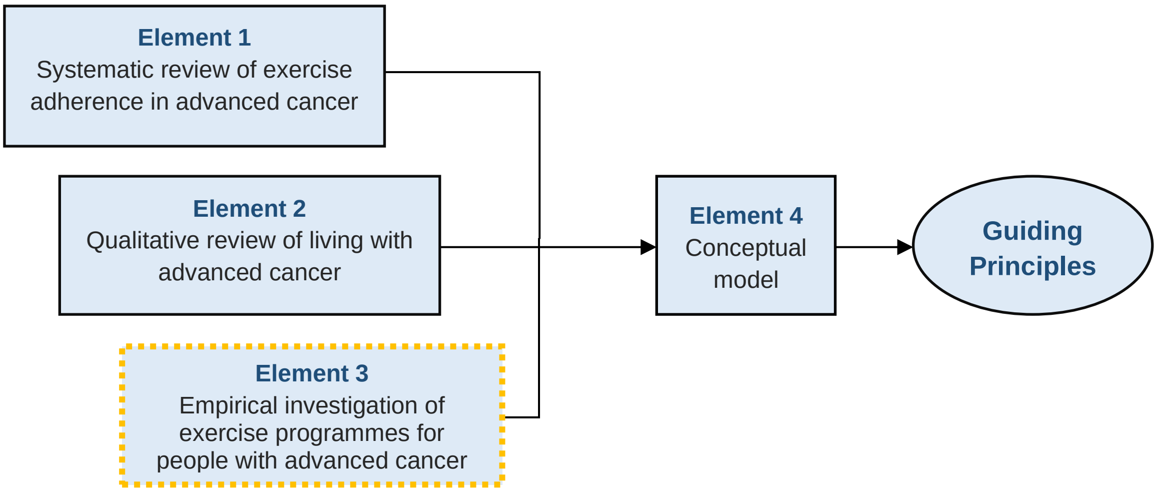


Figure 7: Element 3 schematic representation of the FIT-TOGETHER study

The originally planned study was a mixed method evaluation nested within a hospital to home exercise trial for people with advanced non-small cell lung cancer receiving chemotherapy. As has been mentioned previously the trial in which the evaluation was nested (the EMBRACE trial) achieved slower than anticipated recruitment and ended early due to NICE approval of a new treatment for advanced lung cancer, pembrolizumab. Therefore, a second study was developed to complement data already collected. The second study (MOVEMENT) comprised a mixed method exploration of factors relating to adherence with exercise classes offered by a local hospice day centre and the exercise behaviour of participants after classes had finished. This also provided the opportunity to contrast the experiences of those participating in a trial versus those offered the opportunity to undertake exercise as part of their care. It is accepted that qualitative investigation can provide a much more complete understanding of a problem if it involves multiple perspectives, Element 3 allowed for the collection of data regarding three different exercise interventions (the EMBRACE trial, Chairs class, Circuits class), from the perspective of the exercise participants, a family member or friend of one of the intervention groups, a non-exercise or control group, and HCPs involved in the design or delivery of the exercise.

This research sought to understand the perspective of the people with advanced cancer participating in the exercise programmes and the perspectives of those who had designed or delivered the programmes. This aligns with the aims of the PBA which stipulates the importance of understanding and accommodating the perspectives of the intended population to be involved in an intervention (Yardley et al. 2015a; 2015b). This is the final element that corresponded with the planning stage of PBA and incorporated the PBA specific activities of conducting primary qualitative research to elicit users' views of planned behaviour changes (including relevant previous experience, barriers and facilitators), and the complementary activity of consultation with key stakeholders (Yardley et al. 2015b). Yardley et al. (2015b) stresses the importance of incorporating a diverse range of perspectives from as many groups of people who may use an intervention as possible. Therefore, these additional perspectives included in this study, through those interviewed and those forming the advisory panel add additional sources of valuable knowledge. The common areas as well as any differences in the practical considerations for each study will be discussed together in the following sections.

5.2 Aim and objectives

The aim of Element 3 was to establish the experience of participants exposed to prescribed exercise programmes and determine factors influencing adherence as participants transitioned from a supervised programme in a specialist healthcare setting to a home-based programme without supervision.

The objectives were to investigate:

- Why participants chose to join the exercise programmes, what they feel they might gain and the value they placed on the programmes
- Acceptability of different aspects of content and delivery of the interventions
- What difficulties participants encountered when trying to adhere to the supervised exercise programmes, and what helped or encouraged participants to adhere
- Whether participants continued exercising once the series of sessions had been completed, in what ways they continued to exercise, and why

- What difficulties participants encountered when trying to exercise after the supervised exercise programmes had been completed, and what helped or encouraged participants to adhere

5.3 Description of exercise programmes

The EMBRACE evaluation was a mixed method investigation designed to explore and understand what influenced adherence to the supervised and unsupervised periods in the EMBRACE RCT. The EMBRACE RCT had been designed to primarily investigate the feasibility and tolerability of an exercise programme delivered to people with non-small cell lung cancer during periods of chemotherapy. In addition, the RCT sought to investigate whether such an intervention could prevent or attenuate the decline in physical fitness caused when receiving chemotherapy.

The intervention involved a 12-week hospital to home exercise programme for people with advanced non-small cell lung cancer undergoing chemotherapy and consisted of: weeks one to four supervised hospital-based training two sessions each week; weeks five to six a transition period involving one supervised hospital-based and one unsupervised home-based exercise each week; weeks seven to 12 twice weekly home-based unsupervised exercise sessions only. Hospital-based sessions lasted less than one hour and involved combinations of high intensity aerobic interval training. Interval training was conducted using a computer controlled, electromagnetically braked, cycle ergometer delivered with pre-programmed individualised training intensities determined by baseline cardiopulmonary exercise testing (CPET). Each session involved a five-minute unloaded cycle at the start and end of each session for warm up and warm down. The interval training involved between four to six repeated successions of three-minute moderate intensity cycling followed by two minutes of high intensity cycling. For the first session these intervals were repeated for a total of 20 minutes, for each subsequent session they were repeated for 30 minutes in total. Moderate intensity exercise involved cycling at a power output equivalent to 80% of peak oxygen uptake (VO_2) obtained at the anaerobic threshold. High intensity exercise involved cycling at power output equivalent to 50% of the difference between the VO_2 at the anaerobic threshold and the VO_2 Peak. Participants were screened at the start of each session and assessed for contraindications during the sessions based upon the American Thoracic Society and the American College of Chest Physicians (2009) Cardiopulmonary exercise testing safety guidelines. Blood pressure was monitored every three minutes throughout exercise and heart rate was recorded continuously from the R-R interval. Participants were also aware they could terminate the session at any point if they wished.

The home-based period commenced with a full exercise consultation at weeks five to six and a tailored programme devised whereby participants were instructed to select a combination of exercises, for example involving stair climbing, brisk walking, and resistance exercises, from a specially designed exercise manual. Exercise was monitored during this period using a Polar H7 heart rate monitor and activity monitoring (SenseWear Pro3) and intended to achieve heart rates commensurate with those achieved during the in-hospital exercise training sessions. It was intended for the first session in this period to be supervised at the participant's home and a suitable route for walking-based exercise to be identified, and for participants to receive regular telephone support during this period. Participants in the control arm received no exercise training.

In addition to supervised and unsupervised exercise sessions, exercise-based outcome testing took place at weeks three, six, nine, and 12, involving timed up and go, grip strength, and CPET testing for intervention arm and control participants. The absolute power outputs for subsequent training sessions were adjusted according to the outcome of those CPET tests. Discussions with members of the EMBRACE study team indicated potentially favourable outcomes but adherence to the home exercise component was low.

The MOVEMENT study was a pragmatic, single centre, mixed method, multi-perspective study to identify factors that enhance or impede exercise adherence and continuing exercise behaviour during and after a series of supervised hospice-based exercise classes. The study was conducted at a local hospice day-care centre in the south of England. The service offered two exercise programmes, delivered as a series of supervised exercise classes, for patients with incurable conditions, including advanced cancer. Classes were designed and delivered by a senior palliative physiotherapist, supported by other members of the therapy team. The classes, of two different intensities, were intended to help patients increase their general fitness, and maintain independence and wellbeing. Changes to staffing during the period of data collection meant some minor changes in the classes occurred, as the structure of the classes was based upon the ideas and values of the senior therapist delivering the sessions rather than a strict protocol in contrast to the EMBRACE trial. However, the general format of the classes remained the same. The class of lower intensity, entitled "Chairs Class", involved a four-week, sixty-minute seated exercise class, for people who wanted to be active but had limited mobility. Chairs class was held in what the hospice referred to as a 'day area' an outpatient space for general social and group activity. The sessions involved a variety of activities including seated circuits, chair bingo, tai chi and seated Olympics. Class two, entitled "Circuits Class", involved a six-week, 30-minute dynamic exercise class for the more able patient. Circuits class was undertaken in a specialist therapy gym and involved seven exercise stations to improve: upper limb strength, core stability, endurance, balance, agility, step climbing and slope walking. If participants missed a session in either class, they were given the opportunity to participate in an extra session after their original completion date. Upon completion of the programme, all participants were given advice to continue exercising at a number of recommended local leisure centres. Personal communication with staff responsible for the design and delivery of the exercise classes during the development of this element, revealed previous attendees stated they had found the programme to be a positive experience. Furthermore, according to feedback forms administered by the senior therapist as part of routine service evaluation, ninety percent of participants wished to continue exercising after course completion. However, it is not known what the longer-term exercise behaviour of those completing the classes had been, or what continuing to exercise after class completion involved for participants.

5.4 Recruitment

The recruitment process across the two studies varied considerably. Inclusion and exclusion criteria are described in Table 9 for the EMBRACE evaluation and MOVEMENT study respectively.

Table 9: Element 3 inclusion and exclusion criteria

Investigation	Inclusion criteria	Exclusion criteria
EMBRACE evaluation	Enrolled in the EMBRACE RCT in the intervention arm or the control arm Or, identified by an intervention arm participant as a suitable family member or friend Or, staff member involved in the design or delivery of the exercise trial	Chooses not to consent to the nested evaluation
MOVEMENT	Enrolled in an exercise class at the hospice day centre And, has a confirmed diagnosis of advanced cancer And, in the opinion of a clinician expected to live longer than 6 weeks post class completion Or, is a therapist involved in the design or delivery of the exercise classes	Under 18 years old Or, does not have capacity to give consent Or, chooses not to give consent

For the EMBRACE evaluation recruitment of participants including patients and carers from the exercise arm and patients only from the control arm occurred as part of recruitment to the main EMBRACE RCT. Once recruited into either the intervention arm or the control group the researcher in charge of day to day running of the EMBRACE trial at either hospital site contacted DA to give notice of new participants. Interviews were planned at week three and 12 for the intervention group and week 12 only for the control group. To minimise burden on participants, dates and times of interviews were set to coincide with other data collection appointments. Details of the interviews for exercise and control group participants were included in the main study information sheet (Appendix J) and consent form (Appendix K). Exercise arm participants were also given a modified information sheet (Appendix L) and consent form (Appendix M), which they were asked to give to a family member or friend if they were willing for them to be approached for an interview. This option to recruit a family member or friend was part of a later amendment and no participants were recruited after this was made, therefore no family or friends were interviewed.

Suitable staff members of the EMBRACE RCT team for interview were identified through discussion with the researcher in charge of day to day running at either site. Those identified were approached, provided with the relevant information sheet (Appendix N) and directed to make contact to arrange an interview if they wished to consider participation in an interview and give consent (Appendix O). With respect to the hospice evaluation on a weekly basis DA met with the senior physiotherapist to identify and discuss current and upcoming participants in the exercise classes who might be eligible for inclusion in MOVEMENT. Participants deemed to be eligible were approached by the person delivering that class and asked if they would be willing to be contacted by the researcher via telephone, about participating in the study. Participants were not approached during the first session to allow them to settle into the class before being approached about the study. Those who were willing were given an invitation letter (Appendix P) and a MOVEMENT participant information sheet (Appendix Q), and asked to return an invitation reply slip to indicate they were willing for the researcher to contact them and proving the preferred method of contact and to provide the best means of contacting them (Appendix R). They were then contacted at a time convenient to them to answer any questions they may have about the study to help them decide whether they would like to participate. Those who were interested in participating were given a minimum of twenty-four hours further time before being contacted again to establish if they wished to participate and agree a time to obtain full written consent to participate (Appendix S).

With respect to HCP participants as part of the weekly meetings between DA and the senior physiotherapist delivering the classes, HCPs involved in the exercise classes were identified. The people identified were then approached by DA, introduced to the MOVEMENT study and given the relevant information sheet (Appendix T). A minimum of twenty-four hours later the HCP was contacted and given the opportunity to ask questions and, if wishing to do so, arrange a time and place to obtain written consent (Appendix U) and take part in an interview.

5.4.1 Sample Sizes

According to Malterud, Siersma and Guassora, (2015) the most influential concept in determining intended sample size in qualitative research is that of achieving data saturation. When determining how large a sample size is necessary to achieve data saturation in qualitative studies, research by Guest, Bunce and Johnson, (2006) found the majority of themes are produced from six interviews and very few new pieces of information get generated after twelve interviews. This view is supported by research by Baker and Edwards, (2012) which asked several experienced and novice researchers the question “how many interviews is enough?” Although the most common response given to the question was “it depends”, there was some agreement with the findings of Guest, Bunce and Johnson, (2006) that a sample size, of between six and 12, is likely to be appropriate in situations with a relatively homogeneous cohort, relatively focussed questioning and a focused experience being investigated.

Although identifying saturation as the most influential concept in assessing sample size in qualitative research, Malterud, Siersma and Guassora, (2015) propose ‘information power’ as a more appropriate way of judging sample size adequacy, according to this concept of information power the larger information power a sample holds, the lower the sample size which is needed, and vice versa. Malterud, Siersma and Guassora, (2015) explain that information power of a sample is influenced by 5 factors: study aim, sample specificity, use of established theory, quality of dialogue, analysis strategy, and although these are not intended to provide a checklist to calculate a specific sample size, nor conclusively determine sample size in advance, they do provide recommendations as to what should be considered.

However, with respect to the EMBRACE and MOVEMENT studies sample size was largely dictated by pragmatic factors and included: trial or exercise class enrolment rates; staff changes in the hospice physiotherapy team or the EMBRACE study team; the temporary closure of the hospice exercise classes for approximately four months due to shortages in staff; low recruitment and early closure of the EMBRACE trial; the relatively modest resources and time scales of a PhD study. These pragmatic factors in combination with consideration of the concepts of data saturation and information power described above determined when data collection ceased.

5.4.1.1 Predicted sample size for EMBRACE evaluation

Prior to commencing the EMBRACE evaluation recruitment to the EMBRACE study was estimated to yield approximately one intervention arm participant each month. Suggesting 12 exercise participants could be recruited in approximately one year. Following the subsequent slower recruitment to the EMBRACE RCT only two intervention arm participants were recruited in a 12-month period, indicating that reaching data saturation before the study end date was unlikely. At this point a decision was made to include family members and health care professionals so enabling a broader perspective on adherence. Ultimately the sample size was determined by the early closure of the EMBRACE trial.

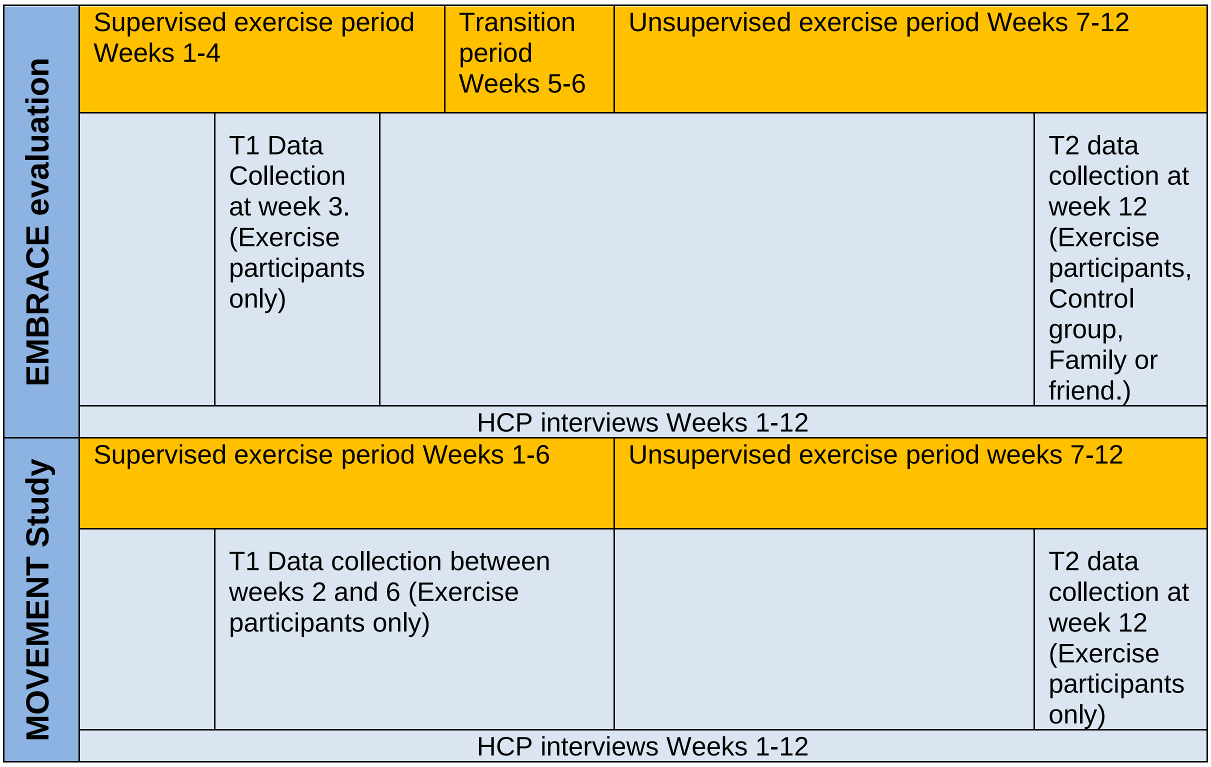
5.4.1.2 Predicted sample size for MOVEMENT study

Between July 2017, when the exercise classes first commenced, until December 2017, attendance figures showed 33 participants all with advanced cancer participated in the hospice classes: 15 for Chairs class and 18 for Circuits class. There was no participant waiting list prior to the first class, therefore it was reasonable to believe enrolment rates would continue or may have increased as the service became better known. This suggested over 60 participants were likely to take part in the classes annually. At the time of planning the study there were three physiotherapists working at the hospice, all of whom had taken a role in supervising the exercise classes of interest to the MOVEMENT study. Taking into account the above considerations, MOVEMENT sought to recruit 30 participants comprising approximately: thirteen from Chairs class, thirteen from Circuits class, and four therapists.

5.5 Data collection

The nature of data collection will now be described for the embrace and movement evaluations. Interviews are open-ended questions or probes which yield in-depth responses about people’s perceptions, opinions, feelings and knowledge (Patton 2015). They are intended to explore the views, experiences beliefs and motivations of individuals on specific matters (Gill et al. 2008).

Interviews align best with the aims and practical considerations of this study and with the objectives of this element and so were selected as the primary method of data collection. An overview of the data collection time points for the EMBRACE evaluation and MOVEMENT study are presented in Figure 8.



<table>
<tr><td rowspan="3">EMBRACE evaluation</td><td colspan="3">Supervised exercise period Weeks 1-4</td><td>Transition period Weeks 5-6</td><td colspan="2">Unsupervised exercise period Weeks 7-12</td></tr>
<tr><td></td><td>T1 Data Collection at week 3. (Exercise participants only)</td><td colspan="3"></td><td>T2 data collection at week 12 (Exercise participants, Control group, Family or friend.)</td></tr>
<tr><td colspan="6">HCP interviews Weeks 1-12</td></tr>
<tr><td rowspan="3">MOVEMENT Study</td><td colspan="4">Supervised exercise period Weeks 1-6</td><td colspan="2">Unsupervised exercise period weeks 7-12</td></tr>
<tr><td></td><td colspan="3">T1 Data collection between weeks 2 and 6 (Exercise participants only)</td><td></td><td>T2 data collection at week 12 (Exercise participants only)</td></tr>
<tr><td colspan="6">HCP interviews Weeks 1-12</td></tr>
</table>

Figure 8: Data collection time points

5.5.1 EMBRACE evaluation

The protocol developed for the EMBRACE evaluation incorporated data collection from participants in both the intervention and control group, a family member or friend of a participant in the intervention arm, and members of the study team involved in the design or delivery of the intervention. All interviews could be conducted face to face or via telephone, if the participant preferred, and were recorded on a digital dictation device with encryption capabilities. Data collection took place between November 2017 and March 2019. Semi-structured face to face interviews with exercise participants were performed at three weeks after commencing the programme (T1) when only hospital-based exercise was undertaken, and 12 weeks after commencing on the programme (T2) at the end of the intervention period (hospital supervised and home unsupervised). If participants withdrew from participating in the EMBRACE intervention they were given the opportunity to participate in the T2 interview if they were willing to do so. Interview guides for both time points can be seen in Appendix V and W. The interview of a family member or friend of the exercise group participants, was intended to take place at week 12 only, an interview guide for this can be seen in Appendix X. People randomised to the control group were interviewed at one time point only (week 12), the interview guide for control group participants can be seen in Appendix Y. Interviews with members of the study team involved with the design or implementation of the intervention were undertaken at any time convenient for each member of the team and the interview guide can be found in Appendix Z.

5.5.2 MOVEMENT data collection

The MOVEMENT data collection process and schedule was designed to follow a similar structure to the EMBRACE evaluation. Data collection took place between July 2018 and May 2019. MOVEMENT was also a multi perspective study involving the thoughts, views and opinions of the exercise participants and of the staff delivering the classes. However, some modification had to be made to the context of the movement study. Interviews were conducted with exercise participants at two time points. T1 interview (Appendix AA) was conducted face to face between week three and the end of the supervised exercise class. The T2 interview (guide in Appendix BB) was conducted either face to face or via telephone if participants preferred, six weeks after the end of the supervised classes. Health professionals involved in the design or delivery of the exercise classes were invited to a face to face semi-structured interview (Appendix CC) at a time point convenient to them. To reduce the burden of travelling to an additional appointment participant interviews at T1 were conducted face to face, in a pre-booked room, when attending a scheduled exercise class, unless participants requested otherwise. The first possible time for T1 interviews was immediately prior to, or after, the week three class. This was to allow participants to get experience of following the programme before data collection, but still to allow for possible subsequent dates if they were unable to be interviewed at that time. T2 interviews took place six weeks after completion of the supervised classes and were conducted via telephone at a date and time pre-agreed with the participants, unless participants requested otherwise. Before making contact for the second interview, to avoid causing potential distress to family, the patient’s GP was contacted to establish if the participant was still alive and in well enough health to be contacted via telephone. Interviews were expected to take no longer than thirty to forty minutes.

5.5.3 Problematic experience of therapy scale

Peräkylä (2006) explains interviews are often complemented by additional quantitative data collection methods, such as questionnaires, to provide a more thorough understanding of phenomena being investigated. Both the EMBRACE evaluation and MOVEMENT incorporated a scale to enquire about any perceived difficulties participants had performing the exercise. The Problematic Experience of Therapy Scale (PETS) was developed by Yardley and Kirby, (2006) and validated by Kirby, Donovan-Hall and Yardley, (2014). PETS is a 12-point, participant completed questionnaire, which establishes the extent to which an intervention user perceives something has prevented him or her from adhering to an intervention. It was developed from clinical experience and research to reflect the most commonly reported reasons for discontinuing prescribed rehabilitation therapy. It is acknowledged that it may not capture all factors perceived to contribute to non-adherence and is intended to be to be used in conjunction with further questions (Kirby, Donovan-Hall and Yardley, 2014). PETS Questions are split into four subscales: Q1-3) symptoms: Q4-5) uncertainty about the protocol: Q6-8) doubts about efficacy: Q9-12) practical problems. All questions are scored on a scale ranging from one (disagree strongly) to five (agree strongly). In the EMBRACE evaluation, PETS was administered as a questionnaire at week three and week 12 whilst participants were completing other EMBRACE study questionnaires. The PETS questionnaires can be seen in Appendix DD and EE respectively. PETS was administered in this way, rather than as part of the interview, for pragmatic reasons as the interviews were likely to be performed in between other trial assessments and clinical consultations and so this required they be kept short. In the MOVEMENT investigation at both data collection time points, the 12 questions which make up PETS were read out as part of the interview process and participants asked to give examples to support their answers. The answers and examples given were further explored as part of the interview process.

5.6 Data analysis

5.6.1 Quantitative analysis

Quantitative analysis was undertaken first and findings used to inform qualitative analysis. Data from PETS was entered into SPSS statistical software package. The sample size made inferential statistics inappropriate, therefore descriptive statistics were used to present data. Each returned questionnaire was scored using both the cumulative and binary methods as described in the PETS validation paper (Kirby, Donovan-Hall and Yardley, 2014). The cumulative method involved adding the relevant items together and dividing by the number of items in that subscale, to provide an indication of the aggregate quantity and magnitude of perceived barriers encountered for performing the intervention. The binary method involved recoding the scores into just two categories. Any participants who responded ‘strongly disagree’ to all items in a subscale are coded as ‘no barriers’, whereas any other scores are recoded as ‘some barriers or doubts’. This method is based on the assumption that unless the participant strongly disagrees with a statement some element of the statement must have been present, therefore some form of barrier must have been present, which could reduce adherence. Means and standard deviation of the responses for each subgroup and each individual scale element were calculated from the cumulative scoring of each time point.

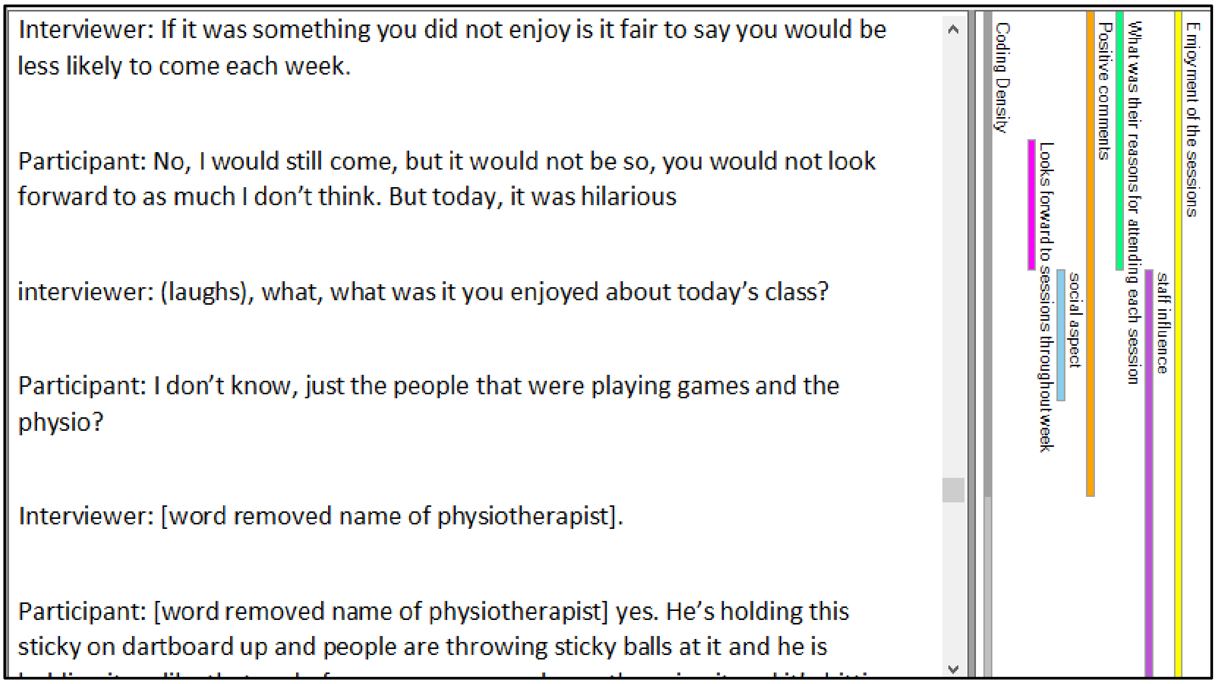
5.6.2 Qualitative analysis

Interview analysis was guided by the framework approach as described by Ritchie and Spencer, (1994) to examine participants’ experience of participating in the intervention in relation to the identified aims and objectives. Use of the framework approach to analyse semi-structured interviews, as being proposed here, is the most common use of this technique (Gale et al. 2013). Ritchie and Spencer, (1994) propose five steps to framework analysis: 1) Familiarisation; 2) Identifying a thematic framework; 3) Indexing; 4) Charting; 5) Mapping and interpretation. ‘Familiarisation’ involves emersion in the data to gain an overview of what has been collected. ‘Identifying a thematic framework’ involves identifying and/or constructing a framework or index that will provide a mechanism for labelling the data in manageable pieces for further exploration. ‘Indexing’ involves applying that framework to the data. ‘Charting’ involves building a picture of the data as a whole by considering the range of what was revealed from ‘Indexing’. ‘Mapping and interpretation’ involves the researcher gathering key characteristics of what has been produced so far with the aim to provide outcomes such as: definitions of concepts; identification of the range and nature of phenomena, creation of typologies, associations, explanations and development of strategies (Ritchie and Spencer, 1994).

For Element 3, Patient data were analysed first, then HCP data, finally the two separate analyses were brought together. Comprehensive ‘Familiarisation’ was achieved through first conducting each interview, then verbatim transcription of all recordings, first into a Microsoft word document then transferred into NVivo data analysis software. Following transcription, the interview data were read and re-read prior. As part of this process descriptive profiles for each patient were created, that presented summarised accounts of their qualitative data along with quantitative data to gain a thorough understanding of each person. An example of one of these profiles, participant EMB-014, can be seen in Appendix FF.

A pre-constructed thematic framework was developed through discussion in supervision meetings and informed by the COM-B model (Michie, van Stralen and West, 2011), the Conceptual Framework of Implementation Fidelity (Carroll et al. 2007, Hasson 2010), findings of elements one and two, issues identified in PETS results, and questions asked during interviews.

'Indexing' involved application of this framework to the transcripts. This framework was applied to the first few transcripts, modifications and changes were then made, and discussed during PhD supervision, before continuing analysis of the remaining data. Figure 9 provides an example of the use of NVivo for indexing of the T1 interview of MO-CH-03.



Interviewer: If it was something you did not enjoy is it fair to say you would be less likely to come each week.

Participant: No, I would still come, but it would not be so, you would not look forward to as much I don't think. But today, it was hilarious

interviewer: (laughs), what, what was it you enjoyed about today's class?

Participant: I don't know, just the people that were playing games and the physio?

Interviewer: [word removed name of physiotherapist].

Participant: [word removed name of physiotherapist] yes. He's holding this sticky on dartboard up and people are throwing sticky balls at it and he is

Figure 9: Example of indexing of patient MO-CH-03 transcript

'Charting' involved scrutinising of the date with similar questioning as used in Element 2 to identify commonality and variability between the participants, causes behind issues raised, changes over time, issues relating to control and management, impact upon the participants, and interactions between factors being identified. The framework was used to compare and contrast similarities and differences within and between each patient group: EMBRACE participants, Chairs class participants, Circuits class participants. When new areas of interest developed previously analysed transcripts were re-analysed with a focus on the new areas.

Mapping and interpretation involved pulling together of the characteristics of the data identified during the charting process to produce themes which elicited new meaning and understanding of participants' experiences of the programmes and what had influenced adherence. This involved further sorting and organising of data performed to develop the theme then refinement during supervision meetings to ensure a comprehensive and coherent explanation was produced which accurately represent what influences exercise adherence to both supervised and unsupervised contexts in people with advanced cancer.

After patient analysis the same process was used to analyse HCP data. Separate reports were initially written showing themes of what influenced adherence to exercise from both patient and HCP perspectives. These reports were integrated together through comparison against one and other looking for what was consistent between the reports as well as ambiguities and further explanation or solutions to issues raised in each. This generated a fuller understanding of any issues raised and generated a higher more complete understanding of exercise adherence in advanced cancer.

5.6.3 Formation and consultation with advisory panel

Involvement of collaborative groups comprising stakeholders with a variety of complementary expertise and views is recognised as a method to improve the fit of interventions with the service into which it might be introduced and the people who will use it (Curran et al. 2008, Connell et al. 2015). For pragmatic reasons the synthesis of findings was carried out by DA, with support from PhD supervisors. The involvement of an Advisory Panel was used to test assumptions and decisions made during analysis.

People identified as possessing knowledge or skills relevant to exercise in advanced cancer were contacted to inquire if they wished to participate as part of an advisory panel. Potential members were contacted three months before the anticipated date of the first panel meeting. Several dates were proposed, and participants asked to select dates on which they could attend. Other commitments meant It was not possible to identify one date when all members of the panel could attend, therefore two meetings were arranged with five members attending the first meeting and four the second. The panel consisted of one person with advanced cancer, two oncologists, a palliative medicine consultant, a palliative physiotherapist, a palliative occupational therapist, a cancer nurse specialists, a behavioural scientist, and a personal trainer. An additional panel member with advanced cancer had intended to attend the meeting, but was unable to.

Both meetings had the same objectives and followed the same format, beginning with discussion regarding the intervention problem statement to clarify the purpose and scope of the study. Early findings from Element 3 were presented to the panel. The panel were encouraged to comment on the emergent findings as well as the processes and decisions that led to their formation. This was done to validate the early analysis and identify other potential lines of examination.

With permission, the advisory panel meeting was recorded on a pin protected digital dictation device and stored on a University of Southampton computer for the purposes of capturing the discussion. The transcript was discussed during PhD supervision.

5.7 Ethical considerations

5.7.1 Research in palliative care

The ethics of research in palliative care has been the source of considerable debate (Addington-hall 2002; Stevens et al. 2003; Lee and Kristjanson, 2003; Casarett, Knebel and Helmers, 2003; Koffman et al. 2009). There is general agreement that research in palliative care presents many issues which must be considered when designing research. Such issues can include amongst others, reduced chances of the participant benefiting directly from the research and a greater impact of any time burdens caused by the research due to the limited life expectancy. Although it has been argued that palliative research is unique, due to a possible difference in how patients who are near death experience the above factors compared to those who are not, the literature agrees that in fact all patient groups are likely to have some unique traits which warrant careful consideration. Therefore, the established principles and guidelines for ethical research can guide the design of palliative research as for research into any other patient group. However, research involving people with advanced cancer still raises many ethical considerations due to the vulnerability of the population (Reid 2009). Lasagna (1969) explains that consideration must be given to how vulnerable individuals may benefit from partaking in the research. The main benefit of involvement in Element 3 was that participants had an opportunity to tell a story about their involvement in the programmes and a chance to contribute to improving services for others in the future, a process that palliative patients have previously described as empowering (Gysels, Shipman and Higginson, 2008). Several participants interviewed commented positively about being given the opportunity to talk about and reflect on their experiences. The main burdens for participants were anticipated to be the time required for the interviews, and a possibility of experiencing distress caused by the interview content and reflexive processes. To minimise the time burden, whenever possible interviews were scheduled when the participant would already be attending clinical appointments, and in the case of MOVEMENT, time point two, intended to be conducted over the telephone, unless the participant requested otherwise.

Interviews can elicit negative emotional responses in participants such as anger, embarrassment, and distress (Yeo et al. 2014). However, research investigating the use of interviews in palliative patients has found the majority of participants find interviews to be a positive experience (Gysels, Shipman and Higginson, 2008). Interventions seeking to change health-related behaviour, such as exercise, have at times been open to accusations of hassling, victim blaming and stigmatising (Carter et al. 2012). Previous studies using one to one interviews in the context of exercise interventions in advanced cancer did not report any distress (Burke et al. 2013; 2015). However, those studies evaluated an intervention which reported adherence levels of over 90%, therefore, it may be that negative feelings are more likely to occur when reflecting upon situations in which adherence is substantially lower. In accordance with the principles of Good Clinical Practice (GCP) (training completed 2017), Element 3 provides the best possible quality data with the minimum risk of harm to participants. To achieve this patient and participant involvement (PPI) of people with advanced cancer was used to test and, inform development of all study materials (i.e. PETS questionnaires, Participant Information Sheets, study consent forms, and interview guides). This helped minimise the likelihood that such materials could generate negative feelings such as hassling, victim blaming or stigmatisation, and increased the likelihood that all information would be comprehensible.

Participant confidentiality was preserved throughout the interviews. However, participants were made aware that if anything arose that could be considered unsafe or a contraindication to continuation with the exercise, then concerns would be escalated to the clinical study team.

5.7.2 Ethical approvals

Approvals for the study were sought from University Hospital Southampton Research and Development department via the University's Ethics and Research Governance Online (ERGO) system, University of Southampton Faculty of Health Sciences, and a Research Ethics Committee determined through the Health Research Authority (HRA) process.

To incorporate the nested evaluation into the EMBRACE RCT an amendment to the EMBRACE protocol was initially submitted to the HRA to allow for interviews with exercise arm participants and approved in April 2017 REC reference 13/YH/0354 substantial amendment 4. However, it became apparent that slower recruitment rates, due to changes in treatment of advanced lung cancers in summer 2017, would not allow adequate investigation of the identified aims. Therefore, another amendment was submitted to allow for additional interviews with participants who had been randomised to the control group, family and friends of the intervention group participants, and staff involved in the design or delivery of the study. This amendment was given favourable opinion by the Research Ethics Committee on the 8th March 2018, and approved by the Health Research Authority on the 21st of March 2018, REC reference 13/YH/0354 substantial amendment 5.

MOVEMENT was originally submitted for proportional ethical review, however it was decided due to the vulnerability of the participants it should undergo full Research Ethics Committee review and HRA assessment. Research Ethics Committee review meeting was attended 25th of April 2018 and joint approval from REC and HRA received 16th May 2018 REC reference 18/SC/0212.

The study was conducted in accordance with the recommendations for physicians involved in research on human subjects adopted by the 18th World Medical Assembly, Helsinki (1964), as recognised by governing laws and EU Directives and in accordance with GCP principles.

Specific consideration included:

- Each subject's written consent to participate in the study was obtained only after a full explanation of the study had been given, opportunity to ask questions provided and allowed a minimum twenty four hours to consider whether to enrol into the study
- The right of the subject to refuse to participate in the study or drop out from the study without giving reasons was respected. The participant was informed of this right and informed that it will not prejudice their care and onward participation in the exercise programme

- When designing interview questions, and carrying out the interviews, consideration was given to the fact that the wellbeing of the human subject takes precedence over the interests of science. Interviews were designed with input from people with advanced cancer to ensure they were less likely to cause any undue distress. Before beginning any interviews, the interviewer ensured that the participants were comfortable, not experiencing any symptoms of their condition or showing any signs of distress
- The privacy and dignity of the subject was maintained at all times during the interview process and throughout the study. Private rooms were pre-booked for the face-to-face interviews and for the interviewer during the telephone interviews to ensure conversations were not overheard by others
- Predicted risks and burdens associated with participation, such as the impact of the additional time needed for the interview was identified and communicated to potential participants as part of the PIS. Participants were at an advanced stage of illness and symptoms of the disease, treatments, and physical functioning could vary overtime, for this reason the participants ability and wish to continue with the study may have changed and therefore consent was rechecked at the second time point
- If any participant was considered to be in a dependent relationship to the interviewer, DA, through virtue of his clinical role as a staff nurse, consent to participate in the research would be sought through a health care professional with appropriate GCP training and who was independent to this relationship

5.7.3 Data management and protection

All data were handled in compliance with the principles of GCP and of the Data Protection Act (1998).

- Subject’s anonymity was maintained. On study documentation, subjects were identified not by name, but by an identification code. A subject enrolment log containing codes, names and contact details was kept secure. In any published work all subject names will be changed to pseudonyms
- All interview data collected during the study were recorded on a pin protected digital recording device with encryption capabilities

- All data collected during the study such as transcripts, questionnaires and consent forms were stored on a password protected University of Southampton computer
- Data will be retained for 10 years in accordance with University of Southampton retention requirements (University of Southampton 2016)

Chapter 6 Element 3: Empirical research findings: Supervised exercise

This chapter details findings generated from interviews (n=29) and completed PETS questionnaires (T1 n=14, T2 n=11) pertaining to the experience of patients with advanced cancer (n=16) who participated in therapeutic exercise programmes, and health care professionals (HCPs) (n=12) involved in design and delivery of those programmes. Table 10 presents patient basic demographic data, Table 11 presents HCP basic information.

Table 10: Patient basic demographic data

Participant number	Sex	Age	Type of exercise	Type of cancer
EMB-014	M	76	EMBRACE Exercise arm	Lung
EMB-015	M	64	EMBRACE Exercise arm	Lung
EMB-016	F	58	EMBRACE Exercise arm	Lung
EMB-024	M	81	EMBRACE Control arm	Lung
EMB-025	F	77	EMBRACE Exercise arm	Lung
MO-CH-01	M	80	Chairs class	Prostate
MO-CH-02	F	71	Chairs class	Renal
MO-CH-03	M	76	Chairs class	Lung
MO-CH-04	F	71	Chairs class	Breast
MO-CH-05	F	72	Chairs class	Breast
MO-CH-06	M	81	Chairs class	Colorectal
MO-CH-07	M	88	Chairs class	Mesothelioma
MO-CR-01	M	67	Circuits	Myeloma
MO-CR-02	M	69	Circuits	Colorectal
MO-CR-03	F	68	Circuits	Breast
MO-CR-04	M	74	Circuits	Pancreatic

Table 11: Health care professional, sex, study involvement, and role details

Participants number	**Sex**	**Study**	**Role**
EM-ST-01	F	EMBRACE evaluation	Recruitment and delivery
EM-ST-02	F	EMBRACE evaluation	Recruitment and delivery
EM-ST-03	F	EMBRACE evaluation	Recruitment
EM-ST-04	F	EMBRACE evaluation	Recruitment and delivery
EM-ST-05	M	EMBRACE evaluation	Recruitment and delivery
EM-ST-06	F	EMBRACE evaluation	Design and delivery
EM-ST-07	M	EMBRACE evaluation	Recruitment
EM-ST-08	F	EMBRACE evaluation	Delivery
MO-ST-01	F	MOVEMENT	Design and delivery
MO-ST-02	F	MOVEMENT	Delivery
MO-ST-03	M	MOVEMENT	Delivery
MO-ST-04	F	MOVEMENT	Design recruitment and delivery

Quantitative analysis of PETS questionnaires was performed for both time points using the cumulative and binary methods of analysis, as outlined by Kirby, Donovan-Hall and Yardley, (2014). Appendix GG shows complete responses to the PETS questions. Cumulative analysis across all subscales and both time points did not identify any factors which greatly impeded participation in exercise. Figure 10 shows the binary analysis results across both time points, indicating the number of participants who experienced some difficulty with the factor in each PETS statement. Binary analysis indicated that responses, relating to severity of symptoms (Questions 1-3), uncertainty of how to perform the exercise (Questions 4-5), and doubts about treatment efficacy (Questions 6-8) all showed very little difference between the two time points. However, responses relating to the subscale of practical issues (Questions 9-12) showed many more participants indicated these issues impeded them at time point two than at time point one. The greatest difference was reported for statement 11, being ‘too busy or tired’ did not prevent a single participant from performing the supervised exercise but impeded seven of the 11 (63%) who completed the questionnaire for the second time point. Further questioning indicated this was most frequently due to being too tired not too busy

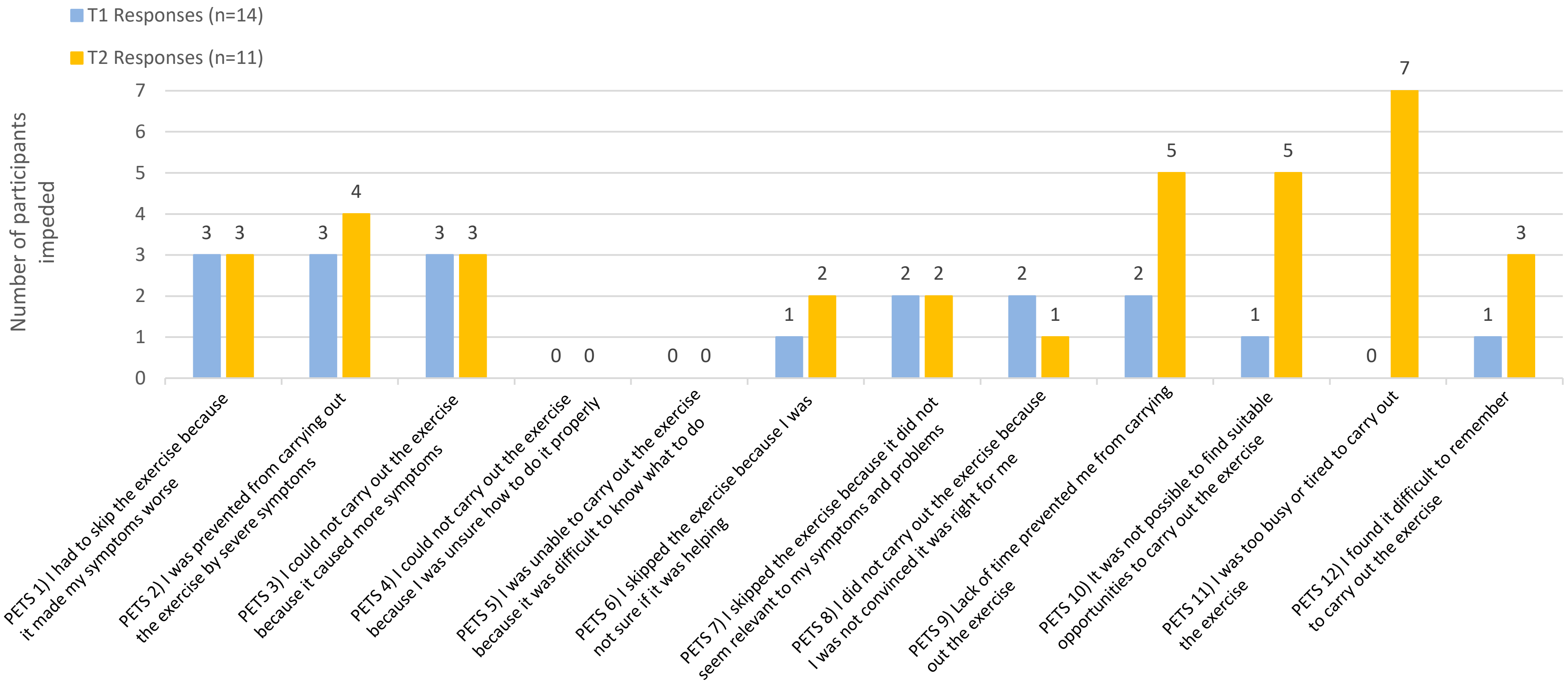


Figure 10: Problematic experience of therapy scale binary analysis results for all exercise groups

The quantitative findings were used to help direct attention to particular areas of focus during subsequent qualitative analysis to try and identify why the majority of impediments experienced did not vary between the two time points, and why tiredness had such greater influence during the unsupervised period. For the qualitative analysis Patient and HCP accounts were analysed separately. Qualitative analysis of patients' perspectives of the supervised period was conducted first, followed by patients' accounts of the unsupervised period, and finally HCPs' accounts of both periods. These three data sets were then synthesised. Themes were developed from participants' accounts to identify and understand factors that influenced participation in, and adherence to, exercise programmes. The themes formed a hierarchy comprising three levels. A meta-theme, 'Moments of conscious decision', was apparent and important across the supervised and unsupervised periods. Four common 'Moments of conscious decision' were identified, three in the supervised period and one in the unsupervised period, where participants ask themselves the questions 'Should I do it' and 'Could I do it'. Within each 'Moment of conscious decision' two further themes informed the outcome of that decision, consisting of 'Drivers of participation' and 'Mitigation and accommodation of impediments'. Within these two themes, subthemes were developed to represent factors which influenced the theme at each point and informed the decision at that particular moment. The arrangement of the meta-theme, themes, subthemes, and outcomes of each decision point for the supervised period are presented in Figure 11.

Analysis of HCPs' accounts largely supported the themes developed from patients' accounts. These accounts contributed further understanding of what informed patients' decisions at each moment, particularly around areas of work performed by HCPs, the feedback HCPs received and their subsequent level of understanding of the participants' situation, and the relationships which formed between HCPs and patients. These will be discussed in relation to, and woven through, patient identified themes at each applicable moment.

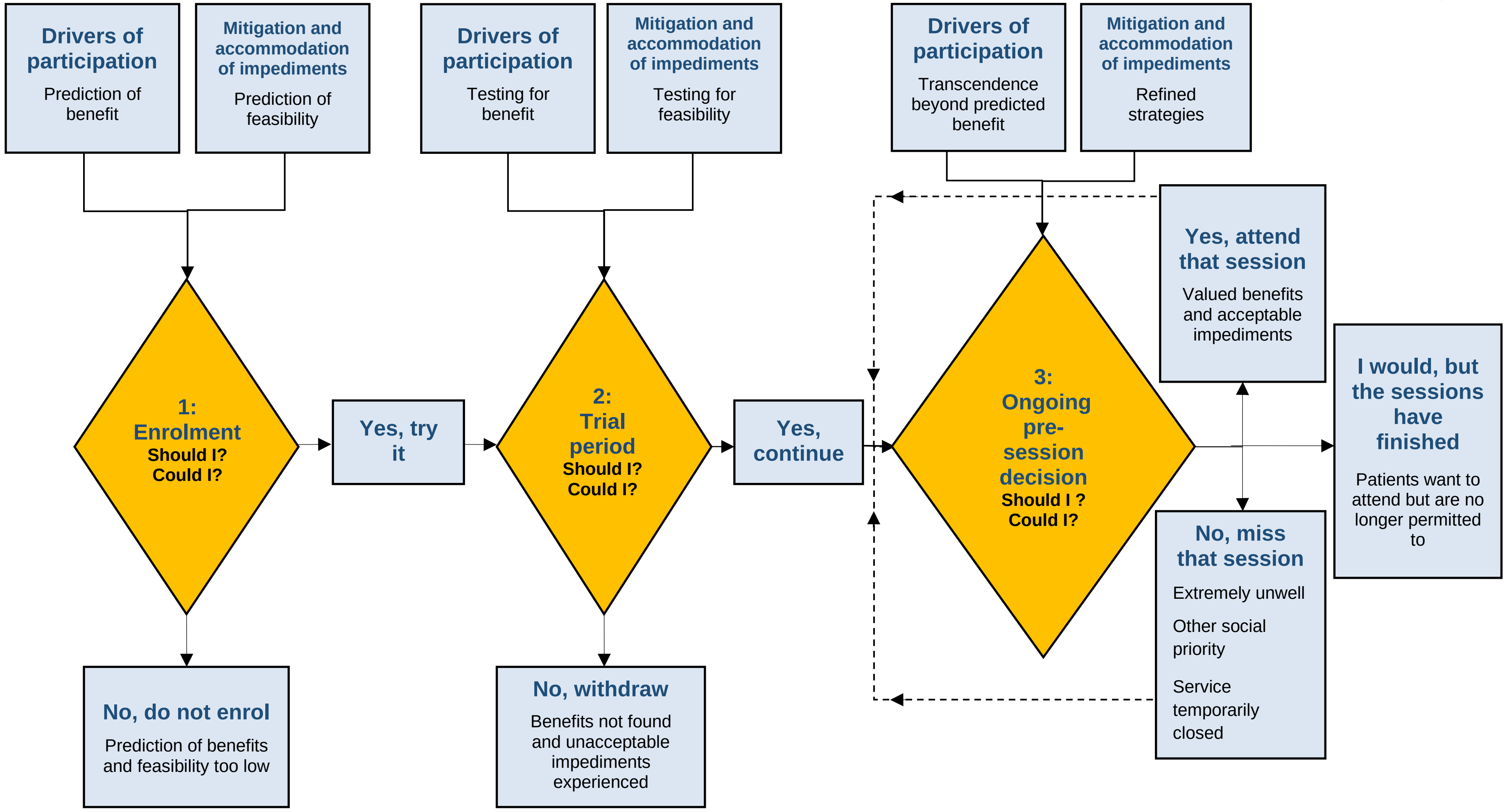


Figure 11: Moments of conscious decision supervised period

6.1 Moments of conscious decision

An overarching meta-theme was identified across all the programmes and time periods, that of ‘Moments of conscious decision’. Due to the intrinsic features of the exercise programmes and patients’ intentions, moments were created at which patients assessed their options and decided whether or not to initially participate, and then continue with participation at each scheduled opportunity.

Patients’ descriptions revealed three moments (or time-points) during the supervised period when decisions were made: 1) At enrolment 2) During the trial period 3) On an ongoing basis before each session. Each time point was characterised by the questions patients asked of themselves, and the decisions they reached. During the supervised period the structure for the programmes made these ‘Moments of conscious decision’ unavoidable.

Across these moments of conscious decision, further themes were developed to characterise what influenced the decisions made. At each time point there was something which motivated patients to participate, but for the majority there were also considerable challenges which needed to be addressed in order to participate. This combination of motivational drivers and challenges experienced formed the two main themes identified at each ‘Moment of conscious decision’; 1) ‘Drivers of participation’, and 2) ‘Mitigation and accommodation of impediments’. These two themes were present at each ‘Moment of conscious decision’. But the individual factors which operated within each theme, their level of influence on the decision and how they were perceived by patients varied as the programmes progressed and are explained in this chapter as subthemes.

6.1.1 First conscious decision: at enrolment

This section concerns the first point at which a decision had to be made. When introduced to the opportunity of exercise, patients had to decide if they would accept the offer or not. Patients were introduced to exercise in a variety of ways. MOVEMENT patients were typically informed of the exercise classes when first introduced to the services on offer at the hospice, usually by a palliative care consultant or palliative care clinical nurse specialist. The role of these staff only became apparent during patient interviews so they had not been accounted for in the study protocol, and hence not interviewed. If patients were interested they were referred to the relevant service. EMBRACE patients were introduced to the trial shortly after the consultation in which they learned of their incurable diagnosis, again initially by a consultant and subsequently by one of the HCPs who would deliver the exercise. Most patients had a family member present. HCPs identified involvement of family at enrolment and throughout the programmes as much more common amongst these advanced cancer patients than amongst other non-terminal patient groups they had worked with previously.

At the point of enrolment very few patients were exercising regularly. Generally, patients were not performing regular exercise, either because it had not been important to them during their adult life, or because their cancer had forced them to stop. HCP accounts of participants' exercise histories and levels of fitness were largely congruent with those of patients. There were predominantly elderly individuals with a range of exercise histories but with a tendency to be sedentary and generally unfit, only rarely would a fit patient be enrolled. Some were described as simply deconditioned, whilst most demonstrated significant negative consequences of their illness or treatment:

> HCP: They are all….in common terms would be considered to be very unfit. Many of them are breathless on exertion, many of them are experiencing other symptoms,… cough, lack of appetite, lack of energy, severe fatigue, needing to have a rest during the day. Some of them are at the point where they are having difficulties with their activities of daily living, getting themselves dressed or having a shower….they are a population with very significant challenges.
>
> **(EM-ST-03 Enrolment)**

This 'Moment of conscious decision' was determined by the predicted benefits participants thought they might gain, and how feasible they thought it would be for them to participate in the programmes.

6.1.2 Drivers of participation

HCPs' and patients' accounts revealed that for a patient to enrol they had to anticipate the programme would help, either themselves, or in the case of the EMBRACE patients, help others as well. Patients' accounts revealed each typically had several reasons for choosing to enrol, usually one main driver supported by other contributing factors. Patients reported wanting to try anything that might help them. Exercise histories, knowledge about exercise, and their personal beliefs, all informed how they perceived the opportunities presented by each programme may help them.

There were distinct differences discernible in patients' exercise histories and prior knowledge of exercise between the three exercise programmes. EMBRACE patients, with the exception of one, had never participated in deliberate exercise or sports since finishing school. However, they had been active throughout their lives performing physically demanding jobs. "*Never thought about doing exercise….Work was hard enough"* (EMB-014 Male 76). These participants had also previously participated in frequent, physical, leisure activities. If for pleasure these leisure activities were typically performed with others, usually family.

Chairs class patients had more varied exercise histories. Some patients had never been interested in exercise, except for very brief periods relating to wanting to lose weight or get fit "*well I did at one time tried to get myself fit and I did not do too badly"* (M0-CH-06 Male 81). Other Chairs class patients had previously exercised a lot but stopped exercising due to progressing cancers or other illnesses, either recently or many years in the past:

> Patient: ….that was when they found the cancer in the prostate. I was still quite active even then, until 2007, really so five years of going up the hospital and that for check-ups all the time. 2007 I started to get these pains in my back and it stopped me doing things that I used to be able to do. Running, gardening.
>
> **(MO-CH-01 Male 80)**

Circuit class patients all had extensive histories involving regular performance of exercise or participation in sports. They may have changed exercises and sports over the years, but had only recently stopped completely, due to their cancer. This was often because the cancer prevented them from undertaking exercise, but could also be because they had to modify the activity to such an extent they no longer wished to perform it:

> Interviewer: Are you still playing golf?
>
> Patient: I could do, if I wanted to….you are only allowed to do a half swing when you have PICC lines in. You are allowed to play golf but I have got to be very careful….this one here (points at himself) can hit it 150 yards. This one here (points at his wife) can hit it 200 yards. It is not right. (Shakes head and laughs).
>
> **(MO-CR-02 Male 69)**

HCPs reported both patients and their families had strong views of exercise. Some were very interested to hear about exercise, others were of the belief it would do nothing for them. Patient accounts, with very few exceptions revealed family to be encouraging and supportive. HCPs thought patients' and their family's views usually aligned, but for some, disagreement regarding exercise was a regular cause of stress within a family.

HCPs who delivered the interventions were often not involved in enrolment and both HCP and patient accounts revealed the professionals involved at this point provided little information for patients as to why patients might choose to enrol. Some HCPs reported providing detailed explanations of potential benefits and reasons for participation, but this was not uniform across each of the programmes. More commonly very little information was given as to the benefits of joining the programmes. This meant a decision was largely informed by a patients' own understanding and knowledge.

Those with less knowledge and understanding of exercise may not have had a clear understanding of why they joined:

> HCP:… some people know that they have got a specific area where there is a problem, and they have actually requested to be referred into the exercise groups. Some people I think it has been suggested to them and they are not really sure what they are signing up for which is why I explain things…. Some people are turning up for assessment and do not really know who has referred them and why.
>
> **(MO-ST-04 Design, recruitment and delivery)**

At this 'Moment of conscious decision' there were five ways in which patients predicted exercise might help them :1) Prediction of non-specific benefit, 2) Prediction of specific benefit, 3) Prediction of receiving specialist knowledge, 4) Prediction of benefit of joining a group, 5) For the sake of others. All patients reported an awareness of the general health benefit of exercise which related to driver 1) Prediction of non-specific benefit. For some this was their only, and therefore, main driver. For others, drivers 2), 3), 4) or 5) provided another layer of motivation. For patients motivated by multiple drivers, 2, 3, and 5, were typically considered to be more important than 1) or 4). No patient reported 4) to be their main driver.

6.1.2.1 Prediction of non-specific benefit

All patients expressed at least some level of awareness that exercise was beneficial to health *"The common thinking is that exercise is beneficial"*…(EMB-016 Female 58).

Across all programmes HCPs and patients expressed the opinion exercise would likely be of some benefit to them and so would be a positive thing for them to do. This opinion was based upon understanding that exercise had physical health benefits but also that engagement in a positive act may bring some kind of emotional benefit as well:

> Interviewer: Did they share with you their reasons for joining?
>
> HCP: yes, I think they all did…. well the impression I got was it was just something positive in this situation. It had obviously been suggested to them by their doctors as well, yes they just wanted to do something positive. I think that is generally the reason it has always been.
>
> Interviewer: So non-specific but positive is that right?
>
> HCP: Yes…., they think it would only bring something beneficial, it could not be negative.
>
> **(EM-ST-02 Recruitment and delivery)**

Patients were rarely given additional information to deepen understanding of any potential benefit that might be derived from participating in the programmes:

> Interviewer: When the consultant said it would help you, did they describe how it would help?
>
> Patient: No not really just said it is good for you.
>
> **(MO-CH-02 Female 71)**

Non-specific benefit seemed to be the basic motivating driver all patients were aware of, even those who had little understanding of exercise. Participants knew exercise was likely to be somehow beneficial, even if some were not certain of how or why.

6.1.2.2 Prediction of specific benefit.

In general, across each programme, patient and professional accounts indicated those with more extensive exercise histories had more specific, exercise-related reasons for enrolling on the programmes. These participants appreciated exercise would provide general benefits but also had an understanding of how exercise could help with particular areas they wanted to improve. These patients were more likely to have greater understanding of what specific benefits exercise could offer. However, they were also more likely to have either previously found they could no longer exercise or had been actually advised to stop by health professionals involved in their care. This was reflected in their reasons for enrolment which included many of the same reasons they had for exercising before they became ill, such as improving fitness and/or strength. But now also included reasons relating to their illness such as a desire to regain the strength they had previously, regain a range of motion in certain joints, or slow further decline. For these patients the opportunity to exercise was important to them either for its own sake, as they had always exercised, or because it would help them return to previous activities:

> Patient: …I wanted to regain a lot of the balance that I felt I had lost (following chemotherapy). That was important to me because I do quite a reasonable amount of bowling…. But I feel that I was not as capable, for the simple reason that I was losing my balance.
>
> **(MO-CR-04 Male 74)**

Patients with more extensive exercise histories were more likely to know what they wanted to achieve and viewed the exercise programme as an opportunity to achieve this.

6.1.2.3 Prediction of receiving specialist knowledge.

Some patients had been exercising until their condition impeded their ability to do so, or they were told by health professionals not to. These patients wanted to access the specialist knowledge of staff delivering the interventions to learn how to exercise again without causing themselves harm. Exercise was previously an important part of their lives; it had ceased because of their condition and they were enthusiastic about the opportunity to restart:

> Interviewer: When you heard that there was an opportunity to come and do some exercises here can you remember how you felt?

> Patient: I felt really pleased, it was really good.
>
> Interviewer: Can you remember what you had hoped to get from the classes?
>
> Patient: I hoped I would get some exercises that I could practice at home, and that, it would just give me a routine that I could follow.
>
> **(MO-CR-03 Female 68)**

HCP accounts indicated some patients enrolled to regain some control and do something for themselves. However, patients' accounts revealed they valued the opportunity to do something for themselves, but also wanted professional input to ensure what they did was safe and suitable for them:

> Interviewer:…you like to do things for yourself, but you like a bit of guidance…., as to what's suitable to do for yourself?
>
> Patient:… Yeah trying to pick something and finding that I can't manage I can't control because I've taken on something that was far too much. Whereas with other people's guidance in that way it lets me know what they think I should be capable of.
>
> **(EMB-015 Male 64)**

According to HCP accounts, there was general agreement across all programmes that despite it being a time of emotional distress, the earlier enrolment occurred the better. It was believed this period presented a teachable moment in which patients were most amenable to learning and taking on new health-related behaviours such as exercise, including for those who previously may not have been interested.

6.1.2.4 Prediction of benefit from joining a group.

Although it was not a main reason for wanting to enrol, anticipated benefit of joining a group usually supplemented either specific or general exercise-related benefits. Some patients wanted social interaction and to be able to regularly talk with other people. One patient who had previously engaged in group exercise classes believed being in a group would motivate her to exercise harder than if she/he were to exercise alone. For many it was not only about interacting in a group, but specifically interacting in a group with others who had cancer:

> Interviewer: What was your main reason for coming?
>
> Patient: well, basically fitness also I was hoping there would be people here that, I could interact with. I would get friendly with so, social…. So yes, it was mainly fitness and meeting different people, hopefully who had the same, some, with the same illness that I had.
>
> **(MO-CH-05 Female 72)**

Although not spoken of in HCP accounts as a reason for initial enrolment, and only a secondary driver in patient accounts, benefit from being in a group gained in popularity during the programmes and became a key driver for patients wanting to re-enrol a second time.

6.1.2.5 For the sake others.

The EMBRACE programme was unique compared to the other programmes in that, as a randomised controlled trial, it presented patients with an opportunity to help contribute to generating knowledge for the benefit of others. All patients given the opportunity to help others with cancer wanted to do so. All patients in EMBRACE, bar one, enrolled primarily because they wanted to help other patients in the future or give back to the service helping them. The one exception enrolled primarily in the hope of physical benefit, however even then helping others in the future still contributed to the decision, but to a lesser extent. The way patients interpreted their contribution to helping others varied from person to person. One patient (EMB-015 Female 58), had regularly been involved in altruistic activity throughout her life and viewed this as an opportunity to continue to do something important to her. Another was making a conscious effort since diagnosis to create positivity in his life at every opportunity. He viewed the study as a chance to give something back to the health service. Another patient, however, believed exercise would not provide any benefit because of the terminal nature of the disease, but he still wished to participate to help others:

> Patient: Well the nurse spoke to me about it…. he explained it’s a thing they are looking into…., if it can help people who have got cancer… and I spoke to my wife about it. We thought, yeah if It’s going to help somebody, it’s not going to help me, but if it helps somebody later on.…If it’s possible, all to the good.

> **(EMB-014 Male 76)**

Other examples existed outside of the EMBRACE programme of patients enrolling, at least partly, for the sake of others. Some patients reported enrolling to appease family members. These patients enrolled primarily due to prediction of benefit, but also felt they needed to enrol to demonstrate to family that they had tried everything they could.

> Interviewer: Can you tell me what your reason was for joining the class
>
> Patient: Probably because it was recommended by, my daughter came with me, we saw three people one after the other. I forget their names,…... They suggested that there would be classes that might be beneficial. Then when you got your little un (daughter) sat next to you, you dare not say no do you.
>
> **(MO-CH-03 Male 76)**

For the sake of others was a strong driver, but mostly applicable to patients given specific opportunity by the nature of participating in a RCT.

6.1.2.6 Lack of anticipated drivers.

HCPs reported that when approached for any of the three exercise programmes patients were either very positive about the offer or apathetic, with few in between. This was also reported to be true of both family members and patients. All patients interviewed had decided to accept the offer of participating in the exercise programme therefore they likely represent the views of those who were positive about the offer. HCP accounts, however, suggest reasons for those who declined.

It was commonly reported that patients chose not to enrol if they believed it was not likely to provide benefit. HCPs report that when first approached to participate in EMBRACE, most patients expressed a sense of disappointment. Exercise was viewed as a less favourable opportunity, and less likely to produce benefit, than research involving pharmacological interventions:

> HCP: The people who are less keen on it. So I definitely think that when I say the word research most people are hoping for a drug. When they hear what it is they feel disappointed, they want a new drug.
>
> Interviewer: Does the disappointment come across strongly?
>
> HCP: Yes. It is verbalised.
>
> **(EM-ST-03 Enrolment)**

Some participants who were approached thought they would not benefit because they believed they were already active enough, others who declined were of the view that the terminal nature of their disease meant there was no point in exercising:

> HCP: I got the impression, although it was quite a difficult conversation on the phone, they did not really want to talk. I got the impression it was a bit of a well "what is the point because I am dying". It was that sort of attitude "I am not going to get better so why do I do this?"
>
> **(MO-ST-04 Design, recruitment and delivery)**

HCP accounts indicate if a patient did not appreciate how the offer may benefit them they were less likely to enrol.

6.1.3 Mitigation and accommodation of impediments.

At each 'Moment of conscious decision' participants also had to consider potential obstacles or impediments to exercise. Usually for the decision to be in favour of exercise those impediments had to become less severe or 'mitigated'. Often impediments could not be mitigated entirely so participants worked to 'accommodate' them somehow.

During this time, as well as considering how they might benefit from the programmes, patients were also considering all of the things that participating in the programmes would entail and how likely they would be able to do these? Mitigation and accommodation of impediments at the point of enrolment is characterised by the participant making a ‘Prediction of feasibility’ of being able to participate in the programmes.

HCP accounts spoke of patients and family being emotionally low when first approached about a programme. Some had recently been diagnosed with advanced cancer and needed to quickly understand and come to terms with their diagnosis and treatment options. Others had recently stopped treatment and needed to adjust to the fact their previous expectations of treatment had not been achieved. Some were described as ‘crushed’ from the continual efforts of attempting to halt their disease, and which they now viewed as failure. Patient accounts, however, relayed few concerns about impediments at this decision point. It is possible patients most concerned by these types of impediments had chosen not to participate in the exercise programmes, and so were not interviewed.

Three aspects emerged regarding whether or not participants felt it would be feasible to engage with the offers of exercise: 1) Predicted impediments. 2) Prior mitigation and selective inclusion. 3) Predicted inability to participate.

6.1.3.1 Predicted impediments

Again, patients’ exercise histories seemed to influence concerns they had regarding factors which might prevent them from being able to participate. Those with the greatest and most contemporary exercise histories had recently been forced to stop exercising or advised they should stop. These patients had learnt cancer might impede exercise but were also anticipating that staff knowledge and expertise may enable to them to exercise again:

> Patient: I am frightened of overdoing it,… I do not know my limits. … you don’t really know if you are going to damage yourself or not. So you don’t do it at home…you’ve got to put trust in somebody… I mean, if [HCPs] are confident that they can help you, then you think “okay I’ll play”, “I’ll go along with this”, “I’ll give it a go”.
>
> **(MO-CR-01 Male 67)**

Those who had more limited previous engagement with exercise were less likely to be concerned whether exercise would aggravate any negative consequences of their cancer. They were comfortable in the knowledge they could stop if needed. However, some were worried as to whether they were fit enough to participate, having been sedentary for a long time, and were concerned as to how this may look in front of others:

> Patient: Oh it was more apprehensive about what I could do. What was going to be expected of me? I think, no matter where you go when you do something for the first time, you do feel there are people looking at me what are they going to think?
>
> **(MO-CH-02 Female 71)**

Patients also had concerns that did not directly relate to exercise, such as feelings of being self-conscious about joining a new group of people and fear of possible emotional distress due to the location being where their partner had died. These concerns made patients apprehensive but did not prevent enrolment.

6.1.3.2 Prior mitigation and selective inclusion

All the services had experience of offering exercise programmes to people with serious health conditions. Therefore, many potential impediments had been managed through design and planning before being offered to prospective patients. HCPs also had access to health records, and all patients had been assessed as capable, through review of medical notes and discussion with other professionals, before being offered the opportunity to enrol. However, the selection of participants prior to being approached could have a positive and negative influence on enrolment. In the case of the EMBRACE programme, strict inclusion criteria meant only suitable patients would be approached:

> HCP: There is always an assessment of the patient isn't there, whether do you think they will be able to cope with the additional intervention of the clinical study…. So if they met the criteria I felt it was worth having that discussion.
>
> **(EM-ST-07 Enrolment)**

However, hospice HCP accounts indicated communication with other services to be less well developed. Examples were given where other HCPs were selective in who they referred, and it was suspected could have prevented some patients from being given the opportunity to enrol:

> HCP: I think they (oncology HCPs) are looking, and thinking “now you do not have to be palliative yet”. “Nothing is going to change imminently and you know you are quite high functioning on AKPS” [Australia-modified Karnofsky Performance Status] ….“you are pretty good”….. They do not feel like it is a good label to give them... These groups should be oversubscribed, and they are not, probably for those reasons.
>
> **(MO-ST-01 Design and delivery)**

It was also suspected by HCPs delivering the hospice programmes that patients being referred at a later stage in their disease course was limiting the extent to which they could benefit from the exercise.

6.1.3.3 Predicted inability to participate.

Other reasons reported by HCPs for patients not enrolling related to impediments such as being too unwell, particularly with fatigue and breathlessness, not wanting to exercise with other people or in a group, transport and distance, finding the proposed hospice location too upsetting, or commonly in the EMBRACE trial, finding all the new information and additional tasks associated with their new diagnosis too overwhelming to want to take on anything extra:

> HCP: the few that said no were “sorry…. it is too much for me to take on board, my head is spinning with that news” that was the main thing. There were not any other consistent barriers issues that you might have thought may be an issue… it was more a generic “it is all too much”.
>
> **(EM-ST-05 Enrolment and delivery).**

The above quote highlights how multiple issues occurring all at once could be hard to deal with for patients and lead them to predict that they would be unable to successfully participate.

6.1.4 Second conscious decision: during the trial period

This section concerns the second conscious decision patients had to make. Patient accounts revealed that very few enrolled with the intention of committing to the entirety of the programme. For the majority their intention was to give it a try and then make a decision whether to continue. Most HCP accounts suggested they were aware some patients may be testing the programmes to check if they should continue, but were unaware that this was the majority. The earlier decision as to whether or not to enrol, and, the later decision regarding whether or not to continue to attend each session were integral to the programme itself. However, the ‘Trial period’ was different in that the intention to try the programme for a short period first was constructed by patients’ own thoughts. Only occasionally was trying the programmes first suggested by health professionals, or by family if asked for their opinion:

> Patient: [name of CNS], suggested that I come to this, because they might help me in a lot of things... I thought about it for some time. Then I spoke to my son, and he said “well dad you are not going to lose anything”. “You really do need to go and see what it is all about”. So I decided then that I would try and come to see what it was like. If I did not like it then I didn’t come again.
>
> **(MO-CH-01 Male 80)**

Patients entered the trial testing for themselves to confirm their expectations for joining (should they do it?) and/or alleviate concerns they had regarding the feasibility of them participating (could they do it?). For patients to conclude they “Should do it”, their anticipated ‘Drivers of participation’ had to be confirmed or reassured as likely to occur. To also conclude they “Could do it”, work usually had to be carried out by themselves and others towards successful ‘Mitigation and accommodation of impediments’.

The programmes had very different aims and approaches, which may not have been apparent to patients during enrolment, but became apparent once the sessions started. EMBRACE, was intended to achieve the biggest impact upon a persons’ fitness to generate the greatest benefit during the supervised period. To do this it was highly specialised involving specific equipment and strict protocols:

> HCP: I would definitely want this kind of session rather than a gym membership… this is very real science, the exercise physiology that they are doing…So I would want, basically the biggest bang for my buck… best results for the time spent… this is what this is designed to deliver…. The high intensity interval training is specifically for that.
>
> **(EM-ST-05 Recruitment and delivery)**

Conversely, the intention displayed in the Chairs class and to a lesser extent the Circuits class, was a focus upon increasing activity away from the classes with less impetus placed upon improvements occurring during the supervised period. They employed less specialist equipment and less intense exercise.

> HCP: My goal for [patients] is giving them something that they can realistically carry on. Which is why I have changed the classes slightly so that there is more repetition. So they get used to what we are doing….. I think if you are more familiar with something and then they get their exercise booklet at the end hopefully they will feel that they can carry on….it has, hopefully, motivated somebody to do something rather than nothing.
>
> **(MO-ST-04 Design, recruitment and delivery)**

Both approaches were intended to best meet the needs of people with advanced cancer and are vindicated by the experiences of staff. The EMBRACE approach involved understanding that time was precious for people with advanced cancer and so sessions should seek to maximise improvements in fitness in a short period of time. The hospice class approach was built on the view that people with advanced cancer continuously have to accept various losses and do not want overly strenuous exercises which may become yet another source of failure or loss if patients were not able to continue in the future:

> HCP: There is nothing worse than saying do these exercises it will be really good for you, and then they developed a problem that those exercises will not help with, and you go "okay then do not do that anymore do this, and maybe do not do them so hard".
>
> Interviewer:….You try to choose things that they will be okay with for the long haul rather than "do that", "now you can't do that"?....
>
> HCP: Yes. Because then I am contributing to the goalposts moving. So I definitely take that approach, and that makes them feel more confidence in me and confident in themselves and confidence in the exercise.
>
> **(MO-ST-01 Design and delivery)**

6.1.5 Drivers of participation.

During this period participants were continuously testing to determine if the benefits they anticipated would occur. HCP accounts showed that patients had varying reasons for taking part, and varying levels of understanding as to why they were attending. HCPs had to appreciate patient differences and convey suitable reasons to continue.

For patients to continue they had to decide it was worth their while to do so. This was down to finding some form of improvement or benefit in response to the exercise, or through attendance itself providing its own inherent benefit. For most patients multiple positive consequences occurred, and encouraged further participation:

> Patient: The first few weeks I thought…"Am I wasting my time going there can they do anything for me?" Because I had sort of given up,… after about three weeks I started to feel, I enjoyed coming here, it is doing me a lot of good….I noticed improvements in not only my body but in my mind…. I look forward to it in the week I think Tuesday is coming round…it has given me some motivation to do these things.
>
> **(MO-CH-01 Male 80)**

6.1.5.1 Gaining predicted benefit

Patients enrolled with expectation or prediction of what they would gain. Interviews indicated that if the interventions did not produce the benefits anticipated patients would consider them a waste of time. For patients to decide to continue expectations had to be met, or at least be reassured as likely to be met.

In both the Chairs and Circuits class an early physical improvement noted by patients included easing of pain and stiffness in joints and muscles:

> Patient: I sit a lot, I read a lot, and that is very sedentary, I do find myself getting stiff and sometimes even getting sore, and I find that doing exercises that I have been taught in the classes eases my muscles and make me a lot more comfortable.
>
> **(MO-CH-07 Male 88)**

However, some expectations could not be met immediately, and would take more weeks to develop, particularly those which required some form of cardiovascular or muscular adaption:

> Patient: I did not think it was very strenuous at first I thought “this is not going to do a lot of good” but it did, you know, I did notice that over weeks I could do things that I could not do before.
>
> Interviewer: So it took a few weeks for you to start notice?
>
> Patient: It did yes it did.
>
> **(MO-CH-01 Male 80)**

In the most intense intervention, EMBRACE, the repetitive nature of the exercise meant both HCPs and some patients reported the exercise becoming easier soon after the first session:

> HCP: It has happened in two weeks, because in some of the other trials we do it has been three sessions a week for two weeks. That is still six sessions. If they really struggle on the first session by the fourth session they can complete it much easier, they have already seen a benefit and that is a week….The adaptations (physiological adaption to exercise) that you can make in that time I think is really good, really important for them.
>
> **(EM-ST-08 Delivery).**

In addition to this the collection and reporting of physiological data reassured patients of likely benefit sooner than they noticed themselves:

> Patient: He did say to me (research HCP), I think the second time we come here that it was up 10% percent…. something to do with the oxygen in the blood…. you know it was up.
>
> Interviewer: one of the indicators of your fitness levels?
>
> Patient: Yeah, that’s right, it was up by 10%.
>
> **(EMB-014 Male 76)**

Some patients who did not notice any benefits during this period, in the hospice programmes, still continued as they had been reassured by elements of the exercise that benefit would likely occur.

Reasons given by patients which reassured them of likely benefit included exercises replicating functional activity such as getting out of bed, physical sensations they felt in their bodies during and after the exercises, or staff descriptions of what each exercise was aiming to achieve. Other patients simply remained faithful that exercise must be of benefit to them because they trusted the service would only be offered if it was likely to benefit those asked to attend:

> Patient: I am pretty sure that, doing the exercises that they (the service) give you there has to be some benefits otherwise you are wasting your time doing it.
>
> **(MO-CH-03 Male 76)**

Patients in the EMBRACE study were primarily participating for the sake of others, predominantly helping others with cancer in the future. Seeing data being collected as they participated in the EMBRACE programme, reaffirmed what they were doing would be of benefit to others "*I know that the information is being recorded*' (EMB-015 Male 64), and so were happy to continue.

Some patients chose to enrol on the relevant programme because they anticipated benefit such as receiving specialist knowledge from staff, and benefit from joining a group. These benefits occurred very quickly and immediately impacted on intention to continue. Patients joined the Circuits and Chairs programmes because they anticipated a benefit from the group format. Interaction with a group provided different kinds of benefits for different patients. For some, it provided them with motivation to exercise harder. For others the benefit provided by the group had little to do with exercise but provided a social interaction they felt was missing from their life:

> Patient: I just thought, not only that it gets me out…when I go there (local gardens), I was on my own, you can have a cup of tea at the café but you are on your own, whereas I can come here (exercise classes) have a cup of tea and a chat. It was a relief for me. That was the reason I came, and that was the reason I kept coming.
>
> **(MO-CH-01 Male 80)**

Patients derived benefit from the fact they were meeting not just other people, but people with the same illness, and concerns they had, believing it is good to meet "*people in a similar situation to myself*" (MO-CR-02 Male 69).

Patients who joined due to prediction of receiving specialist knowledge, often hoped to learn how to return to exercise safely with their cancer. These expectations were met and contributed to their continuation. However, one patient, who greatly valued the knowledge he gained, had not previously anticipated this. He had joined to meet other people which he hoped would improve his low mood. This expectation was met, but he also quickly gained an understanding of exactly why exercise was important for him, and how to exercise safely with his condition:

> Patient: I find the class to be very informative very helpful, quite detailed… very thought-provoking and useful….They have helped me to realise the need for exercise, and they have helped me to realise that although an elderly man, because I am 88, I can actually exercise and benefit from It.
>
> **(MO-CH-07 Male 88)**

This demonstrates that as well as meeting peoples' expectations it was possible for HCPs to influence patients and give new reasons for continuing. However, whilst any new reasons may increase the drive to continue beyond the trial period, if anticipated benefits were not met, new reasons alone were insufficient.

6.1.5.2 Development of unexpected benefits

As well as predicted benefit, other benefits emerged, most commonly enjoyment. Enjoyment was generated by many influences. For a small number it was an intrinsic pleasurable feeling from the movement of the exercise. A common element to patients experiencing enjoyment was the input of HCPs, which was felt immediately. HCPs ensured patients felt welcomed and did not expect them to try things they were unable to do:

> Patient: What I have liked, you are welcomed….You are not pushed to do things you cannot do. You are allowed to go at your own pace as well….Everybody is friendly, they make you feel at home…. There is no, is the word, "discrimination". There is no "oh you are in a wheelchair you cannot do this". You are all treated the same, which is good….I just basically feel welcome that is the only way I can put it.
>
> Interviewer:….that is a feeling that started right from the first class?

> Patient: yes .
>
> **(MO-CH-02 Female 71)**

Staff were reported by many patients to use humour to develop enjoyment. Humour was reported to release nerves or concerns patients initially had and contributed to continued participation:

> Patient: The staff that have been here they have really been very helpful. They have been always been, in a good mood, you know, they never put you off from coming. I think the general sort of way of treating you is very good….they have a laugh, and a joke, it just sort of. It eases tension when you first come into a class like this and you were not knowing what to expect.
>
> **(MO-CR-04 Male 74)**

Although enjoyment was an important driver, it did not appear sufficient to lead to continuing attendance through the trial period. Patient EMB-025 enjoyed the sessions but did not believe they were providing the non-specific health benefit for which she enrolled. Conversely, she suspected rest would be better for her, and so withdrew. This was supported by the views of other patients who enjoyed the social elements of the group classes but said they would not be interested in joining other, purely social, classes as they would not provide the purpose for which they had joined the exercise sessions. When exercise sessions clashed with other socially oriented classes, both were considered enjoyable, but exercise classes took priority:

> Patient: ….I have cancelled things so that I can come here. My art group …I miss them to come here. I am missing them regularly….to come here. I think it is more important. …I feel it is important to take advantage of the fact that it is being offered, and it is good for me.
>
> **(MO-CR-03 Female 68)**

Furthermore, two patients in the EMBRACE trial reported very little enjoyment, but had been reassured their contribution would benefit others. This was their reason for enrolling, and so they were happy to continue despite little enjoyment. Conversely when one of the patients who dropped out of the hospice classes was asked if she would have continued had she enjoyed the classes, she replied “*Possibly but that was not why I came really*” (MO-CH-05 Female 72).

HCP accounts revealed generating enjoyment to be a deliberate strategy to enhance adherence and reported success with this:

> HCP: I had one patient in chairs who for the first week….she felt it was not an appropriate class for her because she had done pulmonary rehab, classes in the past. We said to her why don't you give it a go….. By week two we were playing chair bingo which she loved... and she did the whole eight weeks and actually found it quite beneficial.
>
> **(MO-ST-03 Delivery)**

This indicates enjoyment was an important secondary driver of attendance at this point, but only if patients' anticipated reason for joining was believed to have been met or likely to be met.

6.1.5.3 Without benefit, programmes were unacceptable.

All participants had reasons to not attend. When anticipated benefits were met these were of minimal influence. If the anticipated benefits were not met, the reasons to not attend took on greater influence and participants developed a negative view of the session. For two patients anticipated reasons for joining were not met, they also suspected continuing would be detrimental to them, so dropped out. Patient EMB-025 enjoyed the first session, particularly what she referred to as the camaraderie with staff. But, when she started chemotherapy treatment, became unwell with fatigue and believed she stood a greater chance of recovering more quickly if she rested, rather than attend the sessions. She had joined the study with the 'Prediction of a non-specific benefit', she did not notice any benefit, suspected it may be detrimental to her recovery, and so asked to withdraw:

> Participant: I just wanted to see, if it would help. But I got so far and I said to Dr [word removed], I couldn't, I felt dreadful…. I just thought because it was suggested to us I thought the programme would have been really experienced, and there would have been loads of people doing it, which would mean it must be working. But it didn't…once the chemo went in….it knocked me sideways and I thought no, I am dragging myself out, and the family.
>
> **(EMB-025 Female 77)**

She experienced several difficulties associated with attending sessions including long journey times and felt guilty that she had to rely on family to provide transport. She also experienced fatigue and nausea after starting chemotherapy which made both attending and performing the exercise more troublesome. She was encouraged by her family to stop, who felt the exercise and associated burden related to participating in a trial was not something a patient should be doing:

> Participant:…my son said when I spoke to him on the phone 'hang on a minute mum you are the patient'…. He said 'come on mum there must be somewhere closer'…He said 'you are the patient and you are feeling like you do, you are dragging yourself over to that hospital'.
>
> **(EMB-025 Female 77)**

Despite chemotherapy being the cause of many distressing side effects, which impeded exercise and daily life, she anticipated specific benefit from chemotherapy and it delivered that benefit. Benefit produced was considered to outweigh any negative issues the treatment caused:

> Patient: As I say it is, the chemo has not been very good to me has it really. Well it has because it (the cancer) has shrunk tremendously.
>
> **(EMB-025 Female 77)**

She therefore sought to have as much chemotherapy as permitted and spent the interview eagerly anticipating a telephone call to tell her when her next treatment session could be. This participant gained an important benefit from her chemotherapy so was prepared to tolerate the physical side effects it caused as well as the burdens associated with attending chemotherapy sessions, such as long journey times and being dependent on others for transport. Conversely, exercise, was thought to cause no benefit, and so the same associated burdens of attending like long journey times and guilt of being dependent on others, were reasons the participant wanted to withdraw. This suggests burdens associated with an intervention are acceptable if the benefits achieved are considered worthwhile. The other patient who withdrew, MO-CH-05, had a very different experience. This patient was experiencing a period of improving health following radiotherapy, and was beginning to re-engage with old exercise routines. She had joined with the 'Prediction of specific benefit' and 'Prediction of benefit from joining a group'. During the trial period she concluded the exercises being offered would not be intense enough to provide her with benefit, because she was much fitter and in much better health than others in the class:

> Patient: When I first came, I thought that it would be a mixed class of ages, and, different types of cancer. When the people started coming in they were all so much older than I was, also they seemed to be in a much poorer state of fitness than I was. I felt the classes were not going to really be of any benefit to me.
>
> **(MO-CH-05 Female 72)**

This participant felt attending regularly with others who were in worse health than herself would be detrimental to her state of mind. The experiences of these two patients highlight that if anticipated benefits are not met, or reinforced as likely to be met, patients typically conclude the sessions to be detrimental and withdraw. This conflicted with many HCP accounts which indicated patients withdrew solely due to being too unwell, as this was usually the reason HCPs had been given:

> Interviewer: Okay. They had all dropped out before week six, or were removed before week six?
>
> HCP: Yes.
>
> Interviewer: In each case it was because they had been to unwell?
>
> HCP: They had felt too unwell, to be able to carry on yes.
>
> **(EM-ST-01 Recruitment and delivery)**

Typically HCP's were only aware of the influence of the physical illness when participants withdrew, they had not been informed about the disillusionment that occurred if participants began to feel they would not gain benefit.

6.1.6 Mitigation and accommodation of impediments.

At enrolment patients had predicted how feasible they thought it would be for them to participate in the programmes. At this point they were testing that prediction. Patients faced several challenges which influenced their ability to participate in the exercise programs. Their cancer, treatment side effects, other comorbidities or short term illnesses, travel, and initial anxiety about the sessions, all posed challenges. To mitigate the impact of these impediments various features of the exercise programmes, strategies of the participants, or resources such as family and friends were employed. If the impediment could not be mitigated entirely patients had to accommodate it somehow if they wished to continue.

6.1.6.1 External mitigation

External mitigation involved anything which made impediments less severe or reduced their impact upon the patient, but not controlled by patients directly.

Generally, patients found most of their initial concerns were unfounded. Prior mitigation by the service ensured only suitable patients were approached, and at the start of the programmes further assessments were conducted to ensure patients were suitable:

> Patient: Things have been set as to what they know of my condition. It is all very informed.
>
> Interviewer: Am I right in thinking then from what you said, at the start of the classes the physiotherapist finds out a lot about you?
>
> Patient: Yes, in fact they already have notes about you beforehand.
>
> **(MO-CR-03 Female 68)**

The patient who had earlier been concerned about being unable to do the exercise in front of others found the attitudes of staff and other patients alleviated her fears:

> Interviewer: So related to the shyness you were worried of coming and not been able to do some of the things other people seeing you not been able to do these things….
>
> Patient: Letting myself down….that is the way I see it.
>
> interviewer: From what you have said after the first class, that was something you worried about less?
>
> Patient: That’s right yes I felt at home with the people, I felt comfortable.
>
> **(MO-CH-02 Female 71)**

The greatest influence on participation was the input of HCPs delivering the sessions. HCPs assisted patients by planning for potential issues from the start and 'trouble shooting' issues as they arose. Patients' trust in staff due to their professional knowledge was key to patients persevering with the exercises. Staff would tailor exercises in advance to ensure it was safe and achievable and accommodate any existing problems or concerns the patients had:

> Patient: I was not prevented from doing the exercise it is adapted.
>
> Interviewer:…Was it the physiotherapist's suggestion that adapted it?
>
> Patient: yes…. Certainly, I mentioned the ball, lifting the ball I was told just to lift it to 90 degrees.
>
> **(MO-CH-04 Female 71)**

Staff ensured patients knew exactly how the exercise should be performed, and if any difficulties were experienced in any aspect of the programmes, would rectify this immediately. This included a variety of issues which needed attention, including resolving incorrectly issued car parking penalties and fixing uncomfortable cycle ergometer saddles. More commonly when patients struggled with an exercise staff would offer alternatives or encourage them to rest and restart when ready. Staff made sure patients realised this was normal and not something for concern:

> Interviewer: So there have been no occasions where you've had to stop because your symptoms have started to get worse, for example the pain?
>
> Patient: What they do is they adjust it. If I say it is hurting me…. they will just adjust it and we will do it a different way instead. So it has never actually stopped me.
>
> **(MO-CR-03 Female 68)**

The other frequently used resource patients called upon was family and friends. There was no deliberate attempt in the programmes' design to utilise support from friends or family, but many patients used them for support. If an issue arose which was unaccounted for by staff, family or, typically for those without family, friends would help if they could. This could involve reminding patients of the times of appointments or making food to bring to the session to help control blood glucose levels. If patients could not drive, family or friends would provide transport or accompany them. Those participants with effective support networks knew who could support them and used them accordingly:

> Patient: my colleagues from work (now retired) have got a rota to get me here on Tuesdays… I ring them up...
>
> **(EMB-016 Female 58)**

HCP accounts agreed that family were often involved in supporting patients and that common methods of support were employed across different families:

> HCP: ….Often with EMBRACE, family members would be doing the admin so we would end up ringing the family member…. booking appointments everything went through them…. I would say there was a good involvement with families.
>
> **(EM-ST-05 Enrolment and delivery)**

The final source of support patients acknowledged was the service delivering the programmes. The service required no costs to be met by patients, car parking was free or reimbursed, transport was often provided by volunteers for those who needed it, and session times were acceptable. In the EMBRACE group session times were co-ordinated to not clash with clinical appointments and flexible to participants' requests. Mitigation of potential impediments by the service was mentioned less frequently than others, possibly because much of it occurred without the conscious realisation of many patients.

6.1.6.2 Self-mitigation and accommodation.

Patients who wanted to exercise, took steps to maximise the likelihood they could. Whereas there were examples of participants for whom difficulties with transport were reasons to not enrol or contributed to withdrawal, there were also examples where they relearnt to drive independently so they could attend:

> Patient: When I got really ill I gave up driving, this made me start driving again, so that was good. It was challenging.

> **(MO-CR-03 Female 68)**

Strategies were established at the start to manage obstacles, or developed in response to issues as they arose. Patients took steps to make unpleasant elements less unpleasant. For example, distracting themselves with music if the intensity of the exercise caused discomfort. Many patients brought pillows or purchased their own saddles to mitigate discomfort felt when using the exercise cycles:

> Patient: I had to buy a gel seat….I don't know how skinny bums get on.
>
> Interviewer:…I take it the saddle was uncomfortable?
>
> Patient: Oh my yes….
>
> Interviewer: How many sessions did you do it, before you thought "I need a different saddle"?
>
> Patient: One.
>
> **(EMB-016 Female 58)**

However, these attempts were not always successful, and sometimes despite several attempts, patients would have to accept that if they wanted to exercise they may have to accommodate some discomfort:

> Interviewer: You didn't like the saddle….You adjusted it? ….and you took a pillow?
>
> Patient: and I just got on with it after that.
>
> **(EMB-014 Male 76)**

Patients took steps to minimise instances where other commitments prevented attendance. Diaries were planned around sessions, if possible medical appointments were scheduled for different days, and social events cancelled if they clashed:

> Patient: We have set aside Tuesday afternoons.

> Interviewer: Tuesday afternoons have become an established slot in the diary?....Is that something you did deliberately, straightaway?...
>
> Patient: Yes, yes it is an eight-week course so it has gone down on the calendar.
>
> **(MO-CH-04 Female 71)**

To mitigate the impact of their disease on ability to attend the weekly sessions one patient took weekly pre-emptive analgesia, and an ostomy support belt to manage his bag when exercising, and admitted *“I would not be able to do the exercise without the belt”* (MO-CR-02 male 69).

Not all effects of their cancer could be mitigated, and patients had to accommodate them accordingly. Pre-session analgesia would only lessen their pain rather than eliminate it, and often fatigue and breathlessness could not be eliminated and caused patients to pause and rest when necessary:

> Patient: I get tired on almost the slightest exercise. The exercise does make me tired and I have to recover so that I can continue…never to the point that I cannot do the exercise.
>
> **(MO-CH-07 Male 88)**

A small number of patients had entered the trial period already decided they would continue. For them they had said they would, so they intended to keep to their word. In these examples, engagement with the exercise sessions, even when experiencing worsened consequences, was a must. They would not allow themselves to miss the sessions and also looked for reasons that they should attend:

> Interviewer: Have there ever been any times when you’ve considered not coming?
>
> Patient: No it wouldn’t cross across my mind…., if I was any other sort of person I wouldn’t have gone to the session yesterday. I was covered with hives…. It was appalling, and that itch was out of this world….. But I still went. I thought “well it will take my mind off it won’t it” [Laughs]….
>
> **(EMB-016 Female 58)**

6.1.6.3 Absence of mitigation and accommodation

So far different ways in which impediments were mitigated or accommodated have been explored, however on occasion participants were unable or unwilling to do so. If impediments were not mitigated suitably, and patients failed to accommodate them, they did not perform the exercise. The question regarding the feasibility of following the programmes was not a straightforward 'Yes' or 'No'. Most patients found they could do the exercise, but not every session and not every exercise. Even in this short trial period patients would on occasion be unable to attend a session, but most returned when able to:

> Patient: The only one I missed was when I was ill over Christmas….
>
> Interviewer: So you missed that one early on, but then went to all the other ones?
>
> Patient: Yeah.
>
> **(EMB-015 Male 64)**

More frequently patients were unable to perform individual elements, and would simply rest or perform different exercise instead:

> Interviewer: Were you ever stopped from doing the exercise because it caused more symptoms to develop?.... Has the exercise ever caused pain for example and has that caused you to stop doing it?
>
> Patient: It has certainly caused my existing pain to come on. On the stepper, I just had to stop for a bit that is all.
>
> **(MO-CR-02 Male 69)**

Programmes had been tailored by HCPs to ensure they were physically challenging, achievable and safe. It was rare for patients to miss an exercise session. This would only usually occur if their ailments reached a severe level, often to the point of warranting hospital admission, once out of hospital they returned to the next session:

> Patient: I’ve got this flu bug….. I couldn’t throw [it] off, what I have got, it makes it difficult to throw off anything.
>
> Interviewer: I see, because of the cancer it’s difficult to get rid of the flu or the cold?
>
> Patient: Yeah, one holds the other, once I would start getting better then it would get going again and I was in and out of hospital for a couple of times in that period.
>
> **(EMB-015 Male 64)**

Many HCPs felt that the effects of cancer and chemotherapy treatment were the greatest contributors to withdrawal from the programmes. Patients who experienced more disease progression, or significant toxicity from treatment experienced greatest difficulties in continuing. Conversely those who experienced less progression or less toxicity were able to adhere for longer:

> Interviewer:… What do you think is the most important thing to consider when trying to maximise exercise adherence in this patient group?
>
> HCP: General health, is the most important thing….The major challenge comes when people either have toxicity from treatment or from progressive disease. Under those circumstances people find it very difficult to adhere.
>
> **(EM-ST-03 Recruitment)**

The only patient who concluded she “could not” continue to participate in the program was EMB-025, who felt too fatigued while undergoing chemotherapy and asked to be withdrawn from further participation. During interview she also described various inconveniences associated with attending; she did not find it beneficial and expressed a belief that participation in the exercise program was not congruent with the role of being a patient. She did not report any mitigating strategies or attempts at accommodation. This patient said that if she were not feeling at her best she would not attend:

> Patient: It just knocked me sideways so they brought me in and I missed the chemo appointment because of it. And we had to start more or less again so that is why I said no I

> cannot do it. It is too much. It is too far to come to be honest with you and if you are not feeling 100% you don't. You're the patient.
>
> **(EMB-025 Female 77)**

While patients often described going to great lengths to mitigate or accommodate unpleasant elements of the programmes, HCPs reported many other patients did not and consequently withdrew from programmes. Typically, this would take two sessions, the first would raise the suspicion something was wrong, and if the second session confirmed this, there would not be a third session:

> HCP: There have been patients that haven't got through the first session…. the seat, would have been one thing….which is why I mention it's a big part. I would say they have been maybe the more frailer patients that have said that, and two, they have just been so tired that the resistance they found too much….they've had to stop that first session.
>
> Interviewer: How would they respond to having to come in for a second session? Did they generally come back?
>
> HCP: Yes, some of them then didn't continue after that second session they'd give it another go again….If the seat was uncomfortable then that would be it.
>
> **(EM-ST-08, delivery).**

Older patients were thought to be less able to mitigate or accommodate impediments to exercise. It was felt this was in part due to higher levels of frailty but also due to lack of previous exercise experience:

> HCP: Patients tend to be older so I think that possibly their threshold is lower, especially when it comes to exercise…
>
> Interviewer: When you say threshold what do you mean?
>
> HCP: Younger people I think possibly the younger generation understand that exercise is hard work….Whereas I think that the older generation do not quite understand that as much ….they go until they get breathless. Then they think this isn't right I need to stop

> now…but obviously we know that to go as long as you can go means pushing yourself to the limit, and I do not think they do that. ….for them to think, “I do not feel well” “I had chemo last week” “I feel a bit under the weather and I have got to do an exercise” “it makes me feel tired and it is hard work” I think their threshold possibly is lower, to cancel….the older generation I do not think did exercise for the sake of doing exercise.
>
> **(EM-ST-01 Recruitment and delivery)**

It was also felt older patients were less likely to mitigate or accommodate potential impediments around the practicality of attending, or changes to appointments times:

> HCP: Sometimes getting into the hospital was a bit tricky especially if the patient was older. It tended to be more of an ordeal. Whereas younger people…. would say “oh I am coming into the hospital for this” or “I can just squeeze this in”….. Sometimes the older patients say “I am doing this on this day so I cannot do anything else”. If they have got an appointment and they had to go and do something else and we said “we can fit you in in the middle” it tended to be “oh no I could not do that”.
>
> **(EM-ST-01 Recruitment and delivery)**

The decision patients made as to whether they “could do it” or “should do it” appeared not be made in isolation from one and other. For some patients finding they could perform the exercise and the resultant sense of accomplishment became an additional benefit in itself, and may have contributed to the drive they should do it:

> Interviewer: You mentioned you felt it did you good, in what ways do you think it did you good?
>
> Patient: It lifted me up….. It made me feel I can do something, rather than just sitting on my chair (wheel chair) I can do something in my chair. So that made me feel good.
>
> Interviewer: Like a positive can-do feeling is that right?
>
> Patient: yes.
>
> **(MO-CH-02 Female 71)**

Patient EMB-025 decided she “could not do it”, primarily due to fatigue following chemotherapy. But this patient also decided there was no health benefit to attending, and thought the session may be detrimental compared to resting, therefore she “should not do it”. Several patients who achieved their anticipated benefits experienced these same negative potential impediments, however they either overcame these difficulties, or waited for them to subside, then continued once they had abated.

6.1.7 Third conscious decision: attending the next scheduled session?

For the remaining supervised period scheduled appointments focused patients’ thoughts on whether to decide to attend. Patients reported the appointment acted as an anchor which drew them back from whatever was going on in their lives. Patients could not forget the appointment, or avoid the decision; a HCP called to confirm a patient’s planned attendance, as per programme protocols, forcing patients’ attention from their daily life, for that moment, to think about exercise, and whether they would attend the next session.

6.1.8 Drivers of participation.

At this time, patients who continued past the trial period already felt their anticipated benefits were being achieved, or likely to be achieved. Now, confirmation of these benefits continued but more unexpected benefits emerged, relating to what participants wanted or needed in their lives. According to patient and HCP accounts, identified benefits included both psychological and physiological factors, although it was difficult to differentiate which was considered the most beneficial consequence of the programmes. A strong relationship had also developed between patients and HCP and contributed to a sense of obligation to attend.

6.1.8.1 Physical benefit

Previously, in the trial period, physical benefits experienced were largely limited to increases in range of motion as joints adapted to the stretches performed in the hospice classes or the interval training feeling easier after the first few sessions in the EMBRACE trial. Now in the later period more participants reported a greater range of benefit. Physical benefits reported to have occurred included improvements in strength, range of motion, shortness of breath, physical ability to maintain independence, balance, walking, ability to maintain their hobbies, reduction in pain, improvements in sleeping, and slowing physical decline. Some of which were anticipated, others were not. HCPs believed patients who did not achieve improvements were less likely to remain motivated to continue; patients confirmed if the programmes progressed to the later stages without benefit they would consider the exercise a waste of their time:

> Interviewer: If you had done the class for four or five weeks and had not found improvements, in your feet, and had not found improvements in your strength, can you imagine what you would think about it then?
>
> Patient: If I had not noticed any benefits I would be thinking it was a waste of time, and it was not a waste of time. Because I gained some of what I had lost.
>
> **(MO-CR-04 Male 74)**

Some HCPs revealed work at the start of the programmes with patients, to explain the benefits of the sessions and find out what they wanted to achieve:

> Interviewer: How do you find out what it is that they are trying to achieve?
>
> HCP: Asking them, talking to them….at the beginning of the classes what I do now is I meet up on a one to one. To get to know a little bit about the history what they think the problems are and areas of weakness.
>
> **(MO-ST-04 Design, recruitment and delivery)**

Patient accounts revealed this initial conversation was successful, as they were given exercise to meet their specific needs. This conversation helped reassure participants through the trial period that benefit was likely to occur, then in the later period it meant the benefits that did occur were of value to the participant:

> Patient: She (physiotherapist) said to me what is your major problem and I said balance. She said well work on this and when you come to the group we will do a load of exercises to improve your balance. So I think that is why I have improved on that
>
> **(MO-CH-06 Male 81)**

If HCPs knew what patients wanted to achieve, they could explain how each exercise was intended to help with that issue. As the programmes progressed, more patients found those exercises effective and this furthered their drive to participate. Conversely patients who primarily joined the classes due to anticipating a non-specific benefit were less able to pinpoint and describe any improvements.

As programmes progressed, improvements in ability to perform some of the exercises repeated from week to week provided feedback to patients. This suggested increases in their fitness and continued to reinforce the belief that it must be producing benefit. HCPs across all programmes considered feedback to highlight improvement extremely important. The EMBRACE data collection allowed the quantification of any improvements they may be generating, this was considered important in these programmes and in other trials HCPs had been involved in:

> HCP...I think from feedback from the focus groups that was something a lot of patients, all different EMBRACE and ENCOURGE and EMPOWER they all wanted more feedback.
>
> **(EM-ST-02 Recruitment and delivery)**

Noticing benefit in this patient group can be dependent upon general health and stability of disease. The patient below had noticed improved strength between sessions but acknowledged it may have been due to a general improvement in her condition:

> Patient: I have enjoyed them, I think I have probably been able to do more, the more I have come. So I have got stronger, that might not be the classes itself but my general exercise, well my recovery from being in the hospital.
>
> **(MO-CH-04 Female71)**

Some felt the progressive nature of their disease prevented them from experiencing benefit but felt it must still provide some worth even if they did not notice it:

> Patient:….I am never going to know really because the breathlessness side of this is never going to get any better.
>
> **(MO-CH-03 Male 76)**

Most patient accounts revealed some form of benefit was experienced. But HCP accounts varied; some reported patients expressing benefits while others did not. Some felt patients were being referred to the service too late in their disease course to achieve the most benefit. The uncertainty of the physical benefit experienced by some patients led some to question whether the overall benefits generated could be achieved in a less physically intensive regime for the patients:

> HCP: I think it was emotionally beneficial to some of them….but I do not know if it was physically. I'm not saying it was physically negative obviously that is what the study will look at….. It looked really hard work….just had chemo, and do all of that cycling….I am wondering…. was it may be just being able to interact with other people ….where they felt safe and had some sort of emotional well-being….with people who are willing to care and look out for them and would escalate their needs.
>
> **(EM-ST-02 Recruitment and delivery)**

Another benefit occurred from attending the sessions not directly related to the exercise. Across all programmes, professionals reported providing an enhanced care package to patients. This was believed to be something patients appreciated and were grateful for but not mentioned in the patients' accounts. Attendance at an exercise session became an opportunity for additional assessments or to show professionals a specific problem, for example a patient attended with a suspected deep vein thrombosis specifically so they could show the professional. Contact telephone numbers of health professionals delivering the sessions became a much quicker way to get messages to, and hear replies from, their medical consultants or other health workers:

> Interviewer: So in a way being part of this study gives an extra little check-up each time they come in?
>
> HCP: Yes I think they really appreciate that. I think they feel they are being looked after and they know that obviously the things that we do are to make sure they are okay and that if we have any concerns we will speak to someone and let them know
>
> **(EM-ST-01 Recruitment and delivery)**

If patients knew what they want to achieve with regard to specific physical benefits they were more likely to notice that benefit. Whereas the nature of their condition and general fluctuation in general health made noticing non-specific health benefits difficult.

6.1.8.2 Psychological benefit

Both HCP and patient accounts were more certain of noticeable psychological benefit than physical benefit. When asked as to their reasons for joining the classes few patients enrolled primarily with the hope of anticipating psychological benefits from exercise, but those who had hoped to benefit psychologically as a secondary driver did so:

> Patient: It is very much on my mind, thinking that by now probably already be far worse off than I am, just because of the fact that the exercise is there and I've got to get to it as well, and all the other things that are connected to it. Not just the exercise itself. They keep you going, it fills in time, gives me a positive attitude towards it rather than sitting around and thinking "oh I'm dying".
>
> **(EMB-015 Male 64)**

Examples of psychological benefits were reported such as reduced levels of low mood and depression, greater confidence in ability to maintain independence, reduced stress, distraction from the disease, increased feeling of normality, a desire to do more of their previous activity and routines each day, or simply being happy.

Perhaps the greatest psychological benefit participants gained was enjoyment. The extent patients enjoyed the programmes cannot be overstated. After the programmes had ended patients reflected back with immense positivity:

> Patient: It was a very joyful and happy time because it was not only the exercise we did but we used to have quite a laugh.
>
> **(MO-CH-01 Male 80)**

Few people enrolled anticipating enjoyment, however, it became one of the key drivers for weekly attendance. For many, particularly those who noticed less of any other benefit, enjoyment became the main positive consequence of the programmes:

> Interviewer: What do you think is the most important thing to say about the classes from your point of view?
>
> Patient: Well enjoyable…. Because even if it just cheers you up that is beneficial, you know, I always walk out of here with a smile on my face, I always say to my little un (daughter) I enjoyed myself this afternoon.
>
> **(MO-CH-03 Male 76)**

The same person felt that if patients did not enjoy the session, rather than looking forward to attending, they would look for reasons not to attend. This demonstrates how enjoyment gained significance for participants as the programmes progressed. In the later stages of the programme enjoyment for some became the most important driver of participation and they suspected if there was no enjoyment patients would look for reasons not to go:

> Interviewer:…. you said that the thing you liked most overall here was having fun and having a bit of a joke?
>
> Patient: Yes….Because if you came here…. as miserable as sin it sure as hell is not going to do you any good. A, you are not looking forward to it, and B, you are looking for excuses not to go, the end result of that is (gives thumbs down motion). But the way I went through everything was a plus. Win win they say…
>
> **(MO-CH-03 Male 76)**

HCPs recognised the importance of enjoyment. However, most HCPs believed the enjoyment was not a product of the exercise but resulted from interaction with the team delivering the programme, and in the case of the hospice programmes the interaction with other patients as well. Patients largely agreed and spoke of the fun, banter, humour, and general conversation with the professionals delivering the sessions and patients with whom they shared the classes. Those who lived alone due to lifestyle reasons or recent partner bereavements greatly valued the opportunity to interact with other people and felt great enjoyment from doing so. Other, patients who did not live alone also valued the interaction with others, outside of their immediate family, as this was something they did less of since retirement and since developing cancer. Patients who had continued past the trial period liked meeting other people and this contributed to them wanting to attend:

> Patient: I feel comfortable, everybody’s friendly…. if you get two or three of you in there, and you are having a laugh….it’s a good morning out.
>
> Interviewer:…you look forward to the social side as much as the exercise?
>
> Patient: Yes, I think that’s the thing….. It is surprising how much you do look forward to it…. Because like you say when you are at home, well my wife is always keeping an eye on me. “Don’t do this”, “don’t do that”…..She is always running out to the shed “what are you doing”,…. But when you’re here, everybody has a chat.
>
> **(MO-CR-01 Male 67)**

Meeting others who had similar conditions was particularly valuable. It was felt people with similar conditions had a better understanding of each other and so meeting a group of people with similar conditions allowed social interaction without the same stresses involved in meeting others who did not have a terminal condition:

> Patient:… the people who are coming here are people who have got different types of problems but in a way are similar and they understand, why you have lost your hair, why you have lost your beard, why you look different.
>
> Interviewer: Would there ever be any talk about that sort of thing between yourself and other people.
>
> Patient: No, because the people understood, they did not need you to explain. They understood what’s going on, they have their own problems I have my own problems. Really and truly it was not necessary to explain.
>
> **(MO-CR-04 Male 74)**

Professional accounts revealed generating social interaction to be a deliberate strategy to encourage attendance:

> HCP: There has to be a social element to it, so we will come in have a drink and have a bit of a chat, get to actually know each other…..if you do not enjoy something, firstly you probably will not keep coming, and, if you do you're not going to get that much out of it. If you feel like you are just literally getting through that hour and a half and leaving and there is no enjoyment to it, I think you are not going to retain things. You're not going to carry things on.
>
> **(MO-ST-04 Design, recruitment and delivery)**

The structure of the group classes allowed for interactive game type exercises that involved different members of the group and generated enjoyment. The weeks when less people attended were generally more specialist, with staff providing more individualised exercise, but the weeks when more people attended were perceived to be more enjoyable. Across all three programmes (EMBRACE, Circuits, Chairs) staff delivering the sessions were identified as key to the enjoyment experienced:

> Interviewer: You, you don't like the other type of appointments but you like coming to the exercise appointments?
>
> Patient: I do like coming to the exercise. Also I think the [names of research nurse and physiotherapist] is it? They're very positive nice people and I can relate to them whereas most of the other people I deal with are more on a day-to-day basis, you don't get a real connection. But because I'm seeing them often I connected considerably with them.
>
> **(EMB-15 Male 64)**

> Interviewer: What is it that makes it fun?
>
> Patient: The banter (laughs).
>
> Interviewer: Who is that with?
>
> Patient: The helpers [name of physiotherapist], the assistants, and the other members of the class who join in...there is usually music as well, and today there was a lot of singing (laughs).

> Interviewer: who instigated singing?
>
> Patient: Again it is [name of physiotherapist], and the others.
>
> **(MO-CH-04 Female 71)**

> Patient: With classes you are only as good as your instructor, and she is very good. She makes it very enjoyable ….She makes you want to come because she is so jolly.
>
> Interviewer: I have seen her she is dancing and singing.
>
> Patient: She is brilliant.
>
> **(MO-CR-02 Male 69)**

It was often HCPs who initiated and developed the interactions between patients, which meant even patients who considered themselves shy were able to quickly interact with one and other. The specialist knowledge of HCPs contributed to patients learning new information about exercise. Learning was enhanced by the personalities of HCPs who used jokes and anecdotes to enhance the experience. The HCPs were even able to turn negative elements, into positive ones. For example, using humour to turn an exercise a patient did not like into a recurring joke which enhanced their enjoyment of these sessions, turning a potential impediment into a possible driver:

> Interviewer: I pick up that you, do not like tai chi but you find it quite humorous as well.
>
> Patient: Yes because they have made a joke out of it. Rather than say “well you won’t have to do it”, they made a joke out of it. Which was very clever of them.
>
> **(MO-CH-03 Male 76)**

Often a key feature in the development of psychological benefits was the sense that the exercise session replaced something missing or gave more of something patients wanted in their lives.

For some patients continually striving to meet the challenge had been what they previously enjoyed in their sports, the sessions now provided this:

> Patient: She put me on another one this morning which I haven't quite mastered. I will master it and that is what it is about…you have got to have a challenge haven't you.
>
> **(MO-CR-02 Male 69)**

In the case of the EMBRACE programme patients became part of a larger project, feeling valued and interacting with HCPs as equals to achieve the aims of the study together:

> HCP: They value greatly the interaction with the study team. They enjoy feeling part of something they feel valued by the study team. They feel that they are being helpful. They feel that the study team treat them as an individual, and know them as real people… the main thing is I think being seen and being part of something.
>
> **(EM-ST-03 Recruitment).**

Some patients had recently been told there was nothing more the oncology service could do for them, and they would not receive further treatment. These patients spoke of feeling depressed, cut off, rejected, too old, or not good enough to receive the treatment they had wanted. For these individuals exercise became an opportunity to enact their instinct to fight the disease:

> Patient: The oncologists said I was too old to have chemotherapy. That was a hell of a knock to me, my instinct was that I really wanted to fight it but they convinced me that fighting it would probably be counter-productive at my age. That had quite a psychological effect on me…I feel that doing the classes and doing the exercises is a way of fighting. Because it is an attempt to keep, to improve my fitness…. Doing the exercises I feel is a kind of a fight.
>
> **(MO-CH-07 Male 88)**

Patients who had depression reported the symptoms of their depression to have eased since starting the programmes. For some this was the most important element of their participation:

> Patient: ….what it does it has helped me with my depression. Since I have been coming here I am nowhere near depressed. I do not know why, but before I came here my depression was really quite severe. I have still got it, and I still get it. But it is not as bad as

> it was, and also the feeling of finality is nowhere near as bad it seems to have had an effect on me which is difficult for me to quantify….I thought I must tell you that before anything else
>
> **(MO-CH-06 Male 81)**

Less common in patient accounts, HCPs' reported a common benefit perceived to drive attendance was the appreciation patients could do something for themselves to help their situation:

> Interviewer: Did participants on the trial ever share with you what they particularly liked about any aspect of the study?
>
> HCP: Yes, they liked that they were able to do something to help themselves….. rather than everything being done to them….It was something they could actually do to help their, you know their recovery for example and getting fitter.
>
> Interviewer: That was something they expressed to you?
>
> HCP: Yes.
>
> **(EM-ST-08 Delivery)**

Other ways in which patients were said to have benefitted included an appreciation of having a routine to follow in their lives, and an improved sense of confidence.

6.1.8.3 The boost

Patients described an immediate psychological lift and increase in energy generated by individual sessions, referred to by some as a 'Boost'. One reported feeling the boost during the trial period, but more reported such feelings over the course of the programmes. Patients had difficulty verbalising exactly how this felt, but spoke of enhanced senses of energy, positivity, and confidence following the sessions. Patients were not certain what caused the boost, possibly a combination of enjoyment from the sessions, accomplishment from proving to themselves they could do the exercise, and sense that they had performed something which would provide important benefit to them:

> Patient: I don't know whether it was the actual exercise, or the thought of doing something positive, but it made me feel better, more, a positive attitude to everything.

> **(EMB-015 Male 64)**

The boost could be felt immediately after the sessions and induce a substantial impact:

> Patient: Sometimes it was making me feel super fit, like when I walked home, I did it, I walked home…. I wouldn't have even dreamed of it before I started doing it. Being able to do that. I felt so ill I would have never thought of walking all the way….. But when I came out of the gym I felt so good, I knew that in myself I could do it, so I had to prove it, and I did. When I got home I didn't feel bad…. had a cup of tea, sat down for a few minutes. Great, full of life, energy and everything.
>
> **(EMB-015 Male 64)**

This boost could be sustained for the rest of the day making them more positive and increased their activity for that day and could last for a longer period of time, up to the next scheduled session:

> Patient: …I feel a physical boost from it.
>
> Interviewer: Is that something that lasts for a long period of time or is it quite a short thing after each session?
>
> Patient: …normally the boost seems to carry me through near enough till the next time.
>
> **(EMB-015 Male 64)**

HCPs recognised the shorter-term effects of this boost and suggested it was due to hormonal reactions to the exercise such as release of endorphins and dopamine. Patient accounts indicate the longer nature of the boost, lasting between sessions, was caused by memories of the session. Patients described thinking about the sessions throughout the week, evoking happy memories, then remembering the next scheduled class was not far away, and would feel an additional psychological lift from this:

> Patient: The fact that I did look forward to a Tuesday kind of cheers you up a bit. So if nothing else psychologically it worked a bit.

> Interviewer: ….When would you say you would start to look forward to it?
>
> Patient: ….Whenever it crossed my mind….That is how much fun it was, or how good it was.
>
> Interviewer: You said psychologically you felt benefits from it, can you explain how it, how it impacted you psychologically.
>
> Patient: it gives you a lift….
>
> **(MO-CH-03 Male 22)**

This boost developed even in patients unable to attend regularly. One patient was, was unable to attend several sessions due to hospital admission, family holiday and staff holiday:

> Interviewer: How do you feel about it later in the day do you think about the exercise at all?
>
> Participant: at certain points during the day I will say it has done me some good today yes. Because otherwise I just as I say…I will just sit there…It will Make me want to do a bit more today…it does make me feel more like a normal person.
>
> **(MO-CR-02 Male 69)**

The boost had not been anticipated by any patients but as time went on the impact the boost had was great.

6.1.8.4 For the sake of others

During the initial enrolment decision some patients were enrolling for the sake of others who were important to them. For some it was a desire to contribute to research to help others in the future, for others because they felt their family wanted them to accept the offer. Two patients were unmotivated by any kind of benefit for themselves or enjoyment, both in the EMBRACE programme. Both described minor satisfaction from getting away from their house but found the programme neither enjoyable nor unenjoyable. Neither reported experiencing noticeable benefit at the time of interview. However, both patients attended every scheduled session. Both these patients had joined the study for altruistic reasons to help others in the future, ‘For the sake of others’. This was what they had wanted to achieve, and this seemed to generate a work-like attitude of completing the job they said they would, irrespective of any personal physical benefit or enjoyment. For these patients they had committed to something and they wanted to ensure they completed it as best they could.

During the later stages of the supervised period the staff delivering the programmes became increasingly close to patients. A sense of commitment and obligation developed and patients became driven by a desire to do it for the sake of the staff. Patients' accounts indicated a close relationship with HCPs. HCP accounts directly acknowledged this relationship and indicated it was mutual:

> HCP: they definitely liked the exercise appointments and the CPETs. Interestingly….. but they I think they liked the obviously the attention and the relationship with [name of therapist] she was laden with biscuits and cakes ….so they enjoyed that but even the patients on the control arm who were just coming in for repeat CPETs and what have you they would build a relationship with me and also with [name] who was my clinical trials assistant who would come in and take bloods, there was a bit of banter… it was kind of nice and they enjoyed all of that.
>
> **(EM-ST-05 Recruitment and delivery)**

A relationship also developed between HCPs and family members. Patients usually had support from a family member who would attend with them, and some HCPs actively encouraged them to be involved in some way:

> HCP: I can think of a fair few whose spouse would be there in the room. I always encouraged them I really liked it… I wanted them to have as much time together to share experience as much as they could, I liked having that atmosphere in the room as well, building a relationship with them both.
>
> **(EM-ST-05 Recruitment and delivery)**

To some extent the relationship which formed between HCPs and the patients was due to deliberate efforts taken by the HCPs to build a relationship in the hope it would encourage adherence. Usually, these efforts were simple and involved little more than being friendly, approachable, attentive, and helpful. However, much of the relationship building came about as a consequence of inherent elements of the intervention. Actions by HCPs were intended to make the sessions fun, keep the patients safe, help them achieve what they wanted to achieve, answer questions regarding concerns for their health. These actions all served to enhance key drivers or minimise impediments, but also helped build fondness and trust and developed a close relationship. However, what was most apparent in the EMBRACE intervention was time spent together. These patients, and usually, a family member spent a minimum of two one-hour sessions with each other each week, with little else to do but cycle and talk. Topics included health questions and advice but mostly, general life concerns, hopes, fears, holidays, families' issues. If family members were not present, it became an opportunity to discuss issues participants wished to protect their family from:

> HCP: They've got all these worries and concerns which actually, when they are pedalling away it's great to talk about things because it takes their mind off the exercise and it makes it much easier for them….they've asked questions about diet and nutrition….they are in an environment where they feel like they can talk about their worries as well, that they have or haven't told family members….I think just being there to listen while they are doing some exercise, and we have about an hour together so it's a good amount of time…. they're doing the activity so I'm just there to aid them and help them along and just reassure them that it is ok. But they have that time to spend with somebody so I think that makes the difference, having that extra little bit of time.
>
> **(EM-ST-02 Recruitment and delivery)**

It was felt the development of this relationship Between the HCPs and patients was a key contributor to the sense of obligation which developed in the later stages. HCPs who experienced this acknowledged it as helpful for adherence but also felt a sense of unease:

> HCP: If they were feeling unwell, obviously it was difficult sometimes to get through 40 minutes of exercise, high intensity interval training, there were days where it was a lot more of a struggle than others when they weren't feeling very well…. at the same time they wanted to come in and do it, they felt quite guilty if they couldn't come in….Some of them said, "I want to come in for you so I'm not letting you down"... that's really lovely but actually it's not for me, it's for them.
>
> **(EM-ST-08, Delivery)**

The closeness and intimacy that developed during repeated 1-1 sessions raised questions of professional boundaries:

> Interviewer: It is a very close very intimate relationship that you develop with the participants isn't it?
>
> HCP: Yes. Because how can you just be there for an hour and not…..That's why groups I think would be better…. In the exercise and asthma study we often do it in groups or pairs and I find it quite a lot easier…. you do not get into these personal conversations as much, it is a bit more superficial?....there is another human there you know and they may not want to talk about it. But if it is just one-on-one you build a rapport they know you, you know them….yes it is probably good to have this emotional connection with someone, but when it ends they do not feel good about it either…. with a group thing they can exchange numbers and communicate….that is not a professional barrier either so then they can create friends and they might have that support throughout. Whereas we cannot support them in the same way from that point on and it gets a bit awkward we do not really know where the line is.
>
> **(EM-ST-02 Recruitment and delivery)**

As the programmes progressed patients would attend sessions even when perhaps they may not have wanted to. Patient accounts mention this less frequently and indicated it was due to a commitment to the programmes and to themselves. However, HCP accounts suggest it was frequently experienced and largely caused by loyalty to the people delivering the sessions:

> HCP: People would say "I was on my sofa I really did not feel like it, the chemo was you know pretty devastating, fatigue, but I knew [name of therapist] was waiting, I knew I had an appointment I just had to get up and go and do it".
>
> **(EM-ST-05 Recruitment and delivery)**

*S*everal HCPs spoke of situations when patients had found it difficult to ask to withdraw even when it became clear they no longer wanted to participate:

> HCP: That was the participant’s decision although, I am aware that the person who contacted them about it had to kind of tease it out of them. We almost knew that they did not want to do it. But again there is this sort of patient politeness that they do not want to say “no I am not going to come in” so you kind of almost have to help them get to that decision we want them to continue but we could also see that they did not want to do it.
>
> **(EM-ST-02 Recruitment and delivery)**

For the sake of others is different from the other drivers. Whereas the usual interaction between drivers and potential impediments results in questions of ‘Should I do it’ and ‘Could I do it’, and subsequent answers, the addition of obligation shifts the answer to ‘I have to do it’. It is not a sense of wanting to attend, but more a feeling of having to attend. Accounts from patients and professionals indicate this driver to have a lesser role when patients were easily able and very much wanted to attend. But on the occasions when a lot of effort was required to attend and the desire to attend reduced, obligation became an important driver, which got reinforced each week when contacted via telephone the day before each session.

6.1.9 Mitigation and accommodation of impediments

Mitigation and accommodation of impediments during the later part of the supervised period was characterised by the extremely refined and comprehensive strategies being employed to enable them to participate in the programmes. During the course of the programmes patients and HCPs both learnt to take measures to minimise impediments as and when they occurred. Once these measures had been learned they usually became a regular part of future sessions.

6.1.9.1 Self-mitigation and accommodation

Strategies such as resting when needed, taking pre-emptive analgesia, and for those with diabetes, modifying their food intake on the days they exercised to better control their blood glucose were all mentioned as methods which had been devised during the trial period and continued to be employed to enhance likelihood of being able to participate in the exercise sessions.

A common issue which patients experienced was tiredness. It was common for tiredness to be worsened by the exercise sessions and patients would have to rest afterwards. However, tiredness never stopped patients attending. For a patient who had started trying to exercise at home during the supervised period, tiredness impeded home exercise, but only more severe illness prevented her attending the supervised sessions:

> Interviewer: Too tired to be able to carry out the exercise?
>
> Patient: Yes, there have been and I have not been feeling well. I mean I do have off days so there have been days definitely….the home-based exercise. Not the ones here
>
> Interviewer: Has there ever been any times when you have been too busy or too tired to come here?
>
> Patient: No. I did have the time I was too ill to come here one week… [I] really was not well (pain and constipation).
>
> **(MO-CR-03 Female 68)**

The programmes did not negatively impose on patients' lives as might have been expected. Muscle soreness was rare and, on the occasions when patients did feel more significant discomfort following exercise, it was interpreted as a good sign, reassuring patients that the exercise was working. The additional requirements of attending exercise appointments caused minimal disruption alongside numerous other medical commitments:

> Patient: ….What with all the other appointments I've already sort of had to put aside the rest of my life and work around the hospital. So it's only another appointment. …..It's not an inconvenience in any way.
>
> **(EMB-015 Male 64)**

There were less favourable elements which could not be mitigated. Patients found equipment uncomfortable, some wanted longer sessions to get more benefit, others wanted shorter sessions as they felt longer sessions got boring. Some patients reported certain activities to be their favourite, whilst others reported those same activities to be the least enjoyable. However, these examples of dissatisfaction were never felt to impede adherence:

> Patient: I think it may go on a little bit too long for me ….
>
> Interviewer: Do you start to feel tired, or weary, or bored, what is it?
>
> Patient: Bored I suppose, I think the thing is, she makes the effort of including everybody and it takes a long time with certain people...I think you have to suck it and accept it… You have got to think of other people and she thinks of everyone in the class, not just me.
>
> Interviewer: How do you feel about that?
>
> Patient: I consider myself lucky that I can come to such a wonderful little class. That is what cancels out any bad thoughts….. I am so pleased to be able to come, amongst such professional people who I know are doing me good. I stop myself from being selfish. I am quite happy to go along with this.
>
> **(MO-CH-06 Male 81)**

Patients had such positive views of the programme, they were happy to accommodate negative elements when needed.

6.1.9.2 External mitigation

In this period HCPs had regular contact with patients, a very good understanding of patients' experience and therefore were able to help overcome impediments. They met at least once a week, in EMBRACE twice a week, and communicated via telephone before each session, sometimes more frequently. Feedback from participants was immediate, and HCPs could recognise issues quickly and act accordingly. For example, HCPs recognised patients who found the exercise uncomfortable and took steps to minimise this potential impediment, and modify an exercise when necessary to suit individuals' physical limitations. As programmes progressed HCPs built understanding of patients. What was learnt one week informed the support provided the next, and so the strategies deployed by HCPs were refined iteratively and became more comprehensive and better tailored each week. HCPs could also encourage patients to try harder when needed, but also when to put in less effort to avoid risk of injury. In EMBRACE when it became clear patients did not like the muscle biopsy, this was removed from the protocol. HCPs' knowledge of their patients meant complex multifactorial impediments could be overcome:

> HCP: The breathless patient, he did not have any transport, we did arrange volunteer drivers for him but it was a challenge for him to get in because he only had one oxygen canister….he was on very high levels of oxygen, he found that difficult coming in. He would get quite nervous about running out of oxygen but we always took a canister from the ward up for him….so we put him on our oxygen and then would pop him back on his own before he left…..and his phone was not very good so whenever the volunteer driver tried to call him up before coming to the class he found it difficult to receive those… he always mentioned how much of a challenge it was to get transport, to be sure that it was going to come.
>
> **(MO-ST-02 Recruitment and delivery)**

Specialist knowledge allowed HCPs to tailor exercise to each patient each week, ensuring it was achievable for each person's condition that day. Patients' accounts indicate, and HCPs accounts confirmed, the biggest challenge was getting to the sessions. Once in attendance, in all but rare occasions HCPs knowledge and skill enabled them to match any physical limitations that day with suitable exercise:

> HCP: For one chap in particular that (walking from the car park) was quite a challenge getting in. Difficulties while they were actually in?
>
> Interviewer: Yes.
>
> HCP: I do not think so. What I try and do is give people different options to work out their level. If I could see somebody particularly getting out of breath I will do a break time "Let's just catch our breath and have a drink of water". Again say if we are doing an arm exercise and I can see we are causing a bit of discomfort I will just give them a different option….
>
> **(MO-ST-04 Design, recruitment and delivery)**

HCP accounts describe tasks such as providing money for parking, performing comprehensive holistic assessments during each session, checking blood pressure, haemoglobin levels, reassuring patients they could do it, adjusting exercises to be most appropriate etc. Much of which was acknowledged in patient accounts. However, HCP accounts give more insight into the work involved during and away from the sessions.

Part of HCP work involved education to help with potential impediments. This could involve advice on self-management strategies, or reassuring patients of the safety of exercise if they had previously been warned against it. Education also involved introducing new ways to view exercise. For some this meant learning specific techniques to help with impediments, for others it meant learning to accept to exercise to a lower intensity than previously. It also meant advising patients to accept that at times they would be too unwell and that they should not feel guilty about this. If patients' expectations were unrealistic, HCPs would help adjust them to prevent harm or disappointment:

> HCP:… this is a progressive disease…it can get a little bit disheartening that you are trying to strengthen and improve and actually you might see quite a rapid decline in somebody's function so it is adapting that. Not setting too long of a goal. Small achievable things. I explained that a lot of the time this is about maintenance or slowing down weakness.
>
> **(MO-ST-04 Design, recruitment and delivery)**

Much work involved telephone conversations, reminding of appointments and checking if patients were going to attend, and offering assistance if needed. HCPs also took incoming calls to answer questions. It was common to speak with patients, triage a problem and either tell the patient who to contact or get that service to contact the patient. If necessary patients would be told not to attend and contact the acute oncology service. When patients were unwell HCPs could be in contact daily:

> HCP: You would either be talking about during the time when the chemo went smoothly and the time when it is going poorly. Smoothly probably not at all (no phone calls). Poorly, it (phone calls) could be every day if you see what I mean.
>
> **(EM-ST-02 Recruitment and delivery)**

HCPs would liaise with other members of the multidisciplinary team, informing them of issues at the sessions, and hearing about issues which occurred away from the sessions such as falls or hospital admissions. HCPs would check electronic patient records, so if anything had happened in the week which might compromise safety, patients could be contacted and assessed before attending. HCPs felt it was the work that occurred away from the sessions that meant sessions can run safely:

> HCP: it is a lot easier for me to run my group and feel comfortable. And if I am more comfortable and confident and calm, then the patient is going to feel like that too. Because I have already risk managed them.... knowing what is wrong with them, whether they have a DNAR form ….whether or not they are taking anticoagulants or if they have had PEs [pulmonary embolisms] in the past or if they take regular steroids I know everything about everyone in there…I know that if they are following my program the risks are managed.
>
> **(MO-ST-01 Design, recruitment and delivery)**

For those who could not drive, transport was provided from the start. Typically by family or volunteers and in one case previous work colleagues devised a rota to share the duty. Throughout this period if a patient's usual source of transport was not available, another source would be found. No patients were prevented from attending due to lack of transport.

The specialist health care facilities were highlighted as an environment in which potential impediments were minimised, compared to less specialist locations. Some of these features were noticed immediately. For example, patients commented on not feeling self-conscious of their appearance in this setting, compared to commercial gyms. Other features would be unnoticed until a time they were needed:

> Patient: … you have got that wonderful, you do not realise until you need it the loo… you can sit there and do all of your business…. you have got somewhere to put the bag…you can sit on there and do everything, and you have got a proper bin. Sometimes you go in the pub and the bin is only for hand paper and you have got a bag full of bloody stoma stuff.
>
> **(MO-CH-06 Male 81)**

Due to the specialist knowledge of the HCPs the, specialist facilities and the willingness of family and friends to assist, most impediments could be mitigated or accommodated in some way.

6.1.9.3 Inability to mitigate or accommodate

Not all impediments could be mitigated or accommodated. Lesser issues such as mild pain, exacerbated by the exercise, would cause patients to pause briefly. Less often patients would be prevented from attending a session completely. Patients placed great priority on the sessions and were only prevented from participating if the impeding factor could not be resolved. Issues which impeded attendance occurred at three levels: patients' own individual issues, an issue with a significant other usually family, or staff being unable to deliver a session. Missed sessions were rare, however, on occasions when patients experienced several such issues, several sessions would be missed:

> Interviewer: I understand there has been a few occasions where you've had to miss classes or you have been unable to come is that right?
>
> Patient: Yes...Three. When I was on holiday, [name of physiotherapist] was on holiday, and I was in hospital for one.
>
> **(MO-CR-02 Male 69)**

HCP and patient accounts of impediments largely matched each other, and indicated that reasons for missing sessions could involve both pleasant events which participants chose to attend, instead of the sessions, or more unpleasant events, over which participants had less choice. Reports of patients missing or having difficulty attending due to what may be considered pleasant occurrences were fewer and largely limited to holidays. When patients were more unwell, holidays and social events had less of an influence.

> Interviewer: Did holidays ever get in the way?
>
> HCP: Not for this study, generally they are just too unwell. The patient cohort tends to be older and it just kind of takes over everything. They generally did not do very much they were not able to do very much.
>
> **(MO-ST-01 Recruitment and delivery)**

Unpleasant or unwanted factors impeding adherence were more common. Many patients alluded to and HCPs explicitly verbalised the process of 'getting in' or getting to the sessions as the most challenging aspect of the programmes. Once in attendance participants could be provided with exercises at an appropriate level. But the process of getting to the sessions was challenging and demanded not just physical effort but the greatest mental effort particularly to initiate that process.

Chemotherapy presented many challenges, it caused side effects which made attendance more difficult and exercise harder to perform, it placed extra burden on patients due to additional appointments for treatment each week, and importantly, it worsened fatigue. The difference in patients before and during chemotherapy was noticed promptly.

> Interviewer: The largest difference was the chemotherapy you feel?
>
> HCP: Yes, definitely.
>
> Interviewer:…was it a gradual change or did it happen very rapidly?
>
> HCP: I seem to remember it happening quite rapidly...
>
> **(EM-ST-02 Recruitment and delivery)**

Fatigue was highly prevalent in both programmes, although it rarely prevented participation in the hospice programmes it more often caused non-attendance and withdrawal in the EMBRACE study:

> HCP: ….the fatigue…very fatigued because of the chemo they all were so fatigued…
>
> Interviewer: I picked up on the fact that you said “they all were”. Everyone, was very bad with fatigue?
>
> HCP: yes.
>
> **(EM-ST-02 Recruitment and delivery)**

According to HCP accounts, breathlessness was also felt to be problematic for patients, and reported to be worsened by anxiety, and to cause anxiety to worsen. In at least one instance this caused a patient to have to be withdrawn from the hospice classes. Through years of disease some patients had learnt to stop daily activity at the first sign of breathlessness, they translated this learnt response to breathless to their exercise behaviour and would stop exercise as soon as breathlessness occurred:

> HCP: One of the commonest questions you hear anaesthetists asking when they are trying to gauge the fitness of the patient is “do you get breathless for example walking on the flat or going up a flight of stairs?” So I copied them and asked the same question and I remember a couple of patients saying “no no no I do not”. I thought okay that is really good. Then on further questioning it is because as soon as they started feeling remotely breathless they stopped. It was not that they were so fit they could do this without feeling breathless, it was “no I do not get breathless because I make sure that I slow down and stop before I do”.
>
> **(EM-ST-05 Recruitment and delivery)**

Patients experienced pain, either from their cancer or other conditions / comorbidities, but it rarely inhibited exercise. EMBRACE HCPs rarely experienced patients reporting pain, but pain was more common amongst hospice patients. One HCP suggested exercise involving larger or whole body movements were more likely to aggravate pain than a routine which involved solely cycling.

HCP accounts show the complexity of this patient group means issues were not experienced in isolation. Usually, multiple factors were experienced at once creating a complex set of impediments which could influence and interact with one and other:

> HCP: …. the patient group that we have had we have found tend to suffer a lot from symptoms, reactions to the chemotherapy…. fatigued and generally unwell, patients tend to be older so I think their threshold is lower, especially when it comes to exercise….a lot of them experienced severe breathlessness…. A lot of them get coughs or colds quite easily…. If it is cold then they tend to get poorly easier but then also when it was really hot weather we would have patients who were suffering because it was really hot….sometimes they get really poorly and have to come to hospital, obviously patients can get sepsis and things like that.
>
> **(EM-ST-01 Recruitment and delivery)**

Issues involving family could also impede attendance at the sessions. Many of the same events which prevented patients from attending, such as illness or hospital appointments, also prevented attendance on occasions when they happened to a family member. This was reported to be because the dyadic relationship meant “you tend to do most things together” (MO-CR-04 Male 74).

Staff being unavailable to run the sessions was something patients had no control over. It was not raised by any patients in the EMBRACE trial but almost all patients in the Chairs and Circuits programmes had been prevented from attending at least one session due to staff annual leave or staffing changes. For some it was the only occasions in which they had been prevented from attending.

On more than one occasion interviewed patients reported being so determined to attend the EMBRACE sessions despite being unwell, that when they attended they were admitted directly to hospital for further assessment and treatment. HCP accounts in both studies revealed occasions when they in fact stopped the patient from exercising, against their wishes, for reasons of safety:

> HCP: ….For that younger chap….he was really motivated but….he was really quite poorly….acutely from the chemo…. He was so determined it was almost as if he did not want it to defeat him…. I think he was so determined to come in but we often were like “no you are not coming in I am really sorry”. “We would love to see you but you cannot come in today”.
>
> **(EM-ST-02 Recruitment and delivery)**

For all participants, at some point, the supervised period ended. Patients who completed the supervised period wanted to continue with the supervised sessions, rather than transition to unsupervised exercise, but this was no longer an option. Some accepted the programmes could not continue indefinitely, understanding that other patients were waiting to enrol. Other patients were angry, did not recognise a need for the sessions to end, and felt rejected, or cut off. For some this evoked feelings similar to when their cancer treatments had stopped. Even participants who had joined with the hope of being shown exercises they could do at home were disappointed. These participants had already been given exercises to be done at home, but felt the exercises and overall experience were inferior to what they had been doing during the supervised sessions:

> Participant: That’s the last one next week, unfortunately but, I will just push on with it at home and, obviously you can’t do them all without the physio, or without the apparatus to do it all on.
>
> **(MO-CR-01 Male 67)**

Stopping the sessions was viewed as a loss, over which patients had no control. Some had not realised the supervised period would finish. No patients viewed the end of the programmes positively, and some expressed anger or frustration that the sessions had finished.

6.2 Supervised period summary

The first conscious decision, enrolment, was driven by prediction of benefit but was also dependent upon patients' predictions of how feasible it would be for them to participate in the programmes. How patients anticipated they could benefit was based upon exercise history and knowledge of exercise. All patients believed exercise could provide health benefits, those with a more extensive exercise history and knowledge typically had more specific, and usually stronger, reasons for joining. Prediction of feasibility was determined by potential impediments which patients thought they might experience, but was also influenced by their expectations of how the programme would mitigate against these. Therefore, rather than impediments preventing patients from enrolling, expectation of help with managing impediments became a driver for enrolment. Patients referred to the exercise programmes had received little information from those who introduced them. It was also felt many were referred at a later point than was optimal, limiting the benefits which might be achieved.

The second conscious decision involved reflecting upon whether their previous decision to enrol in the exercise programme was right for them, deciding whether the anticipated benefits were being realised and whether their prediction regarding the feasibility of participating was correct. Patients enrolled with the intention of trying the programme to test if they should do it, and if they could do it. For patients to continue they had to either gain the anticipated benefits, or be reassured they were likely to occur. If a patient concluded that they "should do it" they were more likely to conclude that they "could do it". Those who felt they should not do it typically also found any burden associated with attending to be unacceptable and decided that attending the programme would be detrimental to them in someway. Much HCP work was intended to make the sessions an enjoyable patient experience. However, although enjoyment was valued and may contribute to adherence, patient accounts indicate enjoyment alone will not result in continuation through the trial period without belief that anticipated benefits will also occur. By the end of this relatively short trial period a group of patients who had not previously been exercising had learnt they 'should' and ‘could’ exercise. Most had learned that the question of ‘can they do it’ was variable and could change week by week, or moment by moment, during the sessions, whereas the issue of ‘should they do it’ was resolved in the first couple of weeks and once decided remained constant.

For the third conscious decision the programmes transcended beyond patients anticipated benefit and provided benefit in many areas relating to what each participant needed. Moreover, participation became increasingly feasible as support from HCPs and self-management strategies became more refined, producing a more comprehensive level of mitigation. Although some discrepancy existed around physical benefits, all patients valued attending the classes and the vast majority found them an overwhelmingly positive experience. If the influence of key drivers such as gaining benefit or enjoyment waned before individual sessions the close relationship with the HCP and a sense of commitment or obligation usually resulted in attendance. Many of the impediments which may have made participation difficult previously had been removed, or minimised either by patients, family and friends, or most commonly HCPs. The greatest difficulty in participating in the programmes was felt to be getting to the sessions, but participants became increasingly skilled at managing this. Only rare unavoidable occurrences still caused individual sessions to be missed, and a great sense of loss was felt when the series of sessions ended.

Chapter 7 Element 3: Empirical research findings: unsupervised exercise

This chapter presents findings that pertained to unsupervised exercise, and draws on data from T1 and T2. Initially using a version of the framework developed for supervised exercise, this was further iterated. This allowed for a comparative analysis across both periods of exercise to describe and understand what occurred during the shift from supervised to unsupervised exercise.

Analysis confirmed the previously identified meta-theme of ‘Moments of conscious decision’, themes of ‘Drivers of participation’, and ‘Mitigation and accommodation of impediments’. Further subthemes were identified to represent issues influencing adherence at this point. During analysis it became apparent patients enduring exercise behaviour during the unsupervised period clustered into four groups each with common features. This formed a typology of exercise behaviour during the unsupervised period with the groups labelled as: 1) Returned to previous regular exercise; 2) Created new regular exercise; 3) Infrequent exercise; 4) No exercise. Figure 12 depicts the themes and the resulting exercise behaviour for this period.

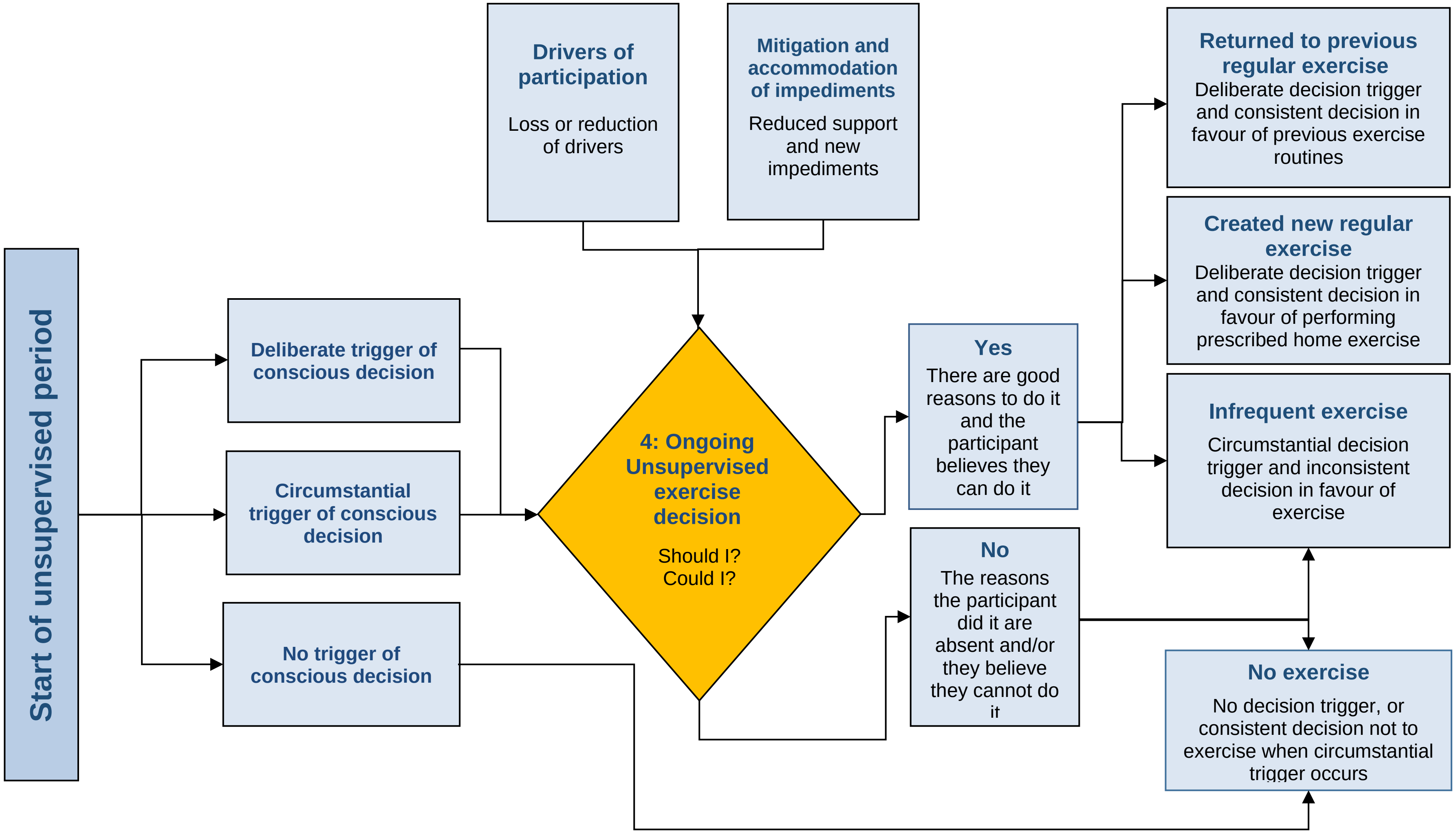


Figure 12: Moments of conscious decision unsupervised period

7.1 Moments of conscious decision

7.1.1 Absence of an enforced decision point

At completion of the supervised period, patients fully intended to exercise regularly. The first factor which contributed to a reduction in adherence to unsupervised exercise was the absence of a scheduled appointment and the pre-appointment phone call. HCP and patient accounts agreed on the importance of an appointment. The inclusion of an appointment added several elements distinct to the act of exercise which enhanced adherence. Removal of an appointment removed many of the drivers:

> Interviewer: So you were aware of some situations where despite there being plenty of things that might prevent someone from exercise….the pull of the appointment would still bring people into the session.
>
> HCP: That is exactly it yes, yes.
>
> **(EM-ST-05 Recruitment and delivery)**

This meant a conscious decision, previously unavoidable, was now less likely to occur. During the period between finishing the supervised sessions and the second interview, two patients did not exercise. Both believed if appointments had continued they would have attended.

EMB-015 was unable to complete home-based exercise because the deteriorating health and subsequent death of his father meant he was not able to find the time to read the exercise manual he had been given and learn the home-based exercises. He tried to read the manual on one occasion, but put it away with the intention to try another time, but that time never arose. He believed if he had had an appointment he would have prioritised this. He gave examples of his other medical appointments, and the study interview as evidence that appointments took priority:

> Patient: It just wouldn’t happen (exercise), because other life would take over. The fact it was done by an appointment tended to make it more important. To keep appointments is what I do. What they are about doesn’t always bother me, some of

> them are never nice appointments, but the gym was… As soon as there was an appointment I would do my very best to keep it.
>
> **(EMB-015 Male 64)**

Patient MO-CH-02 experienced rapid deterioration in his condition and numerous complications including hospice admission due to vomiting. He was adamant appointments would have enabled him to continue to exercise. He believed that an appointment made a commitment to the physiotherapist which was hard to break. In addition to this the known time of the appointment acted as a focal point around which he and his wife could plan and mitigate potential problems before they arose, something they did not attempt during the unsupervised period:

> Interviewer: If the classes had continued in that timeslot, do you think you would have been able to come to the classes?
>
> Patient: …Yes, I would have gone….I would have forced myself. I would have took some pain relief….I mean that’s only just, the oxycodone only knocks it down a slight amount, but it would have been enough for me to have wanted to go.
>
> **(MO-CR-02 Male 69)**

Others reported that without the schedule imposed by supervised exercise daily life had a tendency to take over. Friends, family, household chores, were all reported to have at times prevented patients from thinking about exercise. One patient became so engrossed with helping his son’s work that for a period of two weeks he did not think about exercise:

> Interviewer: So for a period of time… you had some I.T. stuff and that involved a lot of reading and because of that you…
>
> Participant: I was inactive.
>
> Interviewer: Is that because there was not enough time, do you think?
>
> Participant: It was just that I never thought of them. I was so absorbed with what I was doing. It just took me over really. But I will not let that happen again.
>
> **(MO-CH-07 Male 88)**

Conscious moments of decision would still occur. However, previously the supervised appointment and usual pre-emptive telephone call made the decision an unavoidable part of patients' lives. Now, a 'Moment of conscious decision' was dependent upon the occurrence of opportunistic events to trigger thoughts of exercise:

> Participant: I think it was just, by accident in a sense I kind of did a movement and it made me think of an exercise and I just kind of felt "so let's have a go at this" and did it….
>
> **(MO-CH-02 Female 71)**

Social, familial, and domestic, events or responsibilities meant thoughts of exercise were relegated to the back of ones' mind. Two patients had intended to keep to their previous scheduled exercise times, however only one managed this. This patient attributed that success to their strongly held belief in the importance of sticking to planned routines:

> Patient: I suppose a routine is important, for someone like me who has worked, all of their life full time….So, having something to look forward to. (Laughs) I don't really look forward to it. A routine built into your week, was, is, a good thing. Whatever that routine is.
>
> Interviewer:…. by the sound of it you managed to do that with the hospital exercise and with the home exercise. You kept the routine?
>
> Patient: Yes, I think that is probably the nature that I am, the character that I am. I like a routine.
>
> **(EMB-016 Female 58)**

A variety of other methods were employed by patients to create a 'Moment of conscious decision'. These methods were developed based upon previous experiences rather than advice from HCPs. A common method was having a period of time each day to reflect on their daily activity level and perform extra if needed:

> Patient: yes, I feel I have got to give myself goals. So that, that is why I have been doing it, if I feel that I have been not active enough during a day maybe that is when I will do them.
>
> **(MO-CH-04 Female 71)**

Other methods included keeping equipment in places which would be seen and so trigger a decision, trying to restart the scheduled times of their pre cancer exercise routines, and linking the opportunity to exercise to other frequent events such as when family were doing chores. For others, if exercise had brought relief from issues such as pain, stiffness and depression, re-emergence of these issues prompted them to exercise. Those who lived with family reported their partners encouraged and prompted exercise, reminding them of the benefits of exercise, as well as the consequences of not exercising.

7.2 Drivers of participation

7.2.1 Loss or reduction of drivers.

There was agreement among HCPs that adherence to exercise declined during the unsupervised period. During the supervised period, a combination of influences generated overwhelmingly positive opinions of the sessions and meant other than rare occasions, patients would attend. HCPs felt there was nothing specifically wrong with the home exercise, it was just that the drivers encouraging patients to attend supervised exercise were no longer present:

> HCP: ….I suppose in a way flip the good things about coming in and doing the exercise.... it is not something that they got any social benefit from….. breaking that invisible barrier that is keeping you on the sofa when it is just the rubber bands to do at home. I think that, requires significant mental fortitude….you are not getting that positive stroke that you get when you turn up and the music is going and the other physios are all buzzing around and [name of therapist] is there to greet you….and chat while you are exercising. For those people who are not died in the wool exercisers they perhaps need some extrinsic reward.
>
> **(EM-ST-05 Recruitment and delivery)**

‘Drivers of participation’ in supervised classes became stronger and more plentiful as the programmes progressed, then abruptly, they were lost or greatly reduced.

7.2.1.1 Staff influence

During the unsupervised period staff input was reduced to what could be recalled from memory or ascertained from the leaflets provided before the end of the classes, and in some instances delivered via post afterwards. The energy of staff, their friendly manner, and ability to instantly assess patients and adjust exercises as necessary was absent. Leaflets were not viewed as an effective replacement even if, for most, the exercises were functionally possible:

> Patient: I think (laughs), we are all very good at taking these sheets home with us, with exercises we can do, but we are not very good at actually doing them.
>
> **(MO-CR-02 Male 69)**

The end of the supervised period brought the end of the relationship that had previously helped drive adherence:

> Interviewer: What do you think is the most important thing to consider when trying to maximise exercise adherence in this patient group?
>
> HCP: That they have an appointment to go to and that they know there is somebody waiting for them there. To supervise their exercise, certainly to meet and greet and check everything is okay….I think that was the key thing. To a degree we used to call it the [name of therapist] effect, [name of therapist] was the physio who we used to refer to and of course they love going and meeting her and they built a relationship with her….the patients were very positive about that and then less so as we morphed into the at home unsupervised exercise. A lot of them were very honest and said, no I have not done it.
>
> **(EM-ST-05 Recruitment and delivery)**

This relationship was perceived to be one of the reasons for the sense of obligation felt to attend a session. In the unsupervised period there was no evidence of an obligation to exercise, the driver ‘For the sake of others’ was lost in the absence of no face to face contact.

The building of a close relationship, for it to then end abruptly was identified as not just about the removal of a key driver but also represented a source of distress for both HCPs and patients:

> HCP: You get to know them really well and learning how to actually disassociate…. You talk about all sorts of stuff, knowing how to close that conversation….what happens at the end contact….How do both parties feel actually?… they had this constant in their life for a little while…. they had all of this exercise training they were in all day and it was all quite jolly and fun…. It is almost like a loss for some people …. they would come and meet you for a coffee and we would meet up to see how they were doing trying to keep it quite friendly…..it is still quite hard to know when to say, that is the end of that now. “Goodbye”.
>
> **(EM-ST-02 Recruitment and delivery)**

HCPs were aware of the incentives to encourage patients to continue to exercise in the local community but did not know whether they had been successful:

> HCP: …community gyms that we have a rapport with do offer them, I think it’s discounted rate for nearly 12 months, if not a bit longer, six months to a year where they go over and they’re re-introduced back into exercise. That was something I was kind of pointing them in the direction.
>
> Interviewer: Do you know if anyone took that up?
>
> HCP: I don’t know. It’s a shame because it would be really nice to know, how many did do that?
>
> **(EM-ST-08, Delivery)**

All professionals involved in delivery tried to raise patients’ motivation as it was felt to be a central part of their role, and hoped increasing motivation during the supervised period would translate to the unsupervised time. However, professionals were unsure to what extent this strategy was successful.

7.2.1.2 Social interaction

Social interaction was a key driver of participation in the supervised period; during the unsupervised period, whether they lived alone or with family, patients would perform the prescribed exercises on their own. Although family may have prompted and encouraged, only one patient performed the exercise with family. For those who had exercised previously family often played an important role in exercise before cancer diagnosis. Family also often provided much support during the supervised period. However, home exercise, in the form it was prescribed, had no role for family or friends, it was something to be performed alone. Family or friends were viewed as a distraction, and different activities took preference when others were present:

> Interviewer: Did any of your family ever try the exercises?
>
> Patient: No.
>
> Interviewer: Would they ever be in the room when you were doing the exercises or was it something you did just on your own?
>
> Patient: I did it mostly on my own, so you could get on and you were not distracted.
>
> **(MO-CR-04 Male 74)**

The removal of social interaction didn't just remove the driver, it could have a profoundly negative impact upon the person:

> HCP: ….He loved coming in, he loved the social aspect and having to come somewhere. When he did his change (transition), so in hospital and at home (in same period) he was okay, but he got really down in phase three (only home exercise). He wanted to come in, he wanted to be around us….around the vibrancy of the hospital. His family actually came in to talk to us about that, there was nothing we could do it was part of the protocol ….He spent a lot of time just sitting in the house and looking out the window. His family had noted the change in him.
>
> **(EM-ST-06 Design, recruitment and development)**

No patients had joined the classes purely for the purpose of social interaction, but over time this element was developed by HCPs and became an important element of the programmes for participants, then it became absent with nothing to replicate or substitute it.

7.2.1.3 Enjoyment.

Enjoyment is known to be an important influence of exercise adherence. During expert panel meetings, a member revealed that in their experience as a personal trainer, people exercise because they wanted to change something or because they enjoy it. Patients who had exercised previously usually did so in ways they enjoyed.

Patients previously reported enjoyment of supervised sessions to be an increasingly important driver of attendance. No patient reported enjoying the prescribed home exercise. Other patients were not present to talk to and play games with. HCPs were not there to talk with, tell jokes and instil a sense of energy and fun into the session, and if patients had enjoyed a particular piece of equipment, it was usually not available at home.

One patient described home tai chi as quite fun, but admitted, not as fun as the supervised sessions. Another described home tai chi as relaxing but again not as relaxing as the supervised sessions. Some patients took steps to make the exercise more pleasurable by doing it whist watching television, or in nicer locations such as their conservatory. But this was a way to distract and make it less unpleasant rather than enjoyable. For all patients the prescribed exercise was something which, if performed, was now just a means to an end:

> Interviewer: With the home exercise is it something that you look forward to doing?
>
> Patient: No.
>
> Interviewer:… is it right for me to think that the home exercise is something you do….
>
> Patient: Because I feel I need to.
>
> Interviewer: Okay, for a purpose? Because that is a purpose to it?
>
> Patient: Yes.
>
> **(MO-CH-04 Female 71)**

Patients had not joined the classes for the purpose of enjoyment, but over time enjoyment became a very important part of what the programmes meant to the participants, but was absent from the unsupervised exercise.

7.2.1.4 Perceived benefit

HCPs felt patients who exercised at home, either as additional sessions during the supervised period or after the supervised period had finished, did so due to belief in benefits gained. HCPs felt that if patients believed the exercise was producing benefit it helped them remain positive and motivated, and patients who felt this tended to be those who would adhere more closely across the supervised and unsupervised period.

During the unsupervised period patients still reported perceived physical benefit as a driver for participation. However, rather than improvement, patients anticipated the exercise was likely to result in slowing further decline, or maintenance of what had been achieved previously. Reasons for this change in expectation are unclear, some suggested the lack of specialist equipment at home limited the physical benefits which could be achieved but most patients did not offer explanation:

> Interviewer: Can you tell me your reasons for continuing to exercise since completing the [Name of centre redacted] classes?
>
> Patient: To try to maintain the level of fitness and the level of strength and feeling of well-being.
>
> Interviewer:…Those things that you mention now… You got those benefits during the class?
>
> Patient: yes, yes.
>
> **(MO-CR-04 Male 74)**

Patients who had always viewed exercise as a way to maintain their fitness were more likely to accept this. For some, who previously viewed exercise as getting fitter or improving at something, this was not viewed favourably:

> Patient: These other things start to happen… which drove my fitness down. I am on this slope, I am trying to do this and….ahh (Gesticulates with hands he is trying to go up, but is going down)
>
> Interviewer: So there is from what you indicated with your hands that is a slope going down,
>
> Patient: Which is my body and fitness.
>
> Interviewer: You are trying to push up against it….and it looks like you,
>
> Patient: I'm not achieving it. This one is winning all of the time (Points down)…..the disease itself beating all the time.
>
> **(MO-CR-02 Male 69)**

The multi-factorial boost patients had spoken of before, that left them energised and looking forward to the next session was absent:

> Interviewer: ….do you feel you get mental benefits from doing it at home?
>
> Patient: Not as much
>
> Interviewer: In what ways did you feel that the classes had the mental benefits?
>
> Patient: I think it is because it is made fun and you are not really thinking about the exercises that you are doing….it makes you feel lighter, a bit more a bit more energised. Yes, which carries on after the class.
>
> Interviewer: That is not something that you get from the home exercise is that right?
>
> Patient: Not as much.
>
> **(MO-CH-04 Female 71)**

The lack of benefit resulted in the positivity felt towards the supervised exercise being replaced with a general apathy felt towards the home exercise which was endemic across all interventions and most participants:

> Interviewer: Did anyone ever seem particularly positive about the home-based exercise?

HCP: Not that I can recall.

(EM-ST-05 Recruitment and delivery)

Whatever benefits patients had valued during the supervised exercise they either did not derive it during the unsupervised period or derived these to a lesser extent.

7.3 Mitigation and accommodation of impediments

By the end of the supervised period support provided for participants and the strategies they employed themselves to mitigate any potential impediments were well refined and comprehensively dealt with most impediments. During the unsupervised period support previously provided reduced and new impediments arose meaning strategies learnt by patients were no longer applicable.

7.3.1 New impediments

Previously the most challenging part of adhering to the programmes was getting in, and patients had devised self-mitigation strategies to effectively manage this. During the unsupervised period these strategies were redundant and participants' biggest challenge now was getting on and doing the exercise.

Patients found the exercises possible in their home environment to be less varied, less stimulating, less beneficial, and away from the specialist setting patients viewed the whole programme with less regard. Most patients found much of the exercise to be incompatible with their home environment, tried to take or incorporate elements of the supervised exercises into their homes as best they could, or devise their own exercise suitable for their homes. But now they did not have the guidance of the HCPs to help inform them.

Challenges experienced by patients were often influenced by physical wellness and the supervised exercise programme they followed previously. Patients with higher levels of physical function, such as those in the Circuits group and EMBRACE, experienced different challenges to those in the Chairs group, who typically had a lower level of physical function. Those with higher physical function received more demanding exercise during the supervised period, which had been achieved through specialist equipment. This equipment was not available during the home-based period, making the techniques patients had learnt redundant. Therefore, patients had to learn new ways to exercise at the start of the home period. The exception to this were a small number of patients in the Circuits and Chairs group who had been given exercises to do at home during a visit from the physiotherapist before a place in the classes became available. When a place became available these patients were more likely to supplement their supervised sessions with additional home exercise, which may have made the transition to home easier:

> Interviewer: ….You started doing them at home (before a place was available), You were doing the exercises at home and here (in the same period). Then when the classes here stopped you continued doing the ones at home.
>
> Patient: Yes that is right, continued the ones at home yes.
>
> **(MO-CR-04 Male 74)**

Patients in the EMBRACE group, were given completely new exercises to perform in the home period. Only one patient, in the EMBRACE group, felt the exercises to be suitable for their physical status and environment (EMB-016). The other two patients were unable to carry out the new home exercises. One tried the exercise once, was convinced it was not suitable for him as some of them hurt his shoulder and some involved laying on the floor, which he thought was unsafe (EMB-014). In an attempt to replicate the supervised exercise, he sourced his own exercise cycle. His family helped him in meeting the cost of purchase and assembly. He and his wife had used one previously so knew they could use it at home. The final patient had no support from his family and no previous experience of exercising at home. He did not exercise:

> Patient: The exercise really only works with me when I was out of my home environment….. It is a very small house for a start. There are other people around day and night….. What with my dad and everything there just really wasn't any convenient time or place. My bedroom is not very big. It was a bit of a difficult thing to go over to doing it in my own environment.
>
> **(EMB-015 Male 64)**

During the first interview patients in all groups reported wanting to use more equipment, to perform a variety of exercise and gain wider benefit. But, during the second interview patients reported difficulty in performing the home exercise because the equipment they had learnt to use, was no longer available. Therefore, much of their new exercise knowledge, created by the supervised sessions, was wasted. Patients in the Chairs group reported less difficulty transferring the exercises to their home environment. Although they could no longer play the group games, many of the exercises on the handout were the same as in the supervised sessions, and the piece of equipment used most, a chair, was present in everybody's home.

As well as the prescribed exercise patients attempted to perform other forms of exercise and activity, such as the purchase and use of different exercise equipment, use of other sport and exercise facilities, and outdoor physical activity such as walking, cycling, and gardening. All had potential impediments to be overcome. Reasons given for doing the additional activity included an inability to follow the prescribed exercise, a wish to supplement the prescribed exercise to gain further benefit, and enjoyment. Choice of additional activity was informed by past experiences. Often, though, patients would not have returned to a suitable level of health to be able to re-engage with their previous activities and would have to modify the activity or do it to a lesser level. For some doing an activity to a lesser level took away the enjoyment of the activity and they did not continue, for others the adjustment was accepted and they continued:

> Patient: ….Yes since I knew I was ill it has changed considerably…. Because that's when I was doing what I would term real yoga….
>
> Interviewer: You have had to change the exercise you do?....To fit in with your health now.
>
> Patient: Yes, yes.
>
> **(MO-CR-03 Female 68)**

Some patients attended private health centres or exercise classes which successfully replicated the enjoyment, social interaction, perceived physical and psychological benefit of the supervised programmes. However, in only one case were they able to replicate the inclusive, individualised, specialist nature of the supervised programmes. In most cases patients could only access the public classes if they were experiencing little or no negative consequences of their disease. In the supervised exercise period, as long as patients were well enough to get in, HCPs could adapt the exercise to suit their health. In contrast, in the public supervised classes, on occasion patients would be well enough to get in, but were not well enough to participate and so could only watch. One patient was prevented from joining the class his wife attended by the class instructor:

> Interviewer: I think you said that your wife goes to an exercise class at the centre (assisted living residential centre).
>
> Patient: Yes….They will not accept me.
>
> **(MO-CH-06 Male 81)**

HCP accounts raise a different perspective of attempts to engage with commercial exercise, whereby it was felt the commercial exercise professionals did not understand advanced cancer and in one known instance had been setting exercises deemed dangerous by the HCP.

Outdoor activities, such as walking, gardening and cycling all posed difficulties, which had to be mitigated or accommodated. These activities were performed predominantly for pleasure, with a belief that they would also provide some physical benefit. Those with a partner would usually perform the activity together. Improvement in walking was an aim for many patients, it was seen as a key aspect of independence, and they used strategies such as measuring distances and counting steps to assess and confirm if improvements were being achieved:

> Patient: I have recently decided to try and increase the amount of walking that I do on a daily basis….a short distance and then try and increase it over a few days….bit by bit….I count, how many steps I am doing.
>
> Interviewer:…Is there a reason why you are doing the walking?
>
> Patient: Well it is strength, and, I think I said, I am giving (myself) goals, I want to try and be able to walk to the post office. For a bit more independence.
>
> **(MO-CH-04 Female 71)**

These activities were only selected by patients who felt well enough to do activity outside or away from their homes. Symptoms such as shortness of breath meant some patients could not attempt these activities if they did not have suitable areas close by. Some patients no longer wanted to do activities which they had previously done with others because they feared their limited ability would now spoil the experience for the other people. The most commonly reported limiting factor with outdoor activity was unsuitable weather. Rain made the activities less pleasurable, hot, or more commonly, cold weather was viewed as a risk to health, particularly during periods receiving chemotherapy.

Two patients bought exercise bikes to replicate the supervised exercise. They did not enjoy them. They did, however, find them a convenient, not unpleasant, way to exercise in their own homes without having to undertake additional learning, and could be performed easily at times when they wished to do so:

> Interviewer: ….Tell me about one of those little bikes you have bought.
>
> Patient: There is not a lot to tell. It is down by the side of my chair. I just pull it over put my feet in and sit there and pedal. That is all there is….
>
> Interviewer: you tried it here first of all?
>
> Patient: yes.
>
> **(MO-CH-03 Male 76)**

This posed its own challenges in terms of cost, ordering and assembly, but demonstrated how if sufficiently motivated patients were prepared to accommodate these potential impediments and find ways to fit exercise in to their lives.

7.3.2 Reduced support.

7.3.2.1 No direct support

During the unsupervised period the input of staff had been reduced to what could be recalled from memory or ascertained from leaflets provided. HCPs report giving advice to patients during the supervised sessions which they hoped would help with the unsupervised period. For example, suggestions to maintain the day and time that exercise had previously been performed, not to feel guilty if they missed some sessions, or how to cope with certain impediments they might encounter. Patient accounts report some of this advice to have been beneficial:

> Patient: The worst symptom I have and it is a direct result of my cancer is the breathlessness. That will take over and stop me doing things. But as I say I have got

> techniques and breathing exercises and I have got medication to take, to combat those symptoms….That helps and it restores me to reasonable normality. In which case I can get on with what I planned to do.
>
> Interviewer: What sort of things help with the breathlessness?
>
> Patient: The breathing control exercises that [name of physiotherapist] taught and the medications.
>
> **(MO-CH-07 Male 88)**

Additional supportive material for EMBRACE given to people once the supervised period had finished provided no continuity with the exercises in the supervised sessions, it was considered overwhelming and off putting:

> Patient: I wasn't shown, it was all written…., it took two or three days of reading. I would read some of it and think did I understand what they just said? You know, read that again and go oh God, I'll put it down for a while.
>
> Interviewer: And you didn't try any of the exercises?
>
> Patient: No, because I knew I would have to get prepared reading it all through and like I say there was so much going on at the time that nothing happened really. I just read it and then thought oh God, and got on with all the other things.
>
> **(EMB-015 Male 64)**

HCPs in EMBRACE were aware that the number of exercises contained in the home exercise manuals were confusing, even though patients were instructed they only needed to pick some of the examples. HCPs were also of the opinion that the handouts were insufficient to replicate face to face input. The handouts for Circuits and Chairs programmes repeated many of the exercises from the classes, and had been tailored to the extent of crossing off unsuitable exercises. These were considered by patients to be a useful aid for home exercise, however in instances where additional handouts were later delivered via post this was again found to be overwhelming and unhelpful.

In EMBRACE regular telephone contact was planned, but not undertaken. A home visit was also planned for each patient at the start of the home period. But this was only performed for one patient. The patient (not interviewed) had previous exercise equipment, had the motivation to purchase additional equipment to mimic the supervised exercise, and had a suitable area at home. For that patient home exercise was a suitable solution. However, it was decided by the team to be unfeasible to continue home visits, and no more occurred:

> HCP: I only did one visit… there were issues with travel and being on my own in their home… that probably wasn't something that was sustainable. That was a really interesting visit….he was very motivated and was committed to the exercise…. He had a bike in the house. He had some weights. I watched him do his exercises…. I knew going to this man's house that he understood it because he had obviously had in the lab for six weeks so he just mimicked what he did in the lab at home.
>
> **(EM-ST-06 Design, recruitment and delivery)**

Staff accounts recognised that some form of direct support through either home visits or telephone calls was likely to be important, but difficult to do.

7.3.2.2 Patients were ill prepared

Removal of staff influence meant more responsibility had to be taken on by patients to learn and carry out the exercises, creating more burden for less reward. It was not only, in many ways considered better to exercise under supervision, it was also easier:

> Patient: Yeah, and that's what I say, it (doing home exercise) would require a lot more commitment in the sense that I would have to prepare for it I couldn't just come and do it.
>
> **(EMB-015 Male 64)**

Many patients did not feel adequately prepared for the home exercise. Although a planned part of the protocol for the EMBRACE programme, no patients had practiced the home exercise under supervision prior to their first home session, and some unaware the supervised exercise would stop:

> Patient: I didn't know I was going to the home exercise until it actually happened…..Nobody had told me, I was just told to go and collect the stuff from the gym, and in there would be a home exercise leaflet or pamphlet telling me what to do…..
>
> **(EMB-015 male 64)**

In the Chairs and Circuits classes' again some patients did not know the sessions would stop, others reported staff being too busy at the final session to be able to give advice to everyone. Some could not remember any formal instruction to continue:

> Interviewer: ….Did [name of physiotherapist] tell you to keep exercising after the classes have finished?
>
> Patient: ….Not in so many words. It is obvious you have got to keep doing these exercises. She does not actually say "just keep doing the exercises". But it is obvious that you have got to do them…. I suppose she is sort of hinting at that sort of thing, over the weeks.
>
> **(MO-CH-01 male 80)**

7.3.2.3 Lack of contact and lack of understanding

HCPs appreciated patients wished to continue exercising after the supervised period ended, but knew little about what happened after regular contact finished. In both EMBRACE and the hospice programmes HCPs gave patients information 'signposting' them to local leisure centres which people with cancer could refer themselves to. They did not know whether any patients took up that offer:

> HCP: They get the exercise referral leaflets for their area. I say wherever they go if they want to talk to me they can call me and I can discuss this if you are concerned in any way….
>
> Interviewer: When you said, they can all phone you, as of yet has that happened?

> HCP: No….
>
> **(MO-ST-01 Design, recruitment and delivery)**

Commonly HCPs who delivered the sessions only heard from patients if their paths crossed briefly when patients were attending appointments with other clinicians. Often feedback came via conversation with other HCPs involved in patients' care, in which case it was usually a request to be provided with classes.

Of those HCPs interviewed, medical consultants maintained the most regular contact, and would often talk about patients' physical activity. But as they had not been involved in the delivery of the programmes they did not understand the details of what patients had been asked to perform. Therefore, although understanding of importance of physical activity was good, understanding of set exercises and related complications was based upon speculation:

> Interviewer: Did participants ever share with you any challenges they experienced during the Homebase stage of the trial?...
>
> HCP: …No I do not think they did.
>
> Interviewer: and using your own experience what challenges do you imagine they may have faced, or, may need to be thought about when designing a program?
>
> HCP: I think it is the same things isn't it. Really, I think it is the reassurance that it is okay to do this stuff. Enthusiasm and encouragement and the flexibility to say that some days it will be okay and some days it won't.
>
> **(EM-ST-07 Recruitment)**

In the hospice programmes some patients began performing the homes exercises whilst still attending the supervised sessions. In these instances HCPs still had a better understanding of how patients were findings the exercises and were able to offer assistance. Increasing contact after the supervised period was something HCPs felt should be improved in future interventions.

7.3.2.4 No role for family and friends.

As described earlier in this chapter the lack of a role for family and friends contributed to exercise being an isolating experience and meant an important driver was missing. In addition to this family and friends had all been an important source of support who helped to mitigate potential impediments to supervised sessions. Now they were no longer involved or took less interest and so patients no longer had this source of support to manage impediments as they arose:

> Interviewer: When you were doing the classes here, your daughter used to speak to you on the phone after the classes and ask how they went is that right?
>
> Patient: Yes.
>
> Interviewer: Does she ever ask about your bike or when you go for the walk? Do you speak to her on the phone about that?
>
> Patient: No.
>
> **(MO-CH-03 Male 76)**

During the unsupervised period all previous sources of external support were reduced and no additional support, apart from written handouts, was provided.

7.3.3 Reduced desire to mitigate or accommodate

Patients with higher levels of physical function, such as those in the Circuits class, tended to be at an earlier point in their disease course. They had more interaction with friends, and often more responsibilities within their own families, both factors reported to impede exercise:

> Interviewer: So there were some days that you said you did not do the exercise. What would you say the reasons were for not doing the exercise on those days?
>
> Patient: Just the fact that other things were going on that took precedence…. it could be friends coming, family coming, going shopping, going to bowls, whatever.
>
> **(MO-CR-04 Male 74)**

Typically, patients who were earlier in their disease course, and generally with higher physical functioning, were also more likely to report large acute variations in their physical health. This made life more unpredictable into which to incorporate exercise, particularly during periods of treatment. Those with lower levels of physical function, had less social interaction, less family responsibilities, and less daily variation in their physical condition. However, this group reported more psychological issues, like depression, anxiety and feelings of hopelessness. During such periods, exercise as well as other activities, were more likely to be neglected:

> Patient: The only time is when I am really tired. Or like the last couple of days when I get upset that stops me doing exercises….when I am upset I do not like to do anything.
>
> Interviewer: and does that feel, does that go back to like you said before you just cannot feel bothered to do it?
>
> Patient: Yes something triggers, something tweaks a memory of [name of deceased wife]… it sinks into me
>
> **(MO-CH-01 Male 80)**

Even the most determined patients could reach a threshold, where they felt unable to mitigate or accommodate impediments irrespective of how much they may have wanted to. EMB-016 missed no supervised exercise despite severe chemotherapy side effects, and at point of interview had continued the set home exercises twice a week. She believed missing sessions let herself down, and was determined not to. There was, however, a period when side effects from her new immunotherapy treatment made her feel unable to exercise:

> Participant: They booked me in for immunotherapy and that had a very adverse effect on me. Profoundly so, chemotherapy was a walk in the park compared to immunotherapy I could not have done exercises. I started getting dizzy spells, getting week, sort of not falling over but sort of dropping to the floor as it were and the fatigue was unbelievable. I could not have picked up a feather let alone an elastic band to do exercise.
>
> **(EMB-016 Female 58)**

During the unsupervised period with reduced drivers and reduced support the threshold for not exercising lowered. Previously an illness episode, for example, usually had to reach a level to prevent patients from being physically able to attend. During the unsupervised period, illness only had to reach a level that caused patients to lose the desire to exercise. A patient who previously had devised several methods to 'mitigate or accommodate' discomfort during supervised exercise, chose not to perform the prescribed home exercise as it felt awkward the first time he tried it:

> Interviewer: So was it, complicated to work out what to do with the elastic bands?
>
> Patient: No, it was just awkward…It was awkward, being my age, I'm not as strong as I was, it was just awkward and I felt uncomfortable with it, that was the only reason.
>
> **(EMB-014 Male 76)**

Although patients often spoke of fatigue during the first interview it only prevented one from performing supervised exercise (EMB-025). During the unsupervised period fatigue was reported by many patients across all programmes to have impeded exercise. For some it worsened during periods of treatment, for others it had no discernible pattern. Descriptions of fatigue varied. Most commonly fatigue involved combinations of unexplained tiredness, low mood, and a psychological lack of interest or desire to perform any activity including their exercise or other basic activity. It could last for short periods or whole days:

> Patient: I've just got no energy….No energy…I didn't have any sickness or loss of appetite… it was just I felt, a bit depressed.
>
> Interviewer: So, when you felt bad from the chemo it was….
>
> Patient: …lack of energy... I would want to do something like go down in to the garden, to the shed and go "oh I won't bother". You know just like that, I didn't want to do anything.
>
> **(EMB-014 Male 76)**

Patients found it hard to distinguish physical fatigue from feelings of low mood, both had the same effect:

> Interviewer: So if you are really tired or if you are really upset and it has the same effect that you just won't do it.
>
> Patient: yeah won't do it.
>
> **(MO-CH-01 Male 80)**

The threshold for social impediments also lowered. During the supervised period, family and social occasions were re-scheduled to fit around the exercise. During the unsupervised period this reversed, exercise now had to fit around other responsibilities:

> Interviewer: ….Is there anything else that has prevented or made it more difficult to exercise since finishing the classes?
>
> Patient:… I think it is merely fitting it into a busy lifestyle, making sure that I have got time enough to do it that is all.
>
> **(MO-CR-04 Male 74)**

It is likely the reduced threshold for exercise was related to the reduction in the drivers, without those drivers the impetus to exercise was missing and so even when something brought about a conscious decision as to whether or not to exercise patients were more likely to choose not to:

> Interviewer: You miss the social side is there any other difference between doing it at home and doing it in the class ….
>
> Patient: You have got to have the motivation to do it. That is one big thing. I think when you are at home you do not try as hard….. Because when you are in a group you are kind of thinking I can do this…..
>
> Interviewer: On the days when you don't do them (home exercises) can you explain what it is you are feeling?
>
> Patient: ….hopeless….. I feel as if I am no good for anything I cannot do it…. if I had the class to look forward to….I would say later on today I will be doing that and that will make me feel better.

> Interviewer: ….Were there any days when you had that feeling of being hopeless but still came to the class?
>
> Patient: Yes, and it made me feel better at the end.
>
> Interviewer: Whereas at home….if you had that feeling of hopeless at home…
>
> Patient: I would not be doing the exercises….
>
> **(MO-CH-02 Female 71)**

The complex relationship between fatigue, motivation and low mood could generate a negative cycle where feelings of low self-worth made starting exercise harder. In turn, missing an exercise session increased feelings of low self-worth. Previously having an exercise appointment to attend pulled patients out of this spiral. Without the appointment this spiral continued. The longer the patient went without exercising the harder it became to start:

> Interviewer: Can you explain differences in feeling between the good days and the not so good days
>
> Patient ….. it is difficult to put into words, it is just a feeling of life and no life…..you feel as though “na it is not worth bothering” but at the same time you might say “yes it is worth bothering” do it.
>
> Interviewer: ….is that feeling of not worth bothering specific to the exercise?
>
> Participant: It is towards other things as well. The exercise kind of comes into it because that is probably what I am thinking of at the time…. I kind of think “what is the use”,….I tried to push myself into the way of thinking “yes it is worth doing the exercise” it is the exercise at the end of the day “oh remember a few days ago you felt better”. So that is the way I tend to look at it.
>
> Interviewer: …. it gives you a positive feeling from it. But you need a certain amount of positive feeling in the first place to gee you up to do it?
>
> Participant: Yes I, I tend to feel doing the exercise is what makes me feel good. You know, it is the only way I can say it having done the exercise makes me feel good….and then I am more positive about things. I will go on more and I will do the exercises more.

> **(MO-CH-02 Female 71)**

Once patients had exercised they were glad that they had, accompanied by a sense of accomplishment and reassurance that they still could.

7.4 Typology of exercise behaviour.

During analysis it became apparent that the resulting exercise behaviour of patients during the unsupervised period could be arranged into four types.

7.4.1 Type 1) Return to previous regular exercise.

A small number of patients were able to re-engage with their old exercise regimes, which they had enjoyed and found beneficial. This was achieved either because of a return to previous levels of health and physicality, or adaptation to their routines combined with adequate support to accommodate their ill health:

> Participant: Well my yoga teacher has started a class for older people. It is sort of semi-yoga but not as strenuous as the one I used to do so it is brilliant…she is very careful she always tells me if she thinks an exercise is not right for me she tells me don’t do that one. She is very good, you know she is very professional.
>
> **(MO-CR-03 Female 68)**

For these patients, exercise was previously, and had again become, a normal part of life, despite their illness.

7.4.2 Type 2) Created new regular exercise.

For these patients exercise may or may not have been a regular part of their life previously, but they had found a way to ensure it was going forward. Some strongly believed they obtained significant benefit from exercise and were prepared to make significant adjustments to fit regular exercise into their lives and prioritise it over other demands. They may not have enjoyed the exercise compared to supervised sessions but accepted this. They also valued exercise as one of the few things they could do for themselves in relation to their health:

> Interviewer: You mentioned before that you find the classes enjoyable. The exercises at home are they enjoyable?
>
> Patient: I just never think of it I just do the damn things and get on with it, and I feel benefit from it.
>
> **(MO-CH-07 Male 88)**

Other patients in type two were not certain, but believed they probably gained benefits from exercise. They found a way to perform what they considered an acceptable amount of exercise, with minimal additional burden. One particular patient enrolled to exercise in the EMBRACE study for the reason of helping others in the future. She had been withdrawn from the study halfway through the unsupervised period as her treatment changed and so no longer met the inclusion criteria. This meant her primary motive to exercise was no longer met. However, she continued to exercise because she felt it likely to provide physical benefit and could fit exercise in to her life without making great personal sacrifice. This demonstrates patients could be prepared to exercise unsupervised even if their most prominent drivers were removed as long as the effort required matched the new driver:

> Interviewer: Can I ask how you view that now in relation to other parts of your care and your treatment. I am perhaps making the assumption that since you have decided to start doing it again it was quite important to you and you value it?
>
> Patient: I value it insofar as it is something to do that is beneficial….it is no skin off my nose….and yes, it is beneficial. So rather than just sitting at home looking out the window it is something to do that is beneficial.
>
> Interviewer: ….Do you do you view it as a type of therapy at all or a type of treatment?
>
> Patient: no not particularly.
>
> **(EMB-016 Female 58)**

The more these participants felt they gained from the exercise the more they were prepared to adapt to fit exercise into their lives now.

7.4.3 Type 3) Infrequent exercise.

Patients in this group performed exercise in a less structured way, it conflicted with other priorities and was more likely to be missed if experiencing even mild symptoms:

> Interviewer: ….Have you, have you tried to continue with any of the exercises at all?
>
> Patient: I have… at home I do little things…sitting there trudging my feet like that (marches feet up and down while sat in chair)….I do try to do some exercises, but, it is not so enjoyable doing it on your own as it is with the group….the idea is in my head to do the exercises. I do still think about it and do some of them at times.
>
> **(MO-CH-02 Female 71)**

These patients were less sure the benefits they experienced were transferable to home, and really felt the loss of enjoyment from the supervised sessions.

7.4.4 Type 4) No exercise.

Life for these patients was too chaotic due to their disease or home situation to successfully make home-based exercise a normal part of their lives. They had intended to continue with home exercise but this never happened. They could see no other way in which they could continue exercising other than restarting supervised face to face appointments to take them away from a situation which was not conducive to exercise:

> Interviewer: Did you manage to try any of the exercises that were in that book?
>
> Patient: No...I went through it and by the time I'd read it through things were happening at home… I was going to do it over the weekend I was ill. I had the chemo and the sickness over the weekend…. That was when my dad went into hospital it was all getting out of control…..in the end it was, "oh well I will have to come back to that". There was nothing, no appointments….so of course I didn't get round to that, and the longer you don't do something the more it is to get yourself to actually do it, …. In the end you think, "oh it doesn't matter anymore". It's so long now, and I haven't even bothered.

(EMB-015 Male 64)

These patients had been the most positive about the supervised sessions during the first interviews, but benefits reported were largely related to the interaction and so did not transfer to the home environment. During the second interview they were angry and dismissive of the need for the supervised sessions to end.

7.5 Unsupervised period summary.

The overall experience of home-based unsupervised exercise was that of loss. The structured moments of conscious decision were no longer present, meaning there was no unavoidable point when patients had to consider exercising. If patients did make a conscious decision regarding exercise at any point, the drivers for doing exercise were lost or diminished. Across all periods if patients believed they ‘should’ do the exercise they tried to make sure they ‘could’ do the exercise. During the home period there was less reason that they ‘should’ and less support to make sure they ‘could’. Overall, exercise became less important, less beneficial, less enjoyable, and harder to perform. The exercise required more effort for less reward.

Enjoyment, social interaction, and direct staff input, all of which had contributed to the psychological benefits experienced during the supervised period were absent during the home period. In addition to the loss of these drivers, perceived physical benefit was for most changed from a belief of improvement to slower decline. Support from HCPs, as well as support from others such as family, was largely absent. Whereas previously some patients had been exercising due to a commitment to the staff delivering the sessions, once the direct contact had stopped this commitment appeared to stop also.

The types of supervised exercise performed previously were usually incompatible with patients’ home environments. The lack of consistency between the supervised and unsupervised exercises meant much of what was learnt during the supervised period became obsolete. The supervised period therefore was an underutilised opportunity to develop lasting exercise behaviour.

From patient reports there appeared to be little collaboration between staff and patients to think through factors that might mitigate against or promote exercise in the unsupervised period. From HCP accounts there was little understanding of the home period. HCPs prescribed exercise to be performed at home, with little investigation of patients’ home context or exercise preferences.

The exercise usually required some modification to be adapted to the home environment, and this modification was undertaken by the patient without HCP input. Fatigue was experienced by the majority of patients, and whereas previously it rarely impacted exercise adherence, during the unsupervised period it frequently did.

Chapter 8 Home-based exercise patterns following supervised exercise programmes: a conceptual model

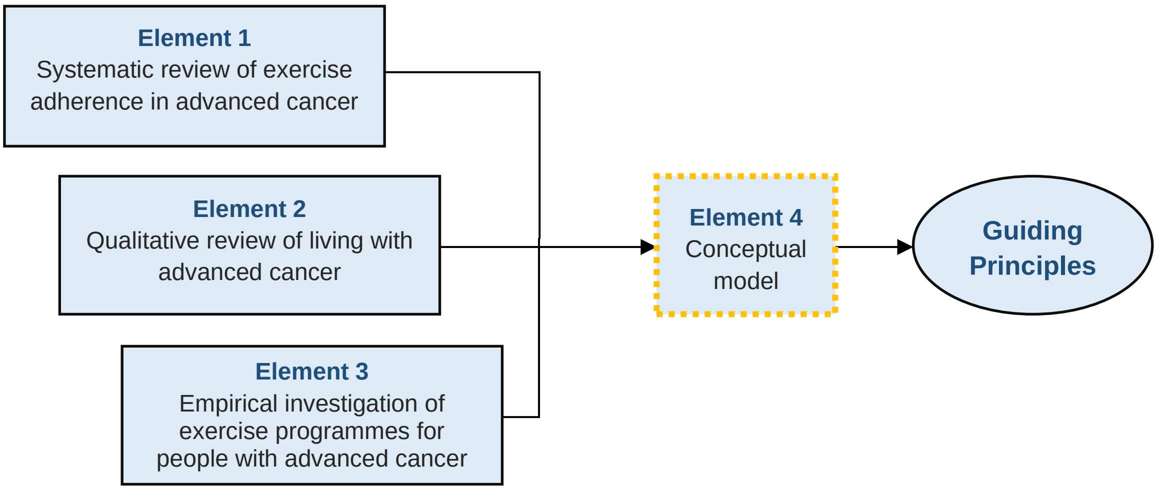


Figure 13: Element 4 schematic representation of the FIT-TOGETHER study

8.1 Introduction.

This chapter will describe key features of a model developed to set out factors that shape continuing exercise behaviour following a supervised exercise programme for people with advanced cancer. The model (Figure 14) has been developed through synthesis of empirical research and reviews of literature presented earlier in the thesis and been informed by findings from other published reviews and theory.

The development of the model was guided by the method described by Hunt and May, (2017) and modified by Lippiett-Chapple (2019). Steps of this process included: 1) identification and characterisation of sensitizing concepts; 2) identification and characterisation of theoretical concepts; 3) integration and refinements of sensitizing and theoretical concepts; 4) modelling constructs.

The term sensitizing concepts originated from the work of Blumer (1954) and described the process of sensitising the user to possible lines of enquiry. They lay the foundations upon which further analysis can be built (Bowen 2006). Here sensitizing concepts were devised from scrutinising the findings of the empirical research conducted into patient and HCP perspectives of exercise adherence (Element 3), and reviews undertaken on the topics of exercise intervention adherence in advanced cancer (Element 1), and living with advanced cancer (Element 3). Early lines of enquiry were determined based upon the exercise (components and delivery), patient characteristics, and, environment, for both the supervised and unsupervised contexts. Findings from Elements 1, 2, and 3, were then read and early lines of enquiry further developed and refined, through discussion in supervision meetings, to improve their suitability to represent what shaped continued exercise behaviour patterns in this population. These refined constructs formed the sensitising concepts.

Theoretical literature and related empirical research reported in earlier chapters were analysed with reference to the COM-B model (Michie, van Stralen and West, 2011), the Attribution theory of achievement motivation (Weiner 1985; 2010), and the Conceptual model of implementation fidelity (Carroll et al. 2007, Hasson 2010). In addition to this, a brief key term search of the electronic database CINAHL, non-systematic internet searching, and further searching of reference lists of identified papers located further theoretical perspectives of relevance. These additional theories for consideration included: Operant conditioning (Skinner 1937; 1948) Self-efficacy theory (Bandura 1978), Social cognitive theory (Bandura 1989), Trans-theoretical model (Prochaska and DiClemente, 1983), Motivational undermining (Camerer 2010; Hidi 2016), Human agency (Bandura 2006). As well as theoretical literature, further reviews investigating exercise in advanced cancer were found and included for consideration to inform the developing model (Dittus, Gramling and Ades, 2017; Sheill et al. 2019). An exhaustive comparison of the study findings with reference to all possible relevant theory was not possible. A scoping review by Davis et al. (2015) indicated 83 theories have been used to explain health related behaviours. The goal here was not to find and incorporate every possible theory, but to have reasonable confidence that the most important and most appropriate theories had been considered and most relevant empirical findings incorporated. Corroboration of this assertion of inclusion of most important theory and concepts was achieved through communication with the behavioural scientist who was involved in the previously formed advisory panel.

The sensitising and theoretical concepts were integrated to develop and characterise the factors found to influence exercise adherence.

The final stage of the process involved modelling the relationship between each developed construct to demonstrate how these influence exercise behaviour. This involved various iterations and discussions of the developing model before an accurate representation was agreed upon.

This model illustrates the ways in which interactions between the features of an individual and his or her environment (pre-existing factors), when introduced to what is required of the exercise (demands of the home exercise protocol) are regulated by several attributes (Home exercise determinants) and proposes the way which these attributes influences exercise adherence (Theoretical mechanisms of action).

The model identifies five ‘Pre-existing factors’, which are features of an individual and his/her environment that pre-exist the introduction of the unsupervised exercise protocol but influence the extent to which an individual can follow said protocol. These pre-existing factors are: ‘Previous exercise experiences’, ‘Consequences of illness and treatment’, ‘Personal traits and characteristics’, ‘Physical aspects of the home environment’, and, ‘Social aspects of the home environment’. The interactions amongst the pre-existing factors in relation to the stipulated demands of the home exercise protocol determine the degree to which those demands can be met and the protocol adhered to.

From the interactions between the pre-existing factors and with the demands of the home exercise protocol three ‘Home exercise determinants’ were identified that regulate the extent to which participants adhere to that protocol. These home exercise determinants demonstrate ‘where’ the interactions of the ‘Pre-existing factors’ and the ‘Demands of the home exercise protocol’ act to influence exercise adherence (Participant, Environment, Support), and make a judgement as to the extent they are ready or suitable for the exercise: the participant needs to be ready; the exercise environment needs to be suitable; and they need to have appropriate support available. Therefore the home exercise determinants are: ‘Readiness of the participant’, ‘Suitability of the exercise environment’, and, ‘Suitability of support’. These determinants need to be in place to some degree for individuals to adhere to an exercise intervention, and so determined their continuing exercise pattern.

Three theoretical mechanisms of action’ within each determinant demonstrates ‘how’ those interactions between the pre-existing factors and the demands of the home exercise protocol act to influence exercise adherence (Motivation, Self-efficacy, Agency). It is the extent to which the interactions between ‘Pre-existing factors’ and ‘Demands of the home exercise protocol’ generate these mechanisms within each determinant that regulates to what extent the exercise determinant satisfactorily meets the demands of the home exercise protocol and therefore is ready, suitable or appropriate for the exercise.

Finally, feedback from both the exercise decision and the exercise behaviour can either reinforce future decisions, or can enable participants to make amendments to influence future exercise decisions and behaviour either through targeting the ‘Home exercise determinants’, or through amendment to the exercise protocol. This can allow for refinement and optimisation of those regulatory factors or for compensation when negative changes occur over time. This refinement and optimisation is performed by the participant unless other support is involved at this point.

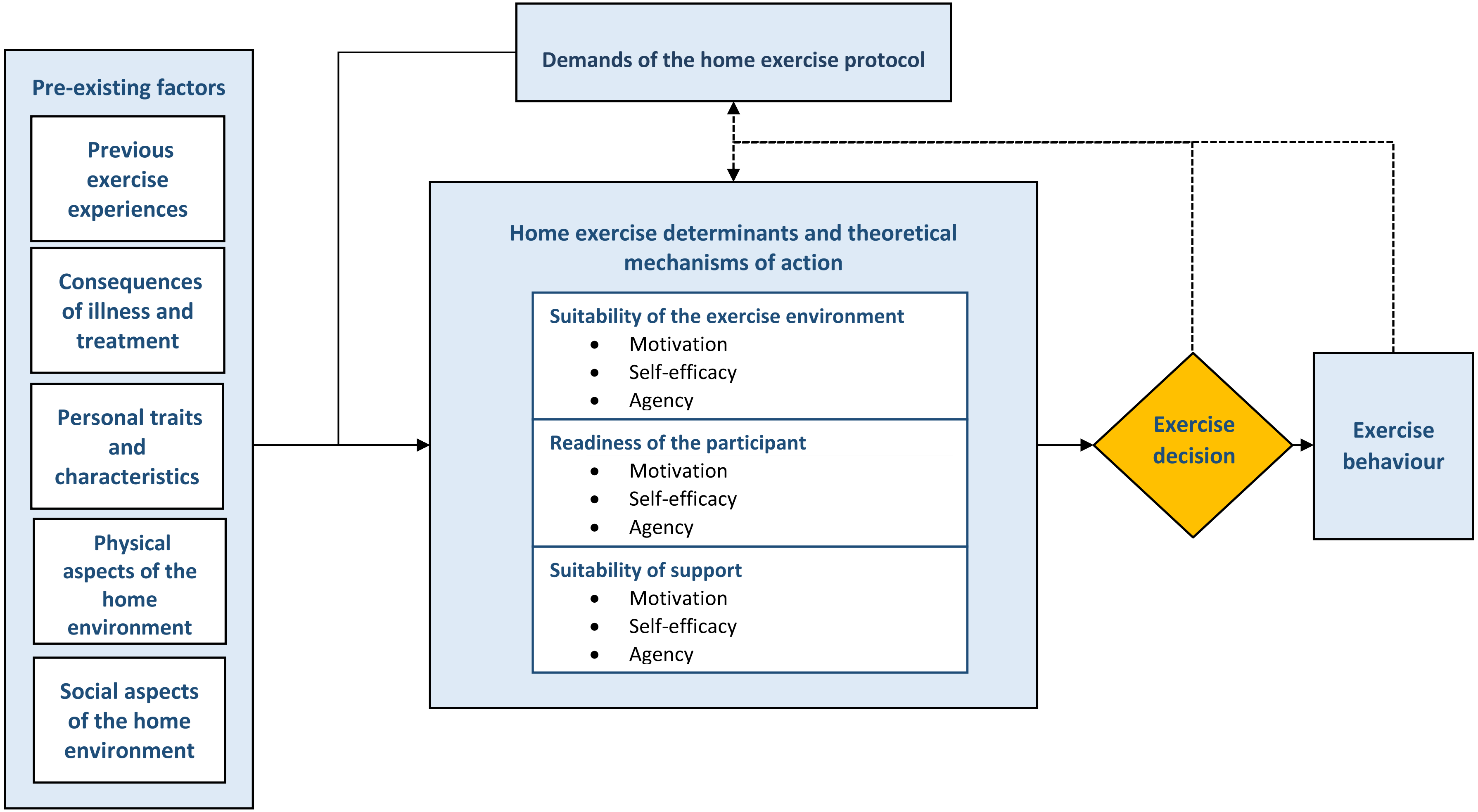


Figure 14: Model of home-based unsupervised exercise behaviour following a supervised exercise programme

8.2 Pre-existing factors

‘Pre-existing factors’ are characteristics of person and place that predate the introduction of the home exercise protocol. Interactions between the ‘Pre-existing factors’ with the demands of the home exercise protocol generate the ‘Theoretical mechanisms of action’ and dictate the adequacy of the ‘Home exercise determinants’. This influence was either through direct impact on the participant or by mediating experience and interpretation of other variables. Kelly and Barker, (2016) term such variables ‘preceding conditions’ and believe them to be a key issue when trying to understand health-related behaviour change as they provide understanding as to why people act as they do. Here the term ‘Pre-existing factors’ has been chosen rather than ‘preceding conditions’ due to the potential for the latter term to cause misunderstanding in this context i.e. refer to a medical condition.

8.2.1 Previous exercise experiences

The pre-existing factor of ‘Previous exercise experience’, involves participants’ historical exercise experiences as well as experiences from the recent supervised programmes. These previous exercise experiences could influence the other pre-existing factors. Systematic reviews demonstrate strong evidence that exercise can abate many ‘Consequences of illness and treatment’ for people with advanced cancer through improvements in physical functioning (Dittus, Gramling and Ades, 2017; Heywood, McCarthy and Skinner, 2018) and growing evidence suggests exercise may improve fatigue (Dittus, Gramling and Ades, 2017; Heywood, McCarthy and Skinner, 2018) and some evidence suggests exercise may improve experience of pain (Heywood, McCarthy and Skinner, 2018). In congruence with this evidence, several participants reported improvement in negative consequences of cancer during the period in which they were attending the supervised sessions. Examples included reduced feelings of depression associated with their terminal diagnosis, as well as increases in their physical fitness and mobility which had been diminished by their illness or associated treatment. With regard to the pre-existing factor of ‘Personal traits and characteristics’, those who had been exercising for longer periods of time typically already had characteristics beneficial to continued exercise such as a natural enjoyment of exercise and an understanding of its importance. Amongst those for whom the supervised programmes were their only exercise experience such characteristics could still develop but were often less well established. ‘Previous exercise experiences’ also influenced the ‘Physical aspects of the home environment’; participants who had exercised in the past were more likely to know which forms of exercise were feasible, to own suitable exercise equipment, or to have modified their homes to be better suited to exercising. Finally, ‘Previous exercise experience’ could influence ‘Social aspects of the home environment’ through previous identification and use of social resources available to them as well as experience of how to fit exercise around any social responsibilities. Again this was more prominent in participants for whom exercise had been an important part of their lives than in those who had only exercised during the supervised programmes. In summary, ‘Previous exercise experiences’ could influence all the other pre-existing factors. Typically, the longer the time period over which those experiences had been established the greater the influence they exerted on other variables.

8.2.2 Consequences of illness and treatment

‘Consequences of illness and treatment’ comprise the physical and psychological effects of a participant’s illness and associated treatments. The most common illness impacting people with advanced cancer was their cancer, but for many participants comorbidities such as diabetes, or mental health issues such as depression were also important. Whereas the other pre-existing factors are relatively constant, ‘Consequences of illness and treatment’ could be highly changeable day by day or even hour by hour, could impact upon many of the other pre-existing factors, and may also have prevented attendance of individual supervised sessions. Physically the consequences of illness were only ever negative, however psychologically some examples existed of positive responses to the illness such as a desire to make the most of remaining good health, an increased interest in learning more about their health and an intention to act upon this new knowledge. ‘Consequences of illness and treatment’ had little impact upon the pre-existing factors of ‘Personal traits and characteristics’ or ‘Physical aspects of the home environment’. However ‘Consequences of illness and treatment’ were more influential over ‘Social aspects of the home environment’ in that some of the social resources participants utilised had developed in response to their illness, such as extra support that some now received from family, friends and former work colleagues. In addition, for some participants the social responsibilities they may have been constrained by had been lessened by the development of their cancer and resultant decisions such as seeking early retirement from their work.

8.2.3 Personal traits and characteristics

‘Personal traits and characteristics’ refer to factors such as a person’s emotional and psychological status, their capabilities, cognitive abilities and opinions and values which influence continuing exercise behaviour. These traits and characteristics can be of a general nature which influences many aspects of life including exercise, or relate only to exercise. Their influence on other ‘Pre-existing factors’ is due to how they influence a person’s preferences and decisions and the interpretation of the experiences they have. ‘Personal traits and characteristics’ influence ‘Previous exercise experiences’ through previous choices made around exercise and how the supervised programmes were experienced. They influenced the ‘Consequences of illness and treatment’ through how a person interpreted illness and their responses to it. ‘Personal traits and characteristics’ influenced the ‘Physical aspects of the home environment’ as they helped to shape the home environment and influence how participants interpret the suitability of that environment. Finally ‘Personal traits and characteristics’ influence the ‘Social aspects of the home environment’ through determining which social resources the person is aware of and values, how they see themselves in their social role and therefore influences which responsibilities they continue to undertake.

8.2.4 Physical aspects of the home environment

‘Physical aspects of the home environment’ involve the setting within which a home intervention takes place, and incorporate issues such as the size and suitability of space, and competition for that space with other functions the home must serve. It had little impact upon other pre-existing factors with the exception of influencing ‘Previous exercise experiences’ and to a lesser extent ‘Social aspects of the home environment’. ‘Physical aspects of the home environment’ influenced ‘Previous exercise experiences’ shaping the types of exercise people had performed previously during historical periods of exercise or during the supervised programmes. ‘Physical aspects of the home environment’ also had some influence upon ‘Social aspects of the home environment’ due to the responsibility held by the participant of managing that environment.

8.2.5 Social aspects of the home environment

‘Social aspects of the home environment’ involve potential sources of support. Friends, family, colleagues, who could encourage, support or discourage participation in exercise and any responsibilities participants may have toward them. ‘Social aspects of the home environment’ had limited influence upon most of the pre-existing factors but very influential with respect to

‘Previous exercise experience’. Few participants with long established histories of previous exercise had done so without some form of involvement from others. Likewise most participants received some form of support attending the supervised programmes. Consequently, examples existed of long-term previous exercise being halted when involvement of those they had exercised with was withdrawn or social responsibilities prevented its continuation. Examples also existed of long term previous exercise and engagement in supervised programmes being interrupted for shorter periods when exercise clashed with other social responsibilities. ‘Social aspects of the home environment’ were less likely to directly impact on other pre-existing factors but did influence the impact those variables had on the person. For example, ‘Social aspects of the home environment’ had little direct influence the ‘Physical aspects of the home environment’ but did influence how that environment could be utilised by the patient. Likewise ‘Social aspects of the home environment’ did not influence ‘Consequences of illness and treatment’ directly but did influence how those consequences impacted the participant.

8.2.6 Pre-existing factors summary

The ‘Pre-existing factor’ of ‘Previous exercise experience’ was the most influential factor, upon the other factors and on subsequent exercise behaviour. This is consistent with Sutton (2001) who states that many theories of behaviour view proximal factors such as beliefs and attitudes to be a much larger determinant of behaviour than distal factors such as social and environmental considerations. Sutton (2001) continues that those proximal factors often mediate the distal factors. The research which informed this model indicates ‘Previous exercise experience’ to be highly influential of participants’ beliefs and attitudes towards exercise and subsequently mediated the other variables in relation to exercise.

8.3 Demands of the home exercise protocol.

The prescribed protocol sets the demands which the determinants must meet in order for the participant to adhere to the exercise. This section shall investigate what those demands are and what influences them. Exercise interventions are highly complex interventions, according to the definition of the Medical Research Council (Craig et al. 2008) and complexity of an intervention is associated with more challenging implementation (Hasson 2010). However, conclusions of Element 2, supported by findings in Element 3 indicate an intervention must accommodate changes in the participants’ capability which adds further complexity. Prescribed hospital to home exercise protocols, identified in published literature in Element 1 (Cormie et al. 2013; van den

Dungen et al. 2014; Winters-Stone et al. 2014; 2015; Kuehr et al. 2014) and the programmes investigated in Element 3, typically involved different combinations of aerobic, resistance, and stretching exercises. Most protocols, published in Element 1 and followed in Element 3, acknowledge the differences between what is possible between the two locations and prescribe different exercises for each. Typically the higher the intensity of the supervised programmes the greater the difference to what was prescribed for home exercise. Aerobic home exercise usually involves walking or use of equipment which may already be available such as bicycles or stationary exercise cycles. Resistance exercise typically involved combinations of body weight exercise such as standing out of chairs or squats whilst holding a chair for support, or use of elastic resistance bands usually provided at the end of the supervised period. Commonly some form of written instructions, with accompanying pictorial representations are provided to describe how to perform the exercise. These instructions usually also give direction as to how frequently the exercise should be performed each week.

8.4 Home exercise determinants

This section identifies constructs formed from interactions between the 'Pre-existing factors' and the demands stipulated by the home exercise protocol to show where these interactions act. Social cognitive theory (Bandura 1989) suggests behaviour is a consequence of an interaction with multi-directional influence between personal determinants such as biological factors, cognitive factors, and habitual patterns, with environmental events. In support of these assertions, findings from interview studies which investigated exercise adherence following a supervised intervention found continued exercise behaviour to be a consequence of an interaction between pre-existing factors and the 'Demands of the home exercise protocol' and that these interactions could be arranged into; biological, cognitive, and habitual factors (Readiness of the participant); environmental factors (Suitability of the exercise environment); social factors (Suitability of support) to show where those interactions are located in relation to exercise behaviour and adherence.

8.4.1 Readiness of the participant.

Several theories of behaviour place the physical and mental abilities of the participants' central to the outcome of a behaviour (Sutton 2001). To follow the home-based exercise protocol participants needed to be physically ready for the exercises in terms of having the required levels of factors such as strength, mobility, stamina, balance, flexibility, to be able to perform the exercise to an acceptable level of comfort and safety. Participants also needed to be mentally ready for the home exercises. Participants required suitable understanding of the exercise, how to prepare for it, perform it, deal with potential barriers as they arise. Participants also required an understanding as to why they, as an individual, might want to perform it.

According to the Trans-theoretical model (Prochaska and DiClemente, 1983), there are five stages to changing a behaviour: pre-contemplation, contemplation, preparation, action, and maintenance (DiClemente et al. 1991). At each stage different factors are considered important and at each stage, different support or intervention is required to progress. All participants interviewed entered the supervised exercise period at either pre-contemplation or contemplation stage, while typically those who had been previously exercising were contemplating returning to exercise, and those who had little or no previous history of exercise were not contemplating this. By the end of the supervised period all participants were in the maintenance stage for supervised exercise behaviour. Those participants who had enrolled in the exercise programmes because they wanted to return to their previous exercise routines, began to practice the upcoming home exercises before the supervised period finished. These participants began progressing through the stages of contemplation, preparation, action, and maintenance for unsupervised home exercise before the supervised period was over. Conversely for some other participants, once the supervised period finished, they remained at pre-contemplation for home exercise either because they had not considered what may happen after the sessions finished or they did not know they would finish.

8.4.2 Suitability of the exercise environment.

‘Suitability of the exercise environment’ involves how appropriate the home environment is for the demands of the exercise prescribed. It must be motivating, enable a sense of self-efficacy, and, provide a suitable space in which agency can be enacted if required. It was predominantly influenced by how the pre-existing factors of the ‘Physical aspects of the home environment’ and ‘Social aspects of the home environment’ related to the ‘Demands of the home exercise protocol’. This involved considerations such as having an area with enough space to perform the prescribed exercise without requiring unacceptable levels of preparation or modification. Having suitable places to use and store necessary equipment, and the level of stimulation or interest that was generated by exercising in this environment was also important to the ‘Suitability of the exercise environment'. However the other pre-existing factors 'Previous exercise experiences', 'Consequences of illness and treatment', 'Personal traits and characteristics', can act as moderators influencing the impact of the interaction between the protocol and the physical environment. Findings showed it is not just the home environment which required consideration as participants also indicated the importance of needing to perform the exercise whist on holiday and during periods of hospital admission. The environment has long been a recognised consideration around theories of behaviour (Bandura 1989), and it is recognised that both physical and social aspects of an environment can influence a persons opportunity to perform an intended behaviour (Michie and West 2013). However, there is little other relevant research which has reported on the suitability of home environment for exercise. Some research has found social aspects present in the home environment, such as family commitments, made continued physical activity challenging, after having completed a physical activity promotion intervention (Grimmett et al. 2020). No other research has been found which identified physical aspects which dictate the 'Suitability of the exercise environment' in home settings for this patient group.

8.4.3 Suitability of support.

'Suitability of support' involves the level and appropriateness of support provided to participants once the supervised programmes have ceased. To be most suitable support should use its own agency to enhance participants' motivation and self-efficacy towards the exercise, or allow the participant to exert proxy agency through them to exert the influence deemed necessary by the participant. The conclusions of Element 2 suggested some portion of external support is likely necessary to aid participants in following an exercise programme. In support of this, findings of Element 3 showed during the supervised exercise participants who benefited greatly from support from HCPs and family or friends. Social support is considered an important technique for changing behaviour according to the behaviour change taxonomy (Michie et al. 2013). Support from family was found to predict exercise adherence in patients following cancer treatment (Ormel et al. 2018) and to improve adherence to home-based physical therapy intervention for people with muscular skeletal conditions (Essery et al. 2017). Professional support during unsupervised exercise has also been found to lead to increased adherence (Essery et al. 2017). Participants interviewed in Element 3 indicated professional support, which previously was provided in the supervised period and incorporated in the pre-existing factor 'Previous exercise experience', was reduced to what Carroll et al. (2007) and Hasson (2010) described as 'Supporting materials' in the form of written instructions and some equipment such as the elastic resistance bands. Some home protocols have attempted to provide direct support in either the form of a regular phone call or home visits. However, attempts to provide such support have often found this to be too challenging to implement and deemed such methods unfeasible. Support provided by the 'Social aspects of the home environment' were dependent on family and/or friends offering support or being sourced by the participants to provide support to them. Typically support was very limited, professional support did not continue and there was no inclusion for support from family or friends in the home protocol. No attempts had been made to train family or friends to be able to support participant's when the professional support was withdrawn. Families were often involved in historical exercise but, usually these exercises were not the same as stipulated in the home protocol and the participants would have been in better health pre diagnosis, therefore this is of less relevance to their current situations.

8.4.4 Home exercise determinant summary

This section has used evidence from research and theory to develop constructs which determine whether or not a person meets the 'Demands of the home exercise protocol' and adheres to the intended home-based exercise: the 'Readiness of the participant', the 'Suitability of the exercise environment' and the 'Suitability of support'. It has indicated how the pre-existing factors contribute to adequacies as well as deficiencies in the home exercise determinants. It has demonstrated how in current programmes deficiencies exist in both the 'Suitability of the exercise environment' and the 'Suitability of support' and how participants demonstrating better readiness are more able to compensate for such deficiencies.

8.5 Theoretical mechanisms of action

This section discusses three theoretical mechanisms of action, that explain how the interaction between 'Pre-existing factors' and 'Demands of the home exercise protocol' influence exercise behaviour through 'Motivation' 'Self-efficacy, and, 'Agency'. The presence of these mechanisms dictate the extent to which the determinants are ready and suitable to exercise and demonstrate how or by what means the previous interaction influence the decision to and enactment of exercise. In this instance 'Self-efficacy' relates to the extent to which participants perceived they were able to successfully perform home exercise, 'Motivation' relates to the extent to which a participant wanted to perform the home exercise, and 'Agency' relates to the extent to which a participant was able to exert influence over the factors which determined whether or not they would perform the home exercise.

These three mechanisms are not discrete and can overlap and influence each other. For example, it has long been proposed that self-efficacy can influence motivation in that if a person has high self-efficacy towards a task they subsequently are more likely to predict strong positive outcomes for themselves resultant from that task and therefore have high motivation towards performing it (Bandura 1997). Similarly Bandura (1997) continues if a person's self-efficacy towards a behaviour is low they are less likely to imagine positive outcomes resulting from that behaviour, and therefore motivation will be lower. More recently a review by Williams and Rhodes, (2016) found evidence suggests self-efficacy does not influence motivation but in fact self-efficacy can be influenced by motivation (Corcoran and Rutledge, 1989; Baker and Kirsch, 1991; McDonald et al. 2010). Which supports the findings of Elements 3 and 4 in this thesis, if a person is very motivated to perform something they subsequently are more likely to also conclude they can do that. This was demonstrated in in Element 3 where when faced with similar challenges participants who seemed more favourable to perform the exercise overcame similar challenges to those who concluded they could not do the exercise. Similarly, agency also interacts with the other two mechanisms. Self-efficacy and agency are closely linked. A judgement of self-efficacy was performed by participants throughout demonstrations of agency, as a key element of agency is to make and view predictions of outcomes in the future, which in certain situations can be a judgement of self-efficacy. Likewise levels of agency held by a person influenced self-efficacy as when a participant successfully exerted their influence upon the area of focus it was more likely the person's self-efficacy towards that increased also. Finally, as agency is the ability to exert influence, a person was more likely to exert their influence over issues they were motivated to exert influence over.

In the following sections, each identified 'Mechanism of action' is characterised and propositions made as to the relationship between them, the 'Pre-existing factors' and the 'Home exercise determinants'.

8.5.1 Motivation

'Motivation' is common to many theories of behaviour, several of which include motivation by name, such as the Information Motivation Behavioural Skills Model (Fisher, Fisher and Harman, 2003), COM-B (Michie, van Stralen and West, 2011), Theory of Planned Behaviour (Ajzen 1991), Trans-theoretical model (Prochaska and DiClemente, 1983). Other theories include concepts comparable to motivation, such as ‘outcome expectancies’ in social cognitive theory (Bandura 1989) and ‘perceived benefits’ in the Health Belief Model (Rosenstock 1974).

Several definitions of motivation have been proposed to describe and explain the concept, and its influence. Michie, van Stralen and West, (2011) defines motivation as all brain processes that energize and direct behaviour, including goals, conscious decision-making, habitual processes, emotional responding, and analytical decision-making. Motivation is described by West et al. (2019) as the impetus that gives purpose or direction to initiate and maintain behaviours, comprising of attitudes, social norms and their interrelations. Baumiester (2016) defined motivation simply as ‘wants’, which can include broad dispositional tendencies such as the want for food or safety, which produce recurrent patterns of desire, or, can be highly time and contextually focused relevant only to particular settings or particular occasions. PRIME Theory (West 2006) attempts to bring together what is known about motivation into a single model using simple to understand language. This theory understands motivation to be more than simply reasons for doing things, and includes innate reactions such as, habits, drives, desires, goals, and plans. PRIME theory contains three central ideas: 1: A person’s wants and needs at each moment drives their behaviour. According to this theory ‘wants’ involve a desire to enact behaviour which will bring about something positive, and ‘needs’ involve a desire to enact a behaviour which will avoid something negative. 2: Intentions and beliefs regarding what is good or bad can only influence actions if they create strong enough wants and needs at that moment in time. 3: A person’s identity, the image they have of themselves and how they feel about that image, can be a strong enough source of wants and needs to overcome those arising from biological drives.

In addition to general definitions of motivation, research and literature have attempted to identify, group, and categorize motives into different types depending on how their outcomes are experienced (Legault 2016, Woolley and Fishback, 2017). Element 2 categorised motives into three concepts based upon patient need, naming these themes as ‘Have life’, ‘Live life’ and ‘Beyond life’, and concluded that if an intervention does not align with one of these motives, or participants can not recognise that it aligns with these motives adherence is less likely to occur. All three motives and how they influenced successful exercise adherence could be identified within the interview data from Element 3. Literature around the area of motivation can group motives into intrinsic and extrinsic categories whereby intrinsic motives involve the drive to perform a behaviour for its own sake, not driven by any separable outcome (Legault, 2016). In contrast, extrinsic motivation involves the desire to achieve an outcome separate from the behaviour itself, in effect, a form of subsequent reward for that behaviour (Legault, 2016). From the interview studies few examples existed of intrinsic reasons for exercising, most were related to extrinsic factors such as expectation of subsequent health benefit or the enjoyment of the sessions not the exercise itself. More recent attention has focussed on the timing of outcomes that result from behaviour, whether the desired outcome is experienced during the enactment of the behaviour or delayed and only experienced after the behaviour has been completed. Such research indicates the closer a reward is experienced to a behaviour the greater its impact upon motivation (Woolley and Fishback, 2017). This is of particular relevance to exercise as many of the traditional benefits associated with exercise occur only after a substantial period of time. Recent research has also investigated how different forms of motivation can interact and the impact this can have on lasting motivation. Motivational undermining involves the notion that providing additional extrinsic incentives for a behaviour can reduce a pre-existing intrinsic motive held for that same behaviour (Camerer 2010). Studies involving assessment of reward related brain responses to incentives support this notion (Murayama et al. 2010). Moreover, Camerer (2010) argues that increased incentives can have a positive effect upon behaviour but should be applied carefully, because removing them can permanently erode pre-existing intrinsic motivation. Zimmerman (1985) further emphasises this caution by recommending that if the immediate positive effects of rewards are offset by long term adverse consequences after the rewards are withdrawn, then such practices should stop.

Mounting empirical evidence highlights the importance of motivation as a moderator of exercise behaviour even in contexts where a person’s physical abilities are hampered by physical illness. Research into home-based exercise for muscular skeletal injury (Essery et al. 2017), patients undergoing cancer treatments (Ormel et al. 2018), home exercise for patients with advanced lung cancer (Adamsen et al. 2012) and physical activity behaviour when living with or beyond cancer (Grimmett et al. 2019; 2020) all support the notion that higher motivation for enacting a behaviour is more likely to result in that behaviour. However, evidence regarding what influences that motivation is less clear.

The next section synthesises the theoretical mechanism of ‘Motivation’ with findings from the interview based studies in Element 3. Links will be made to demonstrate how the ‘Pre-existing factors’ in relation to the ‘Demands of the home exercise protocol’ influence motivation in terms of patient need, whether the motivation is due to internal or external sources, and the time period during which rewards for behaviour are experienced. This will show why motivation to home exercise is often low and why it might be higher in some participants than others.

8.5.1.1 Previous exercise experiences.

‘Previous exercise experiences’ have significant influence on a person’s motivation to perform home exercise primarily through the determinant of the ‘Readiness of the participant’. Participants who had a long established history of performing exercise wanted to return to exercising, some specifically wanted to return to exercising at home. This meant for these participants their motive to exercise was intrinsic to the activity itself and although they may also have motives dependent on subsequent outcomes like gains in fitness, their primary motive to exercise was in fact met every time they performed that exercise, during the time they exercised.

The influence of the supervised exercise programmes was complex and involved both positive and negative impact on participants’ readiness to exercise at home. The programmes influenced participant motivation positively through learning how exercise could benefit them in terms of physical and psychological outcomes gained from the exercise. However, the programmes also influenced motivation negatively through an undermining effect. This undermining effect occurs when artificially created extrinsic motives aimed to encourage attendance to the supervised programmes, are not only absent for the unsupervised period, but their absence also diminished the value of motives which remain. Many features are present in supervised programmes which encourage attendance and participation. Such features include the social interaction with others with cancer, the fun atmosphere created by the HCPs, and the relationship which develops between participants and those professionals. There is also a strong sense of having to attend as the supervision also innately involves elements of surveillance before and during the sessions. These factors act as incentives or rewards to encourage attendance and this inadvertent surveillance acts to discourage non-attendance. These incentives and surveillance are apparent during the time period of the sessions, rather than delayed, and so provoke a powerful intention to attend each session. For the participant the outcome of attending each session involved receiving a pleasurable incentive such as social interaction and also avoiding the perceived negative consequences of the surveillance highlighting their non-attendance. However, both these factors are separate to the act of exercise and the artificial generation of these strong external motives are features likely to undermine or diminish other motives. Once the home protocol starts, remaining incentives for performing the exercise, such as expectation of health benefit, were experienced at a delayed point after exercise, the previously experienced *boost* was lost. Likewise any continued surveillance through session monitoring by health care professionals occurred at a delayed point after the exercise. The delay in both the incentive and the surveillance mean their influence upon motivation is likely to be diminished as explained in Woolley and Fishback, (2017). Interview findings showed all participants were less motivated to exercise in the unsupervised period than the supervised period and for some the undermining effect meant motivation to carry out home exercise, had been reduced compared to the participants pre programme levels.

In summary, motivation is a key mechanism which influences continuing exercise behaviour. A participant motivated to exercise at home has a higher readiness than a person who is not motivated to exercise at home. However, for participants who previously did not exercise at home the supervised periods provided little transferable motive for them to now do so, with the exception of learning how exercise may benefit them. However the supervised programme showed potential to reduce participants previously held motivation to want to exercise at home.

8.5.1.2 Consequences of illness and treatments.

‘Consequences of illness and treatments’, have a complex and multifaceted influence upon ‘Readiness of the participant’ and ‘motivation’ to perform the home exercise. This is because cancer can produce consequences which makes exercise less desirable such as pain, but also because benefits associated with exercise can provide powerful reasons to exercise. Participants who are aware of ways in which exercise can provide benefit to them have a higher level of ‘readiness’. Many participants reported that cancer-related fatigue prevented exercise and other activities due to the way it greatly reduced motivation to perform any activity, and increased desire to remain sedentary. Conversely, the presence of symptoms such as pain and stiffness was for some participants a prompt to perform their exercise, particularly if this would provide instant relief. For others, the motivation for performing the exercise was related to the elimination of slower progressing symptoms such as slowing a general decline and hope/ belief that exercise might provide the chance to ‘fight’ their cancer. With the exception of fatigue, cancer had a positive effect on motivation to exercise, either to achieve identified or suspected benefits relating to the motive to ‘Live life’, or the possibility of benefit in relation to the ‘Have life’ motive. Only patients involved in research viewed it as a chance to enact the ‘Beyond life’ motive.

8.5.1.3 Personal traits and characteristics.

Findings from interview data reported in Chapters 5 and 6 showed the often held view that exercise is good for you provided little motive to engage in exercise unless other strengthening motives were present. However, if a person had a strong sense that exercise had been part of who they were and who they wanted to be, this provided a much stronger motive to return to and continue exercise. Likewise, examples existed of participants who self-identified as a person who completes what they say they set out to do. For people with both those characteristics completing the exercise aligned closely with the identities they held of themselves. In relation to PRIME theory (West, 2006) those people held a strong want to maintain that identity and a strong need to avoid losing that identity, any break in exercise would jeopardize that.

West, (2006) states that a person's beliefs only influences behaviour if it is stronger than other wants and needs at that point but that a person's identity can be a very strong source of motivation. From this explanation it is clear that when exercise aligns with a person's identity it is more likely to successfully compete with other wants and needs than when exercise aligns with a general belief that it is good for you.

8.5.1.4 Physical aspects of the home environment.

Generally, the pre-existing factors of 'Physical aspects of the home environment' had the greatest influence within the home exercise determinant of 'Suitability of the exercise environment'. Typically the home environment had a negative impact upon motivation to exercise. Participants felt some level of legitimacy was lost when the specialist setting was lost, describing it as losing formality and feeling less purposeful but also reporting they struggled to verbalise this issue accurately. This shares some support from the conceptual model of implementation fidelity (Carroll et al. 2007), in which 'Quality of delivery' is considered an important factor in implementation but is thought of in terms of how well an intervention is delivered and does not specifically state the importance of the feeling of quality generated by the setting alone. In addition to this, some of the exercises from the supervised sessions which patients had found intrinsically pleasurable to perform, i.e. participants enjoyed performing them for their own sake, were not typically possible in the home settings due to the equipment required. Both these issues, the environment being viewed as less prestigious and the more favourable exercises being unavailable, may contribute to the undermining effect felt when transitioning from one environment to the other. The home environment also contained other possible competing activities or behaviours which are not a consideration during the supervised period. These competing activities, might be pleasurable activities or less pleasurable chores and responsibilities, but provide more immediate outcomes with regard to meeting wants or needs than that of exercise and so take priority. All these factors indicate the 'Suitability of the exercise environment' to be low and negatively impact upon motivation.

8.5.1.5 Social aspects of the home environment.

The pre-existing factor of 'Social aspects of the home environment' predominantly influenced the determinant of 'Suitability of support' and provided a potential source of promoting motivation to exercise to compensate for the loss of the professional input. Some evidence existed in the form of encouragement from family either face to face or via telephone calls, reminding participants of the benefits or anticipated rewards of performing the exercise. Examples also existed of family members performing informal surveillance, checking if exercise had been performed and prompting participants to do it if it had not. However, both reminding and informal surveillance from family and friends were more notable during the supervised period, which appeared to generate more interest from these sources, than during the unsupervised period.

Typically, while in the supervised programmes social influence was seen as a reward and a key motivator of attending sessions, this was absent from home protocols with no attempt to replicate the valued social interactions through use of family or friends. Instead other largely sedentary social interaction, such as spending time with others watching television or at a public house provided immediately experienced reward and competed against exercise.

In summary, having a valued reason as to why they wanted to continue exercising was an important part of participants' readiness. Those participants who were best able to continue to exercise knew why they wanted to exercise and were able to meet that every time they exercised.

8.5.2 Self-efficacy

The concept of 'self-efficacy', originated from Social Learning Theory (Bandura 1977) and Social Cognitive Theory (Bandura 1989). It involves "the belief in one's capabilities to organize and execute the courses of action required to manage prospective situations" (Bandura, 1995, p. 2). Self-efficacy or, differently named concepts with similar meaning, is identified in many theories and models of behaviour including Health Belief Model (Rosenstock 1974), Information Motivation Behavioural Skills Model (Fisher, Fisher and Harman, 2003), Trans-theoretical model (Prochaska and DiClemente, 1983), Theory of Planned Behaviour (Ajzen 1991). Definitions and interpretations of the concept of self-efficacy can vary, often the concept is simplified to terms such as the perception of ability to perform a task successfully (West et al. 2019). Self-efficacy is becoming increasingly well recognised as a predictor of adherence in both people with cancer in supervised exercise (Ormel et al. 2018) and home-based rehabilitation programmes in non-cancer cohorts (Essery et al. 2017).

Bandura (1989) identified four sources of information upon which people base their judgements of self-efficacy; 1) performance mastery experiences; 2) vicarious experiences for judging capabilities in comparison with performance of others; 3) verbal persuasion and allied types of social influences that one possesses certain capabilities; 4) physiological states from which people partly judge how capable they are, such as strength and vulnerability. These sources of information on which people base their judgements of self-efficacy form the basis of five mechanisms that Gallagher (2012) proposed can develop self-efficacy: 1) Mastery experiences, involve the successful attainment of meaningful goals. This is considered to be the most effective method for developing self-efficacy especially if the success is attributed to a person’s own actions and involves perseverance after adversity. In contrast, if failure is attributed to personal action, self-efficacy declines. 2) Modelling or witnessing the mastery of others can build self-efficacy in persons, particularly when those others viewed are thought to be quite similar to them. As with mastery experiences, if the success is obtained having overcome obstacles the subsequent growth in self-efficacy is greater. Witnessing others offers the opportunity to develop self-efficacy when actual mastery experiences are not possible. 3) Imagined experiences, involves people imagining themselves or others achieving the desired success. Again this method is most applicable when real experiences cannot be gained. 4) Social persuasion, involves encouragement or discouragement from others shaping a person’s beliefs about capabilities. 5) Finally, somatic and/or emotional cues are the least effective mechanism of promoting self-efficacy beliefs, according to Gallagher (2012), and involves learning to manage potentially negative physiological occurrences, to produce positive as well as negative responses.

Findings from the interview data indicate that within the context of home-based exercise, ‘Pre-existing factors’ can influence both the four sources upon which people base their judgements of self-efficacy, and, the five mechanisms upon which self-efficacy can be developed.

8.5.2.1 Previous exercise experiences

Previous exercise experience predominately influences self-efficacy through the determinant of ‘Readiness of the participant’. However, historical exercise experiences have a very different influence when compared to those associated with supervised programmes. Historical exercise experiences often provide mastery experiences for exercising at home. Participants who had exercised at home previously, typically had less difficulties arising in their home environment and already had some additional exercise equipment and had established suitable places to use it.

The supervised programmes contained many elements which allowed for favourable judgements of self-efficacy or increased self-efficacy toward exercise. They provided mastery experiences for exercising with cancer, many participants had been forced to stop exercising previously due to their illness but the programmes provided a safe way to re-engage with exercise. However, many of these experiences were not replicable in the home environment so transfer of any self-efficacy generated was diminished.

The supervised programme also allowed for judgement against the capabilities of other participants in the groups. Participants frequently reported that they could see other participants with worse health concerns doing the exercise and therefore felt they were also capable. Once the supervised period was completed this comparative judgement was no longer possible. In addition the supervised sessions provided verbal persuasion from both the health care professionals delivering the sessions and from other participants. Supervised sessions provide opportunity for people to learn that even when physiological consequences of their illness may be exacerbated some form of exercise is still possible in most instances. Again, once the supervised period was completed, there was no-one to provide this persuasion.

Gallagher (2012) reports that a common theme through all methods that contribute to the development of a person's self-efficacy is overcoming obstacles to achieve desired success. Reports indicated the biggest challenges during the supervised period related to the act of getting to the sessions. Once in attendance most of the challenges were largely overcome through actions of the professionals delivering the sessions. It is possible that although supervised programmes build self-efficacy towards exercise they predominantly build self-efficacy for attending exercise in supervised settings, and to some extent miss an opportunity to develop self-efficacy towards unsupervised exercise in home settings.

8.5.2.2 Consequences of illness and treatment

Mostly influential within the determinant of 'Readiness of the participant', 'Consequences of illness and treatment' can change the fundamental meaning of self-efficacy for people with advanced cancer. Increasing the importance of perceiving their ability to perform the task safely, without causing aggravation to their illness, as well as successfully. In Element 1 it had been suggested if participants did not perceive the exercise to be safe they would not perform it. Findings in Element 3 found this to be true, although there were only rare occasions where participants thought an exercise to be unsafe if this occurred they would not attempt to perform it. Illness, associated treatment, and aging, impact upon the physiological states from which people partly judge their capability. Findings in the interview and review based research show this judgement by participants was typically negative. Symptoms of disease, side effects of treatment, constraints on time imposed by hospital appointments, and limitations associated with aging, all prevented performance of some aspects of the home protocols. On occasions exacerbations could lead to hospital admission and prevent all exercise until that exacerbation subsided. Conversely in periods where negative consequences of illness are minimal, self-efficacy increases which for some participants led to increases in motivation to exercise as well.

8.5.2.3 Personal traits and characteristics

Although some literature acknowledges a general form of self-efficacy, it is not congruent with the definition of self-efficacy used here, and so such features will be discussed later in relation to the concept of agency.

8.5.2.4 Physical aspects of the home environment

‘Physical aspects of the home environment’ acted upon self-efficacy within the determinant of ‘Suitability of the exercise environment’ and often meant the home environment was not suitable for exercise and had a negative impact on self-efficacy. The home environment prevents many of the exercises which had been performed previously from being applicable at home, and many of the mastery experiences gained previously may only partly transfer to the new types of exercise. In addition to this, even exercises prescribed for the home protocol were not possible in the person’s individual home environment, due to issues such as available space. Therefore, attempts to exercise at home could quickly end in failure and diminish self-efficacy further.

8.5.2.5 Social aspects of the home environment

Typically, ‘Social aspects of the home environment’ such as family and friends in relation to the ‘Demands of the home exercise protocol’ act within the determinant of ‘Suitability of support’. Typically, they provided little assistance to participants towards the home exercise, and as professional support had been withdrawn during this period, ‘Suitability of support’ was inadequate to provide positive influence upon any judgements of self-efficacy. Gallagher (2012) explained that the presence of a trusted friend or family member can help people to develop and maintain self-efficacy beliefs in the face of obstacles. Such input could be an important factor toward building self-efficacy towards home exercise but was rarely found to be present within the empirical data of this project.

8.5.3 Agency.

According to Bandura (2017) ‘Agency’ refers to the human capability to exert influence over one’s own functioning and course of events by one’s own actions. Moreover, cognitive regulation allows people to imagine a picture of the future which subsequently influences the present. People can construct, evaluate, and modify alternative courses of action to gain valued outcomes and override environmental influences (Bandura 2006). In relation to home-based exercise, agency involves the influence patients exert towards enhancement of factors which influence whether they can (self-efficacy) and whether they want (motivation) to perform the home exercise. This could target their own 'readiness', the 'Suitability of the exercise environment', the 'Suitability of support', or target the 'Demands of the home exercise protocol' directly. Agency was demonstrated in the previously identified theme 'Mitigation and accommodation of impediments' in Chapters 6 and 7 of this thesis. It is what bridged any discrepancy between what was prescribed in the home-based exercise protocol, what patients felt able to do, and what patients wanted to do. Agency is different to the other theoretical concepts in that it is influenced by the pre-existing factors but can also exert influence upon them.

As Goller and Harteis, (2017) have argued, very limited empirical research currently exists on the importance of human agency in changing behaviour, and the available evidence is much less prevalent than that for motivation or self-efficacy. Some literature has identified self-monitoring, a factor similar to individual components of agency, to be important in continued exercise behaviour (Grimmett et al. 2020). However, evidence could not be found in published literature identifying and making reference to agency as a consideration to adherence to therapeutic exercise. Goller and Harteis, (2017) investigated agency in work contexts and explain agency as an action people do, but also that agency can be a personal feature of an individual. People with higher capacity and tendency for agency, enact agentic behaviour more frequently. Goller and Harteis, (2017) continue that agency competence, agency beliefs, and agency personality, offer explanation as to why some people have a higher capacity and tendency to enact agency.

Bandura (2006) proposes that agency is operated through four functions; intentionality, forethought, self-reactiveness, and, self-reflectiveness. Intentionality, involves people forming intentions and relevant action plans and strategies to meet such intentions. Forethought, involves the extension of agency into the future through setting goals and foreseeing likely outcomes of imagined actions to guide and motivate their efforts. Self-reactiveness involves construction of an appropriate plan of action then the self-regulation of the execution of this plan. The fourth function, self-reflectiveness, involves a person's self-examination of functioning, reflecting on their personal efficacy, their thoughts and actions, the meaning of their pursuits, and making corrective adjustments when necessary. If agency involves a person's ability to exert influence over their own functioning and course of events, the lowest levels of agency would be congruent with the theoretical concept of learned helplessness, where by a person concludes that unfavourable outcomes are uncontrollable and then subsequently experiences decline in motivation, cognition and emotion (Abramson, Seligman and Teasdale, 1978).

Published empirical evidence which identifies the concepts of agency and learned helplessness in the context of therapeutic exercise for people with advanced cancer or other illness was not located. This section will highlight both agency and learned helplessness in the interview-based studies conducted as part of this PhD project, to demonstrate how interactions between 'Pre-existing factors' and the 'Demands of the home exercise protocol' influence home exercise determinants and the theoretical mechanisms of action.

8.5.3.1 Previous exercise experiences

Participants who had exercised previously had predominantly joined the supervised programmes because they wanted to restart exercising at home, and began to practice exercising at home very early in the supervised period. Such participants began demonstrating intentionality, forethought, self-reactiveness, and, self-reflectiveness, the four functions of agency described by Bandura (2006), to enable home exercise before the supervised sessions had finished. Typically, those who had exercised previously used some of the methods they had successfully used before in their old exercise routines to better adhere to the new home exercise protocols. These participants also had greater resources to draw upon if wanting to supplement or replace the prescribed home protocol with their own additional exercises. Because they had begun to exercise at home during the supervised period they also benefited from still being able to receive input and advice from the health care professionals if required.

The influence of the supervised exercise programmes upon agency was less clear. Agency operated individually through the participant, and through their social contacts as proxies, and was very important as part of 'Mitigation and accommodation of impediments' to successfully get to the classes. However, once at the sessions it is the HCPs who performed much of the tasks which influence the success of the sessions through planning, assessing making modifications as and when needed and reassessing the changes made. Therefore, there was less opportunity for participants to demonstrate or practice the functions of agency, intentionality, forethought, self-reactiveness, and, self-reflectiveness, and so competence in these areas, for both the participant and those who could support them in the future, was not increased as a consequence of the sessions.

8.5.3.2 Consequences of illness and treatment

‘Consequences of illness and treatment’ impact agency through several of the functions of agency proposed by Bandura (2006). Evidence from the interview studies and the qualitative review indicate forethought, self-reactiveness and self-reflectiveness could all be complicated or made more difficult for patients by the variable consequences of their illness. Participants with unstable disease reported that the unpredictable nature of their illness prevented them from being able to plan any kind of future activity. As planning is a key element to forethought and self-reactiveness, unstable disease inhibits each of these functions of agency. Likewise, self-reflectiveness involves reflecting on personal efficacy, thoughts, actions, the meaning of what they had been doing, and making corrective adjustments when necessary. All of which are more difficult with the changeable unpredictable nature of uncontrolled disease. This is complicated further due to the difficulty of accurately assessing whether exercise had provided any health benefit whilst their health progressively deteriorated, and may make self-reflectiveness more challenging in this patient group.

In the most extreme examples, uncontrollable illness led to learned helplessness and a subsequent complete cessation to any attempt to perform the home exercise.

8.5.3.3 Personal traits and characteristics

Goller and Harteis, (2017) indicated agency could be a characteristic displayed more commonly in some people than others, determined by the person’s agency competence, agency beliefs, and agency personality. Participants who have higher levels of agency competence, beliefs, and personality, will have a higher readiness for the home exercise than those who do not, and through their agency may be more able to exert a positive influence upon the other determinants as well. Some participants attempted to exert their influence more frequently in their lives than others. Participants indicated that often the extent to which they attempted to exert their influence and many of the ways in which they attempted to exert their influence developed as a consequence of previous life events, particularly their former professions. Although these agentic views and behaviours had been learnt in different contexts they were applied similarly to exert their influence over pursuit of home exercise.

8.5.3.4 Physical aspects of the home environment

‘Physical aspects of the home environment’ had little influence upon a person’s agency but did regulate what options were available for a person to exert their agency. The agency of the participant was used to seek out the most suitable spaces of the home environment for performing exercise, identify and repurpose pieces of furniture to be used to assist with exercise, modify the home environment to better accommodate exercise, and if necessary change the exercise protocol to be better suited to their homes. But all of that could only occur within what the parameters of the home environment allowed. For participants displaying greatest agency, adaptation of the home's physical environment would begin before the supervised period had finished. In participants with less agency, such actions would typically occur only once the supervised period had finished. Those with least agency were less likely to perform such behaviours and more likely to conclude the home environment to be unsuitable for exercise.

8.5.3.5 Social aspects of the home environment.

'Social aspects of the home environment' influence agency within the determinant of 'Suitability of support'. Bandura, (2006) explained that agency is not just operated on at an individual level, but can be manifested with the help of others who have the necessary means to achieve the desired outcomes, and collectively with groups of people acting together to shape their future. Examples existed of supportive social and familial contacts being used as a resource to exert proxy agency in pursuit of performing home exercise for example receiving help from family to source purchase and assemble exercise equipment. However, this occurred infrequently. Efforts to attend supervised sessions often involved the combined agency of the participant and a significant other, participants would select who they felt could best support and friends and family would volunteer to help in the best ways they could. Such support could involve assistance with transport, nutrition, medication management, or management of administrative work such as booking sessions and completing paper-work. In contrast, home exercise was typically performed alone with little or minimal input from others. Bandura, (2006) explains that proxy *agency* is operated through others who have necessary resources, knowledge, and means to act on the person's behalf to secure the desired outcomes. It may be that typically familial and social contacts already have the necessary resources, knowledge, and means to assist with attending a supervised session (they can drive) and so are frequently used option for this purpose. However, family members or friends do not develop the necessary resources, knowledge and means to be of use when attempting to adhere to the home exercise protocol, and so involvement for this purpose is not an available option.

'Social aspects of the home environment' also had potential to reduce agency in a similar manor to the 'Consequences of illness and treatment'. Evidence was found of instability and rapid deterioration of a family member's health to make key agentic functions of forethought, self-reactiveness and self-reflectiveness more difficult. The unpredictability and uncontrollability of such situations was found to reduce the extent to which participants could exert influence over their daily lives including exercise adherence. In the most severe examples this led to a sense of helplessness and complete cessation of any attempt to perform home exercise, even once the primary issue was resolved.

8.5.4 Theoretical mechanisms summary

This section has used research and theory to identify three theoretical mechanisms of action to propose how the interactions between the pre-existing factors and the 'Demands of the home exercise protocol', influence exercise adherence. It has demonstrated how the mechanisms are influenced by pre-existing factors, and can be sourced within the three home exercise determinants.

It has been shown how previous exercise experiences can have a variable impact upon all of these mechanisms where typically historical exercise experiences tend to influence the mechanisms in a positive way where as more recent exercise programmes can influence the mechanisms in both positive and negative ways. The consequences of illness and treatment impacts the mechanisms in different ways, typically increasing motivation (except during worsened fatigue) but reducing self-efficacy and agency. 'Personal traits and characteristics', were highly influential to motivation both in terms of the participants' view of exercise and also their beliefs about self and what was important to them. 'Personal traits and characteristics' were less influential to self-efficacy, but appeared to be influential to agency. 'Physical aspects of the home environment' typically reduced motivation and self-efficacy compared to specialist exercise setting and had minimal impact upon agency. 'Social aspects of the home environment' typically reduced motivation, self-efficacy and agency, but is suggested to be an area which could influence those mechanisms positively.

8.6 Outcomes

8.6.1 Exercise decision.

Whereas it is known some behaviours can happen autonomously without conscious thought due to habit (Kelly and Barker, 2016), this was not evident with exercise in the context of advanced cancer. Kelly and Barker, (2016) continue that it is a mistake to view behaviour of being the outcome of a calculated decision based upon maximising gains and minimising costs, and in many habitual actions very little conscious thought is involved. However, in the case of unsupervised exercise, in this context, Although some level of physical activity may happen as an unintended consequence of other behaviours, without deliberate attention the habitual behaviour was to perform other life activities of minimal intensity or to be sedentary. This is consistent with several theories of behaviour sometimes grouped together as social cognition models (Sutton, 2001) which all involve some kind of conscious decision, regulated by the participants beliefs and attitudes before a behaviour is performed. This decision was regulated by ‘Theoretical mechanisms of action’ which can be located within the ‘Home exercise determinants’ and created by interactions between the ‘Pre-existing factors’ and the ‘Demands of the home exercise protocol’.

8.6.2 Exercise behaviour

The final outcome of the model was the enactment of the exercise. Although no participants adhered perfectly to the exercises which had been prescribed, a typology emerged of four enduring exercise related behaviours: 1) Returned to previous regular exercise; 2) Created new regular exercise; 3) Infrequent exercise; 4) No exercise. The types of exercise patterns identified here are supported by similar finding in studies which have investigated continued exercise behaviour in other stages of disease (Grimmett et al. 2020).

After both the decision outcome and the enactment of the behaviour a feedback loop allowed information gained from that episode to contribute to the next. This could reinforce both positive and negative beliefs regarding motivation and self-efficacy whereby positive experiences enhanced thoughts around motivation and self-efficacy and negative experiences diminished motivation and self-efficacy for exercise in the future. This feedback also allowed for the possible exertion of agency, by the participant or others if suitable support was available, to target the home exercise determinants or to adjust the ‘Demands of the home exercise protocol’, and so increase likelihood of future successful exercise.

8.7 Model summary

This chapter has synthesised findings from Elements 1-3 with theory to generate a conceptual model to explain unsupervised exercise behaviour following a supervised exercise programme. It has demonstrated how both the decision to exercise and performance of exercise are regulated by participants having adequate ‘Motivation’ and ‘Self-efficacy’ to exercise or the ‘Agency’ to influence those mechanisms on occasions when they may be inadequate. It has shown that those mechanisms are influenced by interactions between pre-existing factors and the ‘Demands of the home exercise protocol’ and can be located with the determinants of the ‘Readiness of the participant’ ‘Suitability of the exercise environment’ and ‘Suitability of support’.

In the next chapter will highlight the significance of the contributions to knowledge generated in Element 1-4 and discuss findings in relation to current healthcare, proposing guiding principles which could be used to enhance interventions looking to encourage exercise behaviour in people with advanced cancer.

Chapter 9 **Discussion**

This chapter will briefly review the rationale for this body of work and reiterate the objectives it set out to achieve. Recent developments which have occurred during the final stages of this project in relation to the COVID-19 pandemic will be explored, including the acceleration of remote methods of healthcare, and implications for exercise supervision. The findings from the four elements: the mixed methods systematic review of exercise interventions for people with advanced cancer (Element 1); qualitative systematic review which investigated living with advanced cancer (Element 2); empirical studies (Element 3); and the conceptual model (Element 4) will be discussed drawing out the significance of the research. Findings will be related to the evidence base and its novel contribution. The relevance of the findings in relation to healthcare practice and policy will be discussed and a set of guiding principles described that are intended to augment adherence to interventions in the future. Finally, strengths and limitations will be identified and suggestions made for further research.

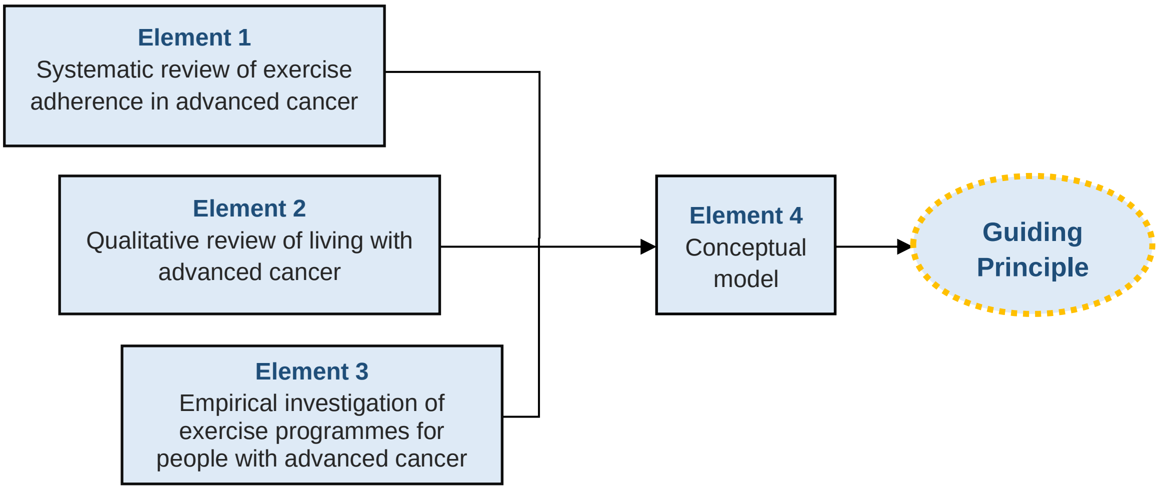


Figure 15: Guiding principles, schematic representation of the FIT-TOGETHER study

9.1 Rationale

This thesis aimed to answer the research question ‘What is the experience of people with advanced cancer participating in supervised exercise programmes delivered in health care facilities, and how can exercise adherence be encouraged and facilitated as people transition to an unsupervised home-based approach?’

Research continues to identify the benefits of exercise for people with advanced cancer, both during and after treatment. These can include: increased measures of strength and fitness; reduction of some of the negative consequences of disease and treatment like fatigue; and improved quality of life (Dittus, Gramling and, Ades 2017; Heywood, McCarthy and Skinner, 2018). However, the majority of interventions are delivered under professional supervision in specialist facilities, such as hospitals. But healthcare resources are limited, and so it is not possible to deliver such interventions to all people who could benefit or for an indefinite period of time. Therefore, interventions have been developed which begin under specialist supervision in specialist settings, and progress to unsupervised home environments. Evidence suggests home-based exercise interventions in other chronic diseases may be more cost effective than hospital-based interventions, in terms of the cost of delivering the programmes and subsequent cost savings from reduced admissions (Cowie and Moseley, 2014). Although the same research ultimately found those interventions to be less effective particularly in terms of quality of life which has been attributed to decline in adherence in the unsupervised exercise (Cowie and Moseley, 2014). A review of exercise in different cancer groups also found supervised exercise to be more effective at improving QoL, strength and aerobic fitness (Segal et al. 2017). However, the studies which informed this conclusion (Ferrer at al. 2011, Baumann, Zopf and Bloch, 2012, Keogh and Macleod, 2012) did not consider or report on the likely difference in adherence between settings. Ultimately delivery of these kinds of interventions in a specialist setting will remain expensive. Resources and facilities will never be sufficiently plentiful to provide hospital-based exercise interventions for every patient that would benefit, nor, for as long as they may benefit. These issues have led researchers and clinicians to consider different approaches to delivering exercise interventions to improve adherence to unsupervised home exercise. One approach includes hospital to home interventions, which are first delivered in specialist facilities under supervision, then, progress to continued unsupervised exercise performed in patients’ own homes. It was hypothesised hospital to home interventions would be acceptable to participants through negating the need for hospital visits (Temel et al. 2009), and align more closely with patient preference for interventions to exercise at home (Lowe et al. 2010, Maddocks, Armstrong and, Wilcock 2011, lowe at al. 2016b). However, all empirical studies conducted involving hospital to home-based exercise for people with advanced cancer have found adherence to home-based sessions to be significantly less than that achieved with hospital-based sessions (Quist et al. 2012; Kuehr et al. 2014; Winters-Stone et al. 2014; 2015; Jack 2016 Personal Communication).

9.2 Relation to COVID-19 pandemic

Although data collection was complete, the final 24 months of this PhD was conducted during the COVID-19 pandemic. This section will briefly consider how innovation necessitated by the pandemic may have accelerated development in the delivery of therapeutic exercise interventions. COVID-19 is a serious life threatening disease caused by a coronavirus previously unknown in humans, Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2). Internationally of July 2021 there are believed to have been 190 million confirmed cases of COVID-19 which has contributed to estimated deaths of over four million people (World Health Organisation, 2021). In the UK there have been five and a half million confirmed cases to date and approximately 130-155 thousand deaths (UK Health Security Agency, 2021). Due to the absence of effective treatments many preventative strategies largely based around changes in behaviour were aimed to reduce the spread of infection such as hand washing, use of facemasks, contact tracing, social distancing and national lock downs of varying severity (Adil et al. 2021). At time of writing vaccines have been developed, and over 36 million are now fully vaccinated in the UK (UK Health Security Agency, 2021), in part due to the success of vaccination most governmental restrictions have been revoked.

Of relevance to the area of exercise oncology during the periods of more severe lock down all exercise facilities nationwide were closed, the pandemic created an environment conducive to inactivity (Pinto et al. 2020). As restrictions eased commercial centres aimed at more physically well groups of participants were reopened and because increased respiratory exertion can facilitate the transmission of SARS-CoV-2 several outbreaks were linked to exercise classes (Lendacki et al. 2021; Stephenson 2021). Therefore, attempting to exercise groups of vulnerable people with chronic and life limiting conditions in settings known to facilitate infection was unwise and many face to face supervised classes like those in this thesis remained closed. However, the importance for such groups to remain physically active increased. Meeting physical activity guidelines has been found to be associated with less severe COVID-19 outcomes (Sallis et al. 2021), and the requirements of social distancing generated feelings of increased loneliness in people with cancer and led to a four and a half fold increase in instances of depression (Gallagher, Bennett and Roper, 2021). Loneliness and depression are both issues found to have been abated by participation in exercise sessions by participants interviewed in Element 3. The need to facilitate a safe way to exercise for people with chronic and life limiting conditions during the pandemic has led to recommendations for remote models of provision (Scherrenberg et al. 2020).

In the field of exercise in oncology use of technology to support exercise at home pre dates the COVID-19 pandemic, but recent events have necessitated increased attention to this area and accelerated focus upon use of telehealth interventions such as video conferencing to deliver real time exercise supervision, mimicking the traditional class format (Bland et al. 2020). A recent review into exercise interventions involving remote support for sedentary people living with and beyond cancer concluded there was insufficient evidence to indicate remote interventions are effective in promoting exercise behaviour or improving physical function (Ibeggazene et al. 2021). A further review investigating the feasibility of telehealth interventions for people effected by cancer found telehealth interventions to be feasible but provided their own additional challenges, such as lack of access to devices and poor computer literacy (Morrison, Paterson and Toohey, 2020). Although interventions have been designed around methods such as web-based, mobile phone applications, short message service (SMS) messaging, and telephone support, no studies in either review were found which had investigated real time video conferencing using platforms such as Microsoft Teams, Zoom, Skype or FaceTime (Morrison, Paterson and Toohey, 2020; Ibeggazene et al. 2021). In clinical settings services have adjusted many of their previous face to face services such as initial therapy assessments, exercise classes and education session to telehealth models, including real-time sessions, but there is minimal evaluation of such models so far (Binkley et al. 2020). COVID-19 specific feasibility studies have now been designed with the purpose of using telehealth to offer exercise to people with cancer whilst maintaining social distancing requirements (Grimmett et al. 2021; Wu et al. 2021).

Wu et al. (2021) investigated the feasibility and effects of a telehealth home-based prehabilitation program for cancer patients. The intervention involved exercise training, nutrition advice, medical optimisation therapies, and psychological support. Real-time conferencing was used for an initial interview then up to twice a week to reinforce concepts covered. However, exercise sessions were not delivered in real–time but remained via online video or online instructions. Early findings indicate a positive recruitment rate of 76% and that 72% of participants adhered to the overall recommendations. However, the stage of disease of participants was not reported, and the interventions were only delivered up until the point of surgery or completion of non-surgical treatments, a mean duration of 4 weeks. Therefore, it is unknown what happened once supervision ended. SafeFit (Grimmett et al. 2021) is a pre-post study designed by the research team who conducted the EMBRACE RCT which was the subject of investigation in Element 3. SafeFit offers any person in the UK with a suspected or confirmed cancer diagnosis the opportunity to self-refer to receive free individual telephone/video conferencing consultations, remote one to one and group exercise sessions, during the COVID-19 pandemic. This trial remains ongoing but early data indicates uptake to have been high having recruited approximately 750 patients in one year.

In summary, the COVID-19 pandemic has made exercise for people with advanced cancer more difficult due to the risks associated with exercise settings (Lendacki et al. 2021; Stephenson 2021) and extra vulnerability due to advanced cancer being associated with a higher risk of death from COVID-19 (Lièvre et al. 2020). But potentially more important due to the association between inactivity and worsened outcomes for those contracting COVID-19 (Sallis et al. 2021). The response to the pandemic has been an acceleration of innovation throughout healthcare, particularly around remote supervision (Bland et al. 2020; Grimmett et al. 2021; Wu et al. 2021), which may remain of benefit during post pandemic recovery and beyond. However, much remains unknown about such methods including what happens once this type of support stops.

9.3 Aims and objectives

The aim of the body of work presented in this thesis was to develop a conceptual model to describe, characterise, and explain factors influencing adherence to exercise programmes for people with advanced cancer. Specifically, those interventions that begin under professional supervision in specialist healthcare settings then progress to unsupervised home-based sessions. Then, with reference to a model, develop a series of recommendations to increase the likelihood of continued exercise behaviour in this patient group.

The objectives were to:

- Investigate the structural characteristics of exercise interventions for people with advanced cancer that may explain reduced adherence to home-based protocols (Element 1, Chapter 3)
- Investigate what living with advanced cancer entails and explore the consequences of this for the design of home-based exercise programmes (Element 2, Chapter 4)
- Explore how patients with advanced cancer and healthcare professionals experience such exercise programmes (Elements 3, Chapters 5, 6 and 7)
- Using the sources of data above, and with reference to existing theory and literature, develop a conceptual model to characterise, explain, and inform adherence to home-based exercise in people with advanced cancer (Element 4, Chapter 8)
- Present recommendations, in the form of guiding principles, for clinicians and researchers to assist in the design of interventions to encourage adherence (Chapter 9)

9.4 Significance and novelty of findings

The four elements – the mixed methods review (Chapter 3), qualitative review (Chapter 4), empirical research (Chapters 5, 6 and 7) the conceptual model (Chapter 8), each contributed new knowledge to the field.

9.4.1 Significance of Element 1

The mixed method review of published exercise interventions, confirmed adherence declines when interventions transition to the unsupervised home setting, something suspected previously, but reinforced by this research. The review revealed a lack of consistency as to how adherence was measured and conceptualised across different studies, preventing accurate comparison and potentially presenting adherence levels to interventions in ways which could appear more or less favourable.

9.4.2 Significance of Element 2

The qualitative review of living with advanced cancer investigated the home context and daily lives of people with advanced cancer and related this to performing exercise. Of particular significance was the uncovering of three themes which grouped patient motives that influenced their behaviour and were referred to as the concepts of ‘Have life’ ‘Live life’ and ‘Beyond life’. These three themes were proposed as an easy to remember, coherent, descriptor by which health professions can think about how their intended exercise interventions might appeal to people with advanced cancer. Findings also suggested the importance of lay support in assisting and enabling participants to enact the behaviours influenced by those motives.

9.4.3 Significance of Element 3

The empirical findings from the research conducted with patients with advanced lung cancer participating in an exercise RCT, and patients enrolled on hospice based supervised exercise classes, provided fresh perspectives in this field of research. Although supervised exercise was not the focus of this body of work, it became apparent unsupervised exercise could not be fully understood without understanding the preceding supervised exercise period. The findings of these studies revealed patients faced a series of decisions regarding whether they should and could exercise. The structures and procedures of the interventions meant these decisions were unavoidable when following supervised programmes. These decisions were influenced by two concepts - ‘Drivers of participation’, and the ‘Mitigation and accommodation of impediments’. The outcomes of these decisions determined whether or not they would exercise. Patients’ faced three core decisions during the supervised period, whether or not to enrol, whether or not to continue after the first couple of sessions, and whether or not to attend each individual session. The identification of these decision points characterised what influenced participants' intentions at each point and highlighted the different considerations and values participants held as they transitioned through a supervised programme. Other novel findings from this research included the importance of considering factors present before the intervention began, the extent to which enjoyment and 'the boost' became an unexpected benefit of attending sessions, what supervision actually entailed and provided, and the closeness of the two-way relationship that developed between patients and professionals. This element also highlighted that when investigating exercise adherence the absence of a strong reason to perform exercise could be just as powerful as the presence of a reason to not perform exercise.

The empirical investigation of unsupervised exercise highlighted the universal multi-factorial loss that occurred when supervision was withdrawn. Without the set appointment and pre-session phone calls there was no longer a set point in time which forced participants to focus attention on exercise. Thoughts may turn to exercise but it was no longer a certainty in their lives and periods of time could pass without the requirement to actively consider undertaking exercise. The element culminated in a typology describing four different outcomes with regard to continuing exercise habits, with common characterises identifiable within each type: 1) Returned to previous regular exercise; 2) Created new regular exercise; 3) Infrequent exercise 4) No exercise. Other findings of note included the universal displeasure with the home exercise protocol, and the near total absence of enjoyment of exercise at home. A sense of loss was also found to be experienced, not just by patients but also professionals, when the period of supervised exercise finished and the relationship between them ended abruptly. The lack of awareness and knowledge professionals had regarding patient progress and experience once the supervised period finished underlined the abrupt nature of the transition. Fatigue was identified as the most disruptive symptom of the disease and could be extremely prohibitive of exercise during the unsupervised period, but did not prevent attendance of supervised sessions. In summary, although it was suspected home exercise was unappealing to patients with advanced cancer, findings revealed how unsuitable home exercise prescribed as part of the programmes studied could be. How the prescribed exercise was unenjoyable for almost all participants. How participants lacked support and encouragement during this period unless they could source it from elsewhere, and how great the sense of loss could be when the supervised periods ended. However, this element also revealed that although adherence to exercise declined compared to the supervised period, most participants were performing more exercise than immediately prior to enrolment in the programmes.

9.4.4 Significance of Element 4

The conceptual model synthesised findings from earlier chapters with other published research and theory. This proposed how factors present before home exercise (pre-existing factors) interact with each other and the ‘Demands of the home exercise protocol’ to inform three determinants of home exercise which govern the likelihood of performing exercise: ‘Suitability of the exercise environment’; ‘Readiness of the participant’; and ‘Suitability of support’. Three theoretical mechanisms, ‘Motivation’, ‘Self-efficacy’, and ‘Agency’, were identified to propose how these three determinants influence patients’ decisions to exercise and continuing exercise behaviour in relation to the previously identified typology. The model constructs of pre-existing factors, determinants of home exercise, and theoretical mechanisms will help intervention designers to begin to understand for which groups of people the supervised sessions contribute to continued exercise behaviour, for which groups of people they do not, and for which groups such interventions, in their current forms, may be detrimental to continued exercise behaviour. It also provides explanation as to why those variations occur. The model suggests areas that might be targeted in attempts to increase continued exercise behaviour. The model also identifies how supervised programmes may increase motivation and feelings of self-efficacy towards unsupervised exercise for some participants, but could also cause motivational undermining and learned helplessness for others.

With regard to motivation the model identifies the importance of intrinsic and extrinsic rewards or benefits participants perceive they get from exercise, and the importance of the timing of those rewards. The creation of external, immediately experienced rewards in the supervised programmes can weaken the motives participants may have previously held towards exercise and contribute to an undermining effect. This provides explanation as to why research, which questioned patients regarding their preferred place to exercise when given hypothetical options, indicated a strong preference for home exercise (Lowe et al. 2010; Maddocks, Armstrong and Wilcock 2011; lowe et al. 2016b), but then adherence levels in hospital to home exercise studies did not support this preference (Quist et al. 2012; Kuehr et al. 2014; Winters-Stone et al. 2014; 2015; Jack 2016 Personal Communication). This discrepancy suggests that participants think they want to exercise at home, until they experience the more appealing supervised alternative. The concept of motivational undermining also offers possible explanation as to why patients who were the most enthusiastic and positive when interviewed during supervised exercise demonstrated the lowest levels of adherence and most dissatisfaction during the unsupervised period. Finally, the model identifies the mechanism of agency as crucial to continued exercise behaviour as it impacts directly on the other two mechanisms, namely motivation and self-efficacy and can mitigate when those mechanisms may otherwise be inadequate to meet the ‘Demands of the home exercise protocol’. Often it was the agency of HCPs during the supervised period which contributed to the successful adherence, the subsequent absence of agency in the unsupervised period is likely crucial to the decline in adherence that is so often witnessed.

The conceptual model constructed in Element 4 provides a novel contribution in relation to existing theories of behaviour such as COM-B (Michie, van Stralen and West, 2011) and the Theory of Physical Activity Maintenance of Nigg et al. (2008). Both are often used in relation to the behaviour of interest, exercise. Firstly, the proposed model makes explicit the factors which predate the introduction of the designated behaviour, and how these affect various aspects subsequent to the introduction of the designated behaviour. A unique aspect of this model is that it has been formed from participants attempts to perform two different behaviours. Firstly, when they attempted to follow a supervised programme and then when participants attempted to follow the unsupervised programme, therefore it demonstrated the consequences of participants being exposed to sequential intervention and how the first may positively but also negatively influence the second. This is an important consequence as it demonstrates to intervention designers that many measures to improve adherence to the unsupervised exercise must be in place before the unsupervised period starts and highlights areas where intervention could be targeted.

The model also makes explicit the importance of ‘Agency’. The empirical findings from this study showed that for a person with advanced cancer to be capable of exercising they typically had to overcome significant impediments. If participants could not exert influence and mitigate or accommodate impediments they did not exercise. Whereas other models such as COM-B propose the importance of being capable of performing the behaviour the model proposed in this thesis highlights the importance making necessary adjustment or influences to achieve that capability. This is likely due to the unique needs of the population interviewed. Central to the COM-B model is the belief that people typically have the capability and opportunity to perform a behaviour and so behaviour is regulated by motivation (Michie and West, 2013). Findings in Element 3 indicate due to the consequences of advanced cancer and treatment a person’s capability is highly changeable and so they more often will need to exert agency or influence to compensate for this. Findings also showed that during the supervised period much agency towards making the sessions appealing therefore increasing motivation, and towards overcoming impediments was exerted by

HCPs. During the unsupervised period this responsibility fell to participants. The concept of agency shares similarity with what Sniehotta, Scholz and Schwarzer, (2005) term action planning and action control and were considered important mediators between exercise intentions and actual behaviour in cardiac rehabilitation patients asked to adopt or maintain exercise programmes. Any model which does not explicitly draw attention to agency and acknowledge that influence must be exerted by one or another source is limited. This is because, in the highly complex and challenging population of advanced cancer and/or in the potential inappropriate unsupervised home environment, agency is of the utmost importance. Finally, the model depicts and distinguishes both the behaviour and the decision immediately prior to that behaviour. Whilst this distinction was clearly apparent from the interviews conducted few other examples of previous work could be found which identify and place importance upon both. The proposed model is also concerned not just with the initiation of unsupervised exercise but the continuation of exercise for the remainder of that session and the repeated continuation of exercise over time. This is depicted by an agentic feedback loop demonstrating how each decision and action regarding exercise can have an influence upon the next. The identification of these features might be because the complexity and frequency of challenges faced by people with advanced cancer, or the challenges of exercising in an unsuitable home environment make the cognitive consideration of a ‘Moment of conscious decision’ before exercise and continuing throughout the exercise much more apparent than in other contexts. Likewise, the complexity and frequency of challenges faced by people with advanced cancer, the challenges of performing new exercises in an unsuitable home environment, and the regularity of the exercise protocol, may have contributed to the identification of agentic feedback. In this new and highly changeable context each time an exercise is considered or performed something is learned which contributes to the next repetition.

The differences above also reflect the specific context and way in which the model is intended to be used. For example, The Theory of Physical Activity Maintenance (Nigg et al. 2008) is intended to advance knowledge and stimulate research around maintenance of physical activity, not prescribed exercise, and so is of less direct applicability to people designing interventions for application directly in practice. COM-B model is intended to be used to identify what needs to change in order for a behaviour change intervention to be effective (Michie, van Stralen and West, 2011) and so requires intervention designers to carry out further analysis to make it applicable for their context. The model presented here is designed to represent only people with advanced cancer and although it is therefore not suitable for wide scale generalisation, it better represents the requirements of people with advanced cancer than other models as it offers greater insight as to what is likely to need considering for people with advanced cancer to continue exercising.

The model proposed here has used empirical evidence synthesised with theory to identify what is likely to need to be changed to lead to increased exercise behaviour for patients with advanced cancer following a supervised exercise programme. The guiding principles, presented in the next section of this chapter, take the findings and translate these into considerations for intervention design.

9.5 Relevance to policy and practice

9.5.1 Relevance to practice

9.5.1.1 Guiding principles

This body of work has shown what influences adherence to prescribed exercise in supervised hospital-based and unsupervised home-based exercise for people with advanced cancer. This new understanding of the reasons as to why adherence is high in supervised programmes and significantly lower in unsupervised sessions presents an opportunity to propose recommendations to address this decline. Proposed recommendations will be presented in the form of guiding principles as per the PBA (Yardley et al. 2015a; 2015b).

According to Yardley et al. (2015a; 2015b), the purpose of creating Guiding Principles is to produce a readily accessible, coherent focus for intervention design, showing what is necessary to maximise acceptability and feasibility. They highlight what the intervention needs to achieve and what features it must contain to achieve this and so are divided into two sub-categories, ‘Key Intervention Objectives’ and ‘Key Intervention Features’ (Yardley et al. 2015a; 2015b).

Findings presented in this thesis indicate for a person to adhere to an exercise intervention they need first for their attention to be focused on exercise through a ‘Moment of conscious decision’, then they need to conclude they want to or should exercise (motivation), they are able to exercise (self-efficacy), or, they need to be able to exert influence (agency) to address any discrepancy between the assessment of those factors and what is required to meet the ‘Demands of the home exercise protocol’. These form the proposed key intervention objectives.

1) Create a moment of conscious decision
2) Maximise motivation towards the home exercise
3) Maximise self-efficacy towards the home exercise
4) Maximise agency

Three ‘Key features’ of an intervention have been developed to meet those ‘Key intervention objectives’.

1) Continuation of professional support through either continuation of the supervised sessions, use of telehealth, or use of an external exercise provider
2) Incorporation of non-professional support such using as friend or family as an exercise partner
3) Preparation for the deficiencies of home exercise

An infographic has been designed to depict the proposed ‘Key features’ indicate which ‘Home exercise determinant’ would be targeted and suggest the extent to which that would impact each ‘Key objectives’ (Figure 16). Following the infographic the rational for each of the four ‘Key objectives’ is presented after then ‘Key features’ to address those objectives will be discussed.

Key features	Determinants targeted	Objectives impacted
CONTINUE SUPERVISED SESSIONS		
	Targets suitability of support & suitability of environment	Moment of decision ++++
		Motivation ++++
		Self-efficacy ++++
		Agency ++++
USE OF TELEHEALTH TECHNOLOGY		
	Targets suitability of support	Moment of decision ++++
		Motivation +++
		Self-efficacy +++
		Agency +++
USE OF EXTERNAL EXERCISE PROVIDERS		
	Targets suitability of support & suitability of environment	Moment of decision ++++
		Motivation +++
		Self-efficacy +++
		Agency +++
INCORPORATION OF NON-PROFESSIONAL SUPPORT		
	Targets suitability of support	Moment of decision ++
		Motivation +++
		Self-efficacy ++
		Agency ++
PREPARATION FOR DEFICIENCIES OF HOME EXERCISE		
	Targets readiness of the participant	Moment of decision +
		Motivation +
		Self-efficacy +
		Agency +

(+ symbols depict anticipated level of impact)

Figure 16: Infographic of proposed guiding principles

9.5.1.1.1 Key objective 1) Create a moment of conscious decision.

Loss of appointments and pre-session phone calls at the end of the supervised period meant a participant's focus and attention often did not turn to exercise during the unsupervised period. Therefore, any unsupervised intervention needs to create a point where a participant's attention is drawn to focus upon exercise.

9.5.1.1.2 Key objective 2) Maximise motivation towards the exercise.

Findings showed motivation to unsupervised home exercise to be very low. Motivation to this period may have been further undermined by the high motivation levels generated towards session attendance, rather than towards exercise, by additional externally created short term rewards in the supervised sessions. Motivation for unsupervised exercise was diminished further by fatigue which reduced the desire to perform all activities. Therefore, greater focus should be placed on creating motives which are applicable to home exercise. In addition, consideration needs to be given as to whether factors that create motivation to attend supervised sessions, should be avoided if they cannot be continued into the unsupervised period so they do not undermine any other motives that are present.

9.5.1.1.3 Key objective 3) Maximise self-efficacy towards unsupervised exercise.

The physical limitations of the home environment, negative physical consequences of cancer, and inadequate support all reduced participants' perception of whether or not they could perform the prescribed exercise. In addition to this, although the supervised session enabled participants to increase their self-efficacy to exercise with their condition this did not always transfer to increased self-efficacy to exercise at home.

Therefore, interventions must ensure each participant feels that the exercise is suitable to be performed at home, taking account of individual context including their variable physicality, and resources available to them.

9.5.1.1.4 Key objective 4) Maximise agency.

Interview findings showed that the absence of a created 'Moment of conscious decision' combined with inadequacy between what is required of an unsupervised exercise protocol and a person's motivation and self-efficacy towards that protocol reduced adherence. Typically, this was due to insufficiency in the home exercise determinants of 'Readiness of the participant', 'Suitability of support', and 'Suitability of the exercise environment'. Participants displayed agency to exert their influence to better match those 'Home exercise determinants', with the 'Demands of the home exercise protocol', and so increase their exercise behaviour. Bandura, (2001) highlights the importance of equipping people with the self-regulatory capabilities to deal effectively with whatever problems arise rather than merely equipping them with explicit solutions to specific problems. Likewise, although it is important for supervised programmes to prepare participants for common problems, the greatest need is to prepare participants to be able to exert their influence over whatever may arise. Therefore, future interventions must attempt to maximise 'Agency' in patients, and those who may be able to support them. It is equally important to equip patients to not only exert influence over barriers which may be impeding exercise but to be able to exert their influence to establish a way to exercise in a way which continues to be appealing to them.

The next few sections address key features.

9.5.1.1.5 Key feature 1) Continuation of professional support

Intervention designers should consider the continuation of professional support. If resources allow consideration should be given as to whether the supervised sessions can be continued as these were found to be highly successful, participants were motivated to attend them, had the self-efficacy to perform the exercise, and the agency demonstrated by the HCPs assisted to overcome most challenges. If this is not possible consideration should be given to either using telehealth technology to extend support from the personnel who delivered the supervised sessions or using an external service to provide further supervised sessions. Use of telehealth or external providers would increase the 'Suitability of support' in this period and could be used to target each of the four key objectives depended on identified needs. In addition to this use of an external exercise provider could also increase the 'Suitability of the environment'.

Providing a regular telephone/video call during the unsupervised period, would create a 'Moment of conscious decision' turning participant's attention to exercise. This would replicate the success of the pre-session call incorporated into many supervised programmes but in a time-period in which findings suggest it would be more beneficial. If resources do not allow for such a telephone/video call then interventions could consider use of technology, such as software applications, to generate automated reminders.

If resource allow, the video call could be used to provide direct real time supervision of an exercise session, as some research has begun to investigate in response to the COVID-19 pandemic. Again this would create a 'Moment of conscious decision' to focus thoughts away from daily tasks to exercise and would replicate the surveillance which created significant motivation towards attendance of the supervised sessions. Such video calls could replicate the social interaction between the patient and professional which again was a strong cause of the enjoyment and motivation during the supervised sessions. This would also maintain the relationship which commonly developed between HCPs and patients and so reduce the loss that is experienced when sessions end. Such real time video calls would allow a HCP to exert their own influence, agency, over areas they identify as needing attention, whether that be areas relating to motivation or self-efficacy. If these sessions could be delivered in a group format, using video conferencing technology, this could also create an element of social interaction between the participants which was also a very strong source of enjoyment and motivation for attending the supervised sessions. In addition to a positive impact upon motivation a group format video call has potential to allow for modelling of others, an identified method to develop self-efficacy (Gallagher, 2012). Bandura, (2006) suggests the internet can be used to connect individuals in pursuit of common cause and bring together large networks for unified action. Therefore time should be allowed for discussion of participants' experience of their exercise in this period, this could enable both collective agency from the group as a whole and proxy agency through HCP input with the intention of solving challenges that have been encountered.

Interventions should look to increase engagement with suitable external exercise providers, as such services should offer exercise that participants want to do (motivation), feel they can do (self-efficacy), and the staff delivering the sessions can provide additional influence over anticipated and unforeseen problems (agency). Evidence showed participants who used external providers, typically to participate in classes, during the unsupervised period gained many of the elements which had led to high levels of adherence in the supervised sessions. The 'Suitability of the exercise environment' and 'Suitability of support', were both conducive to exercise. The environment allows for a large variety of enjoyable suitably challenging exercises to be selected. The professional support also ensure exercises are enjoyable and tailored to the needs of participants and the set appointment adds an element of surveillance. The exercise protocol of the group-based sessions generated highly valued social interaction. All of these factors meant participants felt motivated to attend and had high self-efficacy towards the exercises performed. In addition to this such services allows for agency from the staff to exert influence towards not only making the sessions appealing for participants but also to address unforeseen difficulties which may arise.

However, participants who used external services had all used these same providers before their cancer diagnosis. HCPs interviewed reported signposting participants to other specialist exercise providers, but were not aware whether participants engaged with these services. No participants interviewed had done so, suggesting these attempts were not successful. It seems participants who used other exercise services previously, returned to those same services, rather than new services. These people used their own agency to select a way of exercising which they knew from previous experience would be most appropriate for them, rather than the prescribed home exercise. Participants who had not used external exercise services in the recent past, do not have such highly valued options to select and do not appear to engage with new options when signposted to them. Therefore, it is likely strategies to encourage take up of such services need to go beyond current methods of signposting and provision of information leaflets as no examples were found of those methods being effective. Greater relationships need to be built between those delivering the supervised interventions and external services so that those patients who have not previously used such external services feel confident to do so.

9.5.1.1.6 Key feature 2) Incorporation of non-professional support

Interventions should seek to include an exercise partner to increase the ‘Suitability of support’ and impact upon each of the mechanisms of self-efficacy, motivation and agency. There were examples of family and friends prompting participants to exercise, helping overcome barriers to exercise, and finding ways to make exercise more enjoyable. Throughout the supervised period examples existed of family and friends being used as a resource to support participants to exert their own influences, proxy agency. For example, participants would select family or friends who they believed were best able to help them with attending the sessions either through providing transport or accompanying them when nervous about attending the first session. Examples also existed of family exerting their own influence by selecting their own ways in which they felt they could help the participant. This indicates most participants had family or friends who wished to, or were willing to, help in whatever ways were needed. However, these were in largely unstructured or infrequent ways, therefore, attempts should be made to enhance this potential source of support. Interventions should develop and/or encourage a structured role for family and friends who learn about the requirements of exercise during the supervised period and then can provide more informed support during the unsupervised period. Although this method is dependent upon a participant having a suitable social context, this would increase the determinant of ‘Suitability of support’, which could impact upon key objectives in several beneficial ways. The involvement of a partner may assist with creation of a ‘Moment of conscious decision’ if set times to exercise are agreed. The additional support would also add an element of interaction to make the exercise more enjoyable, and could provide encouragement, both of which could increase motivation. The extra support could enable an extra source of agency to exert influence on areas identified as needing enhancement. For example, addressing impediments as they arise, to improve self-efficacy, or, finding ways to exercise in more enjoyable ways to increase motivation. This could also maintain greater consistency between the two periods and so may reduce the previously identified undermining effect and sense of loss which is experienced at the end of supervised programmes. If a suitable partner cannot be found who could participate in the exercise it may be possible to establish a supportive role to assist and provide an element of accountability, however great caution should be taken with this approach as data in Element 3 indicated conversations around physical activity and exercise can be a frequent cause of conflict amongst patients and family.

9.5.1.1.7 Key feature 3) Preparation for the deficiencies of home exercise.

It is known that both the ‘Suitability of support’ and ‘Suitability of the exercise environment’ decrease in the unsupervised period. In addition to this the exercise protocol typically does not contain the elements participants found most favourable. Therefore, interventions should use the supervised period to better prepare and maximise the ‘Readiness of the participant’ so that they have the motivation, self-efficacy, and agency required to exercise successfully despite the likely lack of support and unsuitable home environment, and less favourable protocol. Interventions should look to incorporate this preparation throughout as much of the supervised period as possible as findings in Element 3 suggest attempts to provide a short transition period near the end of the period may be inadequate.

9.5.1.1.7.1 View supervised period as preparation for home period

Sessions should incorporate deliberate attempts to instil participants with the theoretical mechanisms which promote adherence. Sessions should be designed to utilise the five methods for developing self-efficacy as outlined in Gallagher, (2012): 1) Mastery experiences; 2) Modelling / witnessing others. 3) Imagined experiences. 4) Social persuasion. 5) Somatic experiences. Care should be taken to increase the likelihood of what is learnt by participants, during the supervised period, remaining relevant to the exercise which will be performed at home. If a form of exercise cannot be used in the home environment consider an alternative which can. If an alternative cannot be found consider whether or not if its benefit during this period outweighs the possible detriment caused by its loss when transferring to the home environment.

9.5.1.1.7.2 Consultation and discussion to enhance motivation

Participants reported one of the key contributors for their motivation to attending the supervised exercise was the enjoyment they got from doing so. Therefore, efforts should be made to consult participants and try to establish if the unsupervised exercise could be made more enjoyable. However, as no participant interviewed had found a way to make the unsupervised exercise as enjoyable as the supervised period, greater attention should be directed to highlighting motives other than enjoyment.

During the supervised period attempts should be made to establish exactly what participants own motives are for wanting to exercise and what else they place importance upon in their lives. Attempts should then be made to highlight how exercise, both supervised and unsupervised, can align with those motives and align with what they believe to be of importance to them. Suggestions could also be made as to how exercise may align with other common motives, such as those relating to the earlier identified themes of ‘Have life’, ‘Live life’, and ‘Beyond life’. Elements should also be built into the interventions to highlight when improvements or benefits which result from the exercise have been achieved. By establishing and focusing on how exercise, in supervised and unsupervised settings, can benefit the participant, it should reduce the drop in, and undermining of, motivation which often occurs when the supervised sessions finish. In addition to this according to Armstrong, (2014) a focus around reasons for doing exercise should cultivate an environment to better develop competencies and beliefs of agency.

9.5.1.1.7.3 Encourage autonomy

Interventions should attempt to encourage not supress agency. Armstrong, (2014) highlights two general approaches which can allow the cultivation of agency, firstly encouraging a high level of patient autonomy, and secondly, having a focus upon ‘reasons’ for actions rather than upon ‘causes’ of actions. Steps to build autonomy could include reduced surveillance and reduced professional support in the later stages of the supervised period. For example, consideration should be given as to whether or not to include a pre session phone call for all participants before every supervised session, or only use this technique for participants who, it becomes evident, require this close support. It is possible the close support/surveillance provided in this period did not allow participants the autonomy to develop their own ways of working. This may have led to over-dependence upon HCPs and reduce opportunity to develop agency. In addition, lessening HCP workload in the supervised period may allow for a pre-session phone call for participants in the unsupervised period, thereby increasing ‘Suitability of support’ targeted to the period when it is needed most.

Goller and Harteis, (2017) explain that of the three facets of human agency, namely agency competence, agency beliefs and agency personality, both agency competency and agency beliefs can be developed. According to Bandura, (2006) unless people believe they can produce desired effects from their actions they have little incentive to perform those actions. Therefore, unless participants have confidence in or learn that their attempts to exert their agency will be successful, they are unlikely to attempt to exert their agency. Bandura, (2006) argues further that if people develop their competencies, self-regulatory skills, and enabling beliefs, they generate greater range of options that, increase their range of possible action, and so are more successful in achieving their desired futures than people with less developed agency. This means steps need to be built into the supervised period which allow participants to learn how they can exert their influence over the factors that influence adherence. These steps should be similar to those used to increase self-efficacy and could include use of mastery experiences, modelling / witnessing others, imagined experiences and social persuasion.

The suggestion to encourage autonomy shares parallels with ‘Healthy Conversation Skills’. Healthy conversation skills is a method of encouraging lasting behaviour change through conversations based around a person centred approach to empower and support people find their own solutions (Hollis et al. 2021).It is considered to deviate significantly from the traditional medical models as described by (Parsons, 1951) involving the one directional passing of knowledge from ‘expert’ to ‘patient’ . Such directional approaches were at times apparent in the supervised exercise sessions, and considered by Kelly and Barker, (2016) to hinder changing health related behaviour. To facilitate a move toward an approach consistent with healthy conversations skills training HCPs could consider further training available online (Healthy Conversation Skills, 2020)

9.5.1.1.7.4 Maximise consistency between settings

Interventions should maximise consistency between the supervised and unsupervised exercise. Although evidence suggests exercise performed in the supervised period increases self-efficacy towards the exercise in the unsupervised period, this was greater in instances where the exercise was more similar. Consideration should also be given as to whether the commonly used strategies to generate motivation to attend the supervised sessions such as social interaction, and strict surveillance in the form of pre session phone calls, must be included for participants to attend during this period. If these features are deemed not necessary, they should be used with caution unless they can be transferred to the unsupervised period as they may undermine future motivation.

9.5.1.1.7.5 Start unsupervised exercises early

Participants should be encouraged to practice the unsupervised exercise, during and between supervised sessions. If participants begin unsupervised exercise before the supervised period has finished it is likely to increase the ‘Readiness of the participant’ in terms of their ability to create a ‘Moment of conscious decision’ and their self-efficacy towards exercise, and agency to influence potential impediments that arise. Performing unsupervised exercise before the supervised period finishes will allow for HCPs to become better aware of what occurs during the unsupervised period before all contact is withdrawn giving them better understanding of that period and allowing them a period of time to exert agency over unforeseen obstacles. It will also allow participants to begin developing agency competence and agency beliefs through the methods described above. If the participants initially perform the intended exercise whilst being observed by HCPs this will increase the 'Suitability of support' when performing the exercise for the first time and provide mastery experiences. Both of which should increase the 'Readiness of the participant' to exercise at home and generate greater self-efficacy. If time is incorporated into each session to discuss experiences, of home exercise, with HCPs this will further allow some agency to be exerted by HCP over any difficulties that are encountered before contact is withdrawn. For example, it may allow HCPs to better understand the 'Suitability of the exercise environment' at the participant's home and make changes to the protocol if necessary. Importantly it would determine which participants appeared to be ready to exercise at home and which participants would still require some form of professional support, such as the telehealth interventions or use of an external service described in key feature 1. If discussion is encouraged between other participants in the group this could allow for modelling and social persuasion, which can develop a person's sense of self-efficacy. Discussion within the group could allow for successful strategies to be shared and may also facilitate the development of collective agency resulting in greater range of potential solutions for participants to consider towards challenges experienced.

9.5.1.1.7.6 Allow participants to modify the protocol

Interventions should be developed collaboratively during the supervised intervention allowing for and encouraging participants to modify the prescribed protocol to their needs whilst remaining within parameters that maintain efficacy. The home exercise protocol should include a variety of exercises, to allow for variation in physical condition and different settings. Designers could consider three levels of intensity, to be selected for each home exercise session to match the participant's condition at that time, as demonstrated in Kuehr et al. (2014). Similar considerations should be given to designing options which take into account difference in 'Suitability of the exercise environment' which participants reported to encounter when for example on holiday or during hospital admissions. Whilst these considerations will not improve 'Readiness of the participant' or the 'Suitability of the exercise environment' they could assist the participant to match the 'Demands of the home exercise protocol' to any physical or environmental constraints they are experiencing at that time. This should improve self-efficacy, but also by providing some autonomy to select the most appropriate exercise each time may facilitate the development of agency. However, care must be taken to ensure these exercises are learnt before the supervised period finished to prevent the increased options from being overwhelming.

9.5.1.2 Case study examples

Three key features have been proposed to encourage and facilitate continued exercise adherence after the supervised programmes are completed: 1) continuation of professional support, 2) incorporation of non-professional support, 3) preparation for the deficiencies of home exercise. Grimmett et al. (2019) reviewed the effectiveness of interventions to support maintenance of physical activity in adults diagnosed with cancer. This review recognised different levels of intervention and concluded that lower-intensity interventions may be appropriate to sustain behaviour change in people who are motivated, young, white, and well educated. Whereas more intensive support is likely to be required for older people and those with physical limitations. The three key features proposed here can provide three levels of intervention in terms of the extent of support that is provided. If participants begin the unsupervised exercise whilst still in regular contact with the HCP delivering the intervention it may assist determining which level of intervention would be most suitable for that participant. Appendix HH and Appendix II presents two exemplar case studies constructed from an amalgamation the data of participants who were identified as performing ‘No exercise’ or ‘Infrequent exercise’ in the earlier described typology. This amalgamation draws out the key points from each of those two types identified, ‘No exercise’ and ‘Infrequent exercise’, and demonstrates how the key features could lead to increased exercise adherence.

9.5.2 Relevance to policy.

With regard to policy, even though there is substantial knowledge about the benefit of exercise in cancer, there remains a significant gap in implementing this knowledge into clinical practice. Approximately 30% of people living with and beyond cancer in the UK are believed to be completely inactive, and only 20% are thought to exercise in line with physical activity recommendations (Glaser et al. 2013). Despite it being known that activity levels are low in people with cancer, the NHS, (2019) Long Term Plan, makes little reference to exercise except for interventions to target falls prevention in frailty, arthritic and joint pain, disease prevention, heart and lung rehabilitation. Whilst people with advanced cancer may still be able to access and benefit from such interventions, evidence from Element 3 found some patients were excluded from similar classes due to their cancer diagnosis. It is concerning such policy does not recognise the potential of exercise in this patient group, or make reference to the importance of adherence and strategies to change behaviour in the groups for which it is advocating exercise.

In support of reducing the gap between what is known about exercise in cancer and what is provided clinically, The Moving Through Cancer initiative, is aiming to make exercise standard practice in oncology by 2029. One component necessary to achieve this is that research will be needed to study a variety of existing, and new, delivery models for exercise and rehabilitation (Schmitz et al. 2021). The new knowledge presented in this thesis could be used to contribute towards the development of new approaches to enabling exercise, highlighted as a necessary step towards the goal of making exercise standard practice.

9.6 Strength and limitations

9.6.1 Strengths

The main strength of this research is the singular focus on adherence. This has allowed for a deeper investigation of this issue in comparison to previous studies that have either not considered adherence or viewed it as a secondary issue. The multi-perspective mixed method investigation, guided by the PBA, involving a diverse range of participants, interventions, and locations helped develop a comprehensive understanding of adherence in this group.

All interviews and analysis were conducted by the author, who had not been involved in the design or development of any of the interventions. Although sessions of each exercise intervention were observed to gain understanding prior to design of the studies, no participants present at these sessions were interviewed. Participants were made aware that the interviewer had not been involved in any of the intervention designs and these points may have helped remove a potential source of bias. Finally, the assembly of an advisory panel consisting of experts in their relevant fields covering different specialities enabled validation of preliminary findings and gave additional perspectives as analysis progressed.

9.6.2 Limitations

The findings presented in this thesis need to be qualified through a consideration of its limitations. The decision to exclude multi-dimensional interventions from the mixed method review meant the exclusion of interventions which involved exercise and additional lifestyle components such as diet or relaxation. This decision came about following a previous review by Beaton et al. (2009) which identified the inclusion of such studies as a limitation, because it further complicated an already extremely heterogeneous collection of interventions. However, it is also possible that if such papers had been included they may have added further understanding of participant experience. One paper, excluded because it involved exercise and relaxation, was later found to offer useful findings relating to participant experience and supporting the findings reported here (Adamsen et al. 2012). It is unknown whether other excluded papers may have also offered similarly useful findings.

Possibly the most significant limitation concerns the changes that were made to Element 3 due to the slow recruitment and closure of the EMBRACE RCT. This necessitated the design of a further study which recruited participants from contexts significantly different to the originally planned investigation. The heterogeneity of the interventions investigated in relation to the sample size, particularly the sample size of patients. Three very different interventions were investigated, EMBRACE, Circuit class, and Chairs class. However, taking into account the EMBRACE control group, the differences that occurred across the two settings of EMBRACE, as well as the changes in the design of the Chairs class which occurred due to changes in the staffing, it could be reasonable to consider these as six interventions. Therefore, as only 16 patients and 12 HCPs were recruited questions may be raised regarding the trustworthiness of synthesising across such a diverse range of interventions. Other limitations include the relatively small geographical area in which the research was conducted which may limit its relevance to other areas of the UK, or beyond the UK. Similarly, the group was homogeneous in terms of race and no socio demographic measure of wealth was recorded.

All judgements of adherence to home exercise were based upon patient reports, which allows for potential recall error and bias. Patient reports of physical activity measures are known to be prone to over-reporting (Grimmett et al. 2019). This may be due to difficulty with recall from the time of the behaviour to the time of the interview. It has also been suggested that the normative nature of exercise behaviour and the desire to give socially desirable responses might be the reason for such errors (Brenner and DeLamater, 2014). It is possible patients need to give socially desirable responses may also influence the reasons that are given for any deviations in adherence from the prescribed exercise (Essery et al. 2017). Examples existed of inconsistencies in individual patient reports of the amount of exercise they had been performing. Where such discrepancies were noted attempts were made to clarify this. However, it cannot be certain that these were all the incidences of incorrect recall.

Finally, it was anticipated that further input would be provided by the advisory panel. However, constraints on meeting in groups and changes in working patterns and demands on time of many in the group due to the SARS-CoV-2 pandemic meant this was not feasible. Although some members remained involved at later stages of analysis, the model development phase, and generation of guiding principles, most did not, and therefore those steps involved fewer perspectives and people with specialist knowledge than had been anticipated.

9.7 Implications for further research

There are several considerations for further research that arise from this body of work. Firstly, research should consider investigations into exercise adherence to be of equal merit to those focussed on efficacy and effectiveness. Previously more attention has been given to investigating benefits of exercise, with little consideration of adherence and even less towards understanding factors that contribute to adherence. However, full benefits of exercise will not be known if participants do not adhere to the intervention and likewise findings from Element 3 indicate adherence may increase if links between exercise and benefits in this patient group become more established. Therefore, both adherence and efficacy should be given equal attention in future research.

Secondly, Element 1 highlighted the heterogeneity of outcome measures employed making accurate aggregation of findings across studies difficult. Therefore, efforts should be made to reduce heterogeneity of measures where possible to increase comparisons across studies in future. Of particular concern should be establishing a consistent way of measuring and reporting adherence which minimises bias and enables appropriate collation of data across studies. Current methods for measuring and reporting adherence, which for example include no standardisation for whether or not to include data from participants who have withdrawn, can be misleading.

Thirdly, research is needed to examine and implement the contributions to knowledge made in this thesis, exercise protocols that incorporate the guiding principles should be developed and tested for feasibility and effectiveness. Is it possible for intervention designers to successfully implement the three key features 1) Continuation of professional support, 2) Incorporation of non-professional support, 3) Preparation for the deficiencies of home exercise? Do the key features effectively target the three home exercise determinants, of ‘Suitability of the exercise environment’, ‘Readiness of the participant’, ‘Suitability of support’, and the mechanisms of ‘Motivation’, ‘Self-efficacy’, and ‘Agency’? Does this lead to higher levels of adherence compared to previous interventions? How can interventions be designed which build self-efficacy, and motivation towards the home exercise and encourage the generation of agency within the participants?

Fourthly, research is needed to identify and categorise groups of participants who may or may not be appropriate for such interventions. This would establish for which groups of participants supervised to unsupervised programmes in their current form are effective in producing lasting exercise adherence and for which groups the proposed key features are likely to lead to lasting adherence. Findings from the relatively small sample indicate supervised to unsupervised programmes work best for participants who had exercised previously and had been forced to stop due to their cancer diagnosis. The supervised programmes gave such people the self-efficacy to exercise with their illness, and because they were already motivated to exercise and knew how to exercise in their home context, they were able to return to their old routines. Further research is needed to explore this proposition.

Finally, given the limited resources available to healthcare services a particular focus of future research should be directed at generating better understanding of agency. Findings of this study have shown that the consequences of advanced cancer as well as physical and social aspects of the home environment can reduce a person’s self-efficacy and motivation to a point where they do not meet the ‘Demands of the home exercise protocol’. In situations where it is not possible for HCPs to continue some form of supervision it becomes dependent on a person’s own agency to address inadequacy between motivation, self-efficacy and the demands of the home exercise protocol. Therefore, methods to measure and increase human agency need investigating.

9.8 Conclusion

The elements conducted in this thesis have together shown why adherence to exercise declines when therapeutic programmes transition from specialist settings with supervision into unsupervised home-based settings. It has been demonstrated how attempts to maximise adherence during the supervised period may not have a positive influence on adherence in the subsequent unsupervised period and may in fact undermine or prevent the development of factors necessary to adhere to an unsupervised home intervention.

It has shown that to perform unsupervised home exercise participants need the necessary ‘Motivation’ and ‘Self-efficacy’ to perform the exercise or the ‘Agency’ to influence and correct occasions when motivation and self-efficacy are inadequate. It also demonstrated how those mechanisms which enable exercise can be located within the ‘readiness of the participant’ the ‘Suitability of the exercise environment’ and the ‘Suitability of support’ which in turn are influenced by an interaction between pre-existing factors and the ‘Demands of the home exercise protocol’.

Finally, suggestions were made as to how a targeted stepped approach involving combinations of continuing support and better preparation to continue without support may lead to enhanced exercise behaviour after completion of supervised programmes.

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Appendix A Element 1: MEDLINE search strategy for quantitative studies

#	**Searches**
To get advanced cancer related content	
1	(MH “Neoplasms+”)
2	(cancer* or tumor* or tumour* or neoplas* or malignan* or carcinoma* or adenocarcinoma* or choriocarcinoma* or leukemia* or leukaemia* or sarcoma* or teratoma* or oncolog*).mp.
3	1 or 2
4	(terminal care or terminally ill or terminal illness or terminal disease$ or palliat* or hospice$ or terminal patient$).mp.
5	(end of life or near death or end stage$).mp.
6	4 or 5
7	3 and 6
8	terminal cancer*.mp.
9	(advanced N3 cancer$).mp.
10	(advanced N3 neoplas*).mp.
11	metasta*.mp.
12	9 or 10 or 11
13	7 or 8 or 12
To get exercise related content	
14	(MH "Exercise+")
15	(MH “Recreation+”)

16	(MH “Physical therapy modalities” or (MH “exercise therapy”) or (MH “muscle stretching exercises”) or (MH “plyometric exercise”) or (MH “resistance training”)
17	(MH “Walking+”)
18	(MH “Locomotion”) or (MH “running+”) or (MH “swimming”) or (MH “walking+”)
19	(MH “Exercise Movement Techniques+”)
20	(MH “Dance Therapy”) or (MH “Occupational Therapy”) or (MH “Recreation Therapy”)
21	(MH “Exercise Therapy+”)
22	(MH "Physical Fitness”)
23	(physical* N5 (fit* or active*)).mp.
24	(exercise* or aerobic* or resistance* or strength* or walk* or endurance*).mp.
25	(physical activit* or physically active or exercis* or sports or recreation or stretch* or walking or running or jogging or hiking or pilates or yoga or martial art* or tai ji or tai qi or tai chi or danc* or swimming or cycling or bicycl* or resistance training or weight lifting or skiing or skating or active video game* or wii or Kinect or playstation move or gardening).mp.
26	(physiotherap* or physical therap* or occupational therap* or kinesiotherap* or recreational therap*).mp.
27	or/14-26
To get exercise and advanced cancer related content	
28	13 and 27
To get only Quantitative, systematic review and mixed method content	

29	"clinical trial".pt. or "clinical trial, phase i".pt. or "clinical trial, phase ii".pt. or clinical trial, phase iii.pt. or clinical trial, phase iv.pt. or controlled clinical trial.pt. or "multicenter study".pt. or "randomized controlled trial".pt. or double-blind method/ or clinical trials as topic/ or clinical trials, phase i as topic/ or clinical trials, phase ii as topic/ or clinical trials, phase iii as topic/ or clinical trials, phase iv as topic/ or controlled clinical trials as topic/ or randomized controlled trials as topic/ or early termination of clinical trials as topic/ or multicenter studies as topic/ or ((randomi?ed N7 trial*) or (controlled N3 trial*) or (clinical N2 trial*) or ((single or doubl* or tripl* or treb*) and (blind* or mask*))).ti,ab,kw. or ("4 arm" or "four arm").ti,ab,kw.
30	(((comprehensive* or integrative or systematic*) N3 (bibliographic* or review* or literature)) or (meta-analy* or metaanaly* or "research synthesis" or ((information or data) N3 synthesis) or (data N2 extract*))).ti,ab. or (cinahl or (cochrane N3 trial*) or embase or medline or psyclit or (psycinfo not "psycinfo database") or pubmed or scopus or "sociological abstracts" or "web of science").ab. or ("cochrane database of systematic reviews" or evidence report technology assessment or evidence report technology assessment summary).jn. or Evidence Report: Technology Assessment*.jn. or ((review N5 (rationale or evidence)).ti,ab. and review.pt.) or meta-analysis as topic/ or Meta-Analysis.pt.
31	Feasibility.TI. or Feasibility.AB.
32	(mixed N5 method*).mp.
33	multimethod*.mp.
34	(multiple N5 method*).mp.
35	29 or 30 or 31 or 32 or 33 or 34
<u>To get quantitative papers regarding exercise in advanced cancer.</u>	
33	28 and 35

Appendix B Element 1: MEDLINE search strategy for qualitative studies

#	Searches
To get advanced cancer related content	
1	(MH “Neoplasms+”)
2	(cancer* or tumor* or tumour* or neoplas* or malignan* or carcinoma* or adenocarcinoma* or choriocarcinoma* or leukemia* or leukaemia* or sarcoma* or teratoma* or oncolog*).mp.
3	1 or 2
4	(terminal care or terminally ill or terminal illness or terminal disease$ or palliat* or hospice$ or terminal patient$).mp.
5	(end of life or near death or end stage$).mp.
6	4 or 5
7	3 and 6
8	terminal cancer*.mp.
9	(advanced N3 cancer$).mp.
10	(advanced N3 neoplas*).mp.
11	metasta*.mp.
12	9 or 10 or 11
13	7 or 8 or 12
To get exercise related content	
14	(MH "Exercise+")
15	(MH “Recreation+”)

16	(MH “Physical therapy modalities” or (MH “exercise therapy”) or (MH “muscle stretching exercises”) or (MH “plyometric exercise”) or (MH “resistance training”)
17	(MH “Walking+”)
18	(MH “Locomotion”) or (MH “running+”) or (MH “swimming”) or (MH “walking+”)
19	(MH “Exercise Movement Techniques+”)
20	(MH “Dance Therapy”) or (MH “Occupational Therapy”) or (MH “Recreation Therapy”)
21	(MH “Exercise Therapy+”)
22	(MH "Physical Fitness”)
23	(physical* N5 (fit* or active*)).mp.
24	(exercise* or aerobic* or resistance* or strength* or walk* or endurance*).mp.
25	(physical activit* or physically active or exercis* or sports or recreation or stretch* or walking or running or jogging or hiking or pilates or yoga or martial art* or tai ji or tai qi or tai chi or danc* or swimming or cycling or bicycl* or resistance training or weight lifting or skiing or skating or active video game* or wii or Kinect or playstation move or gardening).mp.
26	(physiotherap* or physical therap* or occupational therap* or kinesiotherap* or recreational therap*).mp.
27	or/14-26
28	13 and 27
To get only qualitative content	
29	((("semi-structured" or semistructured or unstructured or informal or "in-depth" or indepth or "face-to-face" or structured or guide) N3 (interview* or discussion* or questionnaire*))).ti,ab. or (focus group* or qualitative or

	ethnograph* or fieldwork or "field work" or "key informant").ti,ab. or interviews as topic/ or focus groups/ or narration/ or qualitative research/
To get qualitative papers regarding exercise in advanced cancer.	
30	28 and 29

Appendix C Element 1: Context and participant characteristics

	Setting	Supervision	Cancer type	Stage of disease	Treatment	Participant function at study start
Cheville et al. (2013)	Home	Unsupervised	Lung and Colorectal	Stage 4	Receiving chemotherapy at start of treatment 45.5% Receiving radiotherapy at start of treatment 9.1%	Ambulatory Post-Acute Care Computer Adaptive Test scores between 50 and 75. Scores in this range indicate participants are capable of performing the intervention and of greatest likelihood to benefit
Cormie et al. (2013)	Exercise clinic based	Supervised	Prostate Cancer	metastatic to bone	Previous AST 100% Previous Radiotherapy 60% Previous Surgery 10%	Mean self-rated health for intervention group 3.2. = Good 1=Excellent, 2=very good, 3=good 4=fair 5=poor
	Home.	Unsupervised (adherence not measured)				
Headley, Ownby and John, (2004)	Home	Unsupervised	breast cancer	Stage IV	All Chemotherapy	Performance status of 2 or less on the Zubrod Scale**
Hwang et al. 2012	Outpatient clinic	Supervised	Non-small cell lung cancer	IIIA=9.1% IIIB=0% IV=90.9%	All receiving targeted therapy	EORTC QLQC30*** Global health status and QOL 73.1 ± 14.5 Physical functioning 93.8 ± 6.9 Role functioning 96.2 ± 7.3 Scored 0- 100, higher indicates better All participants had Eastern Cooperative Oncology Group performance status of 0 or 1**
Jensen et al. (2014)	Hospital	Supervised	Resistance group Colon 27%, cholangiocellular 9%, rectal 27% gastric 27% pancreatic 9% Aerobic group Colon 30%, cholangiocellular 30%, rectal 20%,	Metastatic	Chemotherapy	EORTC-QLQC30*** Global health status and QOL RET 42.4±29.7 AET 57.5±17.8 Physical functioning RET 89.1±8.0 AET 92.7±10.6 Role functioning RET 25.8±23.9

			gastric 20%, pancreatic 10%.			AET 53.3±29.2
Kuehr et al. (2014)	Thoracic Oncology Department and	Supervised and unsupervised	Non-small cell lung cancer	stages IIa 5% IIIa 8% IIIb 20% IV 67%	Radiochemotherapy 17.5% or chemotherapy 82.5%	Eastern Cooperative Oncology Group status** 0)27.5% I)62.5% 2)10% 3-5) 0%
	Home	Unsupervised				
Litterini et al. (2013)	Community cancer center and a hospital-based fitness facility	Supervised	<u>Cardio vascular group,</u> breast 25%, colorectal 9%, lung 19%, prostate 6%, gynecologic 13%, lymphoma/Hodgkin disease 3%, others 25% <u>Resistance group,</u> breast 18%, colorectal 18%, lung 15%, prostate 12%, gynecologic 0%, lymphoma/Hodgkin disease 12%, other 26%	incurable	Cardiovascular group none 16%, chemo 34%, radiation 9%, combination 31%, other 9%, Resistance group none 18%, chemo 38%, radiation 9%, combination 26%, other 9%.	Short Physical Performance Battery**** Cardiovascular group 9.77 ± 2.25 Resistance group 9.38 ± 2.10
Lowe et al. (2013)	Home	Supervised and Unsupervised (unsupervised adherence not measured)	Gastrointestinal cancer (22%), lung cancer (22%) and primary unknown (22%) head and neck cancer (11%), malignant melanoma (11%) and anaplastic oligodendroglioma (11%)	progressive, incurable, locally recurrent or metastatic. 78% metastatic	67% 0f participants had received chemotherapy	All participants had Palliative Performance Scale level of over 30% ¥¥ Abbreviated version of the Late Life Function and Disability Instrument¥¥¥¥ Score (0-75) mean score 15.75 Physical Activity scale for the elderly. Assessed participants reported physical activity in week before baseline. Only reported for the 3 case studies Case 1 climbing stairs to his bathroom Case 2 walking 30 minutes per day three times a week Case 3 Walking 60 minutes per day three times a week
Temel et al. (2009)	Academic medical centre	Supervised	non-small cell lung cancer	84% stage IV 16% IIIB with effusions	Chemotherapy 72% chemotherapy and radiotherapy 20%, radiation 8%	Eastern Cooperative Oncology Group performance status** 0)40% 1)60%

						2-5)0%
Uth et al. (2014; 2016)	Specialist football training facility	Supervised	prostate cancer	≥T3 n 70.4% Nodal metastases 13.8% Bone metastases 24.1%	ADT	Self-reported leisure time physical activity level Sedentary 7.1% Walking or cycling for pleasure 43.9% Regular physical activity (≥3 h/week) 42.9% Intense physical activity (≥4 h/week) 7.1% VO2 max >35 ml/kg/min
van den Dungen et al. (2014)	Hospital	Supervised	Breast 7 Gastrointestinal 8 Other 11	Metastatic	On going treatment included. Surgery 1 or 4% chemotherapy 10 0r 38%, hormonal therapy 6 or 23%, other 3 or 12%, none 6 or 23%	Participants had average Karnofsky Performance Scale of 79.2, can perform ADL with effort ¥
	Home	Unsupervised (adherence not measured)				
West et al. (2015)	Hospital	Supervised	rectal cancer	Locally advanced (i.e., tumor node metastasis stage on pelvic magnetic resonance imaging, ≥T3N+)	Neoadjuvant chemoradiotherapy	ASA physical status ¥¥¥ 1)50% healthy person 2)41% mild systemic disease 3)9% severe systemic disease 4-6)0% WHO performance score** 0=82% 1=18% 2-5)0%
Winters-Stone et al. (2014; 2015)	Hospital	Supervised	prostate	Advanced Roughly a quarter or fewer men had metastatic disease	ADT 44.8% Had received chemotherapy 6.9% Had received radiotherapy	men who participated in this trial were well functioning to begin with, as reflected by their relatively high scores on the PPB EORTC-QLQC30*** Physical function 87.5±14.3 Short Physical Performance Battery**** 10.9±1.1
	Home	Unsupervised				
*Data shown is for the participants performing the exercise, any control group data not shown, In cases of 2 exercise groups data is separated into each group.						
**Zubrod Scale / WHO performance score / Eastern Cooperative Oncology Group status 0= Asymptomatic (Fully active, able to carry on all predisease activities without restriction 1= Symptomatic but completely ambulatory (Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature. For example, light housework, office work) 2= Symptomatic, <50% in bed during the day (Ambulatory and capable of all self care but unable to carry out any work activities. Up and about more than 50% of waking hours 3= Symptomatic, >50% in bed, but not bedbound (Capable of only limited self-care, confined to bed or chair 50% or more of waking hours) 4= Bedbound (Completely disabled. Cannot carry on any self-care. Totally confined to bed or chair) 5 = Death						

***EORTC QLQC30- Questionaire data is scored is converted to a scale of 0-100 with higher scores indication better QOL.
****Short Physical Performance Battery (Guralnik et al. 1994) assesses balance, gait speed, and time to raise from chair 5 times. Each component is rated from 0-4, 4 being best. Then scores combined for an overall measure. 0= worst performance 12 = best performance
¥ Karnofsky Performance Scale, for classification of functional imparement. Scale runs from 100, no imparement, to 0, Death
¥¥ Palliative Performance Scale, is a modification of the Karnofsky Performance Scale given as a % rather than a score and involves components of ambulation, activity and evidence of disease, self care, intake, and conscious level
¥¥¥ ASA physical status, is used for assessing the fitness of patients before surgery. 1= Healthy Person, 2= mild systemic disease, 3= sever systemic disease, 4= severe systemic disease that is a constant threat to life, 5= a moribund person not expected to survive without surgery, 6= declared brain dead
¥¥¥¥ Abbreviated version of the Late Life Function and Disability Instrument

Appendix D Element 1: Moderating factor of complexity

	Intervention Length Frequency Time	No of components	No of settings	Level of permitted tailoring	Amount of Equipment	Behaviours involved in the intervention
Cheville et al. (2013)	8 weeks 4 sessions a week + 4 days with step targets Time not reported	Resistance exercise and pedometer based walking program 10 different exercises 5 upper 5 lower Exercises involved a rapid initial motion of extremities, slower truncal motion, three count hold, and controlled return to starting position	1	Seated if can't stand for long Progressed reps the resistance band strength Progressed step count target by 10% every 2 weeks if met target	Resistance bands pedometer	Perform 4 home based unsupervised resistance and 4 daily walking sessions each week for 8 weeks
Cormie et al. (2013)	12 weeks 2 a week 60 minutes	Resistance exercise Warm up 8 exercises Cool down Encouraged to supplement with 150 minutes aerobic away from centre, walking or stationary cycling	2	Exercises tailored to avoid putting stress on locations of participants bone metastases Progressing load every 2 weeks	Not listed but in exercise clinic so likely to be substantial	Attend 2 weekly resistance sessions and 150 minutes aerobic activity at home for 12 weeks
Headley, Ownby and John, (2004)	4 cycles of chemotherapy. (Each cycle 12 weeks?) 3 times a week 30 minutes	low- to moderate-intensity seated exercise Warm u seated repetition exercises stretching and repeated flexion and extension of the arms, head, upper torso, and legs Cool down	1	none	Video. No other equipment	Follow 30 min home based video 3 times a week for 4 cycles of chemotherapy
Hwang et al. 2012	8 weeks 3 sessions a week	high-intensity aerobic interval training program Exercise training consisted of 2–5-min intervals, alternating with high intensity [80% VO_{2peak}, or a	1	Exercise intensity determined by base line assessments	Equipment for baseline assessments	Attend 3 sessions a week for 8 weeks high intensity aerobic interval training

	30-40 minutes	rate of perceived exertion (RPE) of 15–17], and active recovery of moderate intensity (60% VO_{2peak}, or a RPE of 11–13). Each exercise session was 30–40 min in length, including 10-min warm-up and 5-min cool-down		Intensity and Duration were adjusted every 1 to 2 weeks depending on exercise response	Cycle ergometer	
Jensen et al. (2014)	12 weeks 2 times a week 45 minutes	Supervised resistance or supervised aerobic Resistance group 5 min warm up Unclear but worked legs, arms, back, and knees 15-25 reps 2 or 3 sets 5 min cool down AET Warm up Bicle ergometer Intensity pre determined on pulse measurements. Cool down	1	Both interventions intensity was based on base line measures No other tailoring. But reps and sets quite flexible as is the perceived exertion target for aerobic group	Uncertain for resistance group Cycle ergometer for aerobic group	Attend appointment 45 minutes 2 times a week of supervised hospital based aerobic or resistance exercise for 12 weeks
Kuehr et al. (2014)	8 weeks Inpatient 5 times a week 3 supervised Suggested 3 aerobic sessions and 2 resistance sessions a week Home 3 times a week Depended on traffic light colours rating system	hospital- and home-based combined endurance and resistance training program Warm up and cool down Different gymnastic exercises conducted with or without dumbbells and a set of color-coded stretch bands with different levels of resistance Three different strength-training protocols were used: (1) focused on extremities, (2) the entire body, or (3) bed exercises (limited to inpatient period) Endurance brisk walks outside or inside for 20-40 minutes, treadmill or a cycle ergometer during the inpatient stay	2	Rated health and symptoms at start of each session. Green , yellow, red. Colour matched to intensity for that session eg green max intensity red lower intensity	Stretch bands, dumbbells training manual Treadmill	Complete 5 inpatient sessions (three supervised) a week followed by 3 home based sessions a week for 8 weeks Perform both aerobic and resistance exercises At start of session assess health and symptoms on traffic light system and match to according training intensity Learn and perform the exercises in different setting with different equipment

Litterini et al. (2013)	10 weeks 2 times a week 30-60 minutes	Individualized exercise programs Aerobic or resistance Warm up and cool down Resistance with 1 set of 8 to 15 repetitions. Circuit consisted of Leg press, Leg extension, Leg curl, Hip abduction, Hip adduction, Chest press, Lat pull down, Arm curl, Arm extension, Seated row, Overhead press, Lateral raise, Back extension, Adjustable hi-lo pulley. 14 exercises Aerobic large choice of equipment exercised at 10-12 on borg scale	1	Choice of many aerobic machines, and swimming pool if difficulty weight bearing Resistance training increased reps and sets as tolerated Initial intensity frequencies and durations decided after assessment and on medical history. Continuously adapted through out the program to keep challenging but also dependent on symptoms and health O2 available if sats dropped	Large choice of aerobic training equipment	Attend appointment for aerobic or resistance exercise for 30-60 minutes 2 times a week for 10 weeks in 1 setting Resistance exercise consisted of 14 exercises plus warm up and cool down Aerobic exercise involved using a choice of different cardiovascular equipment
Lowe et al. (2009)	6 week Daily walking and 3 times a week strength training Varied depended on assessments	Unsupervised walking and supervised strength and balance exercises Warm up and cool down 10 range of motion exercises 7 resistance exercises 2 balance retraining 6 stretching flexibility (25) Walking	1	Individually prescribed The mode, intensity (resistance) and duration of each strength exercise were based on the results of the participant's baseline physical function testing Both walking and resistance exercise changes were made as quickly as possible to get progress or accommodate decline	Ankle/wrist cuff weights and/or resistance bands	Perform home based supervised strength training 3 times a week, and unsupervised daily walking, for 6 weeks. Resistance exercise consisted of 25 exercises plus warm up and cool down
Temel et al. (2009)	2 months 2 a week 90-120 minutes	Structured exercise program. Aerobic and resistance components Aerobic, warm up cool down 15 minutes treadmill Warm up cool down 15 minutes bike intensity based on heart rate. Resistance	1	if a session was missed subjects could make it up as long as whole program was completed in 12 week period Aerobic intensity and strength training based on initial assessments Strength training was modified or discontinued if unable to do them	Treadmill and bike Resistance equipment	Attend appointment to perform aerobic and resistance exercises for 90-120 minutes twice a week for 2 months

		3 sets of 10 repetitions of 6 different exercises (i.e., 3 upper extremity and 3 lower extremity movements) based on assessment of 1RM				
Uth et al. (2014; 2016)	32 weeks (Up to week 9) 2 times a week (Weeks 9-12) 3 times a week (Weeks 13 onward)s 2 times a week Week 1-4 30 minutes Week 5-12 45 minutes Week 12 onwards 1hr	Football training 15 minutes warm up and football specific drills Small matches	1	none	Indoor out door facilities, balls	Attend appointment for football training, of varying session durations on a different number of weeks as the intervention progresses for 32 weeks
van den Dungen et al. (2014)	6 weeks 2 a week 2 hours	Resistance and aerobic Warm up cool down Aerobic training intervention: Cycling on an interval basis for 30 minutes. 4 minutes 80-90% peak heartrate alternated with 3 minutes at 50-70% heartrate 7 exercises in a circuit, targeted to enlarge those muscles involved in ADL. Leg press, lunge, vertical row, lateral pull down, abdo crunch, pull over, bench press Also asked to exercise aerobically at home on non-training days at moderate intensity for 30mins	2	Aerobic and resistances tailored from base line assessment. Interval training from hr and resistance from 1rm Assessed again at 3 weeks and adjusted	Bike. Resistance equipment. Heart rate monitor	Attend sessions comprising aerobic and resistance training twice a week for 2 hours for 6 weeks in a specialist centre 30 minutes aerobic exercise on not intervention days
West et al. (2015)	6 weeks 3 a week	Aerobic interval training	1	The exercise training intensities were responsive to each individual CPET at week 0 and week 3	Bike. Cardiopulmonary exercise testing	Attend 40 minutes of aerobic interval training, 3 times a week for 6 weeks in hospital setting

	40 minutes	5 minutes unloaded cycling for warm up. 2-min exercise bouts at a vigorous intensity, interspersed with 3-min exercise bouts at a moderate intensity 5 minutes cool down Week 1 20 minutes week 2-6 30minutes			equipment, memory chip	
Winters-Stone et al. (2014; 2015)	12 months 3 each week 2 hosp, 1 home. 1 hr	Resistance exercises were all multijoint and emphasized movements common to activities of daily living, including wall-sits, squats, bent-knee dead lifts, multidirectional lunges, 1-arm row, chest press, lateral raise, and push-ups. Impact exercise, consisting of 50 two-footed jumps, was included to mechanically load the skeleton for bone outcomes Exercises at home were similar as in class sessions but performed without weighted vests and replacing weights with resistance bands	2	Not mentioned	Dumbbells, barbells, and weighted vests	Attend hospital resistance sessions of 1 hour duration twice a week whilst also completing 1 home based resistance session for a total of 12 months

Appendix E Element 1: Moderating factor of quality of delivery

	Who delivered the intervention	**Supporting material used.**	**Level of adherence reported**
Cheville et al. (2013)	Unsupervised at home except for initial introductory supervised session	Illustrated REST instruction manual, Five color-coded incremental resistance exercise bands, Perceived exertion rating scale, Calendar to log sessions and step counts, pocket pedometer, Bi monthly phone calls from therapists who gave initial session	76% based on unique frequency of training and progression of step count criteria
Cormie et al. (2013)	Supervised by accredited Exercise physiologist in exercise clinic	Treadmill or stationary cycle for warm up. Weight training equipment not listed	83% frequency including participants. 70% completed every session. 93% of sessions were completed correctly
	Encouraged to do additional 150 mins unsupervised aerobic exercise at home	No supporting material provided	Not measure
Headley, Ownby and John, (2004)	Unsupervised at home	Exercise video, Calendar to log sessions and intensities	75% overall adherence
Hwang et al. 2012	1-1 supervision of physical therapist in hospital	Treadmill or cycle-ergometer. Equipment to measure Heart rate (HR), blood pressure, and oxygen saturation. Cardiopulmonary exercise testing to determine exercise intensity	71% frequency including all participants
Jensen et al. (2014)	Resistance training group. Supervised in clinical facility but unclear who supervised	Bicycle ergometer. Equipment for resistance equipment not listed	72% Frequency including all participants
	Aerobic training group. Supervised in clinical facility but unclear who supervised	Bicycle ergometer. Heartrate monitoring	59% Frequency including all participants

Kuehr et al. (2014)	Exercise specialist for supervised sessions in hospital	Cycle ergometer. Treadmill. Monitoring or temperature, platelet counts and haemoglobin levels Stretch bands. Dumbbells. Illustrated training manual. Standardised diary to record session information. Visual analogue scale to assess relative health at start of session	95% frequency adherence using studies own definition
	Small number of hospital sessions and all home sessions were unsupervised	Weekly phone call Stretch bands. Dumbbells Illustrated training manual. Standardised diary to record session information. Visual analogue scale to assess relative health at start of session	77% Frequency adherence using studies own definition
Litterini et al. (2013)	Resistance training group supervised in hospital by physical therapist and personal trainers with 9 years' experience in exercise oncology	Aerobic equipment to warm up. 14 weight training machines. Leg press. Leg extension. Leg curl. Hip abduction. Hip adduction. Chest press. Lat pull down. Arm curl. Arm extension. Seated row. Overhead press. Lateral raise. Back extension. Adjustable hi-lo pulley	70% frequency adherence including all participants. Difference in adherence between the two groups was not reported
	Aerobic training group supervised in hospital by physical therapist and personal trainers with 9 years' experience in exercise oncology	Stationary recumbent bicycle, Upper body ergometer, Treadmill, Elliptical trainer, Nustep (TRS 4000) LifeGlider 3000, Olympic swimming pool. Oxygen saturation monitoring equipment	
Lowe et al. (2009)	Professional exercise therapist for home based resistance exercise	Ankle/wrist cuff weights. Resistance bands	87% frequency adherence using only participants who completed the study
	Unsupervised home-based walking sessions	None given	Not measured
Temel et al. (2009)	Supervised in hospital by senior physical therapist	Treadmill. Cycle ergometer. Equipment to monitor vital signs. Strength training equipment not listed	58% completed every session

Uth et al. (2014; 2016)	Supervised by an experienced soccer instructor at specialist football facility	Football training equipment, indoor and outdoor training facility. Polar electro heartrate monitors to wear during every training session	76.5% Week 0-12 46.2% Weeks 13-32. Frequency adherence using only participants who completed the study
van den Dungen et al. (2014)	Supervised in hospital by a physical therapist	Cycle ergometer. Polar breast band HR monitor. Resistance training equipment (type not specified)	65% completed every session. 85% completed 8 out of 12 sessions
	Unsupervised home-based aerobic component	None	Not measured
West et al. (2015)	Supervised in hopsital by health care professionals/exercise scientists	Electromagnetically braked cycle ergometer. Chip and pin card to control exercise intensity. Equipment for continuous cardiopulmonary exercise testing	96% frequency adherence including all participants
Winters-Stone et al. (2014; 2015)	2 supervised hospital-based sessions each week. Unclear who supervised	Dumbbells. Barbells. Weighted vests	83% (2014) 84% (2015)
	1 unsupervised home-based sessions each week	Resistance bands	43% (2014) 49% (2015)

Appendix F Element 2: MEDLINE search strategy developed from SPIDER search tool

No	Searches
	Sample: People With Advanced Cancer
1	(MH Neoplasms+)
2	cancer* OR tumo#r* OR neoplas* OR malignan* OR carcinoma* OR adenocarcinoma* OR choriocarcinoma* OR sarcoma* OR teratoma* OR oncolog*
3	1 OR 2
4	palliat* OR hospice* OR ((care OR ill* OR disease) N1 terminal*)
5	“end of life” OR “near death” OR “end stage*”
6	4 OR 5
7	3 and 6
8	(MH "Neoplasm Metastasis")
9	“terminal cancer*”

10	(advanced N3 cancer*)
11	(advanced N3 neoplas*)
12	metasta*
13	OR/8-12
14	7 OR 13
	Phenomenon of Interest: Experience of day to day life, COM-B, Disease and Treatment Burdens.
15	“life story” OR “life history” OR lifeworld OR life-world OR “living with” OR “perspective” OR “point of view” OR “personal experience*” OR “patient* view” OR (lived or life) N1 experience*
16	(MH "Behavior and Behavior Mechanisms+")
17	COM-B OR “COM B” OR ((behavio#r N1 (chang* or pattern*))
18	(MH motivation+)
19	motiv* OR desir* OR want* OR need* OR wish OR preference OR seek OR driv* OR incentive OR expectancy OR valu* OR valance OR reward* OR “self efficacy” OR self-efficacy OR habit OR attribut* OR goal*
20	(MH attitude to health+)
21	(MH attitude to death+)

22	capab* OR able OR abilit* OR “psychological capacity” OR “physical capacity” OR “patient capacity” OR “physical functioning” OR “mental functioning” OR “self care” OR selfcare OR self-care OR skills OR “internal factors” OR “brain processes” OR “thought processes” OR comprehension OR reasoning OR “cultural milieu” OR evaluations OR plans OR “automatic processes” OR “emotional respon*” OR emotion* OR “habitual process*” OR “decision making” OR “conscious decision making” OR “analytical decision making”
23	opportunity OR environment OR social OR society OR “external factors” OR “illness work” OR “everyday life work” OR “biographical work”
24	“work loads” OR “workloads” OR “work-loads” OR testing OR scheduling OR “attending appointments” OR transportation OR paperwork OR selfmanagement OR “self management” OR self-management
25	(MH "Stress, Physiological+")
26	(disease or treatment*) N1 (burden OR impact)
27	(MH Emotions+)
28	depres* OR distress* OR stress OR fear OR happy OR joy OR “social support” OR “social relationships” OR “social function” OR coping
29	Or/15-28 (all phenomena of interest)

30	14 and 29 (Gives people with advanced cancer and phenomenon of interest)
	Design:
31	(MH personal narratives)
32	interview* OR semi-structured OR semistructured OR “semi structured” OR unstructured OR un-structured OR informal OR in-depth OR indepth OR “in depth” OR “face-to-face” OR “key informant*”
33	account OR accounts OR unstructured OR “open ended” OR open-ended OR “open question*” OR text* OR narrative OR narrative analys#s*
34	questionnaire*
35	(guide OR structured) N1 (discussion* OR questionnaire*)
36	(MH focus groups+)
37	“focus group*” OR “group discussion*”
38	“direct observation*” OR “participant observ*” OR “observational method*” OR “observational approach*”
39	emic OR etic OR heuristic*
40	“field study” OR “field studies” OR “field research*” OR “field work*” OR fieldwork*
41	“case stud*”

42	“purposive sampl*” OR “theoretical sampl*” OR “cluster sampl*” OR “theoretical saturation” OR “data saturat*” OR theme* OR thematic* OR “content analys#s”
43	constant N1 (comparative OR comparison)
44	OR/31-43 All of design
	Evaluation: NA/covered in Phenomenon of Interest
	N/A
	Research:
45	(MH Qualitative Research+)
46	qualitative*
47	“mixed method*”
48	phenomenol*
49	“biographical method*” OR humanistic OR existential OR experiential
50	(MH grounded theory+)
51	grounded N (theor* OR study OR studies OR research OR analys#s)

52	(discourse* OR discurs*) N3 analys#s
53	“conversation analys#s”
54	ethnological OR “ethnological research” OR ethnograph* OR ethno-graph* OR meta-ethnograph* OR “meta ethnograph*” OR ethnonurs* OR ethno-nurs* OR “nursing methodology research”
55	“action research” OR “cooperative inquir*” OR “co operative inquir*” OR “co-operative inquir*”
56	(heidegger* OR colaizzi* OR speigelberg* OR “van manen*” OR “van kaam*” OR “merleau ponty*” OR Husserl* OR Giorgi* OR Foucault* OR “corbin* N2 strauss*” OR glaser*)
57	OR/45-56 All of research
58	44 AND 57 Design (E Not applicable A) AND Research
59	30 AND 58. Advanced cancer with phenomenon of interest, and qualitative studies.

Appendix G Element 2: Motivational themes in daily life and supporting evidence

Themes	Subthemes and evidence which contributed to the theme
Have Life	**Desire for cure:** *"Whenever I see boards where it is written that breast cancer is curable, it gives me strength and keeps me motivated that I will be fine".* (Banning and Tanzeen 2013) Supporting evidence can be found in (Banning and Tanzeen 2013; Carduff, Kendall and Murray, 2018; la Cour and Hansen, 2012; Lin 2008; hansen et al. 2015) **Prolongation of life:** *'No, do you see there is no cure for it but do you see, how long you can hold out is another day's work ... what is the longest that someone ever got?'* *(McCarthy and Dowling 2009)* Supporting evidence can be found in (Ekwall, Ternestedt and Sorbe, 2007; Ekwall et al. 2014; McCarthy and Dowling 2009; Lobb et al. 2015; Nissim et al. 2012; Reed and Corner 2015) **Fighting against the illness:** *''As long as I have this and as long as I can fight it, I will fight it, I'm not just going to give up.''* (Hansen et al. 2015)

	Supporting evidence can be found in (Carduff, Kendall and Murray, 2018; Devik et al. 2013; Ekwall, Ternestedt and Sorbe, 2007; Ekwall et al. 2014; Hansen et al. 2015; Haug et al. 2014; Sarenmalm et al. 2009; Sjövall et al. 2011) **Thoughts of family:** *“I don’t want to die now. I think, I feel, there’s so much left to do. I want to go on living and I want to watch my little grandchild grow up. I want to live with my family and my husband and my children”.* (Sarenmalm et al. 20009) Supporting evidence (Adorno and Brownell, 2014; Lin 2008; Missel and Birkland 2011; Sarenmalm et al. 2009) **Decisions around treatment:** *Example: ‘But sure, if you don’t get the treatment you are not going to last anyway, simple as that ... if you don’t keep it up you won’t stay going.’* (McCarthy and Dowling 2009) Supporting evidence can be found in (Adorno and Brownell, 2014; Carduff, Kendall and Murray, 2018; Ekwall, Ternestedt and Sorbe, 2007; Ekwall et al. 2014; Hansen et al. 2015; Haug et al. 2014; McCarthy and Dowling 2009; Nissim et al. 2012; Sarenmalm et al. 2009; Sjövall et al. 2011; Sparla et al. 2016; Sparla et al. 2017; Reed and Corner 2015) **Diminished the have life motive:** “It is torturous … thinking when I am going to die to escape from this suffering. But when I am not in pain, I want to live. When the symptoms disappear, I want to continue living, as I do not want to depart from my loved ones…. But when I suffer the symptoms, I again wish to die to escape the suffering.” (Nilmanat et al. 2010)

<table>
<tr><td></td><td>Supporting evidence can be found in (Hansen et al. 2015; la Cour, Johannessen and Josephsson, 2009; Nilmanat et al. 2010; Nissim et al. 2012; Sarenmalm et al. 2009)</td></tr>
<tr><td>Live Life</td><td>Thoughts of family:
<i>“Don’t you think that to live happily is better than to live stressfully? How lucky I am, living surrounded by love from my husband, nieces, and nephews. They all love me and I do love them, too. That’s all my life is for. Being stressful makes others worry about us, so let’s live life happily everyday”</i>
(Nilmanat et al. 2015)
Supporting evidence can be found in (Adorno and Brownell, 2014; Arber and Spencer, 2013; Carduff, Kendall and Murray, 2018; Ekwall, Ternestedt and Sorbe, 2007; Ekwall et al. 2014; Haug et al. 2014; Krigel et al. 2014; la Cour, Nordell and Josephsson, 2009; la Cour, Johannessen and Josephsson, 2009; la Cour and Hansen 2012; Nilmanat et al. 2015; Lin 2008; Lobb et al. 2015; McCarthy and Dowling 2009; Missel and Birkeland 2011; Nissim et al. 2012; Sarenmalm et al. 2009; Schapmire, Head and Faul, 2012; Shilling et al. 2017; Sjövall et al. 2011; Sparla et al. 2016; Sparla et al. 2017; Willig, 2015)
Maintaining / reclaiming normality:
<i>“… it takes me time after being in the hospital, to get back to what I call normal….I think for me now personally, the more normal things are for me the better it is for me. I love having normality.”</i>
(McCarthy and Dowling 2009)
Supporting evidence can be found in (Adorno and Brownell, 2014; Carduff, Kendall and Murray, 2018; Devik et al. 2013; Ekwall, Ternestedt and Sorbe, 2007; Haug et al. 2014; Krigel et al. 2014; la Cour, Nordell and Josephsson, 2009; la Cour, Johannessen and Josephsson, 2009; la Cour and Hansen 2012; Lin 2008; Lobb et al. 2015; McCarthy and Dowling 2009; Missel and Birkland 2011; Sarenmalm et al. 2009; Schapmire, Head and Faul, 2012; Shilling et al. 2017; Sjövall et al. 2011; Sparla et al. 2016; Sparla et al. 2017)</td></tr>
</table>

	Having a purpose: *"Alice tried to speak openly and confront others with her situation. She wanted to be seen as a role model for someone living with recurring ovarian cancer".* *(Ekwall et al. 2014)* Supporting evidence can be found in (Adorno and Brownell, 2014; Ekwall et al. 2014; Haug et al. 2014; Krigel et al. 2014; Lobb et al. 2015; Nissim et al. 2012) **Being active and healthy:** *"it's been so nice; I've rested and recovered. I've done something fun during the third week every time. Built myself up. You have to be active yourself; that's more clear when you have a recurrence".* (Ekwall et al. 2014) Supporting evidence can be found in (Ekwall, Ternestedt and Sorbe, 2007; Ekwall et al. 2014; Haug et al. 2014; la Cour, Johannessen and Josephsson, 2009; Lobb et al. 2015; Missel and Birkland 2011) **Daily activities:** *"Sweeping the driveway, I know it's stupid for me to do it [since it causes pain] but I also enjoy feeling, what shall I say, healthy and .. . capable of doing such chores"* *(la Cour, Johannessen and Josephsson, 2009)* Supporting evidence can be found in (la Cour, Nordell and Josephsson, 2009; la Cour, Johannessen and Josephsson, 2009; la Cour and Hansen 2012; Lin 2008; Peoples et al. 2017; Sarenmalm et al. 2009)

Exceptional events:

> *"What I think is most important is that afterwards my children, my husband, and my friends can say that it was fun after all, that it was really a great time. . . . Now tomorrow we are going to a party— I'm looking forward so much to being with our friends on the beach. There we are not going to talk about illness—we will have fun. My husband has taken the day off, and we are going to have red wine and that's how it should be!" (la Cour, Johannessen and Josephsson, 2009).*

Supporting evidence can be found in (Carduff, Kendall and Murray, 2018; Devik et al. 2013; Ekwall et al. 2014; Haug et al. 2014; la Cour, Nordell and Josephsson, 2009; la Cour, Johannessen and Josephsson, 2009; Peoples et al. 2017; Willig, 2015)

Make the most of time remaining:

> *"My days may be numbered, but I may as well make some good days out of them, instead of sitting in a corner and having bad days, right?"*
>
> *(la Cour, Nordell and Josephsson, 2009).*

Supporting evidence can be found in (Ekwall et al. 2014; Krigel et al. 2014; la Cour, Nordell and Josephsson, 2009; la Cour and Hansen 2012; Lobb et al. 2015; Missel and Birkeland 2011; Sarenmalm et al. 2009; Schapmire, Head and Faul, 2012: Sjövall et al. 2011)

Changing expectations and priorities:

> *'It makes you more aware of your mortality. It makes you more aware of the people around you. It makes you more aware of yourself. You know, maybe you think a little deeper than you used to. You realise what's even more important and what's less important.'*
>
> (Krigel et al. 2014)

Supporting evidence can be found in (Krigel et al. 2014; la Cour, Nordell and Josephsson, 2009; Nissim et al. 2012; Sarenmalm et al. 2009; Shilling et al. 2017; Sjövall et al. 2011; Willig, 2015)

Maintaining or gaining control:

> *Ivan is using complementary and alternative medicine involving a special diet, and this provided Ivan with a feeling of control and that he could do something positive to help himself, and helped him cope with the many uncertainties around his illness*
>
> (Arber and Spencer, 2013)

Supporting evidence can be found in (Arber and Spencer, 2013; Hansen et al. 2015; Krigel et al. 2014; Shilling et al. 2017)

Decisions around treatment:

> *"I really think taking chemo is an enormous risk; you are taking huge risks, all the time. It's like super gambling because you don't know what's going to happen and nobody knows what's going to happen".*
>
> (Nissim et al. 2012)

Supporting evidence can be found in (Adorno and Brownell, 2014; Arber and Spencer, 2013; Devik et al. 2013; Ekwall, Ternestedt and Sorbe, 2007; Ekwall et al. 2014; Hansen et al. 2015; McCarthy and Dowling 2009; Nissim et al. 2012; Reed and Corner 2015; Sjövall et al. 2011; Sparla et al. 2016; Sparla et al. 2017)

Preferences for how to die:

> *".well, everybody has to die and no one knows when or how, but now I know pretty much how; I'm afraid of it— getting so sick—hospital, unconscious, how sick I'm going to be"*
>
> (Sarenmalm et al. 2012)

	Supporting evidence can be found in (Carduff, Kendall and Murray, 2018; Lin 2008; Nissim et al. 2012; Sarenmalm et al. 2009) **Unable to live life:** *“There is nothing left for me to live for … I lost the dignity as a human being … I cannot [even] perform the greeting; arms and legs are completely weak. The disease has eaten my body up … nothing is left. If it [cancer] only ate only one [affected] side [of the body], it would be better than losing all [function]. Nowadays, my life is worth nothing … [I] cannot do anything.”* (Nilmanat et al. 2010) Supporting evidence can be found in (Haug et al. 2014; la Cour, Johannessen and Josephsson, 2009; la Cour and Hansen 2012; Lin 2008; Lobb et al. 2015; McCarthy and Dowling 2009; Nilmanat et al. 2010; Nissim et al. 2012; Shilling et al. 2017; Sparla 2016)
Beyond Life	**Helping others:** *“The possibility of helping others was perceived as an important secondary benefit of undergoing medical treatment, particularly clinical treatment trials. This potential altruistic benefit was experienced as personally meaningful and beneficial even if the treatment generated no other personal gain.* (Nissem et al. 2012) Supporting evidence can be found in (Ekwall et al. 2014; Haug et al. 2014; Nissim et al. 2012) **Concerns for family:** *“That’s the kind of thing you find yourself thinking. What’s going to happen? What’s going to happen to the others who will still be alive if I die? If I don’t get to go on living, how will they manage? Of course*

	they will manage, they're adults, but still you can't help thinking, they won't have a mom". (Sarenmalm et al. 2012) Supporting evidence can be found in (Adorno and Brownell, 2014; Arber and Spencer, 2013; Haug et al. 2014; Krigel et al. 2014; la Cour, Nordell and Josephsson, 2009; Lobb et al. 2015; Nissim et al. 2012; Sarenmalm et al. 2009; Shilling et al. 2017; Sjövall et al. 2011; Willig, 2015) **Being remembered:** *"I mean, the most important thing is for people to turn around when it's your time to move on and they say 'well, your dad was a gentleman"* (Carduff, Kendall and Murray, 2018) Supporting evidence can be found in (Carduff, Kendall and Murray, 2018; la Cour, Nordell and Josephsson, 2009; la Cour, Johannessen and Josephsson, 2009; la Cour and Hansen 2012; Nissim et al. 2012)

Appendix H Element 2: Physical factors likely to influence exercise capability

Physical factor identified	Number of studies	Studies
Pain	n=24	Adorno and Brownell, 2014; Arber and Spencer, 2013; Carduff, Kendall and Murray, 2018; Dehghan et al. 2012; Devik et al. 2013; Ekwall, Ternestedt and Sorbe, 2007; Hansen et al. 2015; Haug et al. 2014; la Cour, Nordell and Josephsson, 2009; la Cour, Johannessen and Josephsson, 2009; la Cour and Hansen, 2012; Lin, 2008; Lobb et al. 2015; Maree and Mulonda, 2015; McCarthy and Dowling, 2009; Missel and Birkelund, 2011; Nilmanat et al. 2010; Nilmanat et al. 2015; Nissim et al. 2012; Reed and Corner, 2015; Sarenmalm et al. 2009; Schapmire, Head and Faul, 2012; Sparla et al. 2016; Sparla et al. 2017
Fatigue	n=22	Adorno and Brownell, 2014; Arber and Spencer, 2013; Banning and Tanzeem, 2013; Carduff, Kendall and Murray, 2018; Devik et al. 2013; Ekwall et al. 2014; Hansen et al. 2015; Haug et al. 2014; Krigel et al. 2014; la Cour, Nordell and Josephsson, 2009; la Cour, Johannessen and Josephsson, 2009; Maree and Mulonda, 2015; McCarthy and Dowling, 2009; Missel and Birkelund, 2011; Nilmanat et al. 2010; Nissim et al. 2012; Peoples et al. 2017; Reed and Corner, 2015; Sarenmalm et al. 2009; Schapmire, Head and Faul, 2012; Shilling et al. 2017; Sparla et al. 2016
General deterioration	n=17	Adorno and Brownell, 2014; Carduff, Kendall and Murray, 2018; Devik et al. 2013; Ekwall et al. 2014; Haug et al. 2014; Krigel et al. 2014; la Cour, Johannessen and Josephsson, 2009; la Cour and Hansen, 2012; McCarthy and Dowling, 2009; Missel and Birkelund, 2011; Nilmanat et al. 2010; Peoples et al. 2017; Reed and Corner, 2015; Sarenmalm et al. 2009; Schapmire, Head and Faul, 2012; Sparla et al. 2016; Willig, 2015
Changes to appearance	n=11	Carduff, Kendall and Murray, 2018; Devik et al. 2013; Ekwall, Ternestedt and Sorbe, 2007; Ekwall et al. 2014; Krigel et al. 2014; la Cour, Johannessen and Josephsson, 2009; Maree and Mulonda, 2015; McCarthy and Dowling, 2009; Nilmanat et al. 2010; Sarenmalm et al. 2009; Schapmire, Head and Faul, 2012
Nausea and vomiting	n=9	Adorno and Brownell, 2014; Devik et al. 2013; Hansen et al. 2015; la Cour, Johannessen and Josephsson 2009; la Cour and Hansen, 2012; Maree and Mulonda, 2015; Missel and Birkelund, 2011; Nilmanat et al. 2010; Sarenmalm et al. 2009
Difficulties with eating	n=8	Adorno and Brownell, 2014; Devik et al. 2013; Hansen et al. 2015; Haug et al. 2014; la Cour and Hansen, 2012; Maree and Mulonda, 2015; Missel and Birkelund, 2011; Nilmanat et al. 2010
Bowel complications	n=7	Carduff, Kendall and Murray, 2018; Ekwall, Ternestedt and Sorbe, 2007; Hansen et al. 2015; Haug et al. 2014; la Cour, Nordell and Josephsson, 2009; Maree and Mulonda, 2015; Schapmire, Head and Faul, 2012

Breathlessness	n=6	Arber and Spencer, 2013; la Cour and Hansen, 2012; Maree and Mulonda, 2015; McCarthy and Dowling, 2009; Nilmanat et al. 2010; Reed and Corner, 2015
Co-morbidities and aging	n=5	Adorno and Brownell, 2014; Banning and Tanzeem, 2013; Devik et al. 2013; Haug et al. 2014; Maree and Mulonda, 2015
Diminished immune function	n=4	Ekwall et al. 2014; Haug et al. 2014; Nilmanat et al. 2010; Reed and Corner, 2015
Swelling	n=4	Carduff, Kendall and Murray, 2018; Hansen et al. 2015; la Cour and Hansen, 2012; Schapmire, Head and Faul, 2012
Cerebral symptoms	n=3	la Cour, Johannessen and Josephsson, 2009; Reed and Corner, 2015; Sarenmalm et al. 2009
Sleep difficulties	n=3	Adorno and Brownell, 2014; Arber and Spencer, 2013; Sarenmalm et al. 2009
Bleeding	n=2	Carduff, Kendall and Murray, 2018; Schapmire, Head and Faul, 2012
Bone fractures	n=1	Haug et al. 2014
Blured vision	n=1	Nilmanat et al. 2015
Dizziness	n=1	Adorno and Brownell, 2014
Hearing loss	n=1	Adorno and Brownell, 2014
Hot flushes	n=1	Sarenmalm et al. 2009
Organ failure	n=1	Ekwall et al. 2014
Poor balance	n=1	Adorno and Brownell, 2014
Sweating	n=1	Arber and Spencer, 2013

Appendix I Element 2: Psychological factors likely to influence exercise capability

Uncertainty	n=20	Arber and Spencer, 2013; Carduff, Kendall and Murray, 2018; Dehghan et al. 2012; Ekwall, Ternestedt and Sorbe, 2007; Hansen et al. 2015; Krigel et al. 2014; la Cour, Johannessen and Josephsson, 2009; Lin, 2008; Lobb et al. 2015; McCarthy and Dowling, 2009, Nilmanat et al. 2015; Nissim et al. 2012; Reed and Corner, 2015; Richardson et al. 2015; Sarenmalm et al. 2009; Schapmire, Head and Faul, 2012; Shilling et al. 2017; Sjöval et al. 2011; Sparla et al. 2017; Willig, 2015
Depression	n= 16	Adorno and Brownell, 2014; Arber and Spencer, 2013; Banning and Tanzeem, 2013; Dehghan et al. 2012; Hansen et al. 2015; Krigel et al. 2014; Maree and Mulonda, 2015; Missel and Birkelund, 2011; Nilmanat et al. 2010; Nilmanat et al. 2015; Nissim et al. 2012; Reed and Corner, 2015; Sarenmalm et al. 2009; Schapmire, Head and Faul, 2012; Sparla et al. 2016; Willig, 2015
Lowered view of self	n=16	Adorno and Brownell, 2014; Carduff, Kendall and Murray, 2018; Devik et al. 2013; Ekwall, Ternestedt and Sorbe, 2007; Ekwall et al. 2014; Krigel et al. 2014; la Cour, Johannessen and Josephsson, 2009; Maree and Mulonda, 2015; McCarthy and Dowling, 2009; Missel and Birkelund, 2011; Nilmanat et al. 2010; Reed and Corner, 2015; Sarenmalm et al. 2009; Schapmire, Head and Faul, 2012; Sjöval et al. 2011; Willig, 2015
Anxiety	n=14	Adorno and Brownell, 2014; Arber and Spencer, 2013; Dehghan et al. 2012; Krigel et al. 2014; Missel and Birkelund, 2011; Nilmanat et al. 2010; Reed and Corner, 2015; Richardson et al. 2015; Sarenmalm et al. 2009; Schapmire, Head and Faul, 2012; Shilling et al. 2017; Sjöval et al. 2011; Sparla et al. 2016; Willig, 2015
Fear	n=13	Banning and Tanzeem, 2013; Carduff, Kendall and Murray, 2018; Dehghan et al. 2012; Krigel et al. 2014; Lin 2008; Maree and Mulonda, 2015; Missel and Birkelund, 2011; Nissim et al. 2012; Nilmanat et al. 2010; Sarenmalm et al. 2009; Sjöval et al. 2011; Sparla et al. 2016; Schapmire, Head and Faul, 2012
Inability to project into the future	n=12	Adorno and Brownell, 2014; Arber and Spencer, 2013; Banning and Tanzeem, 2013; Carduff, Kendall and Murray, 2018; Ekwall, Ternestedt and Sorbe, 2007; Haug et al. 2014; Krigel et al. 2014; Nissim et al. 2012; Reed and Corner, 2015; Sarenmalm et al. 2009; Shilling et al. 2017; Willig, 2015
Hope	n=12	Banning and Tanzeem, 2013; Carduff, Kendall and Murray, 2018; Devik et al. 2013; Ekwall, Ternestedt and

		Sorbe, 2007; Haug et al. 2014; Krigel et al. 2014; Maree and Mulonda, 2015; Missel and Birkelund, 2011; Nilmanat et al. 2010; Nilmanat et al. 2015; Schapmire, Head and Faul, 2012; Sparla et al. 2017
Shock / disbelief / surprise / inability to comprehend	n=11	Arber and Spencer, 2013; Carduff, Kendall and Murray, 2018; Krigel et al. 2014; Lin, 2008; Lobb et al. 2015; Maree and Mulonda, 2015; Missel and Birkelund, 2011; Reed and Corner, 2015; Sarenmalm et al. 2009; Sjöval et al. 2011; Willig, 2015
Hopelessness / helplessness	n=9	Banning and Tanzeem, 2013; Dehghan et al. 2012; Lin, 2008; Hansen et al. 2015; Maree and Mulonda, 2015; Missel and Birkelund, 2011; Nilmanat et al. 2015; Sarenmalm et al. 2009; Willig, 2015
Loneliness / isolation	n=9	Dehghan et al. 2012; Devik et al. 2013; Ekwall, Ternestedt and Sorbe, 2007; Haug et al. 2014; Lin, 2008; Peoples et al. 2017; Sarenmalm et al. 2009; Schapmire, Head and Faul, 2012; Willig, 2015.
Despair	n=6	Arber and Spencer, 2013; Devik et al. 2013; Ekwall, Ternestedt and Sorbe, 2007; Missel and Birkelund, 2011; Sarenmalm et al. 2009; Willig, 2015
Anger	n=5	Arber and Spencer, 2013; Dehghan et al. 2012; Nilmanat et al. 2010; Sjöval et al. 2011; Willig, 2015
Concern	n=5	Banning and Tanzeem, 2013; Krigel et al. 2014; Nilmanat et al. 2010; Richardson et al. 2015; Shilling et al. 2017
Sadness / upset	n=5	Dehghan et al. 2012; Maree and Mulonda, 2015; Nilmanat et al. 2010; Peoples et al. 2017; Sarenmalm et al. 2009
Unfairness	n=5	Dehghan et al. 2012; la Cour, Johannessen and Josephsson, 2009; Sparla et al. 2017; Sjöval et al. 2011; Willig, 2015
Worry	n=5	Dehghan et al. 2012; la Cour, Nordell and Josephsson, 2009; Lobb et al. 2015; Maree and Mulonda, 2015; Sarenmalm et al. 2009
Acceptance	n=4	Nilmanat et al. 2015; Sarenmalm et al. 2009; Shilling et al. 2017; Sjöval et al. 2011
Joy / enjoyment	n=4	la Cour and Hansen, 2012; Nissim et al. 2012; Peoples et al. 2017; Sarenmalm et al. 2009
Strength	n=4	Ekwall, Ternestedt and Sorbe, 2007; Krigel et al. 2014; Sarenmalm et al. 2009; Schapmire, Head and Faul, 2012
Stress	n=4	Devik et al. 2013; Haug et al. 2014; Krigel et al. 2014; Nilmanat et al. 2010
Appreciation of life in the present	n=3	Nilmanat et al. 2015; Nissim et al. 2012; Sarenmalm et al. 2009

Complex psychological suffering	n=3	la Cour and Hansen, 2012; Lin 2008; Willig, 2015
Denial	n=3	Arber and Spencer, 2013; Lin 2008; Missel and Birkelund, 2011
Disappointment	n=3	Ekwall, Ternestedt and Sorbe, 2007; Sarenmalm et al. 2009; Schapmire, Head and Faul, 2012
Feeling of alienation	n=3	Ekwall, Ternestedt and Sorbe, 2007; Nilmanat et al. 2010; Sarenmalm et al. 2009
Frustrated	n=3	Richardson et al. 2015; Sarenmalm et al. 2009; Sjöval et al. 2011
General positive attitude	n=3	Banning and Tanzeem, 2013; Lin 2008; Sparla et al. 2017
Gratitude	n=3	Ekwall et al. 2014; Sarenmalm et al. 2009; Sjöval et al. 2011
Guilt	n=3	Lin, 2008; Maree and Mulonda, 2015; Sarenmalm et al. 2009
Happiness	n=3	Lin 2008; Nilmanat et al. 2015; Sarenmalm et al. 2009
Insecurity	n=3	Banning and Tanzeem, 2013; Ekwall, Ternestedt and Sorbe, 2007; Nilmanat et al. 2010
Lack of control	n=3	Arber and Spencer, 2013; Nilmanat et al. 2010; Willig, 2015
Low spirits / feeling down	n=3	Banning and Tanzeem, 2013; Missel and Birkelund, 2011; Sjöval et al. 2011
Loss	n=3	Lin, 2008; Sarenmalm et al. 2009; Willig, 2015
Meaning	n=3	Lin 2008; Sarenmalm et al. 2009; Willig, 2015
Overwhelmed	n=3	Missel and Birkelund, 2011; Sarenmalm et al. 2009; Willig, 2015
Pressured	n=3	Dehghan et al. 2012; Nilmanat et al. 2010; Sparla et al. 2016
Relaxed	n=3	Sarenmalm et al. 2009; Sparla et al. 2017; Willig, 2015
Relief or being at peace	n=3	Hansen et al. 2015; la Cour, Johannessen and Josephsson, 2009; Nilmanat et al. 2015

Traumatised	n=3	Banning and Tanzeem, 2013; Maree and Mulonda, 2015; Schapmire, Head and Faul, 2012
Unprepared	n=3	Lin, 2008; Reed and Corner, 2015; Sarenmalm et al. 2009
Certainty	n=2	Maree and Mulonda, 2015; Missel and Birkelund, 2011
Courage	n=2	Ekwall, Ternestedt and Sorbe, 2007; Lin, 2008
Desire to fight	n=2	Carduff, Kendall and Murray, 2018; Schapmire, Head and Faul, 2012
Devastated	n=2	Sarenmalm et al. 2009; Schapmire, Head and Faul, 2012
Feelings of being blessed	n=2	Nissim et al. 2012; Schapmire, Head and Faul, 2012
General feeling of pleasure	n=2	la Cour and Hansen; 2012, Sarenmalm et al. 2009
Grief	n=2	Sarenmalm et al. 2009; Sjöval et al. 2011
Irritable / lack of tolerance	n=2	Haug et al. 2014; Sjöval et al. 2011
Let down	n=2	Missel and Birkelund, 2011; Sarenmalm et al. 2009
“OK emotional state”	n=2	la Cour, Nordell and Josephsson, 2009; la Cour and Hansen, 2012
Powerlessness	n=2	Adorno and Brownell, 2014; Lin, 2008
Reassured	n=2	Banning and Tanzeem, 2013; Sarenmalm et al. 2009
Satisfied	n=2	Banning and Tanzeem, 2013; Schapmire, Head and Faul, 2012
Sorrow	n=2	Banning and Tanzeem, 2013; Sarenmalm et al. 2009
Trapped	n=2	Nilmanat et al. 2010; Willig, 2015
Unhappiness	n=2	Banning and Tanzeem, 2013; Missel and Birkelund, 2011
Abandonment	n=1	Dehghan et al. 2012

Boredom	n=1	Peoples et al. 2017
Cheerful	n=1	Nilmanat et al. 2015
Comforted	n=1	Schapmire, Head and Faul, 2012
Confused	n=1	Willig, 2015
Determined	n=1	Banning and Tanzeem, 2013
Disorientated	n=1	Willig, 2015
Dissatisfaction	n=1	la Cour, Nordell and Josephsson, 2009
Disturbed	n=1	Willig, 2015
Doubt	n=1	Missel and Birkelund, 2011
Endless sense of waiting	n=1	Sarenmalm et al. 2009
Euphoria	n=1	Willig, 2015
Fearlessness	n=1	Schapmire, Head and Faul, 2012
Fed up	n=1	McCarthy and Dowling, 2009
Feeling of being engaged in something positive	n=1	Haug et al. 2014
Feeling of being fortunate	n=1	Sarenmalm et al. 2009
Feeling of being left behind	n=1	Schapmire, Head and Faul, 2012

Feeling of being lost	n=1	Maree and Mulonda, 2015
Feeling of openness	n=1	Missel and Birkelund, 2011
Feeling of safety	n=1	Haug et al. 2014
Good mood	n=1	Haug et al. 2014
Humiliation	n=1	Nilmanat et al. 2010
Inability to cope	n=1	Sarenmalm et al. 2009
Incomprehension	n=1	Willig, 2015
Inner harmony	n=1	Sarenmalm et al. 2009
Inspired	n=1	Haug et al. 2014
Horror	n=1	Willig, 2015
Lack of value in life	n=1	Lin, 2008
Loss of innocence	n=1	Willig, 2015
Loss of meaning	n=1	Willig, 2015
Mental anguish	n=1	Dehghan et al. 2012
Mental torture	n=1	Maree and Mulonda, 2015
Moral distress	n=1	Lin, 2008
Non acceptance	n=1	Sjöval et al. 2011
No purpose	n=1	Adorno and Brownell, 2014
Optimistic	n=1	Schapmire, Head and Faul, 2012
Pleased	n=1	Sarenmalm et al. 2009
Psychological conflict	n=1	Lin, 2008

Psychological weakness	n=1	Willig, 2015
Psychologically wreck	n=1	Sarenmalm et al. 2009
Regret	n=1	Willig, 2015
Self-consciousness	n=1	Schapmire, Head and Faul, 2012
Tense	n=1	Sarenmalm et al. 2009
Threatened	n=1	Sarenmalm et al. 2009

Appendix J Element 3: EMBRACE patient information sheet

Exercise regiMens Before and duRing Advanced Cancer thErapy: (EMBRACE): A pilot study to investigate improvements in physical fitness resulting from an exercise training programme before and during chemotherapy in advanced lung cancer patients

Patient Information Sheet

We would like to invite you to take part in our research study, but firstly we would like to explain why this research is being done. This form should take about 20 minutes to read. Please contact us if there is anything that is unclear or if you have any questions.

Research Purpose

The main aim of the study is to find out if a tailored exercise training programme before and during chemotherapy is feasible and tolerable and can improve physical fitness in patients with advanced Non-Small-Cell Lung Cancer. In the future we aim to find out if exercise training can improve quality of life, physical activity levels and other outcomes including survival.

Patients with advanced lung cancer (where the cancer has spread to other parts of the body) can experience symptoms and side-effects from both the cancer itself and treatment that impact on quality of life. This can include tiredness and lack of energy or appetite. Exercise can help combat these symptoms and people with cancer are now generally advised to remain as physically active as they can both during and after treatment.

However, we don’t know much yet about the types of exercise patients might find most helpful. Some evidence suggests patients prefer mild forms of exercise they can do at home that links with their usual activities. Some specialists argue this is insufficient to improve the patient’s health and well-being. To learn more about this, we have designed an exercise programme which we want to test. Patients will start exercise shortly before starting chemotherapy. There will be a 4-week hospital-based structured exercise programme, followed by a transitional phase of 2-weeks, and finally a 6-week period of home-based exercise. The home exercised will be based around people’s usual activities and preferences The 2-week transitional period will accustom and support patients in moving their tailored in-hospital interval training to incorporating these training regimens into their home environment.

Who has reviewed the study?

The study has been reviewed and approved by South Yorkshire Research Ethics Committee.

Why have you received this invitation?

Patients, such as yourself, with advanced lung cancer are treated with chemotherapy. Chemotherapy can make patients feel tired and less fit. This may have a negative effect on treatment and on quality of life. We are inviting patients like you, who are about to start chemotherapy, to be in our study. We would like to try to improve fitness before, during, and after chemotherapy treatments.

Will my treatment be any different if I take part?

If you agree to take part in this study your cancer treatment will not be any different. If you are assigned to the exercise treatment group you will be asked to undergo a supervised and home-based exercise regime (up to 6 sessions prior to chemotherapy and 2 sessions per week for 6 weeks during hospital and home-based exercise training). Our exercise program will run alongside your treatment, and fit in with your routine visits as much as possible. This study will not cause any delays in your cancer treatment. If you are assigned to the control group you will not be given any exercise training. This study will not cause any delays in your cancer treatment.

Do I have to take part?

No. It is up to you to decide whether or not you should take part. If you decide to give us permission, we will give you this information sheet to keep and ask you to sign our consent form. Any one taking part can withdraw from the research project at any time and without having to give any reason. If you decide to withdraw or not take part, this will not affect the quality of care you receive whilst in hospital.

What will happen to me if I take part?

As part of this research project, recruited patients will be divided into a control and exercise intervention group. We would like to start by assessing your fitness objectively using a test called a ‘cardiopulmonary exercise test’ or CPET. This will involve a symptom limited Cardiopulmonary Exercise Tests (CPET) will be performed before the chemotherapy treatment begins. This test involves cycling on an exercise bike for 8-12 minutes, therefore we advise you to wear suitable clothes for exercising at all CPET appointments. The test will start with a very low resistance on the pedals then pedalling at 60 revolutions per minute. After 3 minutes of cycling, the resistance will gradually increase at a constant rate until you can no longer turn the pedals at the required speed. Your heart will be monitored by an electrocardiogram (ECG). You will be required to wear a soft rubber mask in order to continuously sample expired air with an online breath by breath gas analyser. This test is common practice prior to operations and provides an accurate measure of physical capacity. Each CPET appointment will last approximately one hour. Perceived exertion scores will be assessed at intervals for breathlessness and leg fatigue.

Cardiopulmonary Exercise Testing

This test will be repeated 5 times during chemotherapy at week Day 1 (baseline), and at week 3, 6, 9, and 12.

Patients who join the study will who are assigned to the exercise intervention group start a 12 week exercise program. For the first 4 weeks we will invite patients to exercise in hospital. We will do our best to schedule the exercise sessions to match up with other hospital visits. Patients will have their own sessions, rather than being part of a group. For the next two weeks only half the sessions will be in hospital: the rest will be at home. For the last 6 weeks, all exercise will take place at home. In total we will invite patients to perform up to 16 exercise sessions in hospital, and up to 14 at home. If patients do not feel like exercise on any day, then sessions can be cancelled or rescheduled.

The in-hospital exercise training will take place in a supervised, safe hospital environment, in our new exercise laboratory. Here our staff will help patients perform interval training. Interval training will be performed on an exercise bike, therefore we advise you to wear suitable clothes for exercising at all exercise training appointments.

The level of exercise will be individually tailored to each patient’s previous fitness levels, using the results from the CPET tests. Exercise training sessions will last 30-40 minutes. During exercise sessions patients will be monitored with heart rate and oxygen saturation monitors, to ensure only safe levels of exertion.

The control group will receive exercise advice only, both groups will be asked to perform all the tests at all time points discussed in the separate sections.

Questionnaires and interviews

As part of the research project we would also invite patients to complete four short quality of life questionnaires. These will be done at the start, and again after 6 and 12 weeks. These questionnaires are easy to fill in and will only take 20 minutes of your time.

We would like to find out what the study is like for people who take part in it. To do this we would like to interview people, either face to face or over the telephone, to ask about their experience of the study and ask about their thoughts and views of exercise in general. If you are in the exercise arm of the study we will invite you to be interviewed on two occasions. One interview would be in the third week of the study and the other interview when you finish. We would also like to give those who are in the exercise arm the opportunity to invite a family member or friend to participate in a separate interview to tell their views, at the end of the study, if they choose to do so. If you are in the control arm we would like to interview you at the end of the study to ask about your experience of the study and your thoughts and views about exercise in general. The interviews will be recorded and typed up word for word and then stored on a password protected hospital computer. This part of the study gives you an opportunity to tell what it was like for you to take part. It also gives you an opportunity be involved in helping change or improve the design of exercise interventions for participants in the future.

If you withdraw from the study you will be invited to participate in a semi-structured interview over the phone to give you the opportunity to share your views on the study if you choose to do so.

Blood and Urine Samples

As part of this research project, all patients recruited will have a blood and urine samples taken at baseline (day 1 Week 0 (intervention group only dependent on pre-chemo training sessions) and week 6 and 12 We will also take a small sample of blood after each CPET to assess for acute stress markers. We will use a small needle to take blood samples from a site at your arm. You may feel discomfort due to the needle stick and you may have bruising, bleeding or swelling at the blood site sample. You may feel faint and dizzy while your blood is being drawn and there is a slight risk of infection. A blood sample of 23mls will be taken before and 6mls after each CPET for biomarkers and genetic analysis of exercise induced stress. You will not be told the results of your blood test. A total of 87 ml of blood will be drawn from each patient over the whole study period (pre-exercise training, and at weeks 6 and 12) in both groups. All samples will be stored in appropriate facilities for further analysis.

The total blood sample required over the entire study course is considerably less than that taken during a single blood donation (450-500ml) and therefore does not present any risk to your health

We will also ask patients to provide urine (to explore fuel sources that are being used by the body) (for genetic testing) samples at Day 1, and at week 6 and 12.

Activity Monitoring

We are also interested in how much physical activity you typically do, and whether this changes with your treatment. Therefore on 5 occasions (prior to, during chemotherapy, 3, 6 9 and 12 weeks) we will ask you to wear an “accelerometer”, which is a small watch like device worn on the upper arm (fits underneath clothing). This will be worn on each occasion for a 3-day period (day and night). This unit will measure your typical physical activity levels and is unobtrusive. This will be fitted during the first CPET test and will be shuttled back and forth to you on all 5 occasions, to cause you the least amount of inconvenience.

Muscle Biopsies

In a subgroup of patients (12 patients; 6 in the intervention and 6 in the control group) we would also like to perform muscle biopsies to assess the affect of exercise and chemotherapy on peripheral muscles.

We are interested in muscle changes before and after chemotherapy and after exercise training. You will be asked to give 3 samples of muscle tissue (before, during and immediately after chemotherapy and the 12-week exercise training programme) which will be taken by trained members of staff from the outer part of you thigh muscle under local anaesthetic in a sterile manner. A small 1cm cut will be made in your skin and a small piece of muscle taken (100-150mg - around the size of a small pea). This will be painless, although the injection of the local anaesthetic is usually associated with local discomfort and a stinging sensation. After the sample is taken the wound is closed with one stitch. On the same appointment apart from the muscle biopsy we will also be taking a blood sample (10mls).

Muscle Ultrasound

We are interested in measuring the function and structure of your thigh muscle using ultrasound and strength measurements. These measurements will be taken at baseline (day 1 Week 0 (intervention group only dependent on pre-chemo training sessions) and week 6 and 12. For the ultrasound measurements a transducer is placed on your thigh. The image outlined on the monitor will allow us to measure your muscle structure.

What are the risks or side effects of taking part?

After exercising some people may feel achy or sore, but this should subside within a day or two. There is also a very small risk (1 in 10,000) associated with CPET of heart attacks or irregular heartbeat, but this is very rare and all CPET tests are performed in a safe hospital environment and your heart and lungs and all other vital signs are monitored during the CPET, The test will be stopped if there are any concerns for the your wellbeing.

The risks of taking a muscle sample include a slight risk of skin infection and very rarely a slight risk of damaging a small area of sensation around the site from where the muscle is taken. This usually recovers within a few weeks.

What if something goes wrong?

We have no reason to believe that anyone will come to any harm as a result of this research. If you are harmed by taking part in this research project, there are no special compensation arrangements. However, if you are harmed due to someone's negligence then you may have grounds for a legal action in the usual way. If you wish to complain about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms are available. Any complaint about the way you have been dealt with during the study or possible harm you might have suffered will be addressed. Please raise your concerns in the first instance with the Chief Investigator (that is the lead researcher) via [Name redacted] (Research Assistant) on [Telephone number redacted]. If you wish to make a more formal complaint, please contact the hospital's Patient Support Service (available 9 am to 4.30 pm Monday to Friday, out of hours there is an answer phone).

Patient Support Services
[Postal address redacted]

Email:
[Email address redacted]

Tel: [Telephone number redacted]

What will happen if I don't want to carry on with the study?

All patients in the study can withdraw from the research project at any time and without having to give any reason, with no impact on their future clinical care.

What will we do with the information?

Your personal information (name, address, diagnosis, date of birth etc.) associated with your test results will not be available to anyone outside your medical team. We expect that the data will be published in a medical journal to help doctors make decisions about patients in the future. All information will be anonymised; that is, all figures and numbers will not be traceable to individual patients and personal details (name etc.) will be removed. Your medical records may be accessed for research purposes by members of staff not directly part of the clinical care team.

The information collected will be held by the research team in an anonymous format. Hospital computers including laptops will be used by the clinical research team. These computers will be password protected and have the same security features as hospital computers. All manual files will be kept in a locked filing cabinet in a locked office

What will happen to any samples I give?

All samples will be encoded in order to ensure your identity is kept confidential. Only the investigator will hold the information to link the coding to the person. Samples will be kept frozen until analysis and then transferred to the trial tissue bank. With your permission these samples, a copy of the consent form and other information will be transferred to the trial tissue bank.

You will be given the option to consent for your blood and urine samples to be stored for use in future ethically approved studies. Also for a copy of your consent form and other information with your details on to be transferred to the trial tissue bank.

Involvement of the General Practitioner/Family doctor (GP)

With your permission we will inform your GP if you decide to take part in this trial.

Contact information

If you would like further information you should contact one of the research team by telephone or email below:

Lead Researcher – [Name redacted] [Email address redacted]

Consultant Oncologist- [Name redacted] [Email address redacted]

Telephone: [Telephone number redacted]

Appendix K Element 3: EMBRACE consent form

Consent Form for Patients Participating in:

Exercise regiMens Before and duRing Advanced Cancer thErapy (EMBRACE): A pilot study to investigate improvements in physical fitness resulting from an exercise training programme before and during chemotherapy in advanced lung cancer patients

Name of Researcher: ______________________ Please initial box

1. I confirm that I have read and understand the information sheet dated 08/02/2018 (version 7) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐

3. I understand that relevant sections of my medical notes and data collected during the study, Including scans generated during my care, may be looked at by individuals from the research team, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records and my scans. ☐

4a. I understand that I will be undertaking a series blood tests and urine samples in addition to the proposed exercise intervention study. ☐

4b. I understand that I will be undertaking a series muscle measurements including muscle biopsies, muscle ultrasound and strength tests in addition to the proposed exercise intervention study. ☐

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5a. I understand that I will be invited to take part in interviews that ask about my experience of participating in the study, and my views and opinions of exercise in general. I give permission for these interviews to be audio-taped and transcribed. ☐

5b. I understand that if randomised to the intervention arm I will be invited to select a family member or friend to be interviewed, at the end of the study, regarding their views on the study. ☐

6. I understand that information held by the NHS and records maintained by the NHS Information Centre and the NHS Central Register may be used to help contact me and provide information about my health status. I give permission for this information to be obtained and stored by the study research team to enable long term follow-up. ☐

7. I give permission for a sample of my blood, tissue and CT scan results to be used for future ethically approved studies. I give permission for these samples, a copy of this consent form and other information with my details on to be transferred to the trial tissue bank. ☐

8. I agree to my GP being informed of my participation in the study. ☐

9. I agree to take part in the above study. ☐

Part 2

If you wish to take part in the optional tissue collection study, please initial the following boxes. You do not need to give this permission if you do not wish to; you will still be able to take part in the main trial.

a. I give permission for samples of my blood and urine to be collected and stored for use in future ethically approved studies. ☐

b. I give permission for these samples, a copy of my consent form and other information with my details on to be transferred to the trial tissue bank. ☐

____________________ ____________________ ____________________

Name of Patient Date Signature

____________________ ____________________ ____________________

Name of Person taking consent Date Signature

Original *Informed Consent form to be filed in the Investigator Site File.* ☐

1 copy to be given to the patient ☐

1 copy to be filed in the patients hospital notes. ☐

Appendix L Element 3: EMBRACE family or friend information sheet

Exercise regiMens Before and duRing Advanced Cancer thErapy: (EMBRACE): A pilot study to investigate improvements in physical fitness resulting from an exercise training programme before and during chemotherapy in advanced lung cancer patients

Information Sheet (for family or friends interviews)

We would like to invite you to take part in our research study, but firstly we would like to explain why this research is being done. This form should take about 10 minutes to read. Please contact us if there is anything that is unclear or if you have any questions.

Research Purpose / Why have you received this invitation?

A family member or friend of yours has been participating in a trial called EMBRACE, which involves a 12-week exercise programme. We would like to understand more about what the exercise training is like, what participating in the study involves for people who take part in it, and what is involved for the people around them. As part of this, we are asking EMBRACE exercise participants to invite a close family member or friend to share their views, opinions, and experiences, of the exercise study from their perspective.

Who has reviewed the study?

The study has been reviewed and approved by South Yorkshire Research Ethics Committee.

Will treatment be any different if I take part?

If you agree to take part in the interviews your family member or friend’s cancer treatment will not be any different.

Do I have to take part?

No. It is up to you to decide whether or not you should take part. If you decide to give us permission, we will give you this information sheet to keep and ask you to sign our consent form. Anyone taking part can withdraw from the research project at any time and without having to give any reason. If you decide to withdraw or not take part, this will not affect the quality of care your family member or friend receives whilst in hospital.

What will happen to me if I take part?

If you agree to take part we would like to invite you to be interviewed at the end of the study. This interview can be either face to face at the hospital, or over the telephone. Whichever is most convenient for you. The interviews will be recorded and typed up word for word and then stored on a password protected hospital computer. This part of the study gives you an opportunity to tell us what it was like from your point of view. It also gives you an opportunity to be involved in helping to change or improve the design of exercise interventions for participants in the future.

If your family member / friend withdraws from the study you will still be invited to participate in a semi-structured interview over the phone to give you the opportunity to share your views on the exercise programme if you choose to do so.

What are the risks or side effects of taking part?

There are no known risks to taking part in these interviews.

What if something goes wrong?

We have no reason to believe that anyone will come to any harm as a result of this research. If you are harmed by taking part in this research project, there are no special compensation arrangements. However, if you are harmed due to someone’s negligence then you may have grounds for a legal action in the usual way. If you wish to complain about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms are available. Any complaint about the way you have been dealt with during the study or possible harm you might have suffered will be addressed. Please raise your concerns in the first instance with the Chief Investigator (that is the lead researcher) via [Name redacted] (Research Assistant) on [Telephone number redacted]. If you wish to make a more formal complaint, please contact the hospital’s Patient Support Service (available 9 am to 4.30 pm Monday to Friday, out of hours there is an answer phone).

Patient Support Services Email:

[Postal address redacted] [Email address redacted]

Tel: [Telephone number redacted]

What will happen if I don't want to carry on with the study?

All people in the study can withdraw from the research project at any time and without having to give any reason, with no impact on any future clinical care of yourself or your family member / friend.

What will we do with the information?

We expect that the data will be published in a medical journal to help doctors make decisions about patients in the future. All information will be anonymised; that is, all interview question answers will not be traceable to individual interviewees and personal details (name etc.) will be removed.

The information collected will be held by the research team in an anonymous format. Hospital computers including laptops will be used by the clinical research team. These computers will be password protected and have the same security features as hospital computers. All manual files will be kept in a locked filing cabinet in a locked office.

Contact information

If you would like further information you should contact one of the research team by telephone or email below:

Lead Researcher – [Name redacted] [Email address redacted]

Consultant Oncologist- [Name redacted] [Email address redacted]

Telephone: [Telephone number redacted]

Appendix M Element 3: EMBRACE family or friend consent form

Consent Form for Family / Friends interviewed about:

Exercise regiMens Before and duRing Advanced Cancer thErapy (EMBRACE): A pilot study to investigate improvements in physical fitness resulting from an exercise training programme before and during chemotherapy in advanced lung cancer patients

Name of Researcher: __________________________ Please initial box

1. I confirm that I have read and understand the information sheet for family / friends dated February 2018

(Version 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐

3. I understand that I will take part in an interview that asks about my views opinions and experience of the exercise study and of using exercise as part of cancer treatment. I give permission for these interviews to be audio-taped and transcribed. ☐

4. I agree to take part in the above study. ☐

Name of interviewee Date Signature

Name of Patient Date Signature

Name of Person taking consent Date Signature

Original *Informed Consent form to be filed in the Investigator Site File.* ☐

☐

1 copy to be given to the interviewee

Appendix N Element 3: EMBRACE study team information sheet

Exercise regiMens Before and duRing Advanced Cancer thErapy: (EMBRACE): A pilot study to investigate improvements in physical fitness resulting from an exercise training programme before and during chemotherapy in advanced lung cancer patients

Information Sheet (for study team interviews)

We would like to invite you to take part in an interview, but firstly we would like to explain why this research is being done. This form should take about 10 minutes to read. Please contact us if there is anything that is unclear or if you have any questions.

Research Purpose

The main purpose of this research is to systematically collate the knowledge and experience of the EMBRACE study team members to help answer the question; What aspects of the EMBRACE program promote or inhibit exercise adherence in this patient group?

Who has reviewed the study?

The study has been reviewed and approved by South Yorkshire Research Ethics Committee.

Why have you received this invitation?

We would like to understand more what the exercise training is like for people who take part in it, to try to better understand what promotes or inhibits exercise adherence for this patient group. A more complete understanding of a topic can be developed if it is investigated from multiple perspectives rather than from just one view point. Therefore, we would like to investigate the thoughts opinions and experiences of the intervention from the following groups; participants in the study, family members of those who take part in the exercise intervention, and members of the EMBRACE study team.

Do I have to take part?

No. It is up to you to decide whether or not you should take part. If you decide to give us permission, we will give you this information sheet to keep and ask you to sign our consent form. Any one taking part can withdraw from the research project at any time and without having to give any reason.

What will happen to me if I take part?

If you agree to take part we would like to invite you to be interviewed at a time convenient to you. This interview can be either face to face at the hospital, or over the telephone. Whichever is most convenient for you. The interviews will be recorded and typed up word for word and then stored on a password protected hospital computer. This part of the study gives you an opportunity to voice your thought opinions and experiences of the study and of exercise in general for patients. It also gives you an opportunity be involved in helping to change or improve the design of exercise interventions for participants in the future.

What are the risks or side effects of taking part?

There are no known risks to taking part in these interviews.

What if something goes wrong?

We have no reason to believe that anyone will come to any harm as a result of this research. If you are harmed by taking part in this research project, there are no special compensation arrangements. However, if you are harmed due to someone's negligence then you may have grounds for a legal action in the usual way. Any complaint about the way you have been dealt with during the interviews or possible harm you might have suffered will be addressed. Please raise your concerns with the Chief Investigator (that is the lead researcher) via [Name redacted] (Research Assistant) on [Telephone number redacted].

What will happen if I don't want to carry on with the study?

You can withdraw from the interviews at any time and without having to give any reason.

What will we do with the information?

Your personal information associated with your interview will not be available to anyone outside the study team. We expect that the data may be published in a medical journal and will contribute towards a PhD study investigating what can be done to help people with advanced cancer to exercise. All information will be anonymised; that is, all interview question answers will not be traceable to individuals and personal details (name etc.) will be removed.

The information collected will be held by the research team in an anonymous format. Hospital computers including laptops will be used by the clinical research team. These computers will be password protected and have the same security features as hospital computers. All manual files will be kept in a locked filing cabinet in a locked office.

Contact information

If you would like further information you should contact one of the research team by telephone or email below:

Lead Researcher – [Name redacted] [Email address redacted]

Consultant Oncologist- [Name redacted] [Email address redacted]

Telephone: [Telephone number redacted]

Interviewer- [Name redacted] [Email address redacted]

Appendix O Element 3: EMBRACE study team consent form

Consent Form for Study Team interviewed about

Exercise regiMens Before and duRing Advanced Cancer thErapy (EMBRACE): A pilot study to investigate improvements in physical fitness resulting from an exercise training programme before and during chemotherapy in advanced lung cancer patients

Name of Researcher: ______________________ Please initial box

1. I confirm that I have read and understand the information sheet dated 03/02/2018 (version 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. ☐

3. I understand that I will take part in an interview that ask about my views opinions and experiences of the EMBRACE trial, and of using exercise as a part of cancer treatment. I give permission for these interviews to be audio-taped and transcribed. ☐

4. I agree to take part in the above study. ☐

____________________	____________________	____________________
Name of interviewee	Date	Signature
____________________	____________________	____________________
Name of Person taking consent	Date	Signature

***Original** Informed Consent form to be filed in the Investigator Site File.* ☐

1 copy to be given to the participant ☐

Appendix PElement 3: MOVEMENT exercise participant invitation letter

Invitation letter for

Mixed-meth**o**d investigation of palliati**ve** care exercise: **M**ultiple perspectiv**e**s on adhere**n**ce and con**t**inuing exercise behaviour, in advanced cancer.

(MOVEMENT)

Dear {insert name here}

I would like to invite you to participate in a research study, called MOVEMENT, which aims to investigate the things that help, and the things that make it difficult for people with advanced cancer to exercise. It is hoped that finding these things out will help in the design of future exercise programmes for this patient group.

This research is being conducted by myself, Daniel Aze. I am a staff nurse at [Service name redacted] and Clinical Doctoral Research Fellow at the University of Southampton.

Participating in this research will involve partaking in two interviews. One when you are enrolled in the exercise classes at [Service name redacted] and one six weeks after the classes have finished.

The enclosed Participant Information Sheet contains more information about the study and what participation would involve.

If you would like to participate in the study please complete the reply slip provided and bring it to your next exercise class. On the reply slip please indicate a preferred time and date of the first interview and whether you would prefer the second interview to be face to face or via telephone. Please also indicate how you would like to be contacted to confirm the interview times, for example by telephone, email or letter, and please provide your relevant contact details to do this.

If you have any further questions, or if you would like to contact me directly to arrange your preferred time and date of the first interview, please contact me using the details on the other side of this page.

Thank you very much for taking the time to read this letter.

Sincerely

Daniel Aze

Contact details.

Telephone number	**[Telephone number redacted]**
Email address	**[Email Address redacted]**
Postal address	**[Postal address redacted]**

Appendix Q Element 3: MOVEMENT exercise participant information sheet

Mixed-method investigation of palliative care exercise: Multiple perspectives on adherence and continuing exercise behaviour, in advanced cancer.

(MOVEMENT)

Participant Information Sheet: for exercise class participants

Hello, my name is Daniel Aze I am a registered nurse and am studying for a PhD at the University of Southampton. I would like to invite you to take part in this research study, but first I would like to explain more about the study to help you decide if you would like to take part. This information sheet explains the reasons why this research is being done, what you can expect if you decide to take part and answers some commonly asked questions, it should take about ten minutes to read. Please contact me if there is anything that is unclear or you have any questions that you wish to ask.

Research Purpose

The main aim of this study is to investigate factors which inhibit or promote exercise in people who have advanced cancer.

An increasing number of studies are finding exercise to provide many benefits for people with advanced cancer which in turn can help to maintain independence and wellbeing.

However several studies have found that many people have difficulty adhering, or sticking to, the exercise programmes, and if people do not follow the programmes the expected benefits will be reduced.

The focus of this study is to investigate what it is like for people with advanced cancer to follow a regular programme of exercise, something which so far no other study has investigated. It is hoped this will identify things which make it more likely for a programme to be followed as well as things that make it less likely for a programme to be followed. We hope that in the future the information created from this study will be used to develop and improve new exercise programmes which participants are most likely to follow.

Who has reviewed the study?

This study will be reviewed by University Hospital Southampton Research and Development department, University of Southampton Faculty of Health Sciences, and a Research Ethics Committee determined through the Health Research Authority process. This is the normal process used for research like this, which has been designed by a PhD student at the University of Southampton with support and guidance from a supervisory team who have many years' experience in palliative care research.

Why have you received this invitation?

This study intends to investigate what doing exercise is like for people with advanced cancer. It is hoped to identify and explore factors that make it more likely for people to carry out exercise as well as factors that make it less likely or more difficult for people to carry out the exercise.

To do this we would like to speak to two different groups of people. Firstly people who have advanced cancer and are enrolled on an exercise class at [Service name redacted], this will allow us to find out the experiences, views, and opinions of exercise from the point of view of the people doing the exercise. Secondly we would also like to speak to any of the physiotherapists who have been involved in the design or delivery of the exercise classes at [Service name redacted], this is to bring together any experiences and knowledge they have gained from running these courses. The results we get from speaking to both groups will then be brought together to get a thorough understanding of what exercise is like in this patient group.

Will my participation in the exercise classes or any other treatment be any different if I take part in this study?

No. If you agree to take part in this study your participation in the exercise classes, or any treatment you receive for your condition will not be different in any way.

Do I have to take part?

No. It is up to you to decide whether or not you would like to and are able to take part. If you decide to not take part in the study or if you decide to take part in the study but later change your mind and withdraw, you can still take part in the exercise classes in exactly the same way as before and none of your other treatments will be affected in any way what so ever.

What will happen to me if I take part?

If you decide to take part, first of all we will ask you to sign a consent form which shows that you have understood what is involved in the study and that you agree to take part. We would like to interview you on two different occasions. The first interview will be conducted face to face in a private room, at a time when you are attending the [Name of centre redacted] Centre for your planned classes. This interview will ask you questions about your opinions and views of exercise as well as how you have found participating in the classes. This interview will happen only after you have completed at least two classes, to give you a chance to be more settled into the routine of attending the classes before being interviewed. The second interview will be conducted six weeks after your final exercise class. It can be conducted face to face like before or over the telephone. It will be conducted at a time, date and location agreed with you. The second interview will mainly concern your, experiences, views and opinions of any exercise or physical activity you do since finishing the [Service name redacted] exercise classes. Before we perform the second interview we will first contact your GP, to check that they feel you are fit to continue to take part. Anything you say in the interviews will be confidential and not passed on to those who deliver the classes. However, if you say something that indicates a risk of harm to yourself or others, the confidentiality will have to be breached and appropriate staff members will be informed. The things you tell us in the interviews will also be anonymised, meaning that when the study finishes and results are formed it will not be possible to link anything that was said to the person who said it. We would also like to collect some information from your clinical records held by the physiotherapists such as your age, gender, and medical condition. We expect each participants' involvement in the study to last about 8-10 weeks from interview one to interview two.

What will taking part in the interviews be like?

At the start of the interview we will ask you if you are still happy to be interviewed, to have it recorded and later for it to be typed up and saved on a computer. The interview will be like a conversation in which questions asked are intended to help you to talk about your views opinions and experiences of exercising whilst living with advanced cancer. We will ask questions about participating in the exercise classes at [Service name redacted] as well as about exercise in general. We will ask questions about what you have liked or not liked about exercise, what things make it harder to exercise and what things make it easier to exercise as well as the reasons you have for doing exercise.

It is expected for the interviews to take approximately 30-40 minutes each but ultimately you will be given time to say everything you want and you will decide when the interview finishes.

What are the benefits of taking part?

There are no direct benefits for people taking part in the study. However it is an opportunity for you to tell the story of what participating in the exercise classes at [Service name redacted] is like, and a chance to contribute towards improving services for others in the future.

What are the risks of taking part?

The risks from taking part in this study are minimal. All care will be taken by the interviewer to ensure the interview process is a comfortable discussion about your thoughts, views, opinions and experiences of exercise. However it is possible that interviews can produce strong emotional responses, such as anger and distress, as a result of thinking about topics in a deeper way than previously. If any part of the interview does cause you to become distressed you can pause the interview until a time when you wish to continue or stop the interview entirely if you choose to do so.

What if something goes wrong?

We have no reason to believe that anyone will come to any harm as a result of participating in this study. If you wish to complain about the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms are available. Any complaint about the way you have been dealt with during the study or possible harm you might have suffered will be addressed. Please raise any concerns you have about the study the first instance with senior physiotherapist [Name redacted] who will in turn pass this on to those conducting the study so as to make appropriate changes. If you wish to make a more formal complaint, please contact the hospital's Patient Support Service (available 9 am to 4.30 pm Monday to Friday, out of hours there is an answer phone).

Patient Support Services

[Postal address redacted]

Tel: [Telephone number redacted]

Email: [Email address redacted]

What will happen if I don't want to carry on with the study?

All participants in the study can withdraw from the research project at any time and without having to give any reason, with no impact on your participation in the exercise classes or on any future clinical care.

What will we do with the information from the interviews?

The interviews will be recorded on a digital audio recording device, commonly referred to as a Dictaphone, and typed up word for word. The information you give us in the interviews will be used as part of a PhD project called FIT-TOGETHER which is investigating what can help people with advanced cancer to exercise. The information collected in the interviews will be held in an anonymous format; that is, anything you say in the interview will not be traceable to individual participants and any personal details you say during the interview (name etc.) will be removed. When the study has finished results from the MOVEMENT study may be published in medical journals or presented at conferences for health care professionals, so that the results can help to inform other professionals who design or deliver exercise programmes to people with cancer. Publications and anonymised data relating to the research will be made available through the University of Southampton repository. Data collected in the study will be stored for 10 years in accordance with the University of Southampton research data management policy. If you would like to obtain a copy of any published results, please contact a member of the research team (contact details at the end of this information sheet). The findings may also be used by [Service name redacted] physiotherapy department to promote future classes. University of Southampton computers including laptops will be used to store the information collected. These computers will all be password protected and can only be accessed by MOVEMENT chief investigator Daniel Aze. All manual files will be kept in a locked filing cabinet in a locked office at the University of Southampton.

Contact information

Lead Researcher: [Name redacted]

Address:

[Postal address redacted]

Email: [Email address redacted]

Telephone: [Telephone number redacted]

Appendix R Element 3: MOVEMENT exercise participant invitation reply slip

Invitation reply slip for

Mixed-meth**o**d investigation of pallia**ti**v**e** care exercise: **M**ultiple perspectiv**e**s on adhere**n**ce and con**t**inuing exercise behaviour, in advanced cancer.

(MOVEMENT)

Dear {insert name here}

If you are interested in taking part in this study, and wish to be contacted either to ask further questions or to arrange the first interview, please tick the box on the right and hand this slip in at your next exercise class. Or alternatively, if you would prefer, please contact Daniel Aze directly using the details included in the invitation letter. ☐

If you wish to be contacted, in the box below please provide your preferred method to contact you. If you already know, please also indicate when you would like the first interview to take place, and whether you would like the second interview to be conducted over the telephone or face to face.

My preferred method to be contacted is: Telephone/Email/Postal letter. (Please circle)

My contact details are……….

The date and time I would like the first interview is………………..

Appendix S Element 3: MOVEMENT exercise participants consent form

Consent form for people participating in

Mixed-method investigation of palliative care exercise: Multiple perspectives on adherence and continuing exercise behaviour, in advanced cancer.

(MOVEMENT)

Study Number:

Patient Information Number:

Name of Researcher: ____________________________

Please add your initials to the box after each statement, if you agree with it.

1. I confirm that I have read and understand the information sheet for exercise class participants dated 11th May 2018 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐

3. I understand that I will be invited to take part in two interviews. One face to face interview that asks about my experience of participating in the exercise classes, and another interview 6 weeks after the last exercise class, that asks about my experiences of exercise after the classes have completed. ☐

4. I understand that my GP will be contacted prior to the second interview to check that they feel I am fit to continue to take part. ☐

5. I understand that the person conducting the interviews has a duty of care towards me, and therefore if I say anything that indicates a risk to myself or others, the relevant healthcare professionals will be informed. ☐

6. I give permission for these interviews to be recorded on a digital audio recording device and typed up onto a password protected University of Southampton computer. ☐

7. I understand and give permission for my telephone number, which is held by the [Service name redacted] physiotherapists, to be used to contact me for the second interview. ☐

8. I understand that information I give in the interviews will be used as part of a PhD study investigating what can be done to help people with advanced cancer to exercise, and may be used in published medical journals, presentations to other medical professionals, or , to promote the exercise classes at [Service name redacted]. I understand that if the information I give in the interviews is used for any of the previously mentioned uses, my name will be changed to a pseudonym to maintain the confidentiality of anything I say. ☐

9. If anything were to happen between the two interview times which prevents me from partaking in the second interview I wish for my first interview recording to remain included in the study as I originaly intended. I understand however this does not effect my right to ask for any of my data to be removed from the study at any point should I wish to do so. ☐

10. I agree to take part in the above study. ☐

<u>Name of participant</u>	<u>Date</u>	<u>Signature</u>
<u>Name of person taking consent</u>	<u>Date</u>	<u>Signature</u>

Appendix T Element 3: MOVEMENT healthcare professional information sheet

Mixed-method investigation of palliative care exercise: Multiple perspectives on adherence and continuing exercise behaviour, in advanced cancer.

(MOVEMENT)

Participant Information Sheet: for physiotherapists

Hello, my name is Daniel Aze I am a registered nurse and am studying for a PhD at the University of Southampton. I would like to invite you to take part in this research study, but first I would like to explain more about the study to help you decide if you would like to take part. This information sheet explains the reasons why this research is being done, what you can expect if you decide to take part and answers some commonly asked questions, it should take about ten minutes to read. Please contact me if there is anything that is unclear or you have any questions that you wish to ask.

Research Purpose

The main aim of this study is to investigate factors which inhibit or promote exercise in people who have advanced cancer.

An increasing number of studies are finding exercise to provide many benefits for people with advanced cancer which in turn can help to maintain independence and wellbeing. However several studies have found that many people have difficulty adhering, or sticking to, the exercise programmes, and if people do not follow the programmes the expected benefits will be reduced.

The focus of this study is to investigate what it is like for people with advanced cancer to follow a regular programme of exercise, something which so far no other study has investigated. It is hoped this will identify things which make it more likely for a programme to be followed as well as things that make is less likely for a programme to be followed. We hope that in the future the information created from this study will be used to develop and improve new exercise programmes which participants are most likely to follow.

Who has reviewed the study?

This study will be reviewed by University Hospital Southampton Research and Development department, University of Southampton Faculty of Health Sciences, and a Research Ethics Committee determined through the Health Research Authority process. This is the normal process used for research like this, which has been designed by a PhD student at the University of Southampton with support and guidance from a supervisory team who have many years' experience in palliative care research.

Why have you received this invitation?

This study intends to investigate what doing exercise is like for people with advanced cancer. It is hoped to identify and explore factors that make it more likely for people to carry out exercise as well as factors that make it less likely or more difficult for people to carry out the exercise.

To do this we would like to speak to two different groups of people. Firstly people who have advanced cancer and are enrolled on an exercise class at [Service name redacted], this will allow us to find out the experiences, views, and opinions of exercise from the point of view of the people doing the exercise. Secondly we would also like to speak to any of the physiotherapists who have been involved in the design or delivery of the exercise classes at [Service name redacted], this is to bring together any experiences and knowledge they have gained from running these courses. The results we get from speaking to both groups will then be brought together to get a thorough understanding of what exercise is like in this patient group.

Do I have to take part?

No. It is up to you to decide whether or not you would like to and are able to take part. If you decide to not take part in the study or if you decide to take part in the study but later change your mind and withdraw, it will not effect your working role in any way.

What will happen to me if I take part?

If you decide to take part, first of all we will ask you to sign a consent form which shows that you have understood what is involved in the study and that you agree to take part. We would like to interview you on one occasion. The interview will be conducted face to face in a private room, at in the [Name of centre redacted] Centre at a time of your choosing. This interview will ask you questions about your opinions and views and experiences of using exercise as a therapeutic tool for people with advanced cancer. Anything you say in the interviews will be confidential and not passed on to other members of the physiotherapy team. Anything you tell us in the interviews will be anonymised, meaning that when the study finishes and results are formed it will not be possible to link anything that was said to the person who said it. We expect the whole study to take approximately one year from the very first interview we record to when the overall results will be completed. If you wish, we can send you a copy of the overall results when they are ready.

What will taking part in the interviews be like?

At the start of the interview we will ask you if you are still happy to be interviewed, to have it recorded and later for it to be typed up and saved on a computer. The interview will be like a conversation in which questions asked are intended to help you to talk about your views opinions and experiences of using exercise as a therapeutic tool for people with advanced cancer. We will ask questions about your experiences of the exercise classes at [Service name redacted] as well as about exercise in general for this patient group. We will ask questions about what you think patients have liked or not liked about exercise, what things in your experience make it harder for them to exercise and what things make it easier for them to exercise. It is expected for the interviews to take approximately 30-40 minutes each but ultimately you will be given time to say everything you want and you will decide when the interview finishes.

What are the benefits of taking part?

There are no direct benefits for people taking part in the study. However it is an opportunity for you to tell the story of what the exercise classes at [Service name redacted] are like from the point of view of those who design or deliver them, and a chance to contribute towards improving services for others in the future.

What are the risks of taking part?

The risks from taking part in this study are minimal. All care will be taken by the interviewer to ensure the interview process is a comfortable discussion about your thoughts, views, opinions and experiences of exercise for this patient group. However it is possible that interviews can produce strong emotional responses, such as anger and distress, as a result of thinking about topics in a deeper way than previously. If any part of the interview does cause you to become distressed you can pause the interview until a time when you wish to continue or stop the interview entirely if you choose to do so.

What if something goes wrong?

We have no reason to believe that anyone will come to any harm as a result of participating in this study. If you wish to complain about the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms are available. Any complaint about the way you have been dealt with during the study or possible harm you might have suffered will be addressed. Please raise any concerns you have about the study the first instance with senior physiotherapist [Name redacted] who will in turn pass this on to those conducting the study so as to make appropriate changes. If you wish to make a more formal complaint, please contact [Name redacted], Research Integrity and Governance Manager, University of Southampton telephone: [Telephone number redacted] or email: [Email address redacted].

What will happen if I don’t want to carry on with the study?

If you do not wish to continue with the study you can withdraw from the research project at any time and have your interview removed from the analysis without having to give any reason, with no impact on your working role.

What will we do with the information from the interviews?

The interviews will be recorded on a digital audio recording device, commonly referred to as a Dictaphone, and typed up word for word. The information you give us in the interviews will be used as part of a PhD project called FIT-TOGETHER which is investigating what can help people with advanced cancer to exercise. The information collected in the interviews will be held in an anonymous format; that is, anything you say in the interview will not be traceable to individual participants and any personal details you say during the interview (name etc.) will be removed. However, in small specialist teams such as the [Service name redacted] Physiotherapy team maintaining anonymity can be problematic particularly if a person's views are already well known amongst their peers. To minimise this risk the site will not be named in any, public facing, study publication used by the research team. Results from the MOVEMENT study may be published in medical journals or presented at conferences for health care professionals, so that the results can help to inform other professionals who design or deliver exercise programmes to people with cancer. The findings may also be used by [Service name redacted] physiotherapy department to promote future classes. University of Southampton computers including laptops will be used to store the information collected. These computers will all be password protected and can only be accessed by MOVEMENT chief investigator Daniel Aze. All manual files will be kept in a locked filing cabinet in a locked office at the University of Southampton.

Contact information

Lead Researcher: [Name redacted]

Email: [Email address redacted]

Telephone: [Telephone number redacted]

Appendix U Element 3: MOVEMENT healthcare professional consent form

Consent form for physiotherapists participating in

Mixed-method investigation of palliative care exercise: Multiple perspectives on adherence and continuing exercise behaviour, in advanced cancer.

(MOVEMENT)

Study Number:

Patient Information Number:

Name of Researcher: ____________________________

1. I confirm that I have read and understand the information sheet for physiotherapists dated 31st January 2018 (version 1) for the above study. I have had the opportunity to consider the information,ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any timewithout giving any reason, without my medical care or legal rights being affected. ☐

3. I understand that I will be invited to take part in one face to face interview that asks about my views, opinions and experiences designing and delivering therapeutic exercise for people with advanced cancer. ☐

4. I give permission for these interviews to be recorded on a digital audio recording device and typed up onto a password protected University of Southampton computer. ☐

5. I understand that information I give in the interviews will be used as part of a PhD study investigating what can be done to help people with advanced cancer to exercise, and may be used in published medical journals, presentations to other medical professionals, or, to promote the exercise ☐

classes at [Service name redacted]. I understand that if the information I give in the interviews is used for any of the previously mentioned uses, my name will be changed to a pseudonym to maintain the confidentiality of anything I say.

6. I agree to take part in the above study. ☐

<u>Name of participant</u>	<u>Date</u>	<u>Signature</u>
<u>Name of person taking consent</u>	<u>Date</u>	<u>Signature</u>

Appendix V Element 3: EMBRACE exercise participant interview guide T1

Intervention Arm Week 3 interview

Discuss consent and confidentiality

- Re-confirm consent verbally (emphasise confidentiality, but explain if they say anything which suggests they are at risk of harm or danger, these concerns will be escalated to the clinical study team).
- Check interviewee is happy for interview to be audio-recorded and transcribed word for word.
- Ask if they have any questions or concerns before proceeding.

Purpose of the interview

- We are here today to talk a bit about how you are finding the EMBRACE programme. What your thoughts and opinions are of it, and anything that you think should be changed in the future. It is important to remember there are no right and wrong answers to these questions it is just about how you have felt being part of this study so far.

Confirm time point

- Can you tell me how many weeks you have been doing the intervention?

Questions

1. Please can you describe your overall thoughts and feelings about participating in the EMBRACE programme so far?

2. Please can you tell me about your past experiences of exercise? Both before and after your diagnosis.

3. Can you tell me what your expectations or reasons are for participating in this study?

4. Can you tell us anything you have liked, and not liked about participating in the exercise programme so far?

5. It is quite common for people to experience difficulties keeping to an exercise programme and people may miss or not fully complete a session/s. Did you experience any difficulties at all completing this programme? If so, can you explain what the difficulties were?

Summary

Before we finish I would like to give you the opportunity to say anything else that you feel is important about your experience of participating in this study so far?

Appendix W Element 3: EMBRACE exercise participant interview guide T2 / end of study

Intervention Arm End of study interview

Discuss consent and confidentiality

- Re-confirm consent verbally (emphasise confidentiality, but explain if they say anything which suggests they are at risk of harm or danger, these concerns will be escalated to the clinical study team).
- Check interviewee is happy for interview to be audio-recorded and transcribed word for word.
- Ask if they have any questions or concerns before proceeding.

Purpose of the interview

- We are here today to talk about how you found participating in the EMBRACE programme. What your thoughts and opinions are of it, and anything that you think should be changed in the future. It is important to remember there are no right and wrong answers to these questions it is just about how you felt being part of the study.

Confirm time point

- Can you tell me for how many weeks you have done the intervention?

Questions

If the participant finished the intervention before week 12 please start at question 1. If the participant finished at week 12 please start at question 2.

1. Please can you explain the main reason or reasons for finishing the exercise programme when you did?

2. Please can you describe your overall thoughts and feelings about participating in the EMBRACE programme?

3. In the previous interview we spoke about your expectations or reasons for participating in the study. Did the study meet your expectations or reasons for participating? Please explain.

4. Can you tell us anything you liked, and did not like about participating in the exercise programme?

5. It is quite common for people to experience difficulties keeping to an exercise programme and people may miss or not fully complete a session/s. Did you experience any difficulties at all completing this programme? If so, can you explain what the difficulties were?

Summary

Thank you very much for your time and for taking part in this study. Before we finish is there anything else that you feel is important to say about your experience of participating in this study or for the future development of this exercise programme?

Appendix X Element 3: EMBRACE family or friend interview guide

EMBRACE interview guide (Participant Family or Friend).

Discuss consent and confidentiality

- Read through consent form (emphasise confidentiality, but explain if they say anything which suggests their partners or themselves are at risk of harm or danger these concerns will be escalated to the clinical study team).
- Check interviewee is willing for interview to be audio-recorded and transcribed verbatim.
- Ask the interviewee whether he or she has any questions or concerns before proceeding.
- Gain written consent.

Purpose of the interview

- We are here today to talk about your thought opinions and experiences of the EMBRACE study. It is important to remember there are no right and wrong answers to these questions. It is just about your thoughts, your opinions, and your experiences.

Questions

- Please can you describe your overall thoughts and feelings about the EMBRACE programme?

- Can you tell me what your hopes or expectations of the EMBRACE programme were when you first heard about it?

- Did you have to do anything differently yourself to enable or help your friend/relative/partner to participate in the trial?

- Can you tell us anything you particularly liked, and did not like about the exercise programme?

- It is quite common or normal for people to have difficulties sticking to an exercise programme and people may miss a session or not finish the whole session, it is certainly nothing people should feel embarrassed about if this happens. Are you aware of your friend/relative/partner having any difficulties sticking to this programme? If so, can you talk about the things that have made it difficult and whether anything helped overcome those difficulties?

Thank you very much for your time and for taking part in this study. Before we finish is there anything else that you feel is important to say about your experience of this study, or for the future development of this exercise programme?

Appendix Y Element 3: EMBRACE control group interview guide

EMBRACE interview guide (Control Group).

Discuss consent and confidentiality

- Re-confirm consent verbally (emphasise confidentiality, but explain if they say anything which suggests they are at risk of harm or danger, these concerns will be escalated to the clinical study team).
- Check interviewee is willing for interview to be audio-recorded and transcribed verbatim.
- Ask the participant whether he or she has any questions or concerns before proceeding.

Purpose of the interview

- We are here today to talk about how you found being part of the control group in the EMBRACE study, as well as your thoughts, opinions and experiences of exercise in general. It is important to remember there are no right and wrong answers to the questions, it is just about your thoughts, your opinions, and your experiences.

Questions

- Please can you explain the main reason for joining the study?
- Please can you describe your overall thoughts and feelings about being in the control group of the study?
- Can you please tell me about your experiences of exercise before joining the study?
- Can you tell me about whether you did any regular exercise or physical activity during the study period? If so what did you do, what difficulties did you experience and did you find any ways to overcome those difficulties?

Thank you very much for your time and for taking part in this study. Before we finish is there anything else that you feel is important to say about your experience of participating in this study, or for the future development of exercise programmes designed for people with conditions like yours?

Appendix Z Element 3: EMBRACE study team interview guide

EMBRACE interview guide (Study Team).

Discuss consent and confidentiality

- Read through consent form (emphasise confidentiality, but explain if they say anything which suggests anyone is at risk of harm or danger these concerns will be escalated to the clinical study team).
- Check interviewee is willing for interview to be audio-recorded and transcribed verbatim.
- Ask the interviewee whether he or she has any questions or concerns before proceeding.
- Gain written consent.

Purpose of the interview

- We are here today to talk about the EMBRACE trial, your experience of delivering exercise sessions as a part of cancer treatment, and your thoughts on factors which may influence adherence to exercise in this patient group.

Questions

- From your experience, what do you think is the most important thing to consider when trying to maximise exercise adherence in this patient group?

- Did participants on the trial ever share with you what they particularly liked or did not like about any aspect of the study?

- Did participants ever share with you any challenges they had experienced during the hospital based stage of the trial?

- Did participants ever share with you any challenges they had experienced during the home based stage of the trial?

- Did participants ever share with you any strategies they devised to help overcome the challenges they experienced?

- During the study did you notice any patterns or trends in those participants who you feel adhered to the intervention particularly closely, and may be worth further investigation?

- Lastly, is there anything else you have learnt from the EMBRACE study, or other experiences you have had, that you feel is important for people to consider when designing exercise interventions for people with advanced cancer in the future?

Thank you for your time, it is very much appreciated.

Appendix AA Element 3: MOVEMENT exercise participants interview guide T1

Participant T1.

Discuss consent and confidentiality

- Ensure written consent is obtained. If written consent has been obtained previously re-check consent verbally (emphasise confidentiality, but explain if they say anything which suggests they are at risk of harm or danger, these concerns will be escalated to the therapy team).
- Check interviewee is happy for interview to be audio-recorded and transcribed word for word.
- Ask if they have any questions or concerns before proceeding.

Purpose of the interview -

- We are here today to talk a bit about how you are finding the [Name of centre redacted] exercise class. What your thoughts and opinions are of it? What has worked well, what has worked less well and anything that you think should be changed in the future? It is important to remember there are no right and wrong answers to these questions it is just about how you have felt participating so far.

Confirm class and time point

Confirm whether the participant is in the chairs class or the circuits class, and how many weeks they have been participating for?

Questions

Q1) Please can you describe your overall thoughts and feelings about participating in the exercise class so far?

Q2) Please can you tell me about your previous experiences of exercise? Both before and after your diagnosis.

Q3) Can you tell me what your expectations or reasons are for participating in these classes?

Q4) Can you tell me about anything you have liked, and not liked about participating in the classes so far?

Q5) Can you tell me about any other exercise or physical activity that you do outside of these classes?

It is quite common for people to experience difficulties keeping to an exercise programme and people may miss or do not fully complete a session/s. This next section explores any factors that you think may have prevented or made it more difficult for you to follow the exercise class. This section shall contain 12 statements from a scale called the Problematic Experiences of Therapy Scale (PETS) (Yardley and Kirby, 2006). I will ask you to say how much you agree or disagree with each statement. After each statement we would also like you to explain the reason for your answer, including what is was that prevented or made it difficult to exercise and anything you were able to do to counteract or minimise its impact.

PETS.1) I had to skip the exercise because it made my symptoms worse.
Agree Strongly, Agree Slightly, Not Sure, Disagree Slightly, Disagree Strongly.

Please explain the reason for your answer.
Please describe anything you found or did that helped or improved this.

PETS.2) I was prevented from carrying out the exercise by severe symptoms.
Agree Strongly, Agree Slightly, Not Sure, Disagree Slightly, Disagree Strongly.

Please explain the reason for your answer.
Please describe anything you found or did that helped or improved this.

PETS.3) I could not carry out the exercise because it caused more symptoms.
Agree Strongly, Agree Slightly, Not Sure, Disagree Slightly, Disagree Strongly.

Please explain the reason for your answer.
Please describe anything you found or did that helped or improved this.

PETS.4) I could not carry out the exercise because I was unsure how to do it properly.
Agree Strongly, Agree Slightly, Not Sure, Disagree Slightly, Disagree Strongly.

Please explain the reason for your answer.
Please describe anything you found or did that helped or improved this.

PETS.5) I was unable to carry out the exercise because it was difficult to know what to do.
Agree Strongly, Agree Slightly, Not Sure, Disagree Slightly, Disagree Strongly.

Please explain the reason for your answer.
Please describe anything you found or did that helped or improved this.

PETS.6) I skipped the exercise because I was not sure if it was helping.
Agree Strongly, Agree Slightly, Not Sure, Disagree Slightly, Disagree Strongly.

Please explain the reason for your answer.
Please describe anything you found or did that helped or improved this.

PETS.7) I skipped the exercise because it did not seem relevant to my symptoms and problems.
Agree Strongly, Agree Slightly, Not Sure, Disagree Slightly, Disagree Strongly.

Please explain the reason for your answer.
Please describe anything you found or did that helped or improved this.

PETS.8) I did not carry out the exercise because I was not convinced it was right for me.
Agree Strongly, Agree Slightly, Not Sure, Disagree Slightly, Disagree Strongly.

Please explain the reason for your answer.
Please describe anything you found or did that helped or improved this.

PETS.9) Lack of time prevented me from carrying out the exercise.
Agree Strongly, Agree Slightly, Not Sure, Disagree Slightly, Disagree Strongly.

Please explain the reason for your answer.
Please describe anything you found or did that helped or improved this.

PETS.10) It was not possible to find suitable opportunities to carry out the exercise.
Agree Strongly, Agree Slightly, Not Sure, Disagree Slightly, Disagree Strongly.

Please explain the reason for your answer.
Please describe anything you found or did that helped or improved this.

PETS.11) I was too busy or tired to carry out the exercise.
Agree Strongly, Agree Slightly, Not Sure, Disagree Slightly, Disagree Strongly.

Please explain the reason for your answer.
Please describe anything you found or did that helped or improved this.

PETS.12) I found it difficult to remember to carry out the exercise.
Agree Strongly, Agree Slightly, Not Sure, Disagree Slightly, Disagree Strongly.

Please explain the reason for your answer.
Please describe anything you found or did that helped or improved this.

These next questions will ask you about some other things, which people with a condition such as yours, have suggested might impact their ability to follow exercise programmes. We will ask you whether in your experience these things did impact your ability to follow the exercise classes, and if so how?

Q6) If they have happened can you please describe any times in which your family life has either made it more difficult, or prevented you from participating in the exercise classes?

Q7) If they have happened can you please describe any times in which your family life has either made it easier, or helped you to participate in the exercise classes?

Q8) If they have happened can you please describe any times in which your social life has either made it more difficult, or prevented you from participating in the exercise classes?

Q9) If they have happened can you please describe any times in which your social life has either made it easier, or helped you to participate in the exercise classes?

Q10) Is there anything else that has made it more difficult or prevented you from participating in the exercise classes that has not been covered in the statements above?

Q11) Is there anything else that has made it easier or helped you to participate in the exercise classes that has not been covered in the statements above? If so can you please tell me about it?

Before we finish I would like to give you the opportunity to say anything else that you feel is important about your experience of participating in the classes so far.

Thank you for your time.

Appendix BB Element 3: MOVEMENT exercise participant interview guide T2

Participant T2.

Discuss consent and confidentiality

- Re-confirm consent verbally. Emphasise confidentiality, but explain if they say anything which suggests they are at risk of harm or danger these concerns will be escalated to the clinical study team.
- Check interviewee is happy for interview to be audio-recorded and transcribed word for word.
- Ask if they have any questions or concerns before proceeding.

Purpose of the interview

We are here today to talk about how you found participating in the [Name of centre redacted] exercise classes and your exercise behaviour since finishing the classes. It is important to remember there are no right and wrong answers to these questions it is just about how you felt participating.

Questions

Q1) Please can you describe your overall thoughts and feelings about participating in the exercise classes at [Service name redacted]? Do you think these have changed from when we spoke previously? And if yes why?

Q2) In the previous interview we spoke about your expectations or reasons for participating in the classes. Have the classes met your expectations or reasons for participating? Please explain.

Q3) Can you tell me about anything you liked, and did not like about participating in the [Name of centre redacted] exercise classes?

Q4) Between our last interview and when you finished the classes did you experience any difficulties participating in the classes or miss any classes? If yes can you explain why?

Q5) Can you tell me about any types of exercise or physical activity you have continued to do since completing the [Name of centre redacted] exercise classes?

Q6).Can you explain to me your reasons for either continuing to exercise or not exercising since completing the [Name of centre redacted] classes?

In the previous interview I asked you 12 statements about difficulties you may have experienced following the exercise classes at the [Name of centre redacted], I will now ask you those statements again but focusing on any exercise you have done since finishing the [Name of centre redacted] classes. Again, I will ask you to say how much you agree or disagree with each statement. After each statement I would also like you to explain the reason for your answer, including what it was that prevented or made it difficult to exercise and anything you were able to do to counteract or minimise its impact.

PETS.1) I had to skip the exercise because it made my symptoms worse.

Agree Strongly, Agree Slightly, Not Sure, Disagree Slightly, Disagree Strongly.

Please explain the reason for your answer.

Please describe anything you found or did that helped or improved this.

PETS.2) I was prevented from carrying out the exercise by severe symptoms.

Agree Strongly, Agree Slightly, Not Sure, Disagree Slightly, Disagree Strongly.

Please explain the reason for your answer.

Please describe anything you found or did that helped or improved this.

PETS.3) I could not carry out the exercise because it caused more symptoms.

Agree Strongly, Agree Slightly, Not Sure, Disagree Slightly, Disagree Strongly.

Please explain the reason for your answer.

Please describe anything you found or did that helped or improved this.

PETS.4) I could not carry out the exercise because I was unsure how to do it properly.

Agree Strongly, Agree Slightly, Not Sure, Disagree Slightly, Disagree Strongly.

Please explain the reason for your answer.

Please describe anything you found or did that helped or improved this.

PETS.5) I was unable to carry out the exercise because it was difficult to know what to do.

Agree Strongly, Agree Slightly, Not Sure, Disagree Slightly, Disagree Strongly.

Please explain the reason for your answer.

Please describe anything you found or did that helped or improved this.

PETS.6) I skipped the exercise because I was not sure if it was helping.

Agree Strongly, Agree Slightly, Not Sure, Disagree Slightly, Disagree Strongly.

Please explain the reason for your answer.

Please describe anything you found or did that helped or improved this.

PETS.7) I skipped the exercise because it did not seem relevant to my symptoms and problems.

Agree Strongly, Agree Slightly, Not Sure, Disagree Slightly, Disagree Strongly.

Please explain the reason for your answer.

Please describe anything you found or did that helped or improved this.

PETS.8) I did not carry out the exercise because I was not convinced it was right for me.

Agree Strongly, Agree Slightly, Not Sure, Disagree Slightly, Disagree Strongly.

Please explain the reason for your answer.

Please describe anything you found or did that helped or improved this.

PETS.9) Lack of time prevented me from carrying out the exercise.

Agree Strongly, Agree Slightly, Not Sure, Disagree Slightly, Disagree Strongly.

Please explain the reason for your answer.

Please describe anything you found or did that helped or improved this.

PETS.10) It was not possible to find suitable opportunities to carry out the exercise.

Agree Strongly, Agree Slightly, Not Sure, Disagree Slightly, Disagree Strongly.

Please explain the reason for your answer.

Please describe anything you found or did that helped or improved this.

PETS.11) I was too busy or tired to carry out the exercise.

Agree Strongly, Agree Slightly, Not Sure, Disagree Slightly, Disagree Strongly.

Please explain the reason for your answer.

Please describe anything you found or did that helped or improved this.

PETS.12) I found it difficult to remember to carry out the exercise.

Agree Strongly, Agree Slightly, Not Sure, Disagree Slightly, Disagree Strongly.

Please explain the reason for your answer.

Please describe anything you found or did that helped or improved this.

Like in the first interview these next questions will ask you about some other things, which people with a condition such as yours, suggested might impact their ability to follow exercise programmes. We will ask you whether in your experience they did impact your ability to perform exercise, and if so how?

Q7) Can you please describe any times in which your family life has either made it more difficult, or prevented you from exercising since completing the classes at [Service name redacted].

Q8) Can you please describe any times in which your family life has either made it easier, or helped you to exercise since completing the classes at [Service name redacted].

Q9) Can you please describe any times in which your social life has either made it more difficult, or prevented you from exercising since completing the classes at [Service name redacted].

Q10) Can you please describe any times in which your social life has either made it easier, or helped you to exercise since completing the classes at [Service name redacted].

Q11) Is there anything else that has prevented, or made it more difficult, for you to exercise since finishing the classes, that has not been covered in the statements above? If so can you please tell me about it?

Finally I would like to give you the opportunity to say anything else that you feel is important for people to consider when designing exercise programmes for people with conditions such as yours.

Thank you very much for your time and for taking part in this study, it is very much appreciated. Before we finish is there anything else that you feel is important to say about your experience of participating in the [Name of centre redacted] classes, exercising since finishing the classes, or about taking part in these interviews?

Appendix CC Element 3: MOVEMENT health professional interview guide

Physiotherapist Interview.

Discuss consent and confidentiality

- Read through consent form (emphasise confidentiality, but explain if they say anything which suggests class participants are at risk of harm or danger these concerns will be escalated to the relevant members of the therapy team).
- Check interviewee is willing for interview to be audio-recorded and transcribed verbatim.
- Ask the interviewee whether he or she has any questions or concerns before proceeding.

Purpose of the interview

- We are here today to talk about the [Name of centre redacted] exercise classes, your experience of using exercise with people with advanced cancer, and your thoughts on factors which may influence adherence to exercise in this patient group.

Questions

- From your experience, what do you think is the most important thing to consider when trying to maximise exercise adherence in this patient group?

- Did participants in the classes ever share with you what they particularly liked or did not like about any aspect of the classes? If so can you tell me about what they liked and did not like?

- Did participants ever share with you any challenges they had experienced attending and participating in the classes? If so please tell me about the challenges they encountered participating in the classes.

- Have participants ever shared with you any challenges they have experienced continuing to exercise since completing the classes? If so what are the challenges they encountered after completing the classes?

- Did participants ever share with you any strategies they devised to help overcome the challenges they experienced? If so what were they?

- During the classes or in other areas of your work with this patient group have you notice any patterns or trends or behaviours in those people who you believe manage to exercise or participate in physical activity regularly, and may be worth further investigation? If so please describe what it is?

- Lastly, could you please tell me anything else you have learnt from delivering the classes at the [Name of centre redacted], or other experiences you have had, that you feel is important for people to consider when designing exercise interventions for people with advanced cancer in the future?

Thank you for your time, it is very much appreciated.

Appendix DD Element 3: EMBRACE problematic experience of therapy scale time point 1

Subject ID number:

This questionnaire asks about any times you were unable to perform a planned exercise sessions as part of the trial. We understand that people of all abilities can sometimes skip sessions of an exercise program for lots of different reasons.

Instructions:

If you have not missed any exercise sessions please tick the box at the bottom of the page and do not complete the rest of this form. If there have been times when you missed or skipped an exercise session please read each question statement, think about how much you feel that was a reason for missing the session. Then circle on the right hand side, to show how much you agree or disagree with the statement.

Please do not put your name on this form.

Your answers to the questionnaire will help us find ways for people to complete more sessions of exercise in the future.

Thank you kindly for your time.

	Question statement	Response				
1	I had to skip the exercise because it made my symptoms worse.	Agree Strongly	Agree Slightly	Not Sure	Disagree Slightly	Disagree Strongly
2	I was prevented from carrying out the exercise by severe symptoms.	Agree Strongly	Agree Slightly	Not Sure	Disagree Slightly	Disagree Strongly
3	I could not carry out the exercise because it caused more symptoms.	Agree Strongly	Agree Slightly	Not Sure	Disagree Slightly	Disagree Strongly
4	I could not carry out the exercise because I was unsure how to do it properly.	Agree Strongly	Agree Slightly	Not Sure	Disagree Slightly	Disagree Strongly
5	I was unable to carry out the exercise because it was difficult to know what to do.	Agree Strongly	Agree Slightly	Not Sure	Disagree Slightly	Disagree Strongly
6	I skipped the exercise because I was not sure if it was helping.	Agree Strongly	Agree Slightly	Not Sure	Disagree Slightly	Disagree Strongly
7	I skipped the exercise because it did not seem relevant to my symptoms and problems.	Agree Strongly	Agree Slightly	Not Sure	Disagree Slightly	Disagree Strongly
8	I did not carry out the exercise because I was not convinced it was right for me.	Agree Strongly	Agree Slightly	Not Sure	Disagree Slightly	Disagree Strongly
9	Lack of time prevented me from carrying out the exercise.	Agree Strongly	Agree Slightly	Not Sure	Disagree Slightly	Disagree Strongly
10	It was not possible to find suitable opportunities to carry out the exercise.	Agree Strongly	Agree Slightly	Not Sure	Disagree Slightly	Disagree Strongly
11	I was too busy or tired to carry out the exercise.	Agree Strongly	Agree Slightly	Not Sure	Disagree Slightly	Disagree Strongly
12	I found it difficult to remember to carry out the exercise.	Agree Strongly	Agree Slightly	Not Sure	Disagree Slightly	Disagree Strongly
PETS scale designed by Yardley and Kirby, (2006), validated by Kirby, Donovan-Hall and Yardley, (2014), permission for use obtained.						

I did not miss any sessions	☐

Appendix EE Element 3: EMBRACE problematic experience of therapy scale time point 2

Subject ID number:

This questionnaire asks about any times you were unable to perform a planned exercise session since beginning the home based exercise. We understand that people of all abilities can sometimes skip sessions of an exercise program for lots of different reasons.

Instructions:

If you have not missed any exercise sessions please tick the box at the bottom of the page and do not complete the rest of this form. If there have been times when you missed or skipped an exercise session please read each question statement, think about how much you feel that was a reason for missing the session. Then circle on the right hand side, to show how much you agree or disagree with the statement.

Please do not put your name on this form.

Your answers to the questionnaire will help us find ways for people to complete more sessions of exercise in the future.

Thank you kindly for your time.

	Question statement	Response				
1	I had to skip the exercise because it made my symptoms worse.	Agree Strongly	Agree Slightly	Not Sure	Disagree Slightly	Disagree Strongly
2	I was prevented from carrying out the exercise by severe symptoms.	Agree Strongly	Agree Slightly	Not Sure	Disagree Slightly	Disagree Strongly
3	I could not carry out the exercise because it caused more symptoms.	Agree Strongly	Agree Slightly	Not Sure	Disagree Slightly	Disagree Strongly
4	I could not carry out the exercise because I was unsure how to do it properly.	Agree Strongly	Agree Slightly	Not Sure	Disagree Slightly	Disagree Strongly
5	I was unable to carry out the exercise because it was difficult to know what to do.	Agree Strongly	Agree Slightly	Not Sure	Disagree Slightly	Disagree Strongly
6	I skipped the exercise because I was not sure if it was helping.	Agree Strongly	Agree Slightly	Not Sure	Disagree Slightly	Disagree Strongly
7	I skipped the exercise because it did not seem relevant to my symptoms and problems.	Agree Strongly	Agree Slightly	Not Sure	Disagree Slightly	Disagree Strongly
8	I did not carry out the exercise because I was not convinced it was right for me.	Agree Strongly	Agree Slightly	Not Sure	Disagree Slightly	Disagree Strongly
9	Lack of time prevented me from carrying out the exercise.	Agree Strongly	Agree Slightly	Not Sure	Disagree Slightly	Disagree Strongly
10	It was not possible to find suitable opportunities to carry out the exercise.	Agree Strongly	Agree Slightly	Not Sure	Disagree Slightly	Disagree Strongly
11	I was too busy or tired to carry out the exercise.	Agree Strongly	Agree Slightly	Not Sure	Disagree Slightly	Disagree Strongly
12	I found it difficult to remember to carry out the exercise.	Agree Strongly	Agree Slightly	Not Sure	Disagree Slightly	Disagree Strongly
PETS scale designed by Yardley and Kirby, (2006), validated by Kirby, Donovan-Hall and Yardley, (2014), permission for use obtained.						

I did not miss any sessions	☐

Appendix FF Example of patient profile created as part of data familiarisation process

EMB-014 is a 76 year old male retired shop fitter, who lives in a house just over 2 miles from the hospital. He lives with his wife who accompanied him to all appointments. He also speaks of a daughter in law, daughter and a son who died approximately 1 year before the interview.

His lung cancer was first diagnosed in 2015. Surgery was believed to have removed all of the cancer, then found to have recurrence in 2017. He began receiving chemotherapy shortly after diagnosis of recurrence after completing the first exercise training session as per the EMBRACE protocol.

He has type 2 Diabetes. He has no other co morbidities other than describing a sore neck and bad hip. He is an independent gentleman requiring no additional help in his day to day tasks.

He describes himself as having never been a great exerciser, and explains that he never really thought about exercise because work was always hard enough. He used to do boxing at school, but stopped when he started work. He used to go sea fishing regularly with his son but stopped because he got less enjoyment and interested from it after his son died. Throughout his life he has cycled regularly as a form of transport because he only started driving in his sixties. He also used to regularly walk his dogs around local nature areas with his wife but again stopped several years ago when the dogs had died. He previously owned and used an exercise bike which was for his wife’s physiotherapy exercise due to previous leg surgery.

His current primary concern seems to be based around length of survival and anything which may maximise this.

He is taking part in the EMBRACE exercise arm. He was initially informed of the study by his consultant whilst being informed of his diagnosis and approached by a researcher to be given further information shortly afterwards. He was motivated to participate in the study so that it could help others in the future. His intention was to try it as best as he could to help others in the future with the understanding that if it got too much for him he would just stop.

He did not miss any scheduled exercise sessions or testing sessions. He did have to finish one session early when, during a period in which he was receiving chemotherapy, he began to feel increasingly unwell whilst cycling his blood sugars dropped very low and he ended his session before the planned finish. From then on his wife always brought him a selection of food to eat before and during the sessions to ensure his blood glucose remained higher.

During the home based exercise he only attempted the resistance exercises on one occasion. He decided the exercises were not suitable for him. The booklet he was given was felt to be too big to take in all of the information. He was concerned if he did the exercises which were shown lying on the floor he would be unable to get back up and some of the exercises aggravated pain in his neck and shoulders. He purchased himself an exercise bike which was assembled with help from family and he used in the conservatory whilst watching the birds two or three times a week for five or ten minutes at random times.

During the period of data collection he was the only participant from EMBRACE who completed PETS questionnaires for both time points:

PETS statement	T1	T2
PETS.1) I had to skip the exercise because it made my symptoms worse.	Agree strongly	Disagree strongly*
PETS.2) I was prevented from carrying out the exercise by severe symptoms.	Agree strongly	Disagree strongly*
PETS.3) I could not carry out the exercise because it caused more symptoms.	Agree strongly	Disagree strongly*
PETS.4) I could not carry out the exercise because I was unsure how to do it properly.	Disagree strongly	Disagree strongly*
PETS.5) I was unable to carry out the exercise because it was difficult to know what to do.	Disagree strongly	Disagree strongly*
PETS.6) I skipped the exercise because I was not sure if it was helping.	Disagree strongly	Disagree strongly*
PETS.7) I skipped the exercise because it did not seem relevant to my symptoms and problems.	Disagree strongly	Disagree strongly*

PETS.8) I did not carry out the exercise because I was not convinced it was right for me.	Disagree strongly	Disagree strongly*
PETS.9) Lack of time prevented me from carrying out the exercise.	Disagree strongly	Disagree strongly*
PETS.10) It was not possible to find suitable opportunities to carry out the exercise.	Disagree strongly	Disagree strongly*
PETS.11) I was too busy or tired to carry out the exercise.	Disagree strongly	Disagree strongly*
PETS.12) I found it difficult to remember to carry out the exercise.	Disagree strongly	Disagree strongly*

Appendix GG Element 3: Problematic experience of therapy scale responses

Participant number		PETS statement response											
		PETS.1) I had to skip the exercise because it made my symptoms worse.	PETS.2) I was prevented from carrying out the exercise by severe symptoms.	PETS.3) I could not carry out the exercise because it caused more symptoms.	PETS.4) I could not carry out the exercise because I was unsure how to do it properly.	PETS.5) I was unable to carry out the exercise because it was difficult to know what to do.	PETS.6) I skipped the exercise because I was not sure if it was helping.	PETS.7) I skipped the exercise because it did not seem relevant to my symptoms and problems.	PETS.8) I did not carry out the exercise because I was not convinced it was right for me.	PETS.9) Lack of time prevented me from carrying out the exercise.	PETS.10) It was not possible to find suitable opportunities to carry out the exercise.	PETS.11) I was too busy or tired to carry out the exercise.	PETS.12) I found it difficult to remember to carry out the exercise.
EMB-014	T1	Agree strongly	Agree strongly	Agree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly
	T2	Disagree strongly*	Disagree strongly*	Disagree strongly*	Disagree strongly*	Disagree strongly*	Disagree strongly*	Disagree strongly*	Disagree strongly*	Disagree strongly*	Disagree strongly*	Disagree strongly*	Disagree strongly*
EMB-015	T1	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Agree strongly	Agree strongly	Disagree strongly	Disagree strongly
	T2	With drawn from study before completion of final questionnaires.											
EMB-016	T1	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly
	T2	With drawn from study before completion of final questionnaires.											
EMB-024	T1	Control participant from the EMBRACE did not complete questionnaires.											
	T2												
	T1	Requested to be withdrawn from the EMBRACE study at week 3 before study questionnaires had been completed.											

EMB-025	T2												
MO_CH_01	T1	Disagree strongly*	Disagree strongly*	Disagree strongly*	Disagree strongly*	Disagree strongly*	Disagree strongly*	Disagree strongly*	Disagree strongly*	Disagree strongly*	Disagree strongly*	Disagree strongly*	Disagree strongly*
	T2	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Not sure	Disagree strongly	Disagree strongly	Disagree strongly	Agree slightly	Agree slightly	Agree strongly (tired)	Disagree strongly
MO_CH_02	T1	Agree strongly	Agree strongly	Missing	Disagree strongly	Disagree strongly	Disagree strongly	Not sure	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly
	T2	Agree slightly	Disagree slightly	Disagree slightly****	Disagree strongly*****	Disagree strongly*****	Disagree slightly	Disagree slightly	Disagree slightly	Disagree slightly	Disagree slightly	Agree strongly (Tired)	Disagree slightly
MO_CH_03	T1	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly
	T2	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree slightly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly
MO_CH_04	T1	Agree slightly	Agree slightly	Disagree slightly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Agree slightly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly
	T2	Disagree slightly	Disagree strongly	Disagree slightly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree slightly	Disagree strongly	Agree slightly	Disagree slightly	Agree slightly (tired and busy)	Disagree strongly
MO_CH_05******	T1	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Agree strongly	Agree slightly	Agree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly
	T2	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly
MO_CH_06	T1	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Unanswered	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly
	T2	Disagree strongly	Agree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Agree strongly (tired)	Disagree strongly
MO_CH_07	T1	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly
	T2	Disagree strongly	Agree slightly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Agree slightly	Agree slightly	Agree slightly (busy)	Agree slightly
MO_CI_01	T1	Disagree strongly*	Disagree strongly*	Disagree strongly*	Disagree strongly*	Disagree strongly*	Disagree strongly*	Disagree strongly*	Disagree strongly*	Disagree strongly*	Disagree strongly*	Disagree strongly*	Disagree strongly*
	T2	Participant did not complete second interview.											
	T1	Disagree strongly	Disagree strongly	Agree slightly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Agree slightly**

MO_CI_02 *******	T2	Disagree strongly	Disagree strongly	Disagree slightly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Agree strongly (tired)	Disagree strongly
MO_CIR_03	T1	Disagree strongly	Disagree strongly***	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly
	T2	Disagree slightly	Disagree slightly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree slightly	Disagree strongly	Agree slightly (tired and busy)	Disagree strongly
MO_CIR_04	T1	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Agree slightly	Disagree strongly	Disagree strongly	Disagree strongly
	T2	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree strongly	Disagree slightly	Disagree strongly	Disagree slightly

*	Scored as strongly disagrees as participants indicated they had not ever had difficulties doing the exercises so each individual question was not asked.
**	Patients answer indicated he actually meant he agrees slightly that he sometimes finds it difficult to remember how to do the exercise but he never finds it difficult to remember to do the exercise.
***	Although participant stated disagree strongly, else where in the interview she spoke of missing a class due to being in hospital with constipation.
****	Although disagreeing slightly participant says this has never happened.
*****	Participant would not answer directly but gave detailed response.
******	Participants T2 answers are regarding supervised classes at local fitness and sport centre.
*******	Participant found answering difficult.. Disagreed strongly to most answers but has not done a single exercise since finishing the class due to continual events with his disease. He describes this as illness level but each question did not identify it. At times participant reported never skipping an exercise at other times admitted never doing an exercise since class finished.

Appendix HH Discussion: Case 1 no exercise

Participant ‘A’ joined the exercise programmes to gain general health benefits and do something which he believed must be positive in some way. He was uncertain if any physical benefit was gained but reported very strong psychological benefits. These were felt to be largely from enjoyment of the interactions with the staff delivering the sessions and the sense that he was doing something positive for himself. He had not realised the sessions would finish, and felt a great sense of loss when the relationship he had developed with the HCPs ended. He shared a home with two older family members. He perceived his individual space to be too small to exercise and could not use the larger shared areas of space as his family were unsupportive of exercise. During the supervised period and after it had finished he experienced several exacerbations of symptoms which resulted in short hospital admissions. A combination of his own extremely variable health and the worsening health of his parent, for whom he was a carer, reduced opportunity to exercise. Those same factors were largely uncontrollable so the participant could exert little agency over them. When he first had an opportunity to exercise he felt overwhelmed by the large number of unfamiliar exercises in the manual that was provided and intended to try again another time. When the next opportunity arose he decided it had been too long and therefore there was no point continuing. Despite finishing the supervised programme with the intention of exercising, by the time of the interview no exercise had been performed, but during periods of good health he was more physically active than pre-intervention. Attempts by HCPs to contact the participant in this period were unsuccessful and messages unreturned. The participant believed the only way he could have continued to exercise was if the sessions had continued and he displayed resentment that they had not.

This participant’s account indicates substantial insufficiency to meet their prescribed exercise protocol in areas of the ‘suitability of support’, ‘suitability of the exercise environment’ and ‘readiness of the participant’. He lacked the self-efficacy and motivation to perform the exercise, and the agency to influence this. Many of the key features suggested above may not be suitable responses to the multi-factorial complex difficulties experienced by this participant. Strategies relating to the third key feature, ‘preparation for the deficiencies of home exercise’, outlined above to meet the guiding principles may not be sufficient. A focus upon the benefits of exercise rather than building relationships in the supervised period may reduce the sense of loss when those sessions end. Likewise, better preparation for performing the exercises in the unsupervised period may increase the 'readiness of the participant'. Practicing the unsupervised exercise before the supervised period ends may allow proxy agency through the HCP to accommodate poor 'suitability of the exercise environment'. However, the highly unstable nature of the participants' disease varying day to day, means attempts to better prepare the participant to exercise at home are unlikely to be suitably effective upon the 'readiness of the participant'. It is also unlikely the 'suitability of the exercise environment' and 'suitability of support' would reach sufficient level without further intervention.

Strategies relating to key feature two, 'incorporation of non-professional support', are also unlikely to be successful, the participant did not have suitable family or friends willing or able to become an exercise partner and so 'suitability of support' would not be increased in this way.

Strategies relating to key feature one, 'continuation of professional support', have greater potential to be effective. Attempts to continue to improve the 'suitability of support' via telephone or video call are unlikely to be successful. These methods have limited ability to address the limitations due to the 'suitability of the exercise environment' and previous attempts to communicate via telephone were often unsuccessful. When questioned, this participant believed support in the form of a phone call would not be sufficient as he would remain in an unsuitable environment and felt his family would not want visits from a HCP to provide face to face support. The most likely method to achieve successful adherence would be to use other specialist exercise providers. This would increase 'suitability of support', 'suitability of the exercise environment', and provide exercise in a way that accommodates the 'readiness of the participant'. It is known from the supervised period the participant was motivated to exercise in this way, has a high level of self-efficacy to exercise in this way and proxy agency through the staff delivering the intervention could assist the participant overcoming challenges as they occur.

Appendix IIDiscussion: Case 2 infrequent exercise

This participant joined the exercise programmes because it had been offered to her and she was aware exercise is ‘good for you’ although was not certain how it would be beneficial. She had been concerned of attending the class because of how others would view her, as she had become very self-conscious due to her cancer and other disabilities. However, she found everyone very welcoming and enjoyed the classes, particularly the interaction with the staff and other participants, which became her main reason for attending. She also found improvements in her mobility and experienced a sense of achievement from proving to herself that she could do the exercise, which helped alleviate feelings of depression. During the unsupervised period this participant found the exercises less enjoyable than during the supervised session, and greatly missed the interaction with others. She also missed being able to witness others with similar conditions performing the exercise. She exercised either when prompted by her husband or when spontaneous movement directed attention to exercise. Her husband is supportive of exercise and previously drove her to the supervised sessions. Her depression and fatigue made starting exercise require great effort, but she was aware the sense of achievement after exercising would help lessen the feeling of depression. Home exercise was performed infrequently, when she remembered and felt motivated to, but often lacked structure and varied in intensity and duration. This participant also felt the only thing which would have helped her to perform exercise more often would have been for the sessions to continue.

This participant’s account indicates some insufficiency to meet their prescribed protocol in areas of ‘suitability of support’, and ‘readiness of the participant’. The ‘suitability of the exercise environment’ appeared adequate. She had the self-efficacy to exercise but lacked motivation, and did not have the agency to influence this herself. Despite believing that only continuing the sessions would have helped her maintain regular exercise, several of the proposed key features may offer suitable interventions to promote adherence. From key feature three, ‘preparation for the deficiencies of home exercise’, attempts to prepare the participant to exercise without supervision may be suitable particularly to develop the agency to create a regular ‘moment of conscious decision’ and build motives relating to the benefit of exercise rather than the social elements. The participant also had a partner who was encouraging and provided support to attend the supervised period, suggesting strategies from key feature two, ‘incorporation of non-professional support’, may also be suitable. During the unsupervised period the husband prompted exercise but had little other influence, if he had been involved in performing exercise in the supervised period he may have been able to give better influence as an exercise partner during the unsupervised period, increasing the ‘suitability of support’ in this period. Finally, methods from key feature one, ‘continuation of professional support’ may also have been suitable. Use of an external exercise provider may not be necessary as the ‘suitability of the exercise environment’ was not prohibitive, and the patient had found starting new groups difficult due to her anxiety of such situations. Use of technology to create a ‘moment of conscious decision’, combined with support from her husband as an exercise partner may have been sufficient to increase the regularity and structure of the exercise being performed. Perhaps the most suitable solution would be to incorporate regular group based video calls for the participant and her husband to exercise together. This method would maintain the successful elements of social interaction and surveillance to maintain motivation. It would also continue contact with HCPs to maximise the ‘suitability of support’ in this period and create proxy agency from that HCP as well as collective agency and modelling from others in the group. If the regular group video call was supplemented by unsupervised exercise sessions involving the participant and her partner this would increase the likelihood that the level of weekly exercise reach those recommended. However this method would be dependent upon the HCP being able to deliver suitable exercise individualised sufficiently to accommodate the varying abilities of: the participant, others with advanced cancer in the group, and their partners. All of whom may have different needs to the participant. The feasibility of which is currently unknown.