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## **DOCTOR OF PHILOSOPHY**

### **Development of an intervention to promote Physical Activity for Cancer Survivors (PACS)**

Nafees, Sadia

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**Development of an intervention to promote  
Physical Activity for Cancer Survivors (PACS)**

**By Sadia Nafees**

Submitted in accordance with the requirements for the degree of  
Doctor of Philosophy



PRIFYSGOL  
**BANGOR**  
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School of Healthcare Sciences

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## **Abstract**

Although positive effects of physical activity in cancer survivors are well-established, survivors are often not active enough to benefit. Exercise Referral Schemes are under-used by cancer survivors, largely due to lack of referral. A physical activity promotion pack, “MoveMore”, was developed by Macmillan in 2011, followed by a campaign to promote it to all cancer survivors in Wales. However education alone is not sufficient to effect behaviour change. The aim of this project was to develop a behaviour change intervention to reinforce the “MoveMore” message, and promote physical activity for cancer survivors.

Following the Medical Research Council framework, a systematic review was conducted to determine the effectiveness of physical activity education materials, a literature review identified relevant theory to underpin the proposed intervention, focus groups explored cancer survivors’ views about physical activity advice and informed the refinement of the intervention. Finally a survey of health professionals explored knowledge and beliefs about promoting physical activity to cancer survivors.

The systematic review findings indicated that education materials may increase physical activity levels in cancer survivors. Furthermore reinforcement based on behaviour change theories complements readiness to initiate or increase exercise. Focus group participants wanted consistent, tailored and face-to-face physical activity advice as part of their standard care. The survey confirmed the focus group findings but highlighted inconsistency, with health professionals lacking knowledge or confidence to give physical activity advice.

Physical inactivity in cancer survivors needs addressing to improve quality of life. Behaviour change interventions need to be theory-driven and low-maintenance. The proposed 12 weekly text message reinforcement intervention to promote physical activity in cancer survivors may be beneficial if integrated into existing health services. The feasibility of the proposed intervention can be tested in a pilot randomised controlled trial, the protocol of which has been drafted as part of this research work.

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## Abbreviations

ACSM	American College of Sports Medicine
BCUHB	Betsi Cadwaladr University Health Board
BMI	Body Mass Index
BOS	Bristol Online Surveys
CHD	Coronary Heart Disease
CIs	Confidence Intervals
CNRAG	Cancer Network Rehabilitation Advisory Group
CPG	Clinical Programme Groups
CRedeCI	Criteria for Reporting the Development and Evaluation of Complex Interventions
EQUATOR	Enhancing the QUALity and Transparency Of health Research
HTA	Health Technology Assessment
IARC	International Agency for Research on Cancer
IPAQ	International Physical Activity Questionnaire
IQR	Inter-Quartile Range
IRG	Interdisciplinary Research Group
MET-minutes	Metabolic Equivalent to Task - Minutes
MRC	Medical Research Council
NERS	National exercise referral scheme
NHS	National Health Services
NCCS	National Coalition for Cancer Survivorship
NAEDI	National Awareness & Early Diagnosis Initiative
NICE	National Institute for Clinical Excellence
NCRI	National Cancer Research Institute
NCSI	National Cancer Survivorship Initiative
NERS	National Exercise Referral Scheme
NHS	National Health Services
NWCPCR	North Wales Centre for Primary Care Research
NWPAPC	North Wales Physical Activity Promotional Campaign
PA	Physical activity
PIS	Participant Information Sheet
PPI	Patient and Public Involvement
QoL	Quality of Life
RCT	Randomised controlled trial
SD	Standard Deviation
SMD	Standard Mean Difference
WCRF	World Cancer Research Fund
WG	Welsh Government
WHO	World Health Organisation
WMD	Weighted Mean Difference

## Chapter 1. Introduction

**“Get active feel good”  
What helps to promote  
Physical Activity?**

WHO estimates that one third of the cancer burden could be reduced by taking preventive measures to change lifestyle behaviours among cancer survivors!

Cost-effective behaviour change interventions are needed to promote physical activity (WHO 2010).

## 1.0 Chapter summary

The issues of the global burden of chronic diseases especially cancer and one of the associated risk factors, physical inactivity were explored in a literature review in this chapter. The review provided an epidemiological overview of a high level of physical inactivity in both the general population and the cancer survivors. Furthermore, literature about the challenges of cancer care and survivorship, different approaches to physical activity promotion and available physical activity guidelines for cancer survivors was also explored.

The review brought to light that the beneficial effects of physical activity for the general population and cancer survivors have been widely recognised (WHO 2010; WHO 2012). Hence, physical activity promotion is now recognised as one of the biggest global initiatives to address these challenges. But the cost and resource implications of such initiatives were found to be the biggest hindrance and the need for low-cost, low-maintenance interventions was highlighted.

### 1.1 Introduction

Growing burden of chronic diseases and the associated risk factors particularly physical inactivity are a major concern worldwide (WHO 2010). While there are recent advancements in treating and curing cancer leading to improved survivorship of patients, physical inactivity remains a significant challenge among this group (WHO 2012). This introductory chapter of the thesis presents the rationale of the overall research project through a literature review which explored the following topics of interest:

- Benefits of physical activity and consequences of inactivity in the general population as well as in cancer survivors
- Physical activity promotional approaches
- Challenges of cancer care focusing on survivorship

The chapter briefly outlines the journey of this research project, and concludes with enlisting the aims and objectives of this thesis, highlighting the research questions to be answered and the novel contributions.

### 1.2 Physical Activity

Physical activity has gained a prominent role in recent decades in both maintaining and improving health and well-being in healthy individuals (Department of Health 2011), and treating and managing chronic diseases (Warburton, Nicol et al. 2006). Physical activity promotion has been prioritised in the agenda for improving the health of general populations in recent decades because of its beneficial effects (WHO 2012).

### 1.2.1 Definitions

There is an ambiguity in the clear meaning and use of different terms to describe physical activity such as 'physical activity and exercise' and 'physical fitness and health-related physical fitness', but clear definitions are essential to interpret the findings of different studies, spread the public health messages and perform health impact evaluations.

Caspersen et. al., (1985) defined **physical activity** as any bodily movement produced by the contraction of skeletal muscles to increase energy expenditure above the basal level, including physical activity during leisure time, occupation, transport, household chores, gardening and self-care. Thus **exercise** is a subset of physical activity where it is planned, structured and repetitive and it has a final or an intermediate objective to improve or maintain the physical fitness. **Physical fitness** on the other hand comprises a set of *health-related* attributes including cardio-respiratory endurance, muscular endurance, muscular strength, body composition and flexibility; and *skill-related* including attitudes agility, balance, coordination, speed and power (Caspersen, Powell et al. 1985).

The amount of physical activity or exercise can be measured in terms of total dose of activity and the intensity at which the activity is performed. *Dose* "refers to the total amount of energy expended in physical activity, whereas *intensity* reflects the rate of energy expenditure during such activity" (Pate, Pratt et al. 1995).

### 1.2.2 Benefits of Physical Activity

The benefits of physical activity are widely recognised in healthy populations as well as in those with chronic illness (Thomas and Davies 2007). In healthy populations, evidence has linked physical activity to health maintenance and improvement as well as prevention, management and rehabilitation of a variety of diseases, to reduce the risk of premature mortality and morbidity from chronic diseases such as coronary heart disease and diabetes as well as cancer (WHO 2005). Adopting a physically active life style helps reduce the incidence of acute or chronic pain conditions related to certain professions, especially in the modern age when sedentary work styles and places make people immobile for extended periods of time resulting in stiff and painful joints and muscles (Bauman 2004).

Physical activity has shown promise in the treatment and management of many chronic diseases to halt or decrease deterioration with the potential of reducing premature mortality, disability and handicap, and improving quality of life and well-being (Campbell, Foster et al. 2011). Physical activity is regularly used as an integral part of the treatment regimen in cardiac rehabilitation after cardiac events, and has shown to decrease associated morbidity and mortality (Fletcher 1996). A recent review found that recommended levels of

physical activity are as effective or more effective than drugs “in terms of their mortality benefits in secondary prevention of coronary heart disease, rehabilitation after stroke, treatment of heart failure, and prevention of diabetes” (Naci 2013).

The role of physical activity is well-established in both preventing and treating diabetes, especially type II, with the potential of controlling the milder forms with exercise alone or with minimal drug intervention. It also helps to slow down the deterioration of other body systems and helps to improve the body’s resistance to secondary infections (Bauman 2004).

Physical activity regimens are regularly prescribed for patients with various musculoskeletal conditions such as osteoarthritis (Fransen and McConnell 2008; Bennell and Hinman 2011; Iwamoto 2011) to reduce pain and disability resulting from the condition and improve mobility and quality of life (Williams 2009). It fosters healthy muscles, bones and joints, and helps maintain function and preserves independence (Pate, Pratt et al. 1995; Chief Medical Officer 2004). It enhances the well-being of people with physical disabilities (Rejeski and Mihalko 2001). It is also an important ingredient in the rehabilitation programmes of patients undergoing arthroplasties of the hip or knee (Lowe, Barker et al. 2007).

Physical activity has been shown to have beneficial effects for patients with depression and it has been suggested that it is as equally effective as psychotherapy (Martinsen 1994). These effects have been attributed to the release of factors within the brain to improve mood as well as the social aspect of being engaged with physical activity (Craft and Perna 2004; Cooney, Dwan et al. 2013; National Health Service 2013). It improves mental health, well-being and quality of life in older people (Rejeski and Mihalko 2001; Stephenson, Bebb et al. 2009). However, a recent Health Technology Assessment (HTA) funded randomised controlled trial showed the participants maintained increased physical activity levels to up to 12 months but failed to show statistically significant improvement in depression in the intervention compared to the usual care group. Participants’ knowledge of the group they were allocated was suggested as one of the causes for such findings (Chalder, Wiles et al. 2012).

Although there are potential adverse side effects for some people, most can be avoided with appropriate precautions. For example, physical activity, though, considered useful for its beneficial cardiovascular effects, can trigger an acute cardiac event in people who have been long standing sedentary and who then start exercising. As the incidence ranges from 2.1 per 100 000 person-years overall and 0.3 per 100 000 person-years in those  $\leq 35$  years, overall it is still lower than in the sedentary population (Berdowski, de Beus et al. 2013).

Individually tailored and professionally prescribed exercises are usually safe, and their benefits usually outweigh the risks (Siscovick, Weiss et al. 1984). However, a few hazards may rarely arise in certain groups or in patients with pre-existing conditions. Exercise can cause hypertrophic cardiomyopathy in middle-aged people (Thompson, Franklin et al. 2007). For people without physical fitness, heart problems can follow if vigorous physical activity is undertaken. People with high blood pressure, diabetes, and heart disease are more susceptible to adverse impact on their health if they undertake physical exercise without appropriate guidance and advice from their physicians (Paffenbarger, Wing et al. 1978). Unsupervised exercise has been reported to cause arrhythmias, sudden cardiac arrests, and heart attack in patients with heart disease (Salmon 2001).

For healthy persons, both physical and emotional untoward effects of exercise can result from over exercising (Galea 2012). Eating Disorder Online reports that over exercise can deteriorate personal relationships at the work place, and social isolation is common among those who exercise compulsively. Unnoticed dehydration, muscular atrophy, skeletal injuries such as shin splits, bone fractures, arthritis, or damage to cartilage and ligaments, dislocations, sprains and strains remain some challenging sequelae to overzealous exercise regimes (Koplan, Siscovick et al. 1985; online. 2015). For regular exercisers, leaving it suddenly can cause changes in metabolic rate. Similarly, a sudden drop in the practice can cause body muscles to become loose in those who carry out instrumental instead of aerobic exercises (Mostert and Kesselring 2002).

### **1.2.3 Physical Inactivity and Its Consequences**

It is evident from the above description that physical activity has more beneficial effects than disadvantages for both healthy as well as chronically ill individuals, but the majority of adults are sedentary and not active at recommended levels. UK's Department of health recommends a moderate intensity activity of at least 150 minutes over a week (i.e. 30 minutes on at least five days a week), or vigorous intensity activity of at least 75 minutes in a week to reap the beneficial effects of physical activity ([Department of Health 2011](#)). This is particularly so in high-income countries, but is increasingly the case in low- and middle-income countries (Pate, Pratt et al. 1995; Chief Medical Officer 2004; Hillsdon, Foster et al. 2005; Williams, Hendry et al. 2007; Department of Health 2011; WHO 2012). There might be various reasons ranging from industrialisation leading to advancement in technologies affecting the working patterns with increased dependence on machines, reduced physical labour and energy expenditure (Brownson, Boehmer et al. 2005) among people and unemployment.

Advancement in technologies has affected physical activity patterns in both good and bad ways. It has made people sedentary by modifying peoples' mobility and work practices. The rise of mechanical and motorised mobility has resulted in a decline in walking. Tasks

that were previously physical in nature and more labour intensive have become fewer with the advent of new technologies in the workplace (Stamatakis and Chaudhury 2008; Knuth and Hallal 2009; Palacios-Cena, Alonso-Blanco et al. 2011; Hallal 2012). Additionally, leisure activities have become more sedentary. Television, computers, electronic entertainments, the internet and wireless communication devices have replaced the outdoor social activities leading to an increase in sedentary behaviour especially among the younger generation (Lee, Yu et al. 2011). On the other hand technologies have provided innovative ways to engage in leisure activities increasing the physical activity of those who adopt them. This socio-cultural shift has transformed physical activity patterns from predominantly work related to mostly leisure-based (Knuth and Hallal 2009; Hallal 2012).

Data from different countries have reported varying patterns of sedentary as well as physically inactive behaviour among different populations, between males and females and among different age groups. The proportion of adults spending four or more hours per day sitting ranged from 23.8% in South East Asia to 64.1% in Europe (Hallal 2012). Bauman and colleagues reported the time spent sitting in 20 countries with wide variations between countries and showed that middle aged adults were the most sedentary (Bauman, Ainsworth et al. 2011). Physical inactivity among the general population is a major cause of increased body mass index (BMI) leading to the development of obesity (Prentice and Jebb 2004) which is a growing issue in high-income countries and is recognised as a key risk factor in the development of chronic non-communicable diseases (WHO 2010) such as cardiovascular disease (Chow, Jolly et al. 2010; Li and Siegrist 2012), stroke (McDonnell, Hillier et al. 2013), diabetes (Durstine, Gordon et al. 2013) and cancer (WHO 2012).

This decline in physical activity increases with advancing age. The health survey of England showed that although 21% of men and 18% of women aged 65–74 achieved recommended physical activity levels, the figure dropped to 9% and 6% for those aged 75 and older (NHS 2009). These figures were slightly better in the Welsh health survey 2009, in that 37% of men and 24% of women achieved these physical activity levels (WG 2009).

Physical inactivity was identified as the fourth leading risk factor for the above mentioned diseases accounting for more than three million preventable deaths in 2009 (WHO 2009). It has been estimated that by reducing physical inactivity by 10-25%, more than 0.5-1.3 million deaths respectively could be prevented every year, as well as increasing the life expectancy of the world population by about a year (Lee, Shiroma et al. 2012).

Murray and colleagues calculated disease burden worldwide and for 21 regions for 1990, 2005, and 2010 to enable meaningful comparisons over time (Murray, Vos et al. 2012). They found a continued shift from communicable to non-communicable diseases and from premature deaths to life with disability, especially in western countries. The rising burden from these chronic conditions is imposing new challenges to health systems and increasing

health care costs markedly. This study also showed that the UK persistently and significantly performed poorly compared to many other European countries in terms of premature mortality from several chronic conditions such as cardiovascular diseases and cancer (Murray, Richards Ma Fau - Newton et al. 2013).

Physical inactivity was found to be directly responsible for 3% of disability adjusted life years lost in the UK in 2002. The estimated direct cost to the National Health Service is £1.06 billion (Allender, Foster et al. 2007; Scarborough, Bhatnagar et al. 2011).

## 1.3 Cancer Survivorship

In the last thirty years, cancer has changed from being an invariably fatal disease to becoming a manageable chronic condition, in which the majority of cancer patients survive disease free for a long period of time (Ganz 2013). The concept of survivorship is not new, it is important to define 'cancer survivor' first before talking about survivorship.

### 1.3.1 Definitions

There is a lack of consensus on how to define a cancer survivor (Khan 2012). The term 'cancer survivor' was first used by Fitzhugh Mullan (Mullan 1985), who explained different paths for people diagnosed with cancer, a path for those who live with cancer and a palliative pathway for those who do not survive. To reflect the experiences of people diagnosed and treated for cancer, he suggested the term 'survival' and explained survival as three distinct periods in a cancer patients' life journey:

“**acute survival**, the period after diagnosis, when energies are focused on surviving treatment itself; **extended survival**, the period after completion of treatment, when the survivor's energies are focused on dealing with the physical and psychological consequences of treatment; and **permanent survival**, the period when recurrence seems increasingly unlikely, although the survivor is continuing to deal with the long-term effects of treatment” (Mullan 1985).

A survivor-led advocacy organisation was founded as the National Coalition for Cancer Survivorship (NCCS) in the USA in 1986, which adopted and endorsed the term 'cancer survivor'. The most commonly used definition, and the one that is adopted for this thesis, is the definition proposed by the NCCS of the cancer survivor 'from the time of diagnosis and for the balance of life' and have been extended to include family, friends and caregivers (Hewitt 2006).

### 1.3.2 Cancer Epidemiology

The global cancer burden is increasing and includes cases of newly diagnosed cancer, active cancers diagnosed more than one year ago, cancers in remission and cancers



that have been cured and cancers recurring after treatment. It has been estimated that there were 12.4 million new cases of cancer diagnosed in 2010 throughout the world (American Cancer Society 2010; WHO 2010). Cancer is the world's second commonest cause of death (7.6 million, or 21% of non-communicable disease deaths), and the number of deaths will rise to 12 million per year by 2030 (WHO 2010). The majority of the cancer deaths include lung, breast, colorectal, stomach and liver cancers. More than two thirds of these deaths occur in low and middle-income countries; lung cancer among men and breast cancer among women are the leading causes in high-income countries (WHO 2010).

In the United States, more than 1.5 million people are diagnosed with cancer each year; there are over 11 million cancer survivors, and these numbers are on the increase (American Cancer Society 2010). In Europe, there are more than three million newly diagnosed cancer patients and 1.7 million die each year, representing the second most prevalent cause of mortality and morbidity (Coleman 2008).

In the UK, more than 324,500 people were diagnosed with cancer in 2010 (Cancer Research UK 2013). UK's cancer incidence by jurisdiction is shown in Table 1.1 with the highest in Wales for males and in Scotland for females. There were 159,178 deaths from cancer in 2011 (22% lung; 10% bowel; 7% breast; 7% prostate and 54% all other cancers) (Cancer Research UK 2013). It is estimated that, one in three people in the UK will develop cancer in their lifetime; one in four people in the UK will eventually die from cancer (Cancer Research UK 2013; Office for National Statistics August 2009).

**Table 1.1:** Cancer incidence by country in the UK in 2010

Sex	England	Wales	Scotland	N. Ireland	UK
<b>Males</b>	136,372	9,363	14,036	4,133	163,904
<b>Females</b>	132,386	8,769	15,413	4,107	160,675
<b>Persons</b>	268,758	18,132	29,449	8,240	324,579

**Source:** Cancer Research UK, 2013

There are over two million people living in the UK with or beyond cancer, and the number is set to rise to four million by 2030 (Cancer Research UK 2013). The number of people diagnosed with the disease is rising but the number of people dying from cancer is falling, leading to more people surviving after a cancer diagnosis (Cancer Research UK 2013). This substantial increase is because of improvements in early diagnosis, effective and successful treatment regimens and improvements in post-treatment care (Office for National Statistics August 2009). This increase in the number of survivors, shift in population

demographics and improvement in prognosis is increasing both the complexity and cost of long-term multidisciplinary management and care (Campbell, Foster et al. 2011; Parry, Kent et al. 2011).

## 1.4 Addressing the Challenges of Cancer Care

Over the past decade cancer care has been prioritised. Some of the initiatives in the UK, which are listed below, have led to earlier diagnosis, a fall in cancer mortality, and improvements in overall cancer care.

### 1.4.1 Major Initiatives for Cancer Care in the UK

There have been major initiatives in the UK since 2007, to address the need for improvements in the quality of care among this growing population of cancer survivors.

To address early diagnosis of cancer:

- National Awareness and Early Diagnosis Initiative (NAEDI) 2007
- National Institute for Health and Care Excellence (NICE 2005) urgent referral guidelines for suspected cancer

To address *cancer care*:

- The National Cancer Research Institute (NCRI), strategic plan for 2008-2013, aimed at improving the overall health and quality of life of cancer survivors.
- National Cancer Survivorship Initiative (NCSI)

In Wales:

- Inclusion of cancer care support in National Exercise Referral Scheme (NERS)
- Macmillan North Wales Physical Activity Project
- All Wales physical activity project

### 1.4.2 World Health Organisation Cancer Burden Statement

*World Health Organisation (WHO) estimates that one-third of the cancer burden (newly diagnosed, active cancers diagnosed more than one year ago, cancers in remission and cancers that have been cured) could be reduced by taking preventive measures to change the lifestyle behaviour among cancer survivors (including the improvement in diet, physical activity and body weight)*

**(Source:** International Agency for Research on Cancer (IARC), a division of the World Health Organization (WHO 2010) (<http://globocan.iarc.fr/>)

There is a need to provide cancer survivors with more education and information to encourage active lifestyles (Department of Health 2007) and promote physical activity (NICE

2006) using simple interventions. Low cost, effective physical activity promotion strategies requiring minimal management to change behaviour could improve the long-term management of cancer survivors (Vainio, Kaaks et al. 2002). Interventions could be most effective when targeted at certain time points in the cancer patient's journey, i.e. upon diagnosis or during and immediately after treatment, as these have been shown to be most amenable to trigger behaviour change (Demark-Wahnefried, Pinto et al. 2006; Rowland 2008; Demark-Wahnefried, Platz et al. 2012).

## **1.5 Physical Activity and Cancer Survivors**

Recently health policy and research organisations in the UK have adopted the concept of cancer survivorship (Khan 2012). The growing cancer burden is being driven largely by two developments: the increasing adoption of unhealthy lifestyle behaviours and the growth and ageing of populations. Today, most cancers are linked to a few controllable factors, including tobacco, alcohol and substance misuse, poor diet, lack of exercise, and infectious diseases (WHO 2012). The next section will focus on benefits of physical activity for cancer survivors specifically.

### **1.5.1 Physical Activity Benefits in Cancer Survivors**

Physical activity improves how patients cope with the stresses related to a cancer diagnosis, and the associated anxiety and depression (Biddle, Fox et al. 2000a; Stathopoulou, Powers et al. 2006).

Physical activity can improve quality of life among cancer survivors (McNeely, Campbell et al. 2006; Schmitz and Speck 2010). It also improves physical function by: reducing muscle stiffness; reducing treatment related morbidity and helping to reduce the incidence of recurrence (Mishra, Scherer et al. 2012). Physical activity has been shown to play a protective role against certain cancers and can reduce the chances of recurrence in patients who have already undergone treatment, though there is still a lack of strong evidence (WHO 2012).

It can help to decrease the development of co-morbid conditions like cardiovascular disease, diabetes, obesity and osteoporosis, It can also reduce fatigue and pain among cancer survivors (Holmes, Chen et al. 2005; Doyle, Lawrence et al. 2006; Kruk 2007; Holick, Newcomb et al. 2008; Ibrahim and Al-Homaidh 2011) and the treatment and post-treatment morbidity related to some forms of cancer (Wolin, Lee et al. 2007; Irwin, Alvarez-Reeves et al. 2009). However, the World Health Organization has stated that there is a lack of high-quality studies to confirm the beneficial effects of physical activity on cancer recurrence or mortality (WCRF 2007), although some recent studies have shown the association of physical activity with the reduced risk of recurrence of breast cancer (Holmes, Chen et al.

2005), colorectal cancer (Meyerhardt, Giovannucci et al. 2006; Meyerhardt, Giovannucci et al. 2009), and prostate cancer (Kenfield, Stampfer et al. 2011; Richman, Kenfield et al. 2011). The evidence for other types of cancer is, however, still lacking.

Although physical activity is beneficial for cancer survivors in many ways, it can cause some adverse effects during and after treatment but these are reported to be rare, mild, and mainly musculoskeletal injuries (Speck, Courneya et al. 2010). Hence, caution should be exercised in recommending physical activity to cancer survivors in order to avoid or minimise potential harm that might be caused to some patients and general safety precautions should be observed while prescribing or performing exercise during or after cancer treatment (Table 1.2). The American College of Sports Medicine has published guidance on certain contraindications and modifications of exercise based on cancer site which can be followed to minimise the associated risks mentioned above (Schmitz, Courneya et al. 2010).

**Table 1.2:** General safety precautions to avoid adverse events in cancer survivors

Potential adverse event	Precautions
<b>Exacerbation of symptoms (e.g. pain, fatigue, nausea, dyspnoea)</b>	Avoid high-intensity exercise; monitor symptoms; modify exercise type based on site of treatment (e.g. avoid exercise bike after prostate/rectal surgery).
<b>Immunosuppression</b>	If patient has low white blood cell counts, avoid high intensity/volume of exercise (keep to light – moderate intensity).
<b>Falls</b>	If patient has dizziness, frailty, and peripheral sensory neuropathy: incorporate balance and co-ordination exercises (e.g. tai chi) and avoid activities needing considerable balance/coordination (e.g. treadmill).
<b>Bone fracture</b>	If patient has bone metastases/osteoporosis risk avoid high impact or contact activities.
<b>Lymphoedema</b>	To prevent lymphoedema, progressive resistance exercises in small and gradual increments. To avoid exacerbation of lymph-oedema, avoid strenuous repetitive exercise with affected limb; wear compression garment.

**Source:** Macmillan, 2012 Review (Macmillan 2012).

### 1.5.2 Physical Activity Guidelines

Various world and national health organisations of different countries have issued guidelines for the optimum amount and frequency of physical activity for both the general population as well as chronically ill patients, including those with cancer, to reap the benefits of physical activity and, decrease the disease burden and cost to society.

The WHO has developed global recommendations to address the links between frequency, duration, intensity, type and total amount of physical activity needed for the prevention of non-communicable diseases in different age groups. The different age groups are: children and young people of 5-17 years age group who need “at least 60 minutes of moderate- to vigorous-intensity physical activity daily”; 18-64 years “at least 150 minutes of moderate-intensity, or 75 minutes of vigorous intensity aerobic physical activity, or a combination of two throughout the week”; for 65 years and above, the recommendation for the amount of physical activity is the same as for 18-64 age group but the mode of performing the activity would be more inclined towards leisure, recreation or household chores (WHO 2010). The American College of Sports Medicine (ACSM) recommends a combination of aerobic, resistance and progressive flexibility exercises to attain the desired amount and frequency of physical activity to gain optimal health benefits in both preventing and fighting chronic diseases (Garber, Blissmer et al. 2011). The Department of Health in the UK made the same recommendations for the amount and frequency of exercise as the WHO and emphasised the inclusion of muscle strengthening and flexibility exercises to improve muscle and bone mass and strength in the form of moderate-vigorous activity at least three days a week along with moderate activities for the rest of the week (Department of Health 2011). The importance of physical activity recommendations described above has been further emphasised for cancer survivors to combat diagnosis and treatment related physical and psychological morbidity in the latest update of the American College of Sports Medicine (ACSM) physical activity guidelines for cancer survivors (American College of Sports Medicine 2013).

### **1.5.3 Implications of Physical Inactivity for Cancer Survivorship**

As has been described earlier physical inactivity is a big issue among the general population. Physical activity levels are even lower amongst cancer survivors (Irwin, Tiernan et al. 2004; Stevinson, Lydon et al. 2013; Stevinson 2014), where the tendency to rest and to limit physical activity is a common response to symptoms like pain, fatigue, nausea and depression, even though these symptoms are known to improve with exercise (Stevinson, Capstick et al. 2009).

It has been estimated that 10% of breast and colon cancer each worldwide are caused by physical inactivity (Lee, Shiroma et al. 2012). It is one of the nine environmental and behavioural risk factors, including seven infectious causes, which are responsible for 45% of cancer deaths worldwide (WHO 2009). It has been shown to provide a protective effect along-with a balanced diet, refraining from tobacco and abstaining or moderating alcohol use (Allender, Foster et al. 2007).

Macmillan UK has estimated that at least 1.6 million of the two million cancer survivors do not achieve the recommended levels of activity including 1.1 million who are

aged 65 and over (Maddams, Brewster et al. 2009). This is despite the known beneficial effects of physical activity for cancer survivors, which range from improving quality of life and physical function to reducing the risk of cancer recurrence and of dying from cancer. As the majority of the inactive cancer survivors are older adults, there is a need to target this group of survivors. The following sections will discuss physical activity promotion focusing on the adult cancer survivors.

## **1.6 Physical Activity Promotion for Adult Cancer Survivors**

The benefits of physical activity promotion among cancer survivors are well established (Schmitz, Courneya et al. 2010; WHO 2010; Department of Health 2011). Depression and anxiety related to diagnosis and subsequent fatigue related to treatment can lead cancer survivors to be isolated, inactive and socially restrictive. Encouraging them to be physically active can increase their participation in community activities as well as in household and daily life activities which further support reintegration.

Several ways to promote physical activity among cancer survivors have been used (Fong, Ho et al. 2012; Mishra, Scherer et al. 2012). Various avenues amenable to effective physical activity promotional interventions can both be considered at national as well as regional or local levels. Larger scale interventions include the introduction and implementation of evidence-based policies and provision of appropriate and conducive environments for these policies to work, and mass media campaigns to educate individuals. Interventions at workplaces, and community, primary health care, and religious settings are examples of regional or local initiatives (WHO 2009). A brief description of these follows.

### **1.6.1 Policy and Environmental Approaches**

Government led policy change and implementation has been found to be one of the most important ways to bring about change in attitudes to physical activity (NHS 2008; WG 2009; WHO 2010; Department of Health 2011). It can be achieved by overcoming barriers to public health, by taking inter-sector initiatives in community urban design, and by improving communication between different professional groups (i.e., urban planners, architects, engineers, and public health professionals) (Heath, Brownson et al. 2006; NHS 2008). Some of such suggested steps are listed below:

- Creation of new infrastructure in the built environment such as:
  - Walking and biking trails or creating new exercise facilities (Linenger 1991).
  - Installation of fitness equipment in parks and its promotion to increase physical activity among children, young people, and adults. Physical activity in a natural environment has been shown to be more effective than when

performed indoors. This approach has been shown to be cost effective (Wang, Macera et al. 2004; Cohen, Marsh et al. 2012).

- Improving access to existing facilities through improving affordability and expanded hours of operation (Linenger 1991) to allow working people access to the facilities after working hours.
  - Reduction of environmental and/or structural barriers to improve safety (Hoehner, Soares et al. 2008; NHS 2008) by providing integrated paths dedicated to bike and walking (Kahn, Ramsey et al. 2002), as well as by providing well-lit street design (Heath, Brownson et al. 2006). This type of intervention might be applicable across diverse settings and population groups because of its generic nature and human commonality of the senses of aesthetics and safety (Heath, Brownson et al. 2006; Global Advocacy Council for Physical Activity 2010).
  - Improved provision of social support, and further integration of these structures, facilities, and different programs into communities (Linenger 1991).
- Improving transport or travel infrastructure arrangements and safety by:
- modifying the perceived norms of modes of transport such as enhancing pedestrian, and light rail access (subsidy of transit passes)
  - increasing pedestrian and cyclist activity and safety (creation or enhancement of bike lanes or both; building of pavements; bicycle racks on buses and trains)
  - and reducing car use (cycle-to-work; car share schemes; increases in the cost of parking) (Heath, Brownson et al. 2006).
- Promoting active and healthy travel modes, leading to improved social capital (i.e. expected collective or economic benefits derived from cooperation between individuals and groups) (Nazelle, Nieuwenhuijsen et al. 2011) by:
- Involving communities in policy and intervention formulation (Hoehner, Soares et al. 2008; Matsudo, Matsudo et al. 2010; Reis, Hallal et al. 2010; Díaz del Castillo, Sarmiento et al. 2011) with multicomponent approaches to promote physical activity by reducing environmental and structural barriers (Hoehner, Soares et al. 2008).
  - Promoting through media campaigns and offering incentives at various levels (e.g. individual, corporate, local, and regional) to not only motivate individual behaviour change, but also provides institutional and environmental support to sustain changes in physical activity behaviour (Hoehner, Soares et al. 2008; Sarmiento, Torres et al. 2010; Montes, Sarmiento et al. 2012).

One of the drawbacks of these approaches is that most of the implementation and evaluation studies have been conducted and the interventions shown to be effective in dense urban environments (Heath, Brownson et al. 2006). Further research is needed to investigate whether the same benefits would hold true in rural areas (Heath, Brownson et al. 2006).

### **1.6.2 Campaigns and Informational Approaches**

National or community-wide campaigns can be run and implemented as part of a policy initiative/change or stand-alone promotional activities either through national or local government departments or charities, or both as partnerships (Young, Haskell et al. 1996; Kahn, Ramsey et al. 2002; Reger, Cooper et al. 2002; Macmillan 2012) representing large-scale, high-intensity, high-visibility programmes often using television, radio, newspapers, and other media to raise awareness, disseminate targeted health messages to specific segments of the population (i.e. segmented messages), and reinforce behaviour change.

The above discussed campaigns are resource intensive, and usually targeted at specific populations in countries of middle to high income (Kahn, Ramsey et al. 2002); and the extent and length of the campaigns along with number of sectors and sites involved and communities targeted depends upon the national, regional and local disease prevalence, health priorities and resources available. There is inconsistent evidence for their effectiveness, especially in low to middle income countries (Hoehner, Soares et al. 2008; Baker, Francis et al. 2011).

Mass media campaigns, especially those linked to specific community programmes, despite having insufficient evidence (Kahn, Ramsey et al. 2002), have also emerged as a promising public health practice (Owen, Bauman et al. 1995; Bauman, Smith et al. 2006; Leavy, Bull et al. 2011). Recent evidence suggests that programmes to promote walking in groups have been found useful in increasing physical activity levels of participants. These promotional programmes have been gaining in popularity and many local governments, as well as charity partners in the community, have been promoting them.

Another emerging approach, distinct from mass media campaigns, is the delivery of short informational, educational, instructional, and motivational messages about physical activity (Hoehner, Soares et al. 2008). These could be delivered regularly (from daily to three times per week) to the target population at key community sites such as workplaces, centres for senior citizens, and community centres by a health educator or communicator (Ferreira, Matsudo et al. 2005).

Strategies using single-component point-of-decision prompts designed to remind and motivate people to use physically active short range mobility modes are supported by sufficient evidence when population-specific signage has been used in various settings (e.g. transport stations, worksites, hospitals, universities, and shopping centres). These might



include using stairs in buildings instead of the lift or escalator to ascend or descend to another floor (Kahn, Ramsey et al. 2002), and improved access to stairs (Kahn, Ramsey et al. 2002; NICE 2006; Nocon, Müller-Riemenschneider et al. 2010; Soler, Leeks et al. 2010; Webb, F. et al. 2011).

### **1.6.3 Behavioural and Social Approaches**

These approaches in principal are targeted at individuals and aim to motivate participants to incorporate physical activity into their daily routines (Kahn, Ramsey et al. 2002). The programmes are usually individually adapted having single or multicomponent elements, and might include goal setting, social support, and behavioural reinforcement through self-reward, structured problem solving, and relapse prevention as the basic ingredients (Kahn, Ramsey et al. 2002). Such programmes use various modes or venues for delivery to participants both individually and in group settings. The delivery could be face to face, or through paper or electronic media such as mail, email, internet, or telephone, or any combination of these. Innovative approaches of intervention delivery using electronic tracking and web monitoring technology and employing incentive based performance rewards has been shown to affect short term behaviour modification to physical activity (Lee, Shiroma et al. 2012; Murray, Vos et al. 2012).

Lifestyle physical activity interventions are usually focused on individuals and comprise participants' physical activity assessment and readiness to change, which form the basis of a tailored activity plan, and could be provided through a centralised community programme run by health providers or promoters (Dunn, Marcus et al. 1999).

Social networks can be used to reinforce physical activity behaviour in strategies employing principles of social support to build walking or other physical activity support groups or clubs, or create buddy systems in community settings which might range from worksites, community centres, health facilities, and parks and recreational facilities (Linn, O'Connor et al. 2010). These networks or groups can use various modes of short and/or regular, periodic communication such as newsletters, phone or text message prompts to organise events, create route maps, provide support if needed and keep the members motivated, and to reinforce and sustain the networks (Kriska, Bayles et al. 1986; Lombard, Lombard et al. 1995).

Evidence indicates that if provider based physical activity counselling and advice are integrated into existing community initiatives (Patrick, Pratt et al. 2009), rather than being recommended as single component interventions, the behaviour modification is likely to be successful and maintained over time. Hence, primary health care based systems such as the UK's can be used as a good venue for this purpose as the majority of population consult their primary health care staff including the general practitioners as well as nurses on a regular basis (Brownson, Ballew et al. 2007).

The evidence for physical activity promotion by health-care providers such as brief stand-alone counselling is weak, but office based screening and advice followed by telephone or community support have shown promise to help sustain long-term improvements in physical activity behaviour (van Sluijs, van Poppel et al. 2005). This would indicate that coordination with clinical and community resources could be a better way to promote physical activity (Pavey, Taylor et al. 2011).

### **Physical activity promotion in primary care**

This section will describe various initiatives of physical activity promotion in the UK that make use of the above-mentioned approaches for patients with various chronic conditions including cancer survivors. It will also highlight the areas that lack sufficient or purposeful actions to exploit opportunities for physical activity promotion. The National Institute for Health and Care Excellence (NICE) has made recommendations on various modes of physical activity promotion encompassing brief interventions in primary care, exercise referral schemes, pedometers and community-based exercise programmes for walking and cycling (NICE 2006).

Opportunistic brief interventions in primary care are considered to be best suited for health systems like that of the UK where the majority of the population visit their GPs annually. Cancer patients may be receptive to modify their behaviour towards healthy lifestyle at the completion of their treatment (Costanzo, Lutgendorf et al. 2011). Emphasis has been placed on utilising this opportunity by enhancing the health care practitioners' role in physical activity promotion in both the general population as well as in cancer survivors (Din, Moore et al. 2015). This has also been recommended in both the Cancer Reform Strategy and the National Cancer Survivorship Initiative (NCSI), which also emphasise the need for health care professionals' education and training to effectively help their patients' self-management (Lawn 2009). NICE, NCSI, Macmillan cancer support and other partnerships are trying to address this issue by producing evidence based guidelines, recommendations and strategies for signposting to sources of support by disseminating information both electronically on their websites as well as conducting workshops and seminars (Campbell, Foster et al. 2011; Macmillan 2011). The National Cancer Survivorship Initiative has also produced an Integrated Care Pathway for cancer survivors incorporating physical activity promotion at various stages through the 'Let's Get Moving' initiative of the Department of Health-Macmillan partnership (Health 2009).

Exercise referral schemes such as the National Exercise Referral Scheme (NERS) in Wales are trying to tackle the issue of physical inactivity by providing both the health professionals as well as patients a policy initiative of a tailored, structured supervised programme of physical activity through locally participating leisure centres either free or at a substantially reduced cost depending upon patients' condition and circumstances (Murphy,

Edwards et al. 2012). Recent systematic reviews of such schemes have shown a small but significant increase in physical activity in the short term, although long term effectiveness has been questionable (Williams, Hendry et al. 2007; Pavey, Taylor et al. 2011; National Institute of Health and Care Excellence 2013). Such effects, though, have been largely attributed to better uptake and adherence (Pavey, Taylor et al. 2011; Hanson, Allin et al. 2013). This was highlighted in a randomised controlled trial of the NERS in Wales (Murphy, Edwards et al. 2012), where patients were referred from primary care to specialist physical activity services in the participating local leisure centres. The findings of this trial indicated improvements in both the physical activity levels in those with risk factors for coronary heart disease (CHD), as well as improvement in anxiety and depression in depressed patients without an increase in physical activity. Mediation analysis of the trial data showed that the motivation to change behaviour to enter the scheme was both internally motivated where people requested the scheme entry as well as externally motivated where they entered the scheme on the advice of a primary health professional such as their GP or nurse (Littlecott, Moore et al. 2014).

The information available through various media raises the awareness of cancer survivors of the need to increase their physical activity levels so to improve physical function, quality of life and survival. They may then be receptive to interventions for promoting physical activity (Stevinson 2014).

## **1.7 Summary of the review**

This literature review has provided epidemiological evidence for the growing burden of chronic diseases especially cancer with particular focus on increasing physical inactivity (WHO 2012). Consequently, physical activity promotion has been recognised as one of the biggest global initiatives to address this challenge (WHO 2013). But the cost and resource demands for such initiatives are huge. Hence, the need for low-cost and low-maintenance interventions was highlighted, physical activity advice to patients, and promotional activities across the spectrum of patients' cancer care being among these.

Evidence is lacking about the effectiveness and cost-effectiveness of different modes of physical activity education for adult cancer survivors (WHO 2009). Therefore, the need for further research in different physical activity promotional approaches was identified in the above sections. The overall aim of this research is to develop an appropriate intervention to encourage cancer survivors to be more physically active.

## 1.8 Journey of the research project

Like mostly happens in many research studies, modifications had to be made after commencement in this PhD project. It is important to talk about these at this point to set the scene for the intervention developmental process that would follow.

This research project was funded by the Clinical Epidemiology Interdisciplinary Research Group (IRG), Cardiff University, and was commenced in March 2011, hosted and sponsored by Bangor University. The original title of this research work was “Development of a physical activity booklet for cancer survivors and its evaluation in a pilot randomised controlled trial”. Two phases of the research were planned: the first was to develop a physical activity booklet for cancer survivors modelled after a similar earlier work done in the North Wales Centre for Primary Care Research (NWPCR) on the development of a physical activity booklet for patients with arthritis of the hip and knee (Williams, Amoakwa et al. 2010). The developmental phase intended to use a systematic review and focus groups of adult cancer survivors. The second phase originally comprised a pilot Randomised Controlled Trial (RCT) to evaluate the effectiveness of this new booklet (Appendix A) compared with an existing booklet for cancer survivors which was published by Macmillan that placed less emphasis on the importance of physical activity. The aim of the improved booklet was to motivate cancer survivors to be physically active, to lead a healthy lifestyle and maintain autonomy.

As planned in the first phase, the systematic review was conducted which synthesised the evidence to highlight both the need and the effectiveness of educational materials. It was completed in August 2011 and found that education materials are effective in promoting physical activity, favouring the development of the proposed evidence-based booklet to promote physical activity among cancer survivors.

Further funding (£17K) was arranged from the Betsi Cadwaladr University Health Board (BCUHB) Health & Social Care Research Projects Small Grants Scheme 2011 in North Wales to conduct focus groups of adult cancer survivors to inform the refinement of the evidence-based booklet about physical activity promotion. The funding also covered the cost of a future pilot randomised controlled trial of the developed booklet. The research was adopted as a portfolio study by the Wales School for Primary Care Research and was also advertised on their website (Appendix B) <http://www.wspcr.ac.uk/physical-activity-for-cancer-survivors.php>

### Variation from the original proposal

*Development of a new physical activity booklet by Macmillan:* In August 2011, Macmillan published a new booklet (within a pack called MoveMore) for cancer survivors that focussed on physical activity, with similar aims and content to the one this studentship had

planned to develop (Campbell, Foster et al. 2011; Macmillan Cancer Support 2011). It had very similar intended outcomes to the original plan of this project. Hence, the supervisory team advised to stop work on the development of the booklet to avoid duplication of effort. This was a major setback to this PhD project, since the development of the booklet represented a significant proportion of the planned work.

### ***First revision of the project***

Faced with the above mentioned dilemma, and with discussion and advice from the PhD supervisors, the research plan was amended. Instead of using the older Macmillan booklet as a control intervention, the new plan was to test the new Macmillan booklet in a pilot randomised controlled trial to assess its effectiveness to promote physical activity for adult cancer survivors versus current usual practice (no booklet).

The study protocol was revised and presented for ethical approvals to the regional ethics committee. While the revision process was ongoing, Macmillan started a physical activity promotional campaign based on their newly-developed booklet. Their aim was to incorporate the booklet into the current physical activity promotional practice by offering the booklet to *all* cancer patients during their cancer journey starting from diagnosis until completion of their treatment. As a result of this initiative, by the time the earlier phases of the study were complete and the ethical approvals were in process to conduct the pilot RCT, the new booklet would have become “usual practice” and therefore the control arm of the pilot RCT in the revised protocol would have been lost. Hence the application was not presented for approvals, and further modifications to the study design were needed.

### ***Second revision of the project***

Since the first two research ideas i.e. the plan to develop an intervention, and then the control group of the planned trial had to be abandoned, there was a need to find a new research idea. Findings from the systematic review also showed evidence for the positive role of reminders and telephone counselling in reinforcing physical activity promotional messages and modifying physical activity behaviour. Therefore, this was decided as the focus of a new intervention.

All cancer survivors were to receive the Macmillan booklet as part of usual care so different options were considered for reinforcing the messages within the booklet, and text messages were decided to be a preferred method to reinforce the physical activity advice in cancer survivors.

To summarise, the modification of the original research proposal focused on the design and development of physical activity promotional and/or a motivational intervention based on the theoretical models of behaviour change, especially focusing on the reinforcement technique in the form of regular weekly reminders (physical activity

promotional text messages) during adult cancer survivors' post-treatment period. Medical Research Council (MRC) framework for developing complex intervention (Craig, Dieppe et al. 2008) was considered while designing and developing the intervention for this research which is explained in chapter 6. The outcome of this research, the developed physical activity behaviour change intervention is proposed as a future research study in a feasibility randomised controlled trial (Chapter 7, Section 7.6.1) which may help adult cancer survivors' to adhere and maintain physical activity.

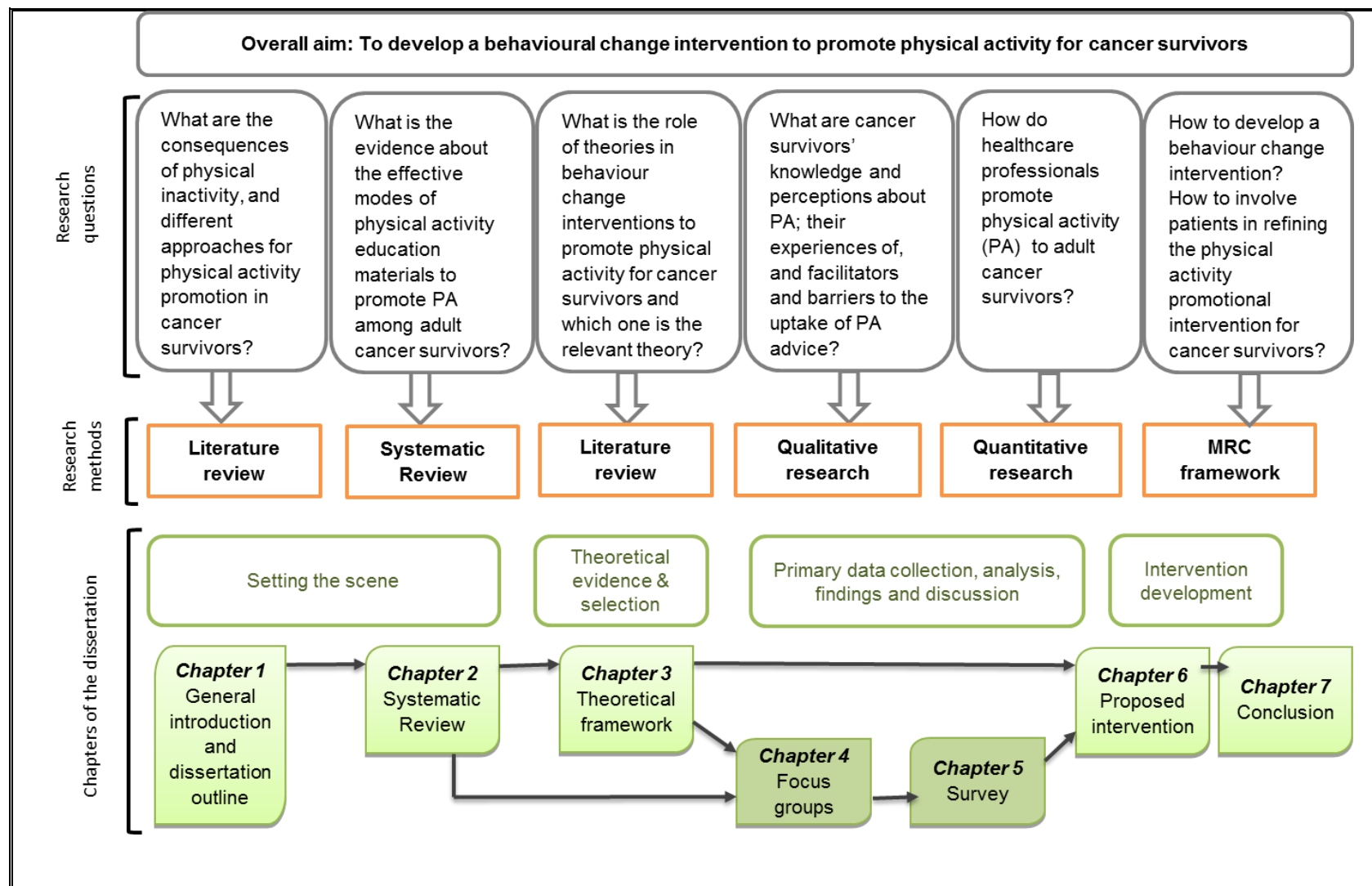
## **1.9 Aim and objectives of the thesis**

The overall aim of this study was to design and develop a psychological behaviour change intervention to promote physical activity among adult cancer survivors. This overall aim was addressed through the following objectives:

- 1) Conduct a systematic review of the evidence for the effectiveness of physical activity education materials among adult cancer survivors (chapter 2)
- 2) Conduct a literature review to explore theoretical underpinning, leading to development of a physical activity behaviour change intervention (chapter 3)
- 3) Conduct a qualitative study examining cancer survivors' perceptions about physical activity; barriers and facilitators to uptake physical activity advice (chapter 4)
- 4) Conduct a questionnaire survey examining physical activity promotional attitudes and practices of health professionals to cancer survivors in North Wales (chapter 5)
- 5) Develop a protocol for a future randomised controlled trial (chapter 7)

The rationale behind these aims and objectives is that the evidence generated through analysing the primary and secondary data as part of the thesis will help formulate a physical activity behaviour reinforcement intervention underpinned by sound psychological theory (Figure 1.1).

**Figure 1.1:** Schematic diagram to show the thesis outline (research questions, methodologies, and layout of the chapters)



## 1.10 Research Questions and novel contributions

### ***Chapter 2: Systematic review with meta-analysis: Effectiveness of physical activity education materials among adult cancer survivors***

*Research question:* What is the evidence about the effective modes of physical activity education materials to promote physical activity among adult cancer survivors?

*Contribution:* This is the first systematic review to describe the effectiveness of education materials to promote physical activity among adult cancer survivors.

### ***Chapter 3: Theoretical framework of a physical activity promotional intervention***

*Research question:* What is the role of theories in behaviour change interventions to promote physical activity for cancer survivors and which one is the most relevant theory?

*Contribution:* This chapter explored various behavior change theories to find out the most appropriate one that was used to underpin the developed intervention.

### ***Chapter 4: A qualitative study: Cancer survivors' perceptions about physical activity; barriers and facilitators to uptake of physical activity advice***

*Research question 4-a:* What are cancer survivors' knowledge and perceptions about physical activity, and their experiences of, facilitators and barriers to the uptake of physical activity advice?

*Contribution:* This is the first qualitative study which explored cancer survivors' perspectives about the physical activity promotion they receive in healthcare settings.

*Research question 4-b:* How to involve patients in refining the motivational messages to promote physical activity in adult cancer survivors?

*Contribution:* This phase employed the principle of patient (service user) involvement to refine and evaluate the acceptability of a newly developed physical activity promotional intervention.

### ***Chapter 5: A questionnaire survey: Physical activity promotional attitudes and practices of health professionals to cancer survivors in North Wales***

*Research question:* How do healthcare professionals promote physical activity to adult cancer survivors?

*Contribution:* This is the first quantitative survey which has explored the attitude of health professional in primary and secondary care about physical activity promotion in cancer patients.



***Chapter 6: Theoretical underpinning and development of a physical activity promotional intervention***

*Research question:* How to design and develop a theory based behaviour change intervention to promote physical activity among adult cancer survivors?

*Contribution:* The development of a novel physical activity behaviour change intervention as an adjunct to usual follow-up care of adult cancer survivors.

## **Chapter 2. Effectiveness of physical activity education materials among adult cancer survivors: A systematic review with meta-analysis**

### **Aim:**

To synthesise the evidence about the effectiveness of patient education materials promoting physical activity for adult cancer survivors

### **Main findings:**

Physical activity education materials help cancer survivors to increase their physical activity levels.

Telephone counselling based on models of behaviour change improve adherence to physical activity.

## **2.0 Chapter summary**

This is the first systematic review with meta-analysis of the effectiveness of education materials to promote physical activity for cancer survivors. Standard review methods as described in the Cochrane Handbook were used. Seven primary studies were included. The findings indicated that educational materials were effective in helping patients to increase physical activity levels. Follow-up counselling was also found to play an important role in adherence to physical activity, especially when based on the behaviour change theories.

### **2.1 Introduction**

The introductory chapter (chapter 1) described the beneficial effects of physical activity and discussed different promotional approaches to attain these benefits in adult cancer survivors. However, it remains unclear what helps these patients to take up and maintain physical activity. This chapter aims to answer this question through a systematic review to explore what helps to promote physical activity in cancer survivors.

### **2.2 Methods**

Nineteen electronic databases were searched using a search strategy developed for Medline, and adapted for other databases without language restriction from inception to Feb 2014 (Appendix C). The bibliographies of the included studies and relevant systematic reviews were screened to identify further relevant studies. The resulting references were imported into reference management software Endnote X5. Multiple publications were grouped together and represented by a single reference. Two reviewers independently screened the references and applied the following inclusion criteria to potentially relevant references:

#### **2.2.1 Study population**

Adult survivors of any type of cancer, who had completed their radical or palliative intended curative treatment including surgery, and/or adjuvant chemotherapy, and/or radiotherapy, or did not undergo any treatment but rather were under a watchful surveillance (i.e. the cancer was slow growing or on border line malignancy i.e. prostate), and for whom there were no plans for further treatment (except hormone treatment for breast cancer).

#### **2.2.2 Interventions and comparators**

We included any kind of patient education material used to encourage physical activity among adult cancer survivors compared with any other intervention, usual care or no

intervention. Studies with an additional intervention arm or combined intervention (e.g., exercise with diet modification) were included only if the effects of exercise could be isolated.

### **2.2.3 Outcomes**

The primary outcome was any measure of increase in physical activity. Secondary outcomes included any change in physical or psychological health related to increased physical activity such as weight loss, reduction in pain or fatigue, and improvement in mood or quality of life.

### **2.2.4 Exclusion criteria**

Studies of cancer survivors of childhood, supervised exercise programmes and home based exercise without education material were excluded. We also excluded exercise interventions delivered during cancer treatment but discontinued after treatment because of cancer treatment related mortality, short life expectancy, refractory treatment response, and/or patient too frail to participate. We excluded reports where limited data were reported, e.g. study protocols and conference abstracts.

### **2.2.5 Data extraction**

Two independent reviewers extracted the data. Any disagreements on inclusion and data extraction were resolved by consensus or by consulting a third reviewer if necessary.

### **2.2.6 Quality assessment**

Two reviewers assessed the methodological quality of each included study independently, using the domain-based evaluation described in the Cochrane handbook (Higgins JPT and (editors). 2011). The evaluations were compared and disagreements were discussed and resolved between the reviewers.

### **2.2.7 Data analysis/synthesis**

The results were pooled using Revman 5.1 (2011) where appropriate using a random effects model. For continuous outcomes, individual study mean differences were reported; pooled statistics were calculated using weighted mean differences (WMD) when data were on a uniform scale and using standardised mean differences (SMD) when data were on different scales. All results were calculated with 95% confidence intervals (CIs). The estimated effect size was calculated for outcomes that were reported in two or more studies. Heterogeneity was assessed using  $\chi^2$  and  $I^2$  statistics, considering a p value of equal or less than 0.05 to indicate significant heterogeneity. When heterogeneity was evident, trials were not pooled and their results were reported narratively. Study methodology varied, with regards to exercise intervention, reported follow-up duration and outcome measures. We used the final study end point scores for the analysis.

## **2.3 Results**

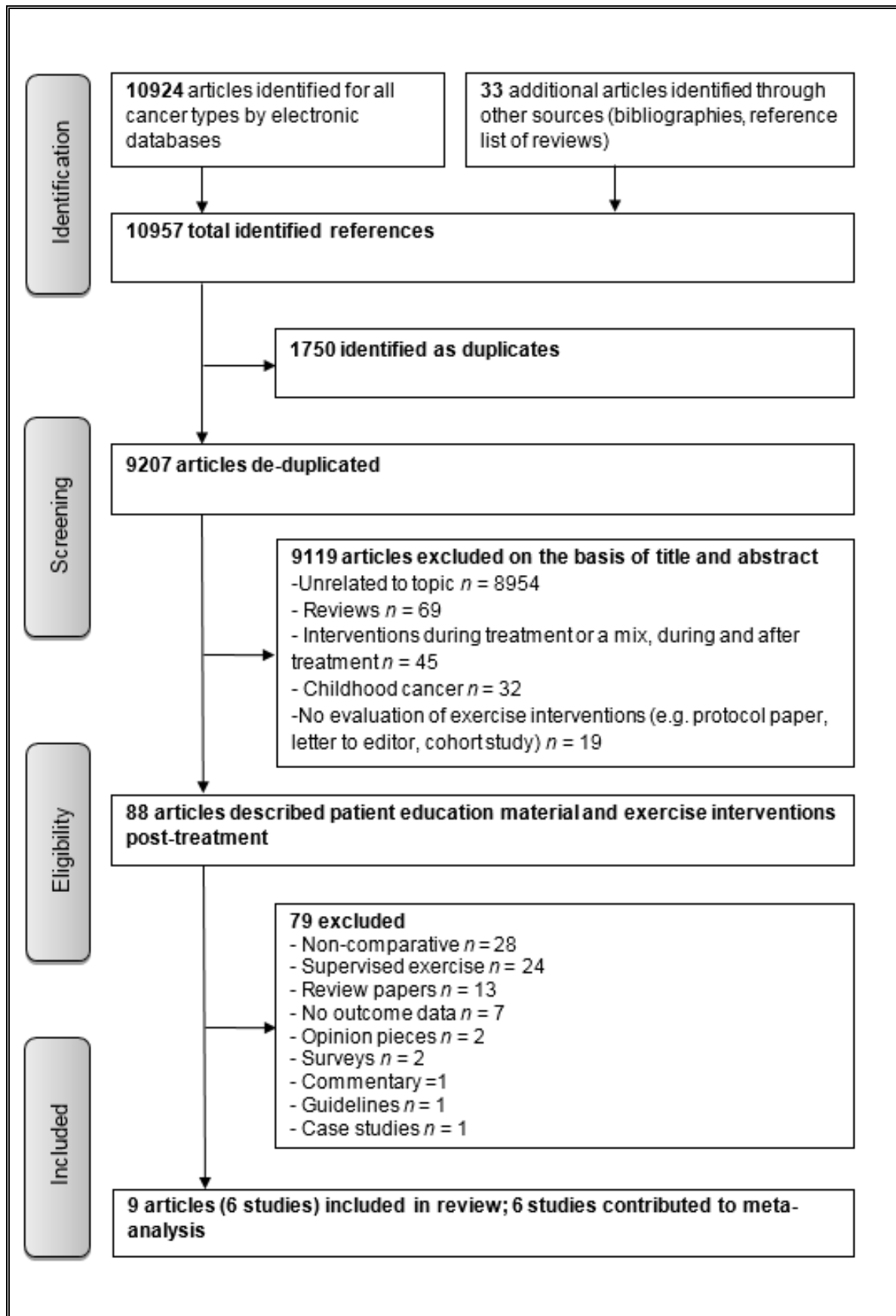
### **2.3.1 Search Results**

88 potentially relevant references were identified and full texts were retrieved for detailed evaluation. Of these, nine reports of six studies (Pinto, Frierson et al. 2005; Basen-Engquist, Taylor et al. 2006; Demark-Wahnefried, Clipp et al. 2006; Demark-Wahnefried, Clipp et al. 2007; Vallance, Courneya et al. 2007; Yuen and Sword 2007) involving 1270 participants fulfilled the inclusion criteria. A PRISMA flow diagram showing the number of references identified, retrieved and included in the review is presented in Figure 2.1.

### **2.3.2 Excluded Studies**

Of the 79 excluded references, 28 did not have a control group, 24 analysed the effects of supervised exercises either by trainers or by physiotherapists, 13 were reviews, seven had insufficient outcome data, two were opinion pieces, two were surveys, one was a case study, one was commentary on a published study and one reported guidelines only.

**Figure 2.1:** PRISMA flow-chart: Effects of physical activity education materials among cancer survivors: a systematic review with meta-analysis



### 2.3.3 Characteristics of Included Studies

We included nine reports of six studies where three studies (Pinto, Frierson et al. 2005; Demark-Wahnefried, Clipp et al. 2006; Vallance, Courneya et al. 2007) reported their findings in two articles. All of the included studies were randomised controlled trials including two pilot trials (Basen-Engquist, Taylor et al. 2006; Yuen and Sword 2007), where the latter was a three armed study (Table 2.1). Five studies (Pinto, Frierson et al. 2005; Basen-Engquist, Taylor et al. 2006; Demark-Wahnefried, Clipp et al. 2006; Demark-Wahnefried, Clipp et al. 2007; Yuen and Sword 2007) were conducted in the United States and one (Vallance, Courneya et al. 2007) in Canada. Four studies (Pinto, Frierson et al. 2005; Basen-Engquist, Taylor et al. 2006; Vallance, Courneya et al. 2007; Yuen and Sword 2007) examined exercise interventions exclusively in breast cancer survivors and two studies (Demark-Wahnefried, Clipp et al. 2006; Demark-Wahnefried, Clipp et al. 2007) examined both breast and prostate cancer survivors. Trial sample sizes ranged from 22 to 543 participants and the follow-up duration ranged from three to 12 months. Only two out of six studies (Pinto, Frierson et al. 2005; Basen-Engquist, Taylor et al. 2006) reported time since diagnosis, ranging from two to three years. The mean age of the participants was 57.6 years with a range of 37-91 years; one study (Demark-Wahnefried, Clipp et al. 2006) targeted an older population (age range 65-91 years). Two studies (Pinto, Frierson et al. 2005; Basen-Engquist, Taylor et al. 2006) did not report the age range. All studies recruited mainly a white/Caucasian population.

In four studies the physical activity education interventions were based on behaviour change models. All four used the Transtheoretical Model (Pinto, Frierson et al. 2005; Basen-Engquist, Taylor et al. 2006; Demark-Wahnefried, Clipp et al. 2006; Demark-Wahnefried, Clipp et al. 2007), and in addition two used Social Cognitive Theory (Demark-Wahnefried, Clipp et al. 2006; Demark-Wahnefried, Clipp et al. 2007).

**Table 2.1:** Characteristics of included studies: Examining the effects of physical activity education materials among adult cancer survivors

<b>Author, year (Country) Settings</b>	<b>Study design, follow-up duration (months)</b>	<b>Participants, mean age (years) (Cancer type)</b>	<b>Physical activity education material</b>	<b>Psychological models</b>	<b>Study author's conclusion</b>
<b>Basen-Engquist, 2006 (US) Hospital, multicentre</b>	RCT(pilot), 6	60 Women, 55 (Breast cancer)	Booklet	Transtheoretical Model	Lifestyle intervention improved physical aspects of quality of life.
<b>Demark-Wahnefried, 2007. (US) Hospital, multicentre</b>	RCT, 12	304 Women & 239 men, 57 (range 22-85) (Breast & Prostate cancer)	Exercise leaflet flyer	Transtheoretical Model Social Cognitive Theory	Fresh start intervention improved diet and exercise behaviour.
<b>Demark-Wahnefried, 2006. (US) Hospital, multicentre</b>	RCT, 12	104 Women & 78 Men, 72 (range 65-91) (Breast & Prostate cancer)	Work book + telephone calls	Transtheoretical Model Social Cognitive Theory	Home-based diet & exercise intervention is effective in physical functioning & lifestyle behaviour.
<b>Pinto, 2005 (US) Hospital, multicentre</b>	RCT, 9	86 Women, 53.1 (Breast cancer)	Tip sheets + telephone calls	Transtheoretical Model	Home-based physical activity intervention increased participation in moderate intensity activity.
<b>Vallance, 2007 (Canada) Hospital, multicentre</b>	RCT, 6	377 Women, 58 (range 30- 90) (Breast cancer)	Print materials + telephone counselling	-	All three intervention groups reported greater increase in physical activity than the control group.
<b>Yuen, 2007 (US) Cancer centre at Medical university</b>	RCT (pilot), 3	22 Women, 53.9 (range 32- 78) (Breast cancer)	Aerobic and resistance training exercise logs + weekly telephone calls	-	Both intervention groups provided valuable benefits to breast cancer survivors.



### 2.3.4 Characteristics of Interventions

These consisted of: a physical activity booklet (Basen-Engquist, Taylor et al. 2006); telephone counselling in combination with a physical activity workbook (the Fresh Start intervention) (Demark-Wahnefried, Clipp et al. 2006); written exercise instructions (Yuen and Sword 2007); physical activity tip sheets compared with cancer survivorship tip sheets (Pinto, Frierson et al. 2005); unspecified printed materials about physical activity (Demark-Wahnefried, Clipp et al. 2007; Vallance, Courneya et al. 2007). Two studies (Vallance, Courneya et al. 2007; Yuen and Sword 2007) had more than one intervention group. The summary of interventions comparing physical activity education material with other interventions is described in detail in section 2.3.7.

### 2.3.5 Risk of Bias

Five studies reported random sequence generation using minimisation (Basen-Engquist, Taylor et al. 2006), random assignment using software (Demark-Wahnefried, Clipp et al. 2007), block randomisation (Demark-Wahnefried, Clipp et al. 2006), and computer generated random sequence (Vallance, Courneya et al. 2007; Yuen and Sword 2007) respectively. One study did not report the method of randomisation increasing the likelihood of selection bias (Pinto, Frierson et al. 2005). Similarly, three of the six included studies reported allocation concealment, reducing the risk of bias: performed remotely and concealed (Demark-Wahnefried, Clipp et al. 2007); performed by statistician with no patient contact (Demark-Wahnefried, Clipp et al. 2006); and by using sealed envelopes concealed from project coordinator (Vallance, Courneya et al. 2007); whereas, the other three studies lacked information about method of allocation to permit a clear judgment (Pinto, Frierson et al. 2005; Basen-Engquist, Taylor et al. 2006; Yuen and Sword 2007).

Two studies were assessed as low risk of detection bias: one reported blinding of the outcome assessors to treatment allocation (Basen-Engquist, Taylor et al. 2006), whereas the other reported self-completed outcome measures (Vallance, Courneya et al. 2007). Four studies provided insufficient or unclear information to permit a clear judgement (Pinto, Frierson et al. 2005; Demark-Wahnefried, Clipp et al. 2006; Demark-Wahnefried, Clipp et al. 2007; Yuen and Sword 2007).

Attrition bias was assessed as low risk in four studies which used intention to treat analysis (Demark-Wahnefried, Clipp et al. 2007), repeated measures analysis (Demark-Wahnefried, Clipp et al. 2006), missing data handled by baseline measurement carried forward (Pinto, Frierson et al. 2005), and by using linear mixed model analysis (Vallance, Courneya et al. 2007) respectively. Two studies were assessed as high risk of attrition bias due to lack of details about handling the missing data (Basen-Engquist, Taylor et al. 2006; Yuen and Sword 2007). None of the studies performed participant blinding resulting in high

risk of performance bias. All of the included studies were assessed as low risk of reporting bias as they reported a wide range of outcomes and sufficient details of interventions, comparators and population characteristics (Pinto, Frierson et al. 2005; Basen-Engquist, Taylor et al. 2006; Demark-Wahnefried, Clipp et al. 2006; Demark-Wahnefried, Clipp et al. 2007; Vallance, Courneya et al. 2007; Yuen and Sword 2007). Overall quality of all the included studies was assessed as high. The assessed domains with support for judgements about each study are presented graphically in Figure 2.2 and further explained in Appendix D.

**Figure 2.2:** Risk of bias summary: Review authors' judgements about each risk of bias domain (columns) for each included study (rows).

	Yuen 2007	Vallance 2007	Pinto 2005	Demark-Wahnefried 2007	Demark-Wahnefried 2006	Basen-Engquist 2006	
Random sequence generation (selection bias)	+	+	?	+	+	+	
Allocation concealment (selection bias)	?	+	?	+	+	?	
Blinding of participants and personnel (performance bias)	-	-	-	-	-	-	
Blinding of outcome assessment (detection bias)	?	+	?	?	?	+	
Incomplete outcome data (attrition bias)	-	+	+	+	+	-	
Selective reporting (reporting bias)	+	+	+	+	+	+	
Other bias	+	+	+	+	+	+	

Footnote: (+) indicated a low risk of bias, (?) indicated an unclear risk of bias, and (-) indicated a high risk of bias.

### 2.3.6 Outcome Measures used in the Studies

#### *Physical activity amount/time*

Three studies (Pinto, Frierson et al. 2005; Basen-Engquist, Taylor et al. 2006; Demark-Wahnefried, Clipp et al. 2007) used the seven day physical activity recall (7 Day PAR) scale administered via telephone interviews, one (Demark-Wahnefried, Clipp et al. 2006) used Community Healthy Activities Model Programme for Seniors (CHAMPS) scale via telephone interviews, and one (Vallance, Courneya et al. 2007) used self-reported Godin's Leisure Score Index (LSI) scale.

**Physical performance**

Two studies (Basen-Engquist, Taylor et al. 2006; Yuen and Sword 2007) used the 6 Minutes' Walk Test which were assessed by physiotherapist and researcher respectively; and one study (Pinto, Frierson et al. 2005) used the 1 Mile Walk Test which was assessed by the researcher on an indoor track.

**Quality of life**

Two studies (Demark-Wahnefried, Clipp et al. 2006; Demark-Wahnefried, Clipp et al. 2007) measured quality of life using Functional Assessment of Cancer Therapy-General (FACT-G) through telephone interviews; one (Vallance, Courneya et al. 2007) used FACT-Breast; and two used the SF-36 scale, with one using self-report approach (Basen-Engquist, Taylor et al. 2006; Demark-Wahnefried, Clipp et al. 2006).

**Behaviour change**

Three studies (Pinto, Frierson et al. 2005; Basen-Engquist, Taylor et al. 2006; Demark-Wahnefried, Clipp et al. 2007) used Stage of Motivational Readiness for Physical Activity to assess the stages of change model but all used different techniques to collect the data. One (Basen-Engquist, Taylor et al. 2006) used interviewer administered questionnaire, the other (Basen-Engquist, Taylor et al. 2006) used telephone interviews, and the third (Demark-Wahnefried, Clipp et al. 2007) utilised computer assisted interview technique.

**Body mass index**

Three studies (Pinto, Frierson et al. 2005; Basen-Engquist, Taylor et al. 2006; Demark-Wahnefried, Clipp et al. 2006) reported Body Mass Index (BMI) kg/m<sup>2</sup>. In one study this was assessed by the researcher (Pinto, Frierson et al. 2005); in the other by the physiotherapist (Basen-Engquist, Taylor et al. 2006); and in third the information was gathered by telephone interviews where the participants were advised to get it measured at a health setting closer to their residence and report back to the researcher while during the telephone interviews {Demark-Wahnefried, Clipp et al. 2006}.

**Fatigue**

Three studies (Pinto, Frierson et al. 2005; Vallance, Courneya et al. 2007; Yuen and Sword 2007) gathered fatigue data through self-reported linear fatigue scale (0-52) (Pinto, Frierson et al. 2005), linear analogue scale (Vallance, Courneya et al. 2007), and piper fatigue scale (Yuen and Sword 2007) respectively.

Details of the outcome measures used in each study with their effectiveness are shown in Table 2.2.

### **2.3.7 Synthesis of Reported Outcomes**

A detailed summary of the interventions and comparators used in different studies is presented in detail in Table 2.3. A description of specific outcomes and the related effect sizes follow in the next sections.

**Table 2.2:** Outcome measures used in each study with their effectiveness

Study ID	Outcomes reported					
	Physical activity	Physical performance	Quality of life	Psychological	Diet/BMI	Pain/Fatigue
<b>PA education material vs usual care</b>						
<b>Basen-Engquist 2006</b>	Telephone interviews: 7-DayPAR	Assessed by physiotherapist: 6-min walk test; 50-foot walk test; Timed sit-to-stand test; Timed reach-up test	Self-reported: Health-related quality of life based on eight health concepts (SF-36)	Telephone interviews: Stage of Motivational Readiness for PA	Assessed by physiotherapist: BMI from height & weight	
<b>Demark-Wahnefried 2007</b>	Computer-assisted telephone interviews: 7-DayPAR		Computer-assisted telephone interviews: FACT-G scale	Computer-assisted telephone interviews: Self-efficacy for PA 150 min/week	Researcher assessed: heights & weights of the 23% subsample at both time points; weight status was expressed as BMI	
<b>Yuen 2007</b>		Researcher assessed: Tests conducted on a level surface indoors in a climate-controlled environment (6MWT)				Self-reported: Piper Fatigue Scale; monthly calendars to complete daily fatigue logs, collected at the end of study
<b>PA education material + Telephone counselling vs usual care</b>						
<b>Demark-Wahnefried 2006</b>	Computer-assisted telephone interviews: CHAMPS		Computer-assisted telephone interviews: SF-36	Computer-assisted telephone interviews: Self-efficacy & Stage of Motivational Readiness for PA	Computer-assisted telephone interviews: Patients residing within 60 miles were asked to report for clinically assessed for BMI	
<b>Pinto 2006</b>	Interviewer-administered: 7-DayPAR	Researcher assessed: 1-mile walk test on an indoor track		Interviewer-administered: Stage of Motivational Readiness for PA	Researcher assessed: BMI-Body weight & height measured on a calibrated scale	Self-reported: Linear Fatigue Scale (0-52)
<b>PA education material + PA advice vs PA advice only</b>						
<b>Vallance 2007</b>	Self-reported: leisure score index (LSI)		Self-reported: FACT-B			Self-reported: Linear Analogue Scale
<b>PA education material + PA advice + Pedometer vs PA advice only</b>						
<b>Vallance 2007</b>	Self-reported: 7-day step log		Self-reported: FACT-B			Self-reported: Linear Analogue Scale
<b>Key:</b>	PA Education materials were more effective than the control(s)		There was no difference between PA Education materials and control(s)		Did not report this outcome	

**Table 2.3:** Summary of the interventions comparing physical activity education material with other interventions

Author, year	Physical activity education material description	Control description
<b>Physical activity education material versus usual care or physical activity advice</b>		
<b>Basen-Engquist, 2006 (US)</b>	<u>Physical activity booklets</u> matched to stage of readiness, assessments every 4-5 weeks; 90 min PA group meetings; weekly-16 weeks, biweekly-8 weeks (21 sessions)	Cancer survivorship workbook with no physical activity advice; No group meetings
<b>Demark-Wahnefried, 2007 (US)</b>	<u>Physical activity workbooks</u> based on Social Cognitive Theory; 6 tailored newsletters (every 6-9 weeks), targeted to PA 150+ min/week; Update cards; 4 weeks before each newsletter.	Usual diet & exercise printed education material
<b>Vallance, 2007 (Canada)</b>	<u>Physical activity printed material</u> Exercise for health and Exercise guide for Breast Cancer survivors; Verbal PA advice (5x30 min activity)	Verbal physical activity advice (5x30 min activity) No written material, no targeted step count
<b>Physical activity education material + telephone calls versus usual care</b>		
<b>Demark-Wahnefried, 2006 (US)</b>	<u>Tailored physical activity workbooks</u> ; Bimonthly telephone calls by physiologist, first 3 months on diet improvement and next 3 months on improvement of PA levels	Non-tailored printed material, unrelated to diet or physical activity; bimonthly telephone calls by physiologist for 6 months on general health topics
<b>Pinto, 2005 (US)</b>	<u>Physical activity tip sheets</u> & cancer survivorship tip sheets; Tailored telephone calls by researcher-readiness to exercise, weekly 12 and later monthly 3 calls; Feedback letters to summarise participant's progress on 2,4,8 & 12 weeks	No physical activity instruction by cancer survivorship tip sheets, or via telephone calls by researcher for 12 weeks
<b>Yuen, 2007 (US)</b>	1. <u>Print material</u> about aerobic exercise; Telephone calls by physical therapist (Weekly for 3 weeks); Monthly calendar to record fatigue levels 2. <u>Printed material</u> about resistance training exercises; Telephone calls by physical therapist (Weekly for 3 weeks); Monthly calendar to record fatigue levels	Normal daily activities, no exercise advice and no telephone calls; Monthly calendar to record fatigue levels
<b>Physical activity education material + pedometer versus usual care or physical activity advice</b>		
<b>Vallance, 2007 (Canada)</b>	<u>Physical activity Printed material</u> Exercise for health and Exercise guide for Breast Cancer survivors; physical activity advice (5x30 min activity); Pedometer wear everyday + 12 week step calendar	Verbal physical activity advice (5x30 min activity); No written material, no targeted step count

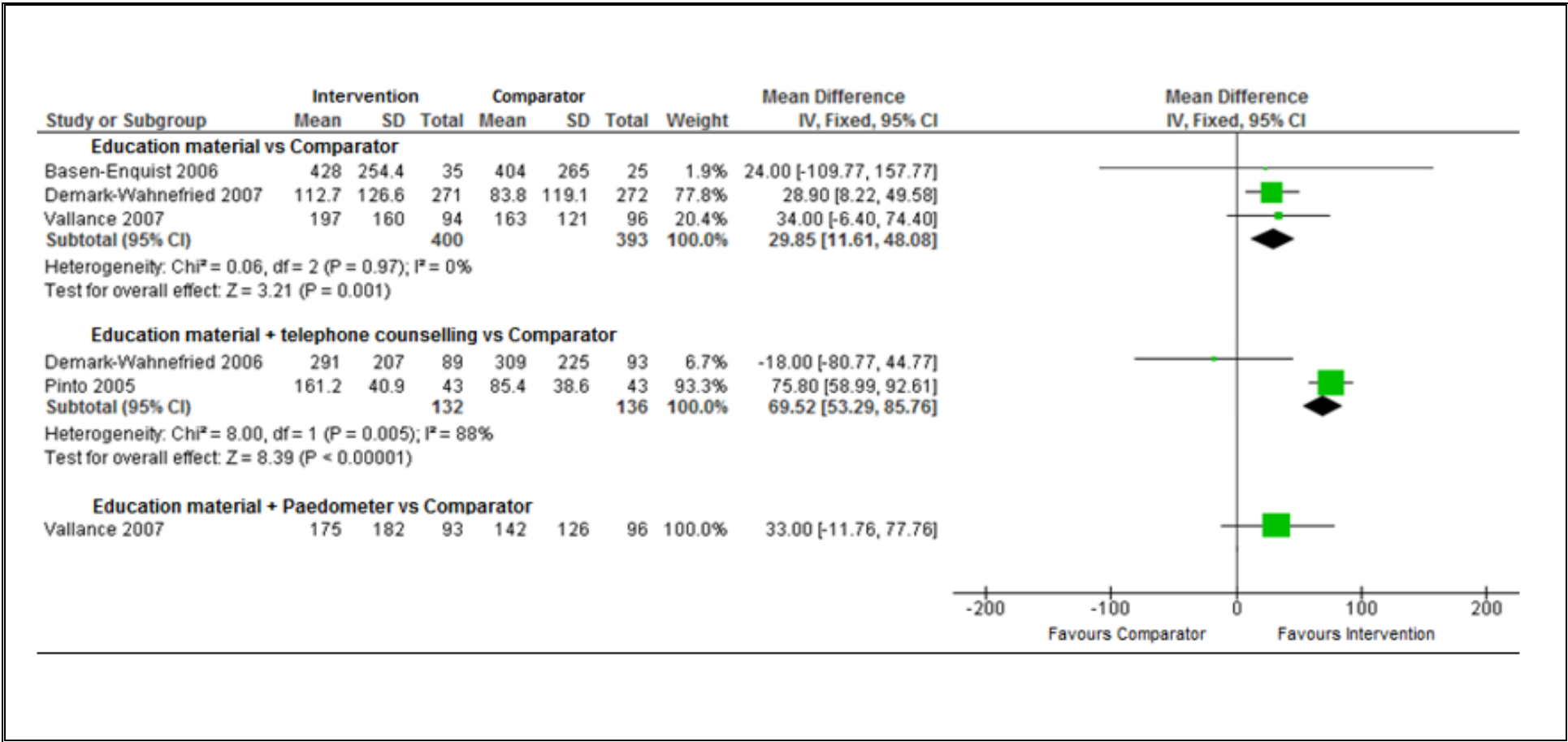
## **Physical Activity Measurements**

### ***i) Physical activity amount/time***

Pooled data from three studies (Basen-Engquist, Taylor et al. 2006; Demark-Wahnefried, Clipp et al. 2007; Vallance, Courneya et al. 2007) found a significant improvement in favour of written education materials versus control, with a weighted mean difference of 30 minutes of moderate/vigorous physical activity per week (95% CI 11.61 to 48.08) with low heterogeneity  $\chi^2 = 0.06$  ( $p=0.97$ ),  $I^2=0\%$  (Figure 2.3).

A significant increase in levels of energy expenditure and minutes per week exercise ( $p=0.001$ ) was reported by Pinto et al. 2005 involving 86 patients, favouring physical activity education materials with follow-up telephone calls versus the comparator, whereas, Demark-Wahnefried, 2006 (Demark-Wahnefried, Clipp et al. 2006) involving 182 patients reported no significant difference ( $p=0.94$ ) in terms of sessions of exercise per week. A comparison, involving 188 patients (Vallance, Courneya et al. 2007) of education material with pedometer versus control reported significant increase in moderate/vigorous physical activity with a mean difference of 57 minutes per week (95% CI 8 to 106), and brisk walking with a mean difference of 58 minutes per week (95% CI, 6 to 109), but no difference in seven day pedometer step count.

Figure 2.3: Physical activity measurements



Effects of interventions on amount/levels of moderate-to-intense physical activity measured in minutes per week (weighted mean difference)



***ii) Physical performance***

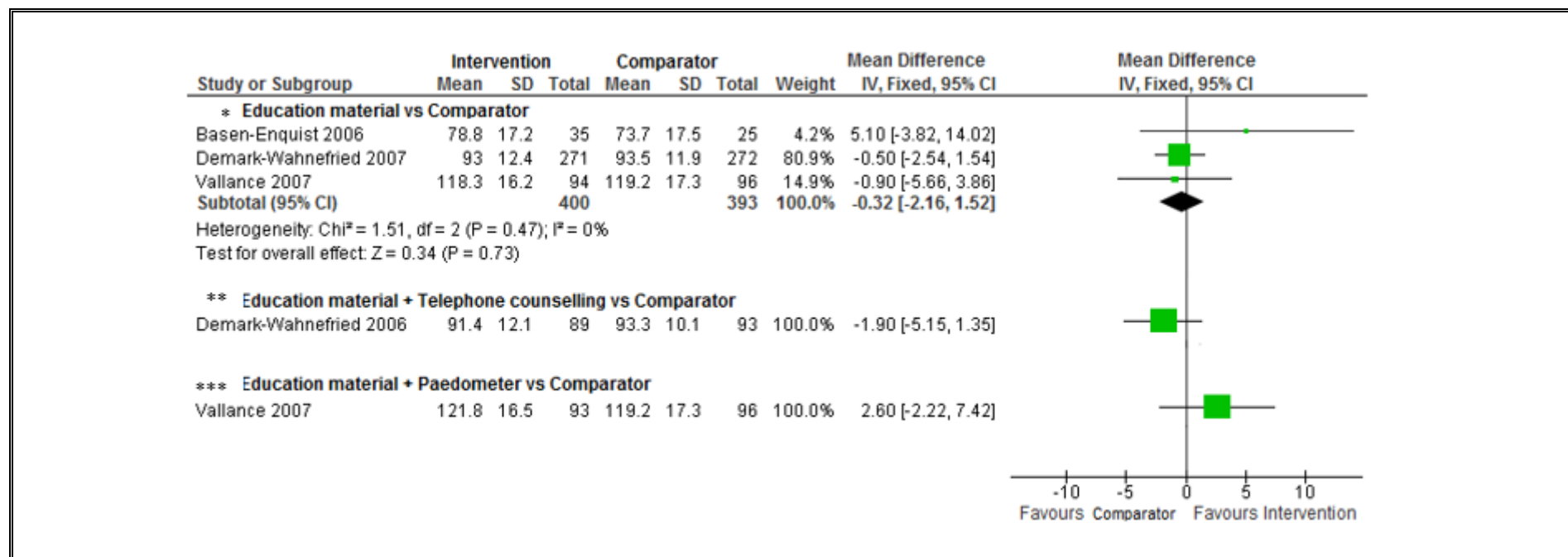
One study (Basen-Engquist, Taylor et al. 2006) involving 60 patients reported significantly better ( $p=0.005$ ) physical performance with the education material versus comparator. Pinto et al. 2005 involving 86 patients found significant improvement ( $p=0.001$ ) with education material plus follow-up telephone counselling versus the comparator; whereas Yuen & Sword, 2007 involving 38 patients, in a three arm study showed a significant difference ( $p<0.01$ ) in resistance exercise group but not in the aerobic exercise versus usual care group.

**Impact of Physical Activity*****i) Quality of life***

Pooled results from the general health domain of the SF-36 (Basen-Engquist, Taylor et al. 2006) and the FACT-G (Demark-Wahnefried, Clipp et al. 2007; Vallance, Courneya et al. 2007), involving 793 patients in total, compared education material versus comparators and found no significant difference in quality of life with a standardised mean difference of -0.02 (95% CI, -0.16 to 0.12) and low heterogeneity  $\chi^2=1.51$  ( $p=0.47$ ),  $I^2=0\%$  (Figure 2.4).

Basen-Engquist, 2006 involving 60 patients reported improvement in the general health ( $p=0.006$ ), bodily pain ( $p=0.02$ ), and physical role limitation ( $p=0.056$ ) domains of the SF-36. Vallance, 2007 involving 188 patients reported a significant improvement in quality of life scores for education material with pedometer compared with control, with a mean difference of 5.8 (95% CI, 2.0 to 9.6). Demark-Wahnefried, 2006 involving 182 patients found no significant difference ( $p=0.97$ ) between education material with telephone calls versus control.

Figure 2.4: Impact of physical activity on quality of life



\* Pooled effects (standardised mean difference) of education materials on quality of life, using general health domain of Short Form-36 (SF-36), Functional Assessment of Cancer Therapy –General (FACT-G) and Functional Assessment of Cancer Therapy-Breast (FACT-B) respectively in three studies

\*\* SF-36 and FACT-G

\*\*\* FACT-B

**ii) Behaviour change**

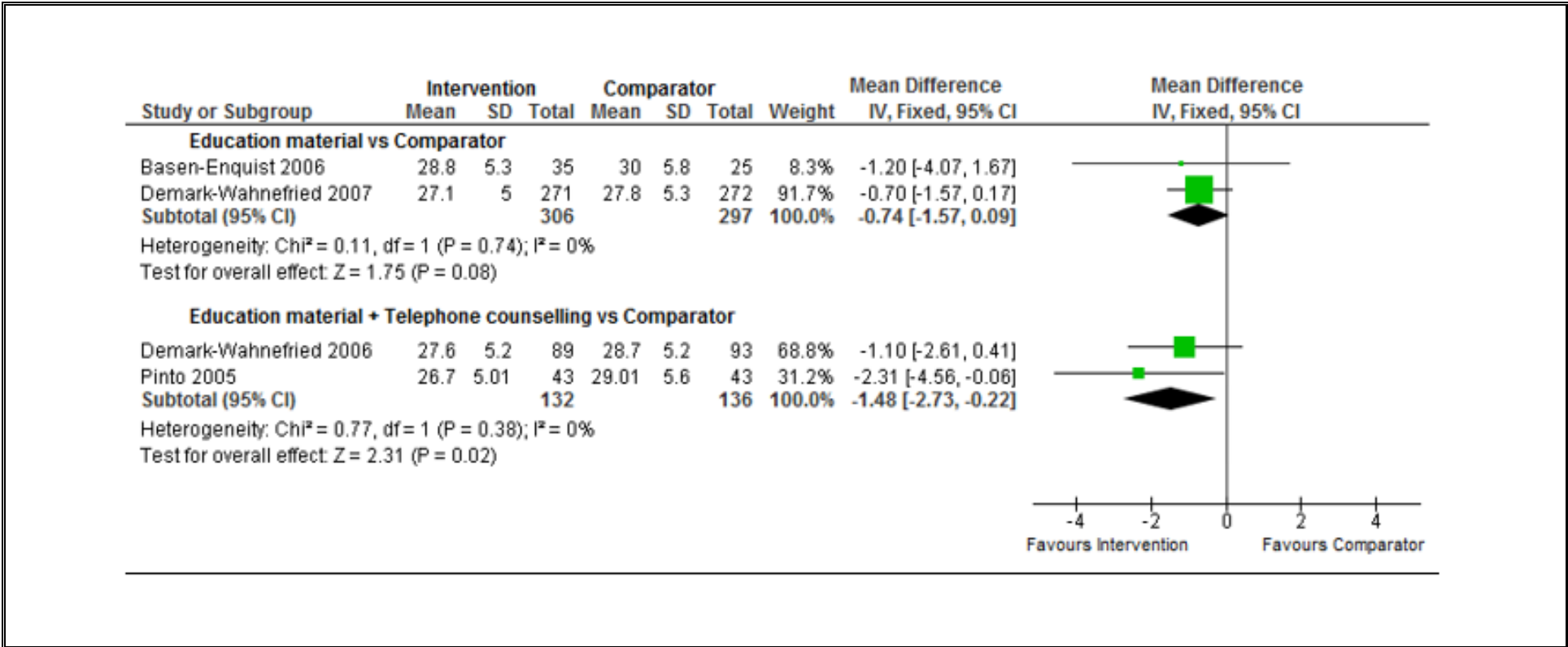
Two studies (Basen-Engquist, Taylor et al. 2006; Demark-Wahnefried, Clipp et al. 2007) showed that education materials were significantly better than control in bringing about readiness for physical activity behaviour change (stage of change  $F=5.4$ ,  $p=0.024$ ; stage of readiness for exercise adjusted  $p < 0.001$  respectively). Pinto et al. 2005 showed a statistically significant improvement ( $\chi^2 = 30.28$ ,  $p=0.001$ ) in motivational readiness when comparing education material with telephone counselling versus control and also found a statistically significant improvement in Profile Of Mood States (POMS) vigour ( $F= 12.80$ ,  $p= 0.001$ ) and total POMS mood disturbance ( $F= 3.41$ ,  $p= 0.069$ ); whereas Demark-Wahnefried et al. 2006 found no statistically significant improvement in self-efficacy ( $p= 0.46$ ) and motivational readiness ( $p= 0.90$ ) to exercise.

**iii) Body mass index**

Pooled data of Demark-Wahnefried, 2007 and Basen-Engquist, 2006 (Basen-Engquist, Taylor et al. 2006; Demark-Wahnefried, Clipp et al. 2007) involving 603 patients showed an improvement in favour of education materials with a difference of  $-0.74$  (95% CI  $-1.57$  to  $0.09$ ) and low heterogeneity  $\chi^2=0.11$  ( $p=0.001$ ),  $I^2=0\%$  (Figure 2.5).

Pooled results from two studies (Pinto, Frierson et al. 2005; Demark-Wahnefried, Clipp et al. 2006) involving 268 patients found a significance in favour of education materials with follow-up telephone calls versus control with a mean difference of  $-1.48$  (95% CI  $-2.73$  to  $-0.22$ ) and low heterogeneity  $\chi^2=0.77$  ( $p=0.38$ ),  $I^2=0\%$  (Figure 2.5).

**Figure 2.5:** Impact of physical activity on Body Mass Index (BMI)



Pooled effects of interventions on BMI measured (weighted mean difference) as Kg/m<sup>2</sup>

**iv) Fatigue**

Pooled data from two studies (Pinto, Frierson et al. 2005; Yuen and Sword 2007) involving 101 patients showed a significant decrease in fatigue for education material with telephone calls group versus control, with a standardised mean difference of -0.55 (95% CI -0.95 to -0.16) and low heterogeneity  $\chi^2=0.74$  ( $p=0.39$ ),  $I^2=0\%$  (Figure 2.6).

One study (Vallance, Courneya et al. 2007) involving 188 patients compared education material with pedometer versus control and showed a significant improvement in symptoms of fatigue for the intervention with a mean difference of 2.3 (95% CI, 0.0 to 4.7) but no significant improvement with a mean difference of 0.5 (95% CI -1.9 to 2.9) was seen when compared education material only versus control.

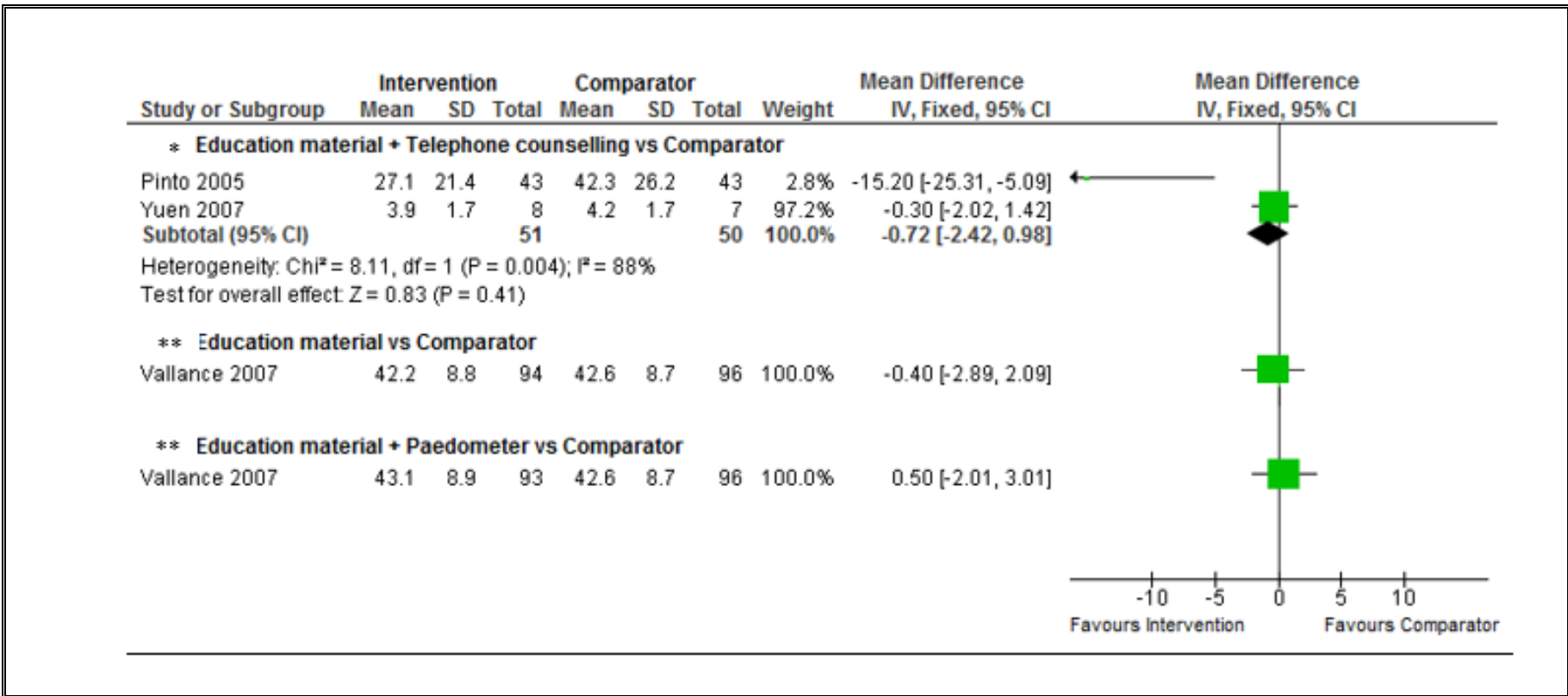
**v) Adverse effects**

Only two studies reported adverse events. One study (Demark-Wahnefried, Clipp et al. 2007) reported no difference between arms, the intervention group reported 137 total events (35 serious and 102 non-serious), and the control group reported 142 total events (39 serious and 103 non-serious). Whereas the serious events were characterised as life threatening, permanently debilitating, or requiring hospitalisation overnight; and the non-serious included all other events. The second study (Pinto, Frierson et al. 2005) reported one participant with chest pain during exercise in the intervention group.

**vi) Health economics**

None of the included seven studies performed an economic evaluation of any intervention.

Figure 2.6: Impact of physical activity on fatigue



\* Pooled effects of interventions on fatigue levels measured (standardised mean difference) using linear analogue and piper fatigue scale

\*\* Linear fatigue scale (0-52)

## **2.4 Discussion**

### **2.4.1 Summary of Main Findings**

The provision of patient educational materials versus control for adult cancer survivors resulted in a statistically significant increase of 30 minutes moderate to vigorous physical activity per week. There was evidence that educational material with telephone counselling versus control improved the physical function, and readiness to change behaviour towards exercise. BMI and fatigue levels also showed significant improvement. There was limited evidence that patient education materials plus provision of a pedometer improved physical activity, quality of life or fatigue. There have been no comparisons of patient education materials plus telephone counselling or pedometers with patient education materials alone. No economic evaluations were identified.

### **2.4.2 Strengths and Limitations**

We conducted extensive literature searches using a wide range of databases without language restriction; however, we could identify studies conducted in USA and Canada only with largely white populations. These studies recruited only survivors of breast or prostate cancer. The limited evidence gleaned from the included studies suggests that exercise improves quality of life, cardiorespiratory fitness, physical functioning and symptoms of fatigue in breast cancer survivors. Though promising, these findings are based on a relatively small number of studies with substantial methodologic weaknesses. The applicability of the results should be interpreted with care for other populations and types of cancer. Similarly, the results might not be pertinent to health care settings dissimilar to the US and Canada.

Studies conducted with adult cancer survivors at the end of their active treatment only were included in this review, whereas those with cancer patients during their treatment, and the survivors of childhood cancer were excluded. The reason for this specific inclusion criteria was that optimal time ('Teachable moment') to promote physical activity in cancer patients varies in the literature. However, such mixed evidence indicates that cancer survivors are more receptive to make lifestyle changes at the end of their treatment (Ref MacMillan review).

There was variability in study interventions with different exercise regimens being prescribed in each study. This diversity likely resulted because of a lack of consensus on the optimal exercise regimen for this patient population. Similarly, a wide variety of outcomes and measures were reported making pooling study results difficult. This might have partly been responsible for inconclusive results to draw meaningful conclusions regarding the relative effectiveness of different exercise programmes. The short duration, inconsistency

and lack of follow-up data examining the effect of exercise on various outcomes were also concerning in some studies.

Poor adverse event reporting limited any conclusions about the relative safety of exercise, a finding that is reported in other studies as well making health professionals' task of making physical activity recommendations in a safe manner difficult. Similarly, small sample sizes in some studies provided inadequate power to detect significant differences in rare adverse events.

The studies described in this review did not specify which type of exercise would be beneficial for specific cancer types, post-operative conditions or other complications e.g. bone pain or lymphoedema, which limits the applicability of findings to all adult cancer survivors. The overall results should also be interpreted with caution because of the small number of studies and small sample sizes.

### **2.4.3 Comparison with Existing Literature**

This is the first review of patient education materials to promote physical activity among adult cancer survivors outside a programme of supervised exercise. A review of self-management rehabilitation for cancer patients including exercise reported that self-management programmes and self-efficacy enhancing techniques were more effective than traditional care programmes (van Weert, May et al. 2008). Systematic reviews of home based and supervised exercise reported improvements in fatigue, body strength and quality of life (McNeely, Campbell et al. 2006; Bicego, Brown et al. 2009; Speck, Courneya et al. 2010). Our review also showed significant improvement in symptoms of fatigue in two studies comparing education materials and telephone counselling versus comparators, but we did not find any significant improvement in quality of life which may partly be because the amount by which physical activity is increased as a result of an educational intervention alone is likely to be less than with a supervised exercise programme.

The management of chronic diseases including cancers is changing and more emphasis is being placed on patient mediated self-management. Patient education programmes including educational materials are playing an increasingly important role in reducing the disease burden and improving quality of life and other outcomes (Cooper, Booth et al. 2001). Education materials including behavioural modification techniques have shown promise in increasing physical activity levels and improving self-management of certain chronic and progressive conditions (Payne, Wiffen Philip et al. 2012). These conditions include chronic fatigue syndrome (Price Jonathan, Mitchell et al. 2008), coronary artery disease (Brown James, Clark Alexander et al. 2011), post-myocardial rehabilitation (Hasnain, Anna et al. 2010), chronic obstructive pulmonary disease (Effing, Monninkhof Evelyn et al. 2007), arthritis (Williams NH, Amoakwa E et al. 2011), post smoking cessation weight gain (Farley Amanda, Hajek et al. 2012), and stroke (Joice, Johnston et al. 2012). Hence affecting



different health outcomes in the respective rehabilitation programmes, it may be safe to assume that the education materials would be helpful in cancer survivors as well.

Though educational materials have shown promise in the avenues described above, uptake of these interventions is poor and the proportion of patients who actually read and act upon these materials has been variably described in the range of 10-35% (O'Loughlin, Paradis et al. 1997). This poses a challenge to health care planners and promotional teams and emphasises the importance of designing strategies based on both the patient preferences as well as educating them in broader life style issues (Timmins 2005) to reach as much of the target population as possible and engage them in the promotional campaigns so that they could benefit from the messages being delivered in the education material (Foster G, Taylor SJ et al. 2007).

Our review included studies that compared only print based educational materials but it is plausible to assume that other media could be of equal or greater effectiveness and cost-effectiveness including web-based (Foster, Richards et al. 2013), mobile phone messaging (Vodopivec-Jamsek, de Jongh et al. 2012), and social networks (Dance 2010; Rovniak, Sallis et al. 2013).

#### **2.4.4 Future Research and Policy Implications**

It needs to be determined whether this small increase in physical activity can be reproduced for broader population groups and other types of cancer. The combination or addition of other strategies such as personal counselling, telephone counselling, the use of other kinds of prompts (text messages), and framing and/or tailoring such interventions according to behaviour change theories and models (Kroeze W and Werkman A 2006) can also be useful to enhance the effectiveness of physical activity educational materials for cancer survivors. In addition, it is not known whether the increase in exercise levels following an educational intervention is more likely to be maintained in the long term compared with a supervised exercise programme once supervision is withdrawn. Educational materials have a low cost and the small increase in physical activity is likely to be cost-effective, but this remains to be determined by economic evaluations. This review showed that physical activity education materials increase physical activity levels, and improve physical function and fatigue in patients with breast and prostate cancer. They should be considered a useful adjunctive component of cancer post-treatment rehabilitation programmes.<sup>1</sup>

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<sup>1</sup> This research was funded as a Postgraduate Research Scholarship from Cardiff University, but the organisation had no involvement in the study design, data collection and analysis, or thesis writing. The author would like to thank Ms Maggie Hendry for her comments and proof reading the final study draft.

## 2.5 Conclusion

Education materials were found to help cancer survivors to increase their physical activity levels. The findings showed that reinforcement in the form of telephone counselling based on behaviour change theories can be effective in cancer survivors' behavioural modification to adopt and increase their physical activity. However, the evidence about which theories are most pertinent was scant. Similarly, evidence was also unclear as to what type or media of education were most effective. There was also no evidence for the cost-effectiveness of the materials that were identified as no cost-effectiveness studies were identified. In light of these findings, the next chapter will explore theoretical models of behaviour change to explore the mediators that may help to design and develop a physical activity behaviour change intervention for cancer survivors.

## Chapter 3. Theoretical framework

**Aim:**

To explore theories and models of physical activity behaviour change, and find out the relative theory to promote physical activity for cancer survivors

**Main findings:**

Social Cognitive Theory fulfilled the criteria to underpin the intervention to promote physical activity for cancer survivors.

All constructs of Social Cognitive Theory were included to form a theoretical framework for this research

## **3.0 Chapter Summary**

This chapter has provided a rationale underlying the role of theories and models of behaviour change in complex intervention development. The process was facilitated by reviewing various such theories and models including the theory of planned behaviour, the health belief model, the trans-theoretical model, PRIME theory, and the behaviour change wheel model. This review helped to highlight the strengths and weaknesses of each for any practical utility in developing and designing the proposed intervention. The basis of the criteria for refutation was that theories to change behaviour must target stimuli that break the existing behaviour. It also emphasised that models must be explicitly derived from a documented theory or theories. The whole exercise helped to explain the importance of maintaining theoretical integrity throughout the process of intervention development.

Social cognitive theory was found to have all the required elements to qualify as a theory that can be used for developing and designing the intervention. It works as a causal framework that enables the interaction of person, behaviour and environment in a dynamic way, rather than one leading to another in a linear fashion.

## **3.1 Introduction**

This chapter aims to understand why theories matter, what are their applications, and how are they implicated in developing a behaviour change intervention. A critical review of theories and models that are often used in behaviour change is presented in later sections. The review explores their methodological strengths and weaknesses in order to single out the most appropriate theory that could be used to develop the physical activity behaviour change intervention in this project. The chapter draws on published sources to take into account the frequency of theories and models in such use, and its conclusion leads to the theoretical framework of this research project.

## **3.2 Role of theories in physical activity promotion**

Studies examining interventions designed to promote physical activity in general as well as in targeted populations (e.g. chronic disease patients) are based mostly on behaviour change models that draw on Social Cognitive Theory, the Trans-Theoretical Model or multiple components from different theories (Smitherman, Kendzor et al. 2007; The Swedish Council on Technology Assessment in Health Care 2007). Similar approaches have been used in the cancer survivor population by Pinto and Floyd (2008) where the use of theory-based interventions in this population targeted diet as well as physical activity (Pinto, Rabin et al. 2008).

The evidence emerging from the systematic review (Chapter 2, section 2.3.7, Impact of physical activity-ii) suggests that physical activity behaviour change interventions among cancer survivors are likely to be effective if they target an individual's readiness to change, employing the constructs of self-efficacy and outcome expectations derived from Social Cognitive Theory and mediated through Trans-Theoretical Model of stage of change (Pinto, Frierson et al. 2005; Basen-Engquist, Taylor et al. 2006; Demark-Wahnefried, Clipp et al. 2006; Demark-Wahnefried, Clipp et al. 2007).

### **3.3 Theory selection criteria for intervention development**

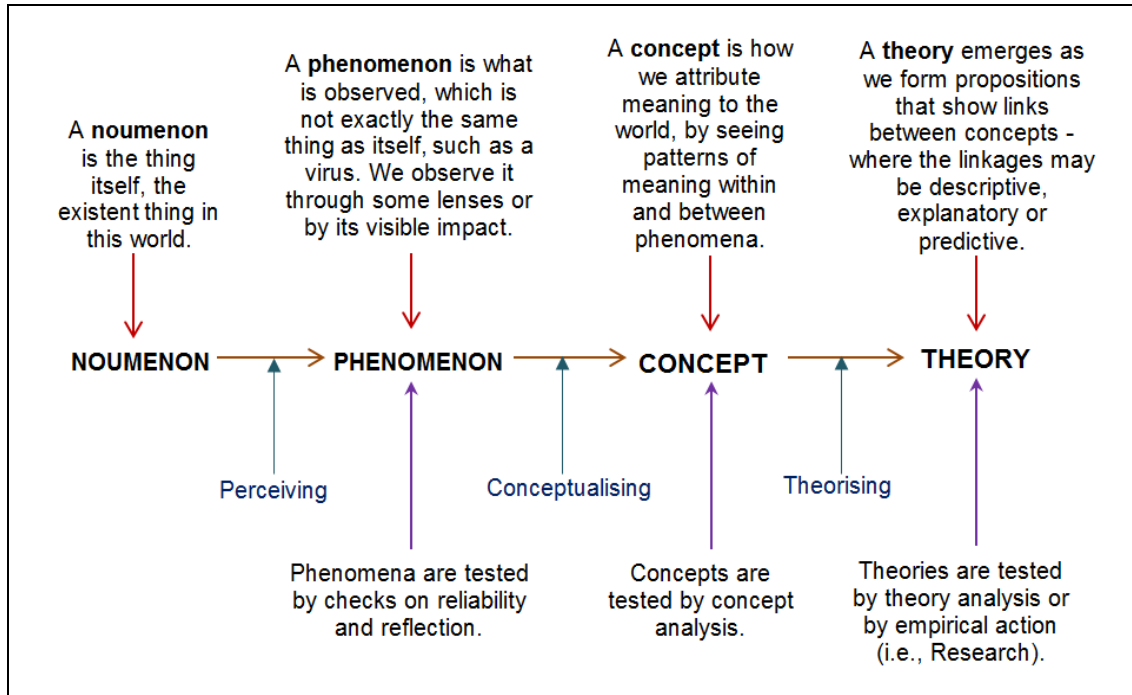
The above section has highlighted the significance of relating behaviour change interventions with theories in health sciences research. However, it is also important to articulate clearly the differences of the terms theory, concept, theoretical model and conceptual model in order to comprehend the underlying mechanisms. These are helpful to understand how theories are translated into workable models and framework, and at the same time how behaviour change interventions can be built upon theory. This section will explore such related terminologies that helped this author to explore and understand the relevant theories, their role, and the required criteria for the development of an intervention. The section will then conclude with the most pertinent theoretical options related to the design and development of a behaviour change intervention to be built on theory for this project.

#### **3.3.1 Defining theories**

Theories are composed of concepts and propositions, and try to build/ explain the relationships between these concepts. The function of a theory is to describe, explain, predict and prescribe (Pearson 2003). Theories concern phenomena or activities that are observable in the real world. Within theories, phenomena are described, categorised and analysed in order to establish the observable relationships between them. Thus the concepts used within theories must be observable as opposed to remaining abstract. The observable phenomena are sometimes measurable, and sometimes one phenomenon is controlled to observe its effect on the other within a theory. When the effect of one phenomenon (for example an independent variable) constantly produces the same pattern of results on the other (dependent variable), the mechanism is termed as law, and the theory is known as a predictive theory. When predictions can be made with certainty, the mechanism becomes a scientific law. Such relationships between theory, phenomena, and concepts are shown by Pearson (2003) (Pearson 2003) in Figure 3.1. It begins with noumenon. According to Kantian philosophy, a noumenon is a thing as it is in itself, as distinct from a thing which is knowable by the senses through phenomenal attributes (Warren 2015). As explained in Figure 3.1, an understanding of the real world is established through perceiving, conceptualising and

theorising. In reality the exercise of reducing meaning of a noumenon into the real world perception through this process is an over simplification. In practice, it is not as linear as might be thought of. It is, rather, a reflective process involving moving backwards and forwards to refine and finalise a theory.

**Figure 3.1:** Relationships between Noumenon, Phenomenon, Concept, and Theory



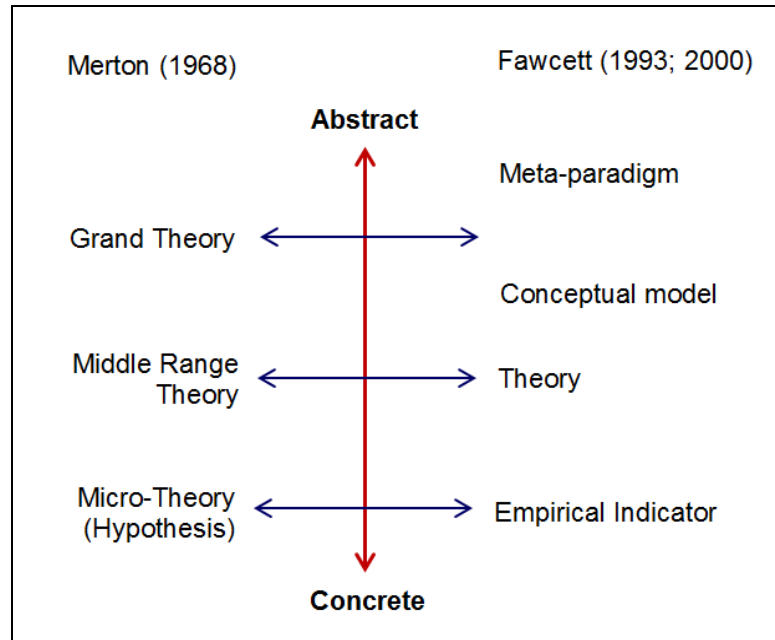
**Source:** Pearson, 2003, p. 265

Theories are tested by theoretical analysis, or research; concepts are tested through specific concept analysis methods, and perceptions of phenomena are tested by further perceptions. Observations are checked by reliability and validity. At the level of theory, they are kind of conjectures that produce cognition, propositions and empirical knowledge. Therefore, the entire process of captivating noumenon into reality is by default creative and insightful. The great discoveries of science to this date involved this creative and insightful process.

It is commonplace to observe this in health sciences, particularly in nursing research. Some authors suggest that there is no difference between the intervening process of this theorising or using theory. This is explainable by the fact that all theories irrespective of their use in any discipline do not reside at the same level of abstraction or perceptibility. That is why theories are classified into three genres - grand theory, middle range theory and micro-level theory (Meyer and Wodak 2001). *Grand theories* are those which are describable but are hardly verifiable. In other words, the transmission of noumenon is difficult for perception. They have high abstract value for those who seek to theorise them, and those who try to apply or use them. Nevertheless, they are universal. The *middle range theories* are closely aligned to the observable reality and they are scientifically or methodologically verifiable,

while the *micro-level theories* are highly and readily translatable, observable, and empirically testable. However, they are time-bound and context specific and have limited applicability. This distinction between and among various levels of abstraction versus concreteness was shown by Merton (1968) (Merton 1968) and the subsequent work by Fawcett (Fawcett 2000) (Figure 3.2):

**Figure 3.2:** Various levels of Theories



**Source:** Pearson, 2003, p. 266

A theory has been defined in several ways, but the themes related to defining a theory are not infinite and there are fewer disagreements as to the notion of what a theory is. According to Fox and Bayat (2007) a theory is a set of interrelated propositions, concepts and definitions all of which express relationships between variables “with a view to predicting and explaining phenomena”. However, all theories do not predict phenomena (Fox and Bayat 2007). All theories do not explain phenomena. All predictions by theories are not testable; and so Fox and Bayat’s definition of theory cannot remain uncontested. Furthermore, ‘explaining’ – as Fox and Bayat (2007) include in their definition - implies being able to demonstrate observable events in relation to theory, which is not always possible (Fox and Bayat 2007). Theories can simply state concepts but not necessarily always demonstrate what they say.

Another definition by Liehr and Smith (1999) (Liehr and Smith 1999) can be mentioned. According to them, a theory is a blueprint for creating a structure. This is a fairly general statement, which can be used more broadly. For example, from this definition, it can be derived that the primary purpose of a theory is to show relationship in a way that a structure can be shown for alignment with observed reality.

Perhaps one of the clearest statements regarding what a theory is comes from Chinn and Kramer (2013) (Chinn and Kramer 2013) who state that a theory is an expression of knowledge, and that it is a rigorous structuring of ideas. Such an expression tries to project a tentative, purposeful and systematic view of one or more phenomena. As a result, a theory is a systematic abstraction of reality, since theories are proposed and built from observations of reality.

The relationship between theory and the reality is an area of tension and the meanings attached to the term 'theory' varies by definition (as noted above) as well as by discipline. For example, in philosophy and arts, theory is understood as a pure level of abstraction, whereas in management including healthcare sciences the conceptual and operational meanings attached to 'theory' are narrowing. Whereas in the former theory refers to ideas rather than directly observable empirical phenomena, in modern science both 'theory' and 'scientific theory' are understood to refer to proposed explanations or empirical phenomena (Imenda 2014).

Tranfield et al. (2003) note that the role of theory in medicine is concerned with the type of work, and whether or not the intervention adopted offers overall benefits in medicine research. But in management science the role of theory is concerned with why something does or does not work and the context in which this occurs (Tranfield, Denyer et al. 2003). This narrowing down of the differences between level of abstractions and the praxis (i.e., the observed realities) partially explains the ever increasing demand for evidence based interventions among the healthcare researchers. It is observed (by the author) that the meaning of 'theory' in health sciences research is narrow as it is today. This is evident in the discussion that follows in this chapter.

Most theories used in healthcare sciences research belong to middle-range and micro-theories as opposed to grand theories (Figure 3.2 above). At this point it is important to note further differences between middle and micro-level theories. According to Merton (1968), middle range theory uses particular phenomenon to produce theoretical accounts that are used by policy-makers and scholars from other disciplines (Merton 1968). On the other hand, micro-level theories are only applicable in certain spatio-temporal settings, and are unable to explain and relate local problems adequately to collective phenomena. Currently there is no such account of how many theories used in behaviour change interventions belong to middle-range and micro-level theories. This is a gross gap in health sciences research, and this author would argue that in the true sense of the term, despite an over-riding emphasis of research for being evidence-based and theory-based, lack of such classification renders many researches in behaviour intervention merely belonging to micro-level theories.

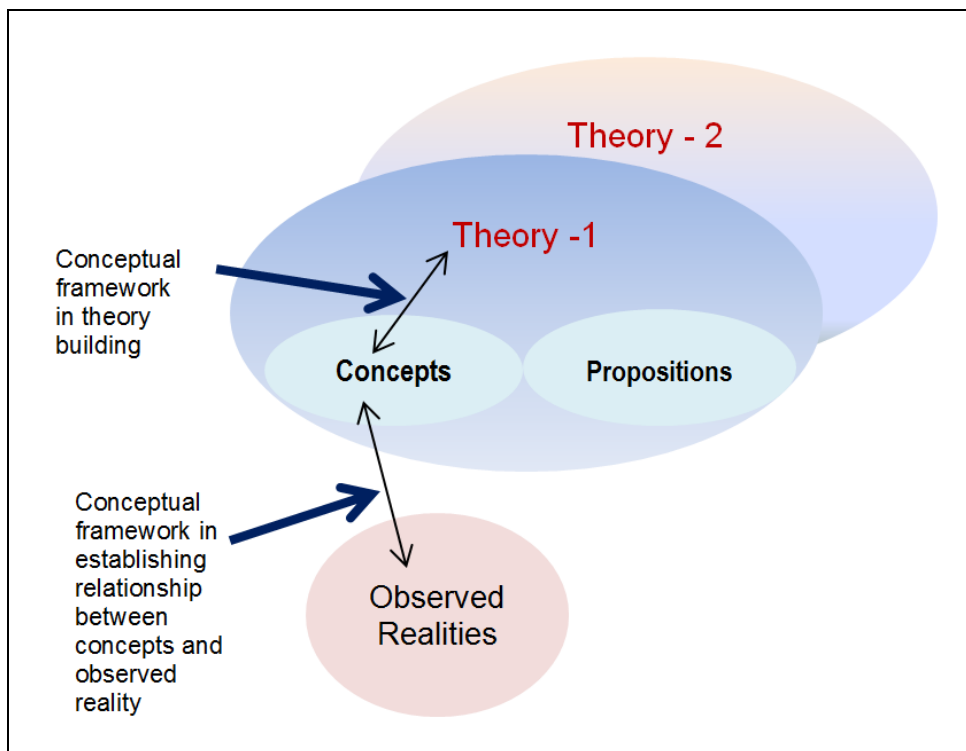


### 3.3.2 Conceptual and theoretical frameworks

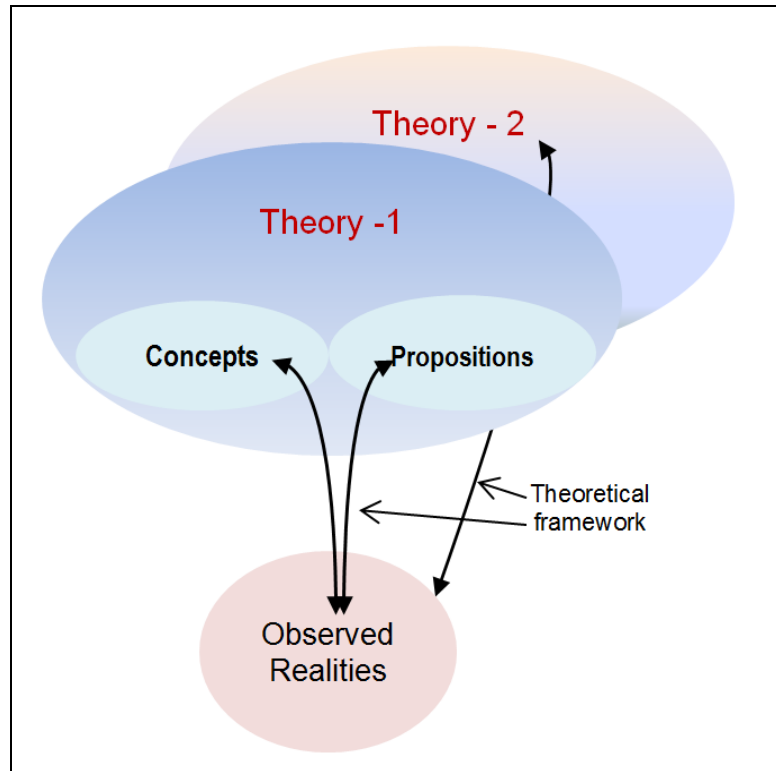
In the preceding discussion it has been stated that a theory is composed of concepts and propositions. Concept is the abstract element in a theory which is defined as an image or symbolic representation of an abstract idea, and help to convey these such ideas within a theory. Concepts within theories are complex mental formulations of observed reality.

A conceptual framework is therefore a structure that provides guidance towards formulating a theory, or towards establishing relationships among various observed realities. A conceptual framework can also be used towards establishing relationship with observed realities, without reference to a theory in cases when there is no explicit theory associated with the concept being used, or the theory is not yet developed in that field. Figure 3.3 shows these two roles of a conceptual framework.

**Figure 3.3:** Two roles of 'Conceptual Framework'



A theory is built on a number of concepts and propositions. Propositions state the relationship between concepts within a theory. A theoretical framework is a structure consisting of number of concepts and propositions, when they (the concepts and propositions) are taken from a single theory. A theoretical framework can also be a structure consisting of a number of concepts and propositions taken from more than one theory. The role of this structure in a theoretical framework is to guide the research within the concepts and the proposed relationships between the variables within concepts. Thus, 'conceptual framework' and 'theoretical framework' convey different methodological meanings. This is shown in the following diagram (Figure 3.4):

**Figure 3.4:** Roles of Theoretical Framework

Strength of a framework, whether it is a theoretical or a conceptual, depends on how succinctly the framework relates to reality. Sometimes a theory alone does not explain the observed realities (or praxis). A number of theories provide the theoretical framework in this case. Conversely, if no theory provides sufficient explanation to observed realities, indiscriminate concepts can provide the framework in such cases, which is then called a conceptual framework (without reference to a theory or theories) instead of a theoretical framework. Nevertheless, regardless of the choice adopted by a researcher, the framework adopted will become the research framework for them. The choice as to whether a conceptual framework or a theoretical framework will be used depends, among many factors, on the explanative power of concepts versus theories.

### 3.3.3 Conceptual and theoretical models

A model (conceptual model, theoretical model, or simply a model) has more rigorous meaning as far as its power to explain and relate the observed realities to theory or concept within and without a theory is concerned. It is a simplified description of a system or a process that assists calculation and prediction, although all models are not necessarily meant to predict. It is also a description or analogy used to help visualise something, such as the structure of an atom cannot be visualised without a diagram. Ideal models embody theories in most instances since they are derived from theories in the first place.

Models provide strong and established structure. Mathematical modelling is one such instance which uses precise structures with predictive results. Models are assessed by

reliability and validity. Reliability is a measure of integrity of the constructs within themselves, and in quantitative research it is measured statistically. Validity of a model is acquired when the same model is used over and over again in various contexts over prolonged periods by researchers. Although models are stronger than frameworks, all models have limitations, particularly in relation to the theory and the scope of embodying varying observable realities. This is the reason why multiple models may exist on the same situation or reality. Clearly then, a researcher can use a model, theoretical framework, or even a conceptual framework to guide a research project. The choice depends on how succinctly any of these can be applied to research problem under investigation.

### 3.3.4 Application of theories in developing intervention models

Much health services research claims to develop interventions that are theoretically based (Fishbein and Ajzen 2005; Hardeman, Sutton et al. 2005; Michie 2008; Ryan, Patrick et al. 2008). However, although this is often claimed, it is often unclear why behaviour change interventions must be theory-based. Most authors cite others with little explanations of their own why this should be the case. The literature can provide few instances where authors do provide rationale which is laudable, but rationales themselves are not very well supported particularly given the discussions that show the differences between concepts, theories and models (Michie 2008).

The following discussion develops this idea further but it does not seek to refute the logic of having theory or theories related to behaviour change models, but that, given the differences between concepts, theories, and models which have been made in the preceding sections, behaviour change intervention techniques or models could be associated with theories implicitly or explicitly depending on at least three conditions.

**First**, behaviour change techniques could be developed from existing theoretical models when such models have been developed from established theory. The degree to which explicit reference to theory (or theories) needs to be made depends on the necessity, and the scope that the theory in question provides. Taking into consideration the differences between grand theory, middle range theory and micro-level theory, the degree to which reference to a theory/ number of theories in question is made, and the abstraction of fundamental concepts within a theory is translatable into perception, would vary. This would be the case even though a research might use a theoretical model.

**Second**, behaviour change intervention models could be developed from theories. In this case the models will be new and they may or may not be radically different from the existing ones. The degree to which these newly developed models are different will depend on several factors such as: (i) the extent to which previous research has generated models in

a particular sub-discipline of the health sciences; (ii) how new is the context in which the new model is being proposed; (iii) the philosophical stance of the research.

Research philosophy consists of four major elements – ontology, epistemology, axiology, and data. Not all philosophies would support the notion that models have to be developed only from theories, but that they could also be developed from observations that do not clearly point to a particular theory. This is one of the fundamental differences between deductive and inductive methods of inquiry.

**Third**, behaviour change intervention models could be developed from ‘concepts’ alone. A concept is part of a theory only when the latter is clearly identified, stated, or founded. Otherwise, it is not a part of a potential theory when theory is yet to be identified. Both options (i.e., when concept is a part of an established theory and when it is not) *may* create behaviour change intervention models. However, given the need that intervention models should be theory-associated, it is important that concepts which are a part of a theory or a number of theories are given priority. At the same time, it should be noted that absence of related theory does not cease concepts to come into existence. Concepts are born from thoughts and observations, which can be novel ideas or otherwise. They may exist without theories which are yet to be made. In such a case, research proceeds with a conceptual rather than a theoretical framework.

### **3.3.5 Theory-association in Behaviour Change Intervention models**

It appears from the literature that most behaviour change techniques and models which are developed for intervention are *implicitly* related to theories rather than being explicit. As it stands today (in 2015), such a stream of research is criticised rather heavily, and the emphasis, as well the professional requirements for these models to be evidence-based, make such criticism more appealing. The relationship of theory with many such existing behaviour change models (that show implicit rather than explicit relationships) are found in three forms of terminologies in health sciences - theory-inspired, theory-driven, or theory-based. It is important to further explore these concepts, as they are often used indiscriminately. Michie et al. (2008) have drawn a straight-forward difference between theory-based and theory-inspired research (Michie 2008). This section explores these concepts and their practical implications, particularly impacting upon the research process at large, and upon the research conducted in this project. The implications will become evident later in this dissertation, as a single theory with a single theoretical framework is applied for theoretical integrity to develop the suggested behaviour change intervention model.

### ***Theory-inspired interventions***

Most research does not differentiate between these terms: theory-inspired, theory-driven, or theory-based. Rather all three of them are used to mean that theory will have some relationship in creating and identifying the appropriate behaviour change techniques. For example, Wensing et al. (2010) used theory-inspired and theory-based intervention technique interchangeably (Wensing, Bosch et al. 2010). In their work, they mention that specialised nurses used counselling-based programmes to help patients with leg ulcers to improve their lifestyle. When developing these interventions, they followed group-based methods in which the nurses suggested what they already knew from their continuous professional training, education and practice. Heinen et al. (2006), and Wensing et al. (2010) stated that the designed intervention was not theory-inspired (Heinen, Bartholomew et al. 2006; Wensing, Bosch et al. 2010). However, Heinen et al. (2006) reported that the intervention was developed in five steps in which the first step was to set the “matrices of proximal program objectives” and it is in this first step that consultations with the nurses were done. In the second step, methods and strategies were selected. The second step involved selecting theoretical models (Heinen, Bartholomew et al. 2006). Thus it is apparent that Wensing et al.’s (2010) explanation of Heinen et al.’s (2006) work being non-theory-inspired is erroneous (Heinen, Bartholomew et al. 2006; Wensing, Bosch et al. 2010). At the same time understanding of what is theory-inspired or not is also missing from Wensing et al.’s (2010) reporting (Wensing, Bosch et al. 2010). Indeed, as noted before, a researcher can select a theoretical model to develop an intervention model and there is no need for explicit work within a single research that uses a theoretical model that is based on theory. This is what Heinen et al.’s (2006) did. They used Precaution Adoption Model which was related to two theories - Social Cognitive Theory and Goal Setting Theory. Unfortunately, Wensing et al.’s (2010) and that of Heinen et al. (2006) understanding of ‘theory-based’ is different (Heinen, Bartholomew et al. 2006; Wensing, Bosch et al. 2010).

Another reference for the use of theory-inspired intervention can be found in the works of Francis et al. (2007) in which the authors clearly state how the relationship between a model and theory are streamlined in health science research (Francis, Grimshaw et al. 2007). They suggested that one was to use well-researched principles that are known to change behaviour. For this, they rely on those principles which were developed by Yale University, and the other was to select theories that purported to predict actual behaviour (Francis, Grimshaw et al. 2007).

### ***Theory-based interventions***

Researchers who argue in favour of theory-based instead of theory-inspired intervention models suggest the differences between these two terms as follows. Studies that

combine a number of theoretical constructs are termed as theory-inspired (Michie and Abraham 2004; Guillaumie, Godin et al. 2010). It is argued that since theory-inspired designs combine a number of constructs, or consider features of various theories into proposing a new model, such attempts may be considered only derivations from initial theory. But in totality, the emerging theoretical model, and in effect the suggested intervention model “may misrepresent the theory or omit key components of it” (Guillaumie, Godin et al. 2010).

These authors criticise the act of “empirically integrating” salient components of different theories into creating more complete theory of behaviour change. In the contents of their own research, they note that certain behaviours, as in dietary habits of the recipients (or patients), behaviour changes may be extremely complicated, and as such creation of an “all-encompassing model” from various theories would not create a useful intervention model. They further suggest that if a model is created by using salient components of various theories, it might be useful under two conditions:

- 1) If previously proven theories and constructs that have been used were found to be effective in changing behaviours.
- 2) If the intervention models following such a procedure were found to be effective in changing behaviours.

In summary, therefore, the idea is that all research must apply theories for creating effective intervention models, regardless of whether the creation of intervention begins from established theoretical models, or from scratch, i.e., building a theory first. This later observation, though, contradicts the idea that in behaviour change interventions a research can simply begin from established theoretical model as suggested before – option first in Section 3.3.4, and as was seen in the example of ‘theory-inspired interventions’ by Wensing et al. (Wensing, Bosch et al. 2010).

### ***Theory-driven interventions***

Another term that is frequently used in relation to emphasising the relevance of theory in behaviour intervention studies is theory-driven. Vanderplasschen, and de Maeyer (2014) provide the following definition of theory-driven interventions (Vanderplasschen and De Maeyer 2014):

*“Theory-driven interventions can be defined as practices or interventions which are based on an explicit theoretical model including an articulation of the causal link between an intervention and its outcomes” (Vanderplasschen and De Maeyer 2014).*

In the above definition, causal relationship has been suggested between the administered interventions and the outcomes. To do this, the model chosen must be theoretical, which implies that as long as a model chosen is theoretically well-founded, it should provide a basis for proposing behaviour change intervention models.

Vanderplasschen and de Maeyer (2014) argue further that a clear description as to how and why the intervention leads to specific outcomes should justify the causality of the proposed framework (Vanderplasschen and De Maeyer 2014). Following the discussions in the foregone section, it can be observed that the definition above by Vanderplasschen, and de Maeyer, 2014 (Vanderplasschen and De Maeyer 2014) is radically different from the explanation provided in the theory-based intervention by Michie and Abraham (2004), and Michie et al. (Michie and Abraham 2004; Michie 2011). Whereas in the former the causal relationship is imperative between the interventions and the outcomes, the latter with reference to theory-based interventions suggests a total causal framework or relationships.

From a wide review of the literature, it clearly appears that ‘theory-driven’ is an approach to evaluate existing intervention models rather than it being an approach to creating new models (Stanton, Black et al. 1992; Heflinger, Bickman et al. 1997; Bamberg and Schmidt 2001; Sidani, Doran et al. 2004; Bamberg 2006; Perkins, Jensen et al. 2007; Scott and Dadds 2009; Coryn, Noakes et al. 2011; De Silva, Breuer et al. 2014). For example, Perkins et al. (2007) relates the term theory-driven in assessing what changes the behaviours of the clinicians (Perkins, Jensen et al. 2007). They use theories of reasoned action and planned behaviour in explaining clinicians’ behaviour in context. Indeed, many studies support the use of theoretical constructs (of theories of reasoned action and planned behaviour) to predict potential behaviour based on what is intended, although behavioural intention and the behaviour are not the same. The starting point of research in Perkins et al.’s (2007) work is an established theoretical model, not theory (Perkins, Jensen et al. 2007). Similarly, Stanton et al.’s work (1992), which does not have any data, and is more of a general discussion on theory-driven behavioural intervention research for the control of diarrheal diseases, suggests a construct that has not been derived from literature, because, as they note, approaches and nomenclature differ, and words and terminologies are frequently used interchangeably (Stanton, Black et al. 1992). The relevance of the suggested construct is based on general discussions of theories and models.

One of the well-known trials in the UK towards making earlier behaviour change intervention frameworks or models “theory-driven” is trial no. NCT02160249 (referred to here as Clinical Trial, 2014). Theory-driven approach in this trial has been explained as adapting and integrating a tool, namely, theory of change into older MRC Framework of 2008 (Craig,

Dieppe et al. 2008). Incorporating this theory, theory of change, was proposed as a response to criticism that the MRC Framework was not theory-driven.

However, theory of change is not a theory such as other theories which are understood to have been developed with well-articulated concepts, propositions and their relationships such as contained in the definition of theory. De Silva et al. (2014) clearly note that theory of change is a pragmatic framework which describes how intervention framework affects changes (De Silva, Breuer et al. 2014). To make sense of this theory of change, it has been suggested that appropriate theories from sociology and psychology should be inserted at key points to explain why particular effects might or would take place in a behaviour. Centre for Theory of Change, located in New York, which is a pioneer in giving wide publicity to this theory, notes that a methodology used to create a theory of change is also referred to as a theory of change, and so "... when you hear or say "Theory of Change", you may mean either the process or the result." (Center for Theory of Change 2016).

Thus theory of change is not a theory in the truest sense of the term; rather it is a tautology between method and "undefined theory", which is susceptible to anyone's convenience or inconvenience. MRC's effort to make its earlier framework "theory-driven" can therefore be considered atheoretical. Incorporation of theory of change to MRC framework is unlikely to provide any epistemological or axiological validity if the framework did not have them before. It is one thing to derive a framework from a theory or a number of theories, and yet it is a different matter to justify a framework by explaining relationships within that framework from unspecified theories from sociology and psychology as noted by De Silva et al. (2014) with reference to clinical trial no. NCT02160249 (De Silva, Breuer et al. 2014).

Based on the works of Flay and Petraitis (Flay and Petraitis 1994), Kok et al. (Kok, Schaalma et al. 1996), Rothschild (Rothschild 2000), and Ball and Crawford (Ball and Crawford 2003), a distinction between theory-driven research and problem- or action-driven research has been offered by Brug et al. (2005). According to Brug et al. (Brug, Oenema et al. 2005), a theory-driven research is conducted to test or improve the validity or applicability of a specific theory. This is done by introducing theory from the stage in which a researcher analyses the determinants of risk behaviours. This stage is preceded by two other stages: (1) stage that analyses health and quality of life and (2) stage that analyses the behaviour and environmental risk factors (Brug, Oenema et al. 2005).

By implication, therefore, the role of theory in a theory-driven intervention is to investigate the mediators and determinants of the risk behaviours, after which these mediators and determinants are (or should be) translated into goals, change strategies and methods, that need to be integrated in a comprehensive intervention package (the next step)



that can be implemented and disseminated (next step). Theory-driven approach is used to test and improve the validity or applicability of a specific theory of physical activity behaviour. Role of the theory is not so much on the individual factors, social factors or physical environmental factors, as much as it is on how to integrate them with motivation, abilities and opportunities (as in COM – B System by Michie et al. 2011). Brug et al. (2005) conclude on the theory-driven approach that the main focus of the theory is not on testing a theory but to draw insights from multiple theories instead of a single theory in order to enrich the interventions (Brug, Oenema et al. 2005).

The discussion and literature review in the above section lead to a question: should a research that seeks to develop behaviour change intervention model be theory-based, theory-driven or theory-inspired? It also brings in the debate of using a single theory versus multiple theories in a single intervention planning. Indeed, Kok et al. (2004) justify the use of multiple theories because environment is created by decision-makers (Kok, Schaalma et al. 1996). To them, to change people's behaviour, decision-makers who impact in the way environment is shaped, have to take into cognizance the individuals. Thus multiple theories can be used in intervention design to address issues at various levels – such as individual (or cognitive), social, or community levels. While there is an increasing theoretical demand from scholars around the world to integrate these levels, which is rightly so, using more than one theory implies that no single theory is compatible to deal with the current range of problems in a single intervention, and that a researcher might not have theoretical integrity.

It is certainly needed that social and community factors are cared for, and unlike what Brug et al. (2005) observed that theory is usually used from the third stage of the research, this author would argue that maintaining theoretical integrity can be achieved when intervention practices designed are explainable throughout the entire process from development of the intervention model to the behaviour outcome by a single theory (Brug, Oenema et al. 2005). No matter which discipline this approach of using multiple theories to explain a single piece of research, research problem, design, or intervention model might belong to, it would create a system which would lack theoretical integrity. Kurt Lewin said that theory is practical - not that it should be practical (Minkler and Wallerstein 2008).

To conclude, the preceding discussion shows that regardless of the approach taken during an intervention development, the role of theory is best fulfilled when a single theory can explain the entire phenomena from the beginning to the end. It may have a number of theoretical constructs which enable researchers to measure observations related to outcomes. The choice depends on whether or not all the concepts in the original theory are being applied to address the question under consideration. All the theoretical constructs of a theory are usually required to answer a research question, but this is not necessarily the case. Similarly, these constructs would need to be measurable (i.e. for quantitative analysis),

and derived either from existing or emerging evidence. Finally, a theory must be able to fit a given context during the design and development of an intervention. This notion then justifies the strategy of devising a pre-determined criteria based on the aim and objectives of the thesis.

### **3.4 Leading Theories and Models in Behaviour Change Interventions**

This section will describe an in depth literature review to undertake a critical analysis of established theories and models of behaviour change in order to accept or refute them as the candidate theory to underpin the intervention development for this project.

A good number of theories are available in contemporary behavioural intervention research. A list of 83 theories named as theories of behaviour change is available in Michie and colleagues' work (Michie 2014; Michie 2015) (Appendix F). This list includes many possible theories that have been used to date in various behaviour modification studies. It has been criticised recently, in that these theories are "often difficult to access and understand by health professionals who do not have a psychology background" (Phillips 2015).

Glanz et al. (Glanz 2008; Glanz 2010) reviewed 697 studies between 1986 and 2005. They found that the most frequently used theories in health behaviour prediction were social cognitive theory (Bandura 1986), theory of reasoned action (Ajzen 1980) and the theory of planned behaviour (Ajzen 1985); and the most frequently used models during the said period were the health belief model (Rosenstock 1966), and the trans-theoretical model (TTM) (Prochaska 1982). More recent behaviour change theories include PRIME theory (West 2005; West 2009; West 2013) and models include the Behaviour Change Wheel (BCW) by Michie *et al.* (Michie 2014).

Barker (2015) observed that there are many conflicting and overlapping theories of behaviour change (Barker 2015). In a work by Davidoff *et al.* (2015), the role of theory for professional and academic researchers has been acknowledged with the note that, for academic researchers, theory itself is frequently the object of study and their aim is to confirm, refute or refine it (Davidoff 2015).

#### ***Selecting a theory for a behaviour change intervention in cancer survivors***

Further scoping searches were undertaken to gain an overview of the range and depth of research that exist particularly on behaviour change interventions about physical activity promotion for adult cancer survivors. The aim was to select appropriate theory and/or model to underpin the intervention development. This search resulted in six notable ones namely Theories of Reasoned Action and Planned Behaviour, Health Belief Model, Trans-

Theoretical Model, PRIME Theory, Behaviour Change Wheel, and the Social Cognitive Theory. These are critically reviewed below to determine if one meets the criteria for developing the physical activity behaviour change intervention for this research project.

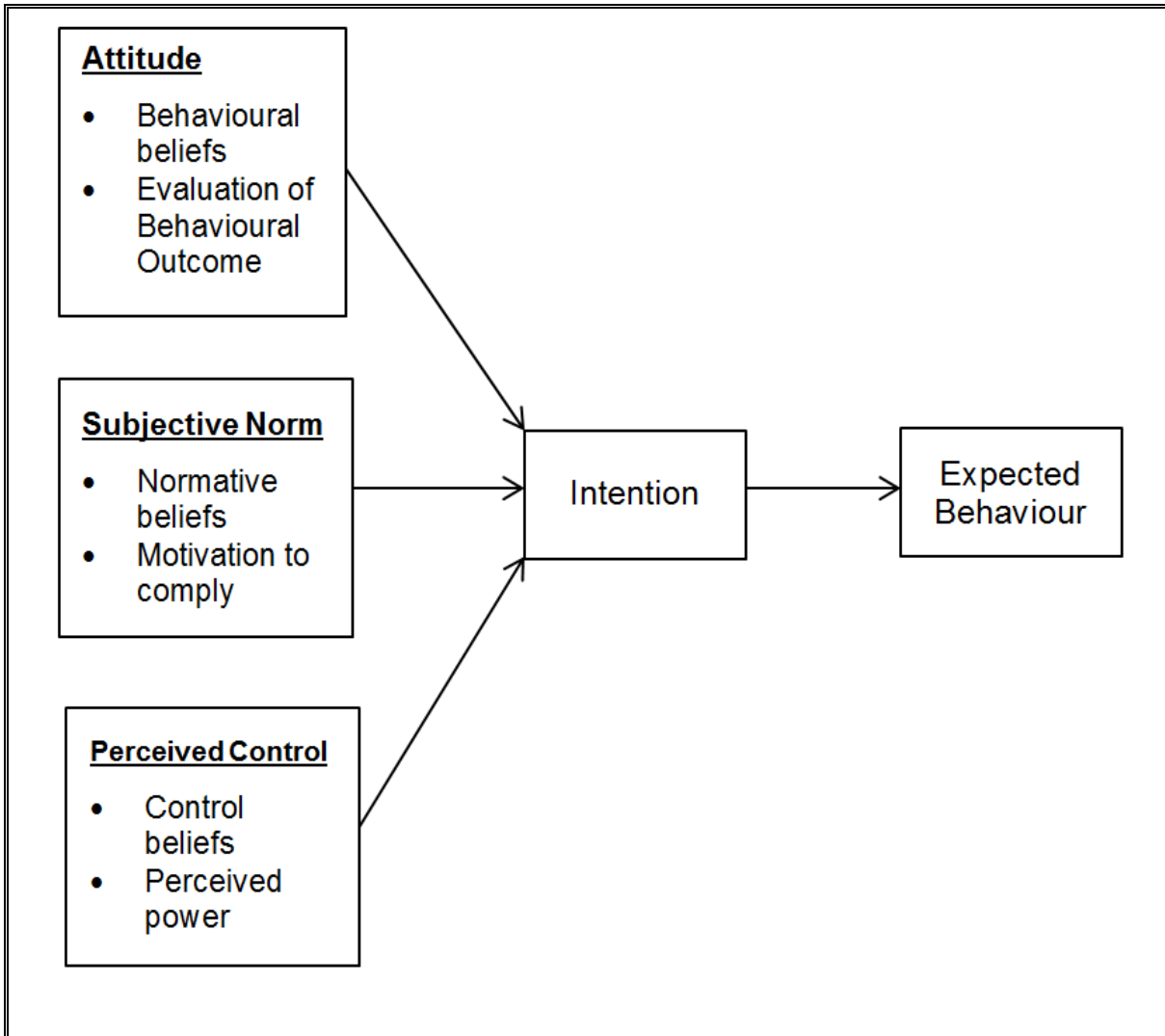
### 3.4.1 Theory of Planned Behaviour

The Theory of Planned Behaviour was developed to address the shortcomings of The Theory of Reasoned Action. The Theory of Planned Behaviour states that a person's behaviour intention is formed by attitude, subjective norm, and perceived control. *Attitude* is formed by (1) behavioural beliefs and (2) evaluations of behavioural outcomes. *Subjective norm* is formed by (1) normative beliefs and (2) motivation to comply with expected behaviour. *Perceived control* consists of (1) control beliefs and (2) perceived power (Ajzen 1991). Behavioural intention leads to expected behaviour (Figure 3.5). This theory is widely used by health professionals in creating behaviour change interventions. However, there are at least two over-riding reasons why this theory does not meet the required criteria for such use in this case:

Firstly, intention is accepted as the outcome criteria. It is assumed that if a person has intention to do an act, he/she *will* do that act. According to Weinstein, there is a gross error in this assumption; there could be many factors that could intervene between the forming of intention and the actual execution of an act or behaviour (Weinstein 2007).

Secondly, this theory assumes that perception leads to behaviour. Attitude, subjective norm, perceived control and intention are all perceptions. So, the flow of causality is from perception to behaviour outcome. This flow can be true if only perception is the cause of the behaviour. This is not always true as research to date has shown that behaviour itself can also cause perception, and therefore the causality can be reversed (Weinstein 2007). In fact, to this date there has been limited empirical support for the theory of planned behaviour's reliability and validity to predict behaviour. As a theoretical construct, the Theory of Planned Behaviour explains only 27 per cent of the variance in actual behaviour (Godin 1992; Webb 2010). Theory of Planned Behaviour studies with full factorial designs are rare and often inconclusive (Webb 2010).

Michie *et al.* (2008) recognise that the Theory of Planned Behaviour was rarely used to design interventions; rather it was more frequently used only to understand behaviour and to develop outcome measures (Michie 2008). They emphatically point out that researchers tend to use it to explain behaviour but not to *change* behaviour (Michie 2014). Thus it can be inferred that theory of planned behaviour does not meet the criteria to be applied in developing a 'theory-based' behaviour change intervention for this research project.

**Figure 3.5:** Theoretical Model for Theory of Planned Behaviour

Source: Developed from Armitage and Conner (2001)

### 3.4.2 Health Belief Model (HBM)

The health belief model states that a person will take health-related action if that person feels that a negative health condition can be avoided, and that by accepting a recommended action, the person can improve their health conditions (Becker 1974). A third condition attached to this theory is the personal belief that can modify a person's ability to act on the recommended health action. An underlying theme within the theory is the 'fear' of facing adverse consequences of unhealthy behaviours leading to negative health conditions. This model is widely used to design health behaviour interventions. However, for the purpose of developing a behaviour change intervention it has been criticised on a number of counts.

Firstly, the Health Belief Model does not represent a single theory; rather it owes to Stimulus Response (S-R) Theory by Watson (Watson 1925) and Cognitive Theory by Lewin

(Lewin 1951) and Tolman (Tolman 1932), and, as is evidenced more recently from Rosenstock *et al.* (1988), to Social Cognitive Theory by Bandura (Bandura 2004). The Health Belief Model has been developed over time from its inception in 1966 (Rosenstock 1966) to 1988 (Rosenstock 1988). Rosenstock (1966) postulated four constructs. Over the years another three constructs have been added to this model. Despite the widespread use of the Health Belief Model, it lacks theoretical integrity.

Secondly, the four original constructs in this model account for only 0.1 to 9 per cent of variance in behaviour (Taylor 2006).

Thirdly, since most studies selectively utilised different combinations of constructs, this review could find no study that could verify the 'effect size' of all the seven constructs within this model on to the outcome behaviour.

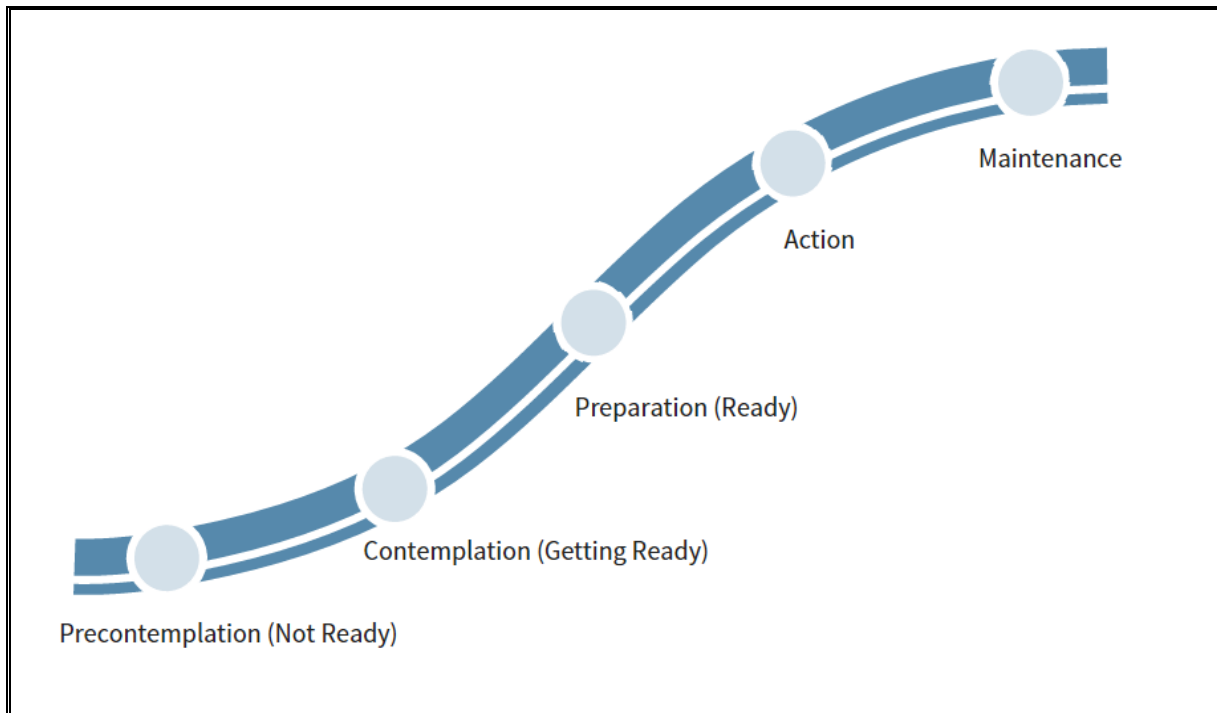
Fourthly, although researchers continue to term its major variables as theoretical constructs, in the truest sense of the term, they are not theoretical constructs. A theoretical construct must follow from a theory and then all the sub-constructs must be inter-related. Such inter-relations between the major variables must be qualified by a reliability score. When a number of variables are gathered together to form a model, it does not represent a 'theoretical construct'.

Lastly, many researchers call it a theoretical framework, which is not correct since the model does not emerge from a single theory. At best it can be termed as a conceptual framework.

The above criticisms underpinned the decision to reject the Health Belief Model as a basis for the development of the behaviour change intervention in this project.

### **3.4.3 Trans-Theoretical Model**

As the term implies, a number of theoretical models, their constructs, or several related theories have been incorporated into this model. There are five stages in this model (Taylor 2006) as shown in Figure 3.6, where the behaviour change in a person is viewed in terms of a process over time. For example, in the *pre-contemplation* phase a person is not ready to change, and this stage is said to last about six months. In stage two, i.e. *contemplation*, a person is thinking about changing a behaviour within next six months or so. In the *preparation* stage one is ready to change within next 30 days. The *action* stage begins six months after actual change has occurred and the person has overtly shown the signs of changes. Finally the *maintenance* stage is a condition in which a person has retained the changed behaviour at least for six months.

**Figure 3.6:** Trans-theoretical Model (TTM)

**Source:** Developed from Taylor *et al.*, 2006

The following criticisms disqualify the Trans-Theoretical Model from use in developing the behaviour change intervention for this research project:

Firstly, the model incorporates fifteen different theoretical constructs (Sutton 2001). The originators of this model, Prochaska and DiClemente (Prochaska 1984) note that it emerged from a comparative analysis of leading theories of psychotherapy and behaviour change. Thus, by definition, it lacks theoretical integrity.

Secondly, many argue in favour of, and elevate this model as a theoretical framework. However, it does not come from a single theory. A model falls short of a theoretical model unless it has theoretical integrity. It can only be a conceptual framework, as discussed earlier under the Health Belief Model.

Thirdly, each of the stages of this model is bound by timeframes. However, there is no justification for how such timelines are suitable for the population of interest in this research.

Fourthly, a person can relapse to a previous stage from any one stage. For example, in smoking cessation, people have many attempts and failures before they finally manage to quit smoking i.e. progress is backwards/forwards rather than in one direction. The possibility that an individual can relapse into any previous stage creates “a circularity of explanation and prediction” (Bandura 1998). In the case of cancer survivors, they may be particularly susceptible to setbacks due to health-related or treatment related complications.

Lastly, shifting from one descriptive category to another, such as between stages one and two does not make the approach a “dynamic process model” (Bandura 1998). As Bandura (1998) further noted, genuine stage progression should not permit recycling through stages as is suggested in the relapse stage. In fact, people do not recycle through discrete stages. Indeed, in a previous work, Bandura (Bandura 1997) noted that a stage theory or model must meet three cardinal properties: (1) qualitative transformation across stages, (2) invariant sequence of change, and (3) non-reversibility.

In conclusion, given these limitations, the Trans-Theoretical Model was considered to be unsuitable for developing the behaviour change intervention in this project.

#### **3.4.4 PRIME Theory**

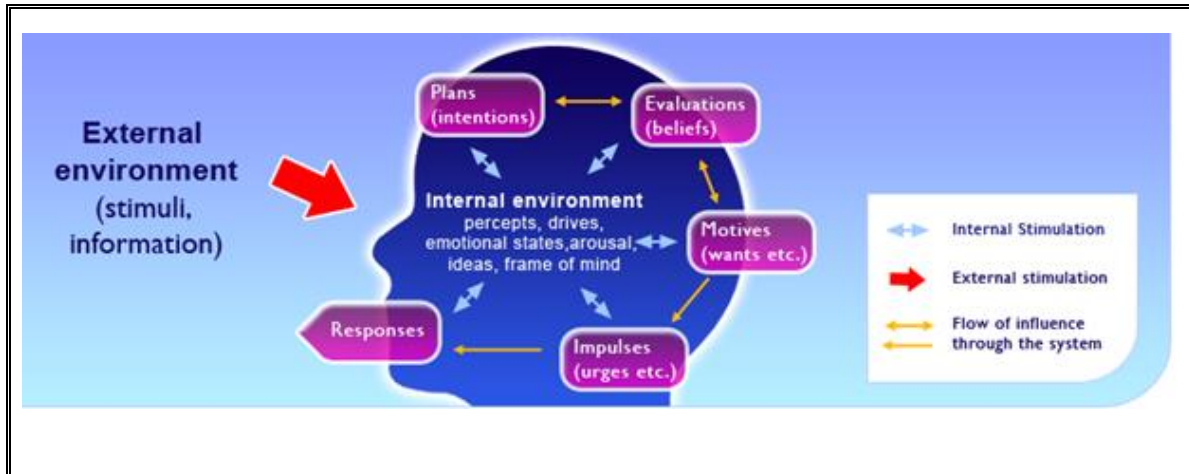
This theory originated from West (West 2005; West 2009; West 2013). It is based on the argument that human motivation to change occurs through five stages (Figure 3.7) including plans, responses, impulses or inhibitions, motives, and evaluation (and hence PRIME). It is also possible that the concept in PRIME originated from a process modelling in implementation research which was published in 2003 by Walker et. al., where PRIME stands for **PR**ocess modelling in **ImpleME**ntation research (Walker 2003).

This review found little evidence of its theoretical origin in published sources. Apparently it is a process model in human psychology, which is widely referenced by many leading researchers, who use it in designing ‘theory-based’ (or -inspired, or -driven) behaviour change interventions (West 2010; Fidler 2011; Fidler 2011; Michie 2011; Smit 2011; Lorencatto 2012; Smit 2012).

West’s PRIME theory has now been printed in a book form, titled, *Theory of addiction*, (West 2013). A review of this theory by Graham (Graham 2007) noted that PRIME is not a theory of addiction (as West might have projected it to be), rather a general theory, and yet a better word for PRIME is that it is a ‘template’. PRIME is stocked with a lot of concepts and sub-hypotheses. West mentioned in his book ‘three dozen theories of addiction’ from psychology of learning and motivation, neuroscience, and social psychology (West 2013).

Although PRIME has been termed a theory by its originator, this can at best be a ‘conceptual framework’ with many concepts, and with references to over three dozen theories of addiction. It was considered to demonstrate insufficient theoretical integration or grounds to be used as a theory, and did not appear to be a theoretical framework that could predict behaviour intervention. That is why it did not fulfil the criteria of theory selection for this research.

**Figure 3.7:** Five stages of the PRIME Theory including plans, responses, impulses or inhibitions, motives, and evaluation



Source: West, 2009

### 3.4.5 Behaviour Change Wheel

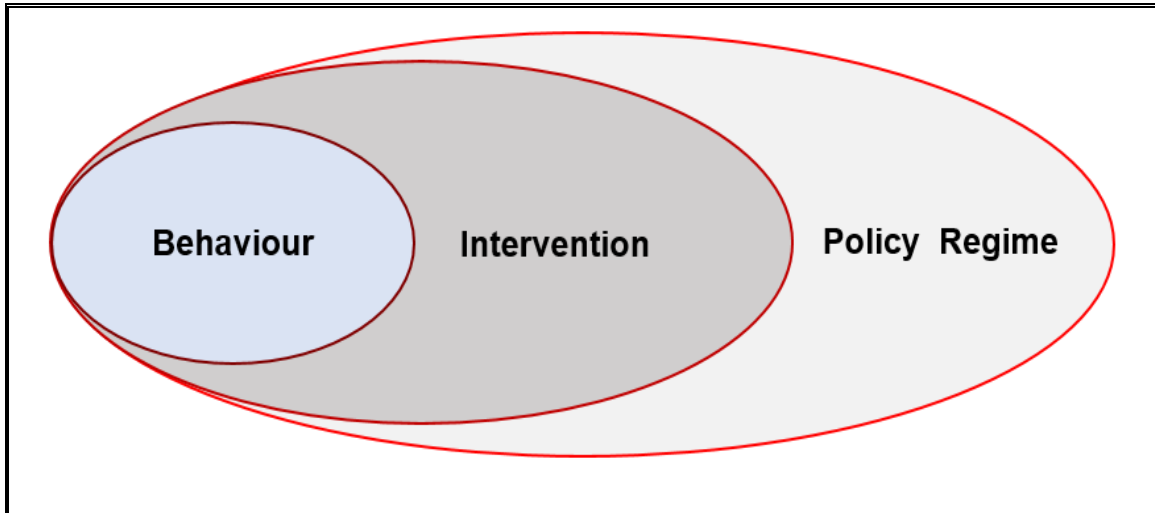
According to the Behaviour Change Wheel, a person's behavioural changes occur through interventions, while the intervention is potentially linked with the policy regime that creates situations favourable to change a person's condition (Figure 3.8).

The Behaviour Change Wheel uses the COM-B ('capability', 'opportunity', 'motivation' and 'behaviour') model. This model recognises that behaviour is part of an interacting system involving all these components (Figure 3.9). Interventions need to change one or more of them in such a way as to put the system into a new configuration and minimise the risk of it to revert (Michie 2011).

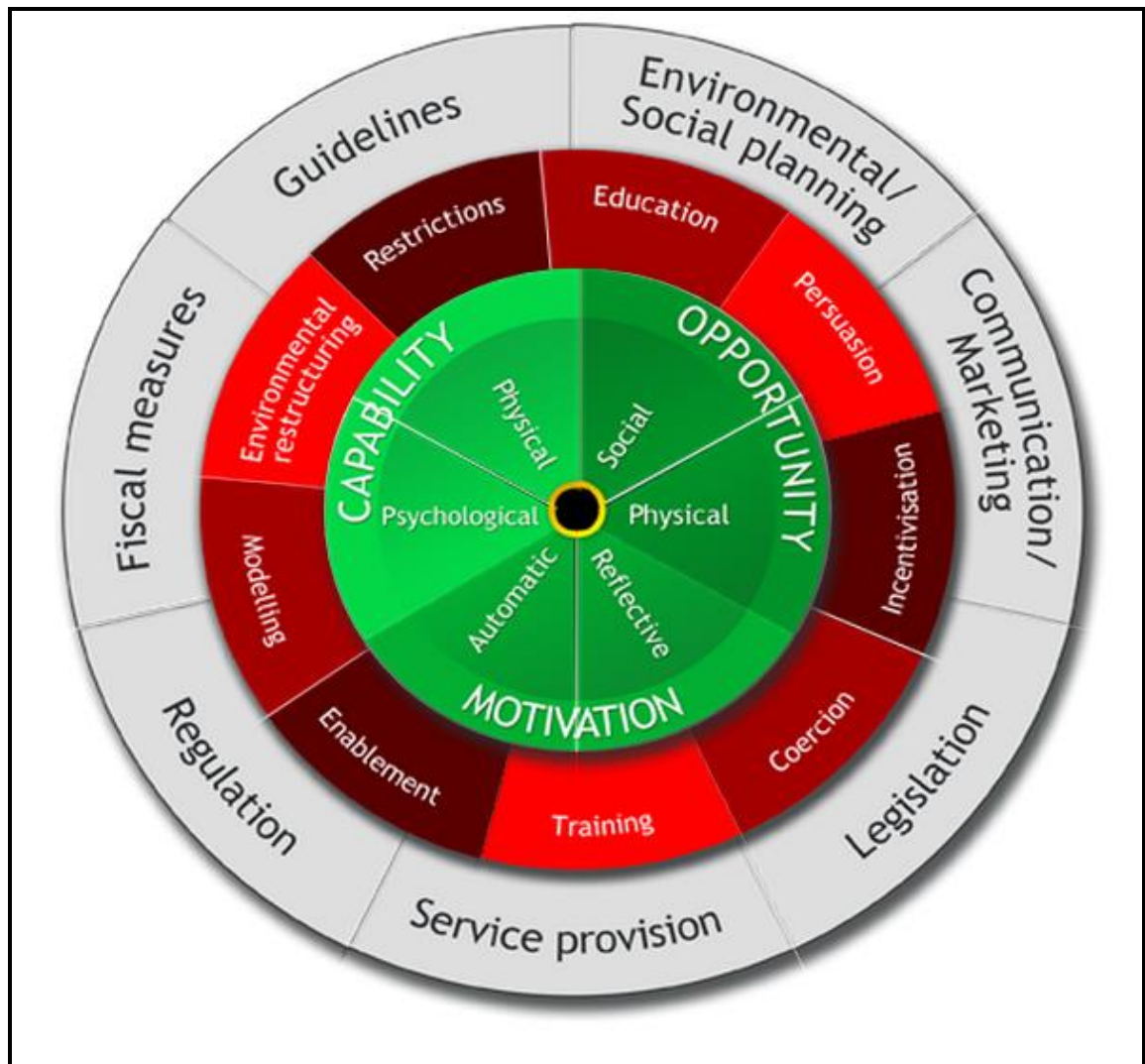
The Behaviour Change wheel by Michie *et al.* (Michie 2011; Michie 2014) was created after thorough criticisms of contemporary research in health services. However, this model involves multi-level change including policy and service provision and thus was not suitable for the purpose of development of the physical activity behaviour change intervention to target cancer survivors on an individual level.



**Figure 3.8:** Outcome Behaviour – Intervention – Policy Regime



**Figure 3.9:** Behaviour Change Wheel



**Source:** Michie, S., van Stralen, M. M. and West, R. (2011)

### 3.5 Social Cognitive Theory

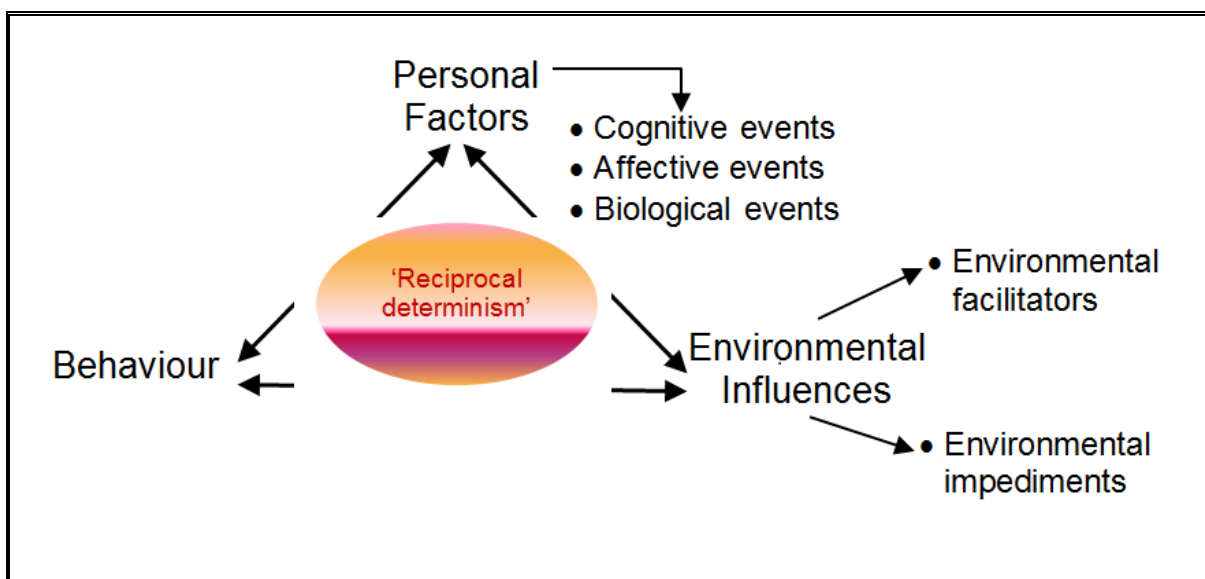
Social Cognitive Theory has its roots in the work of Miller and Dollard (1941) having evolved from their theory of social learning (Miller 1941). Bandura and Walters (Bandura and Walters 1963) reframed this theory in 1963, and in 1977, Bandura refuted the social learning theory of 1941 (by Miller and Dollard) as traditional learning theory, while at the same time he added the concept of self-efficacy (Bandura 1997). The result of which was that Social Cognitive Theory came into being. A series of works by Bandura (Bandura 1988; Bandura 1989; Bandura 1991; Bandura 1992; Bandura 1994), and one particular work with his colleague Wood (Wood 1989) introduced the use of Social Cognitive Theory in varied contexts.

#### 3.5.1 Core concepts of Social Cognitive Theory

There are three core concepts in this theory: personal factors, environmental influences and behaviour. There are also a number of other concepts found in the theory, which are related to these three fundamental concepts: environment, situation, behavioural capability, expectations, expectancies, self-control, observational learning, reinforcements, self-efficacy, emotional coping responses, and reciprocal determinism.

The key proposition of the theory is that human functioning is determined by the common relationship between the main three concepts of this theory as shown in Figure 3.10. Bandura has called the interaction of these three major concepts as 'reciprocal determinism' (Bandura 1986). The success in human functioning, and any behaviour change intervention, is attributed to the application of this triadic interaction (Bandura 1998).

**Figure 3.10:** Three fundamental concepts in Social Cognitive Theory



**Source:** Bandura (1978; 1986, and 1998)

### 3.5.2 Theoretical Constructs of Social Cognitive Theory

The theoretical constructs of social cognitive theory have evolved over time, and more theoretical constructs are evolving from the theory. For example, 'collective efficacy' from the concept of self-efficacy has emerged from this theory later than the original postulation entering the concept in the wake of managing organisations (Bandura 1993; Bandura 1995; Bandura 2000; Fernández-Ballesteros 2002). The most commonly used theoretical constructs for this theory (Bandura 1986) are explained below:

#### **Self-efficacy**

Self-efficacy is the belief in the worth of what an individual does towards an expected outcome, or a changed behaviour (Bandura 1986). It has been defined as one's perceived confidence in overcoming barriers to 'physical activity' (Hatchett 2013), although it can extend to cognitive abilities (Kanfer 1989; Kraiger 1993; Halpern 2013). The self-efficacy of a person is influenced by many variables including the existing barriers and the actual and perceived abilities of a person in overcoming these barriers. Bandura (1998) argues that self-efficacy "may entail regulating one's own motivation, thought processes, affective states and actions or changing environmental conditions, depending on what one seeks to manage" (Bandura 1998).

#### **Outcome expectations and values**

The expectations are those which are held by an individual. The values, also called 'expectancies', are the values that motivate a person to achieve the outcome. They stem from the evaluation of the physical and social environment and from the evaluation of one's capability to change these environments in their favour. It is a subjective probability that a particular behaviour, if performed by someone at a given level of competence, will be followed by a particular outcome (Graves 2003).

#### **Environment**

Everything that is external to the self and which can impact on human functioning is termed environment. Environment is related to human functioning through impediments and facilitators in regulating human motivation, action, and well-being (Bandura 1998). It comprises personal and social factors. A human being is both a product and producer of environment. A unique feature of Social Cognitive Theory is to identify the stimuli that cause impediments in the process of behaviour change. These stimuli are the impediments from personal and social factors, and existing health systems which they are a part of.

#### **Self-control**

Also termed self-regulation, it is a process of planning, monitoring, and executing tasks that an individual believes will change his or her behaviour. This is done in accordance

with one's abilities corresponding to the environment in which one lives (Graves 2003; Bandura 2006).

### **Behaviour capability**

It is the degree to which a person is able to use one's physical and cognitive abilities to execute the tasks that are required for desired human functioning, in this case behaviour change. Knowledge and skills are used to increase the behavioural capability.

### **Observational learning**

Observational learning contributes to an individual's beliefs through the activities of similar individuals or role models. It is a social standard against which people judge their own capabilities. Through the behaviours and expressed ways of thinking, competent models transmit knowledge and teach an individual effective skills and strategies for managing what is required for human functioning.

### **Reinforcements**

In the context of human behaviour, reinforcements are contingencies that control or maintain problem of behaviours (Marcus 1998). Reinforcements are, therefore, tools, resources, peer groups, rewards, punishment, and environmental cues that favour or disfavour the behaviour change.

### **Emotional coping responses**

Named also coping behaviour, this is the ability to manage stress and adversity. It reflects ones strength against stress and depression, particularly in coping with taxing environmental demands, and the life choices that an individual makes and the accomplishments one realizes (Bandura 2001).

### **Impediments**

Impediment is an important concept within social cognitive theory (Bandura 1998). Although nearly all intervention research in health sciences considers impediments, it is not always articulated as an impediment. According to Bandura, impediments in human functioning have three potential sources: personal (cognitive), situational, and (health) system. Impediments in social cognitive theory distinguish it from other theories that are used in designing interventions. Bandura (1998) shows (Table 3.1) the distinctive features of this theory compared to other health behaviour models:

**Table 3.1:** Comparison of the Social Cognitive Theory to other behaviour models/ theories

Theories	Psychological Determinants of Health Behaviour							
	Self-efficacy	Outcome expectations			Goals		Impediments	
		Physical	Social	Self-evaluative	Proximal	Distal	Personal & Situational	Health System
Social Cognitive Theory	✓	✓	✓	✓	✓	✓	✓	✓
Health Belief Model		✓	✓				✓	✓
Theory of Reasoned Action		✓	✓		✓			
Theory of Planned Behaviour	✓	✓	✓		✓			
Protection Motivation Theory	✓	✓						

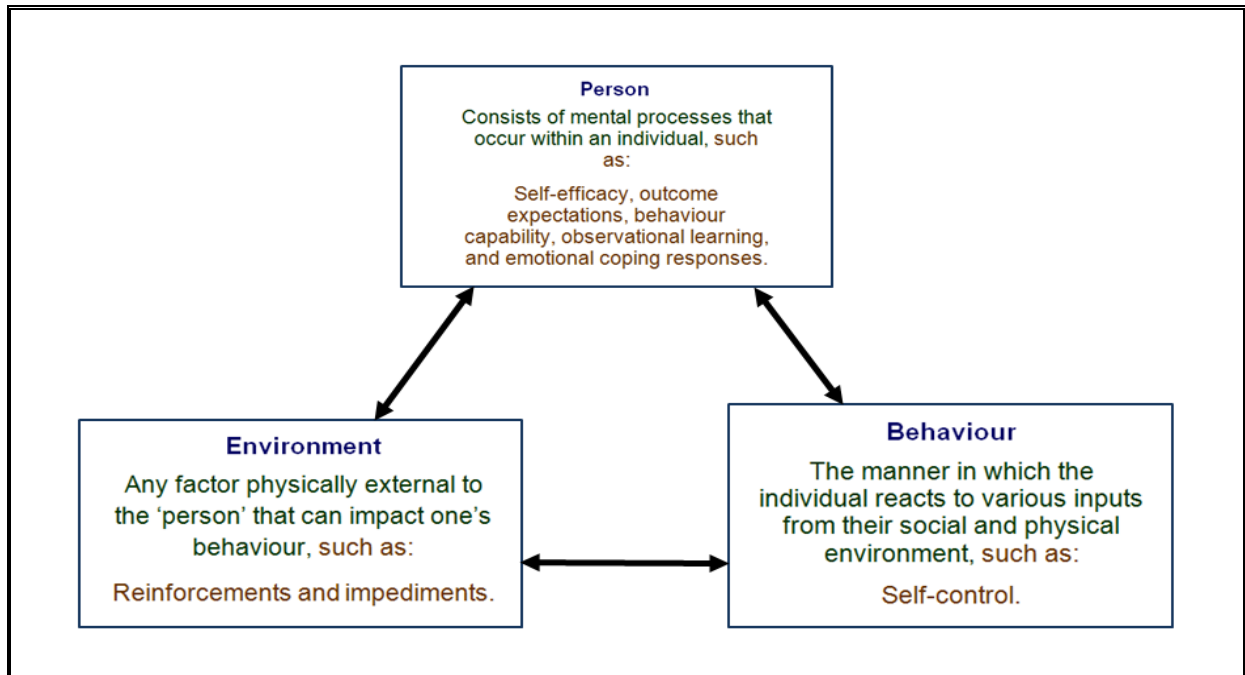
**Source:** Bandura, 1998, p. 625

It should be acknowledged that the number of theoretical constructs that can be derived from a given theory is not limited. However, it is important to realise that theoretical constructs of social cognitive theory must be operationalised (or understood) within the causal framework of triadic reciprocal determinism (Figure 3.11), and as such the theoretical constructs mentioned above will take the following form within this determinism:

*Person:* Consists of mental processes that occur within an individual, such as self-efficacy, outcome expectations, behaviour capability, observational learning, and emotional coping responses.

*Behaviour:* The manner in which the individual reacts to various inputs from their social and physical environment, such as self-control.

*Environment:* Any factor physically external to the 'person' that can impact one's behaviour, such as reinforcements, and impediments.

**Figure 3.11:** Theoretical Constructs in Social Cognitive Theory and their triadic reciprocal determinism

It should be noted that 'behaviour' within the above diagram is an integral part of the causal system. It is not the same as expected behaviour-outcome. In Social Cognitive Theory, the behaviour outcome is termed as a 'goal' (Bandura 1998). According to him, goals can be of two types – 'proximal goals' and 'distal goals'. These goals are what have been referred to as the 'human functioning' in the theory postulation. Proximal goals are the ones that are immediate, or the ones "here and now", as Bandura (1998) puts it. However, to attain the ultimate distal goals, there are the intermediate goals which help to accomplish those distal goals. The interplay of all the variables within the three sets of theoretical constructs (Figure 3.11) generates the ultimate goal, or the expected (changed) behaviour, by meeting one or a series of proximal goals.

Theoretical framework for this research has been drawn from Social Cognitive Theory. The relevance of the constructs of Social Cognitive Theory to mediate physical activity behaviour change in cancer survivors is shown in Table 3.2.

**Table 3.2:** Relevance of theoretical constructs of the Social Cognitive Theory to promote physical activity for cancer survivors

<b>Theoretical constructs of Social Cognitive Theory</b>	<b>Relevance to cancer survivors for physical activity promotion</b>
Self-efficacy	Cancer survivor's confidence in his or her ability to adopt a physically active lifestyle.
Outcome expectations and values	Results expected by the cancer survivors with regards to being able to carry out prescribed physical activity, and the values that drive the cancer survivor in achieving the outcome of performing the regular physical activity prescribed.
Environment	Consists of personal and social facilitators affecting cancer survivors, and existing health systems in which they are a part of.
Self-control	Consists of goal-directed behaviour such as if the cancer survivor is planning for future PA, or currently under a PA plan; and self-evaluation about the physical activity if under a PA routine.
Behaviour capability	Consists of the knowledge about PA both before and after cancer treatment.
Observational learning	Consists of familiarity with any cancer survivor and if or not inspired the cancer survivor (respondent) in following him/her as a role model.
Reinforcements	Consists of an evaluation of whether the cancer survivor feels rewarded by performing physical activity.
Emotional coping responses	Consists of an assessment of the sadness and worries associated with possibilities of failure to begin or to continue with physical activity by cancer survivors.
Impediments	Consists of impediments from personal and social factors of cancer survivors, and existing health systems in which they are a part of.

In summary, the earlier discussions show that in whichever way a research is approached to develop an intervention, the role of theory is best served when a single theory can explain the entire phenomena from the beginning to the end. There may be several conditions as to how theories are used in behaviour change interventions:

When such interventions are developed from an established theoretical model the assumptions are that the model itself has strong theoretical basis. An example of this evident lies in numerous research reports that have used theory of reasoned action as the theory, and related models such as health belief model. It should be made clear that theory of planned behaviour is a modified theory from theory of reasoned action, and many research mention theory of planned behaviour as a model rather than a theory.

When interventions are developed from a theory and all the assumptions about the application of the theory are explicit, the existence of such a condition is largely hypothetical, because there is hardly any research that makes such assumptions evident and clear.

However, this condition ignores, refutes, or adds to the works that are already founded with a given theory, or a number of theories. In some cases, this may seem repetitive and at the same time unnecessary, assuming that health sciences have good number of theories to refer back to. In other cases, a researcher might contribute to fill an existing gap.

Developing the intervention models from the concepts alone, on the other hand, assumes that the researcher is seeking totally new direction or that the concepts are new and such concepts are not an integral part of any theory. Theoretically, intervention models may also be developed from multiple theories. Many studies claim so, although on rigorous review they might not demonstrate that multiple theories can explain all the phenomena equally or consistently. Indeed, many studies that claim to have developed intervention models by using multiple theories, at best, show that they have used constructs from multiple theories or multiple existing theoretical models.

This research has used a single theory to develop a behaviour change intervention for cancer survivors. However, doing so does not restrict other theories and theoretical models to explain the developed intervention models. The main effort in this thesis has been to explain the development process by a single selected the Social Cognitive Theory.

### **3.6 Conclusion**

The literature review in this chapter provided an overview of different physical activity behaviour change theories which provided a context to develop a theoretical framework for this research project. The main purpose of a theoretical framework for research is to guide the research within theory, provide theoretical support to the research output, and enable others to replicate and further the research on same or similar research issues. In keeping with these purposes, the theoretical framework of a research is developed according to the requirement of answering the research question and objectives. Exploration of all the leading theories and models of physical activity behaviour modification deemed that Social Cognitive Theory was the most suitable for answering the research questions in this thesis. The theoretical framework developed for this project was drawn from this theory and includes all of its constructs.



## **Chapter 4. Cancer survivors' perceptions about physical activity; facilitators and barriers to uptake of physical activity advice: A qualitative study**

### **Aim:**

To assess cancer survivors' perceptions about physical activity; barriers and facilitators to the uptake of physical activity advice

### **Main findings:**

The type of physical activity advice preferred by the adult cancer survivors was:

- In person & individually tailored
- Consistent, and part of standard healthcare
- Given throughout their cancer journey
- With reinforcement at the end of their cancer treatment

## 4.0 Chapter Summary

This chapter describes qualitative research to find out what helps in terms of the complex issue of physical activity promotion in cancer survivors. Four focus group discussions involving 21 cancer survivors contributed to the data for this chapter. The participants reported being involved in a wide range of physical activities. Ability to do these varied by person, and their physical and clinical condition. Participants reported that their ability to perform physical activities diminished over time while gradually moving through cancer treatment and the post-treatment phases. Family and/or social support both facilitated and hindered a physically active lifestyle depending upon whether the family members were supportive or over-protective in their approach to the patients' physical activity.

Regarding their experiences of physical activity advice from the health professionals involved in their treatment and care, the majority reported receiving inconsistent and/or conflicting advice which led some not to exercise because of confusion and lack of confidence. Some implementation issues regarding the receipt of Macmillan's 'MoveMore' packs were also highlighted as the majority had not received these after their diagnosis or during their treatment. The 'MoveMore' packs were planned to be included in the patients' treatment planner and their treatment completion packs in a joint venture by Macmillan and Betsi Cadwaladr University Health Board known as the 'North Wales Physical Activity Project'.

Cancer survivors in these focus groups also helped to refine a behaviour change physical activity promotion intervention. They modified the refined messages by the researchers in service users' language. Three stages of the refinement of these messages will be described later in chapter 6, which will describe the developmental process of the intervention. The data analysis also revealed that the theoretical constructs underpinning the intervention seemed relevant to bringing about a positive change in physically active behaviour of cancer survivors by overcoming barriers to exercise.

### 4.1 Introduction

This chapter will first consider the qualitative research methodology used to collect data from cancer survivors in order to achieve the aims and objectives of the study. It will also present the rationale behind the consideration and selection of sampling, data collection, and data analytic techniques.

### 4.2 Study design

Qualitative research has gained popularity in healthcare research since the mid-1980s to understand people's 'meanings' of real life situations in a holistic way because of

the difficulty with quantitative methods to answer the 'why' and 'how' questions. In healthcare research, it is crucial to understand, rather than predict as is the case with quantitative research methods (Laverty 2003), a behaviour before attempting its modification. Such understanding can be achieved by qualitative research methods. Extending these concepts to the context of physical inactivity, the quantitative researcher may wish to highlight the potential problems of sedentary behaviour and challenges it poses to a healthcare system. This understanding may then lead to designing strategies that might work for this population in order to streamline the resources.

However, the qualitative researcher might strive to understand the meanings people attach to their inability to function properly; and how it might affect their self-esteem, and decision making processes. Such data can only be gleaned if the researcher delves into in-depth conversations with the participants and gets the required information interactively. The insights gained as a results can then be used to design strategies to promote healthy lifestyles. There are a number of qualitative research methods available to health services researchers, however the choice of an appropriate method depends upon the individual study aims and objectives (Tracy 2012). This would entail, in the context of the current study, cancer survivors' views, attitudes and perceptions about physical activity; their acceptance of physical activity promotional campaigns including educational materials; and barriers and facilitators to adopting healthy life choices including increasing physical activity.

### ***Data collection method***

Focus group interviews were selected as the method of choice to collect the data from adult cancer survivors fulfilling the inclusion criteria (section 4.4.1) to discuss and comment on issues related to physical activity promotion from their personal experiences. This was selected because the participants are 'focused' to some kind of collective activity (such as debating or discussing a particular set of questions related to the aims of research (Ritchie and Lewis 2003; National Institute for Health Research 2009). Some arguments in favour and otherwise for this approach are presented in the following paragraphs to give perspectives to the readers.

Focus group method evolved during the late 1930s & 1940s when social scientists explored strategies to limit researchers' directive and dominating role and allowed respondents to express their views on areas that they deemed to be most important (Roethlisberger and Dickson 1939; Rogers 1942). Such non-directive interviewing techniques in groups help to create a comfortable environment to ensure that the range of intended data collection is achieved (Mary and Dickson 1997; Krueger and Casey 2015).

Focus groups have the advantage of incorporating views of more participants in less number of interviews and helps bring a mix of respondents under one roof to interact and express their views in the presence of people in similar situation related to the research

question (Ritchie and Lewis 2003; National Institute for Health Research 2009). Jourard (1964) conveyed it as:

*“Subjects tended to disclose more about themselves to people who resemble them in various ways than to people who differ from them (p.15)”* (Jourard and Lasakow 1958).

Desired data can be collected quickly and inexpensively because the researcher can interview many participants collectively, at the same time and place. This process may also enhance the confidence of the group to talk about their shared experiences, and the views of people with very limited literacy can also be captured (Bowen 2009). However, careful consideration during the interview sessions should be given to a systematic approach to get richness of the data by focusing on specific topics of interest. Participants should feel comfortable, respected and free to give their opinion without being judged, in order they can give true accounts of their views about the topic of interest (Ritchie and Lewis 2003).

On the other hand, focus groups may not be suitable for some sensitive or intimate topics. Some people may hesitate to participate in a group discussion; whereas others may dominate the group, or there can be power differentials in an organisational group discussion. Sometimes people can be influenced to change their views to fit with the ideas of others in a group. Some topics of discussion might raise ethical issues about confidentiality and anonymity. Another issue can be the huge amount of data produced which may make analysis laborious and time consuming.

Despite these disadvantages of focus group interviews, some considerations can help to overcome these during the data collection process, which include: good communication skills by the researcher with the ability to direct or control the group; and continuous effort by the researcher to involve less participating group members to express their views on the topic under discussion. In terms of data handling, there are computer assisted techniques available to help the researchers deal with large amount of qualitative data (Ritchie and Lewis 2003).

In summary, based on the above consideration, semi-structured focus group interviews were chosen as a data collection method for this study to capture adult cancer survivors' shared experiences of physical activity both in general and during their cancer journeys from diagnosis to treatment and beyond.

### ***Sampling techniques***

The purposive sampling technique was used for this study because it was found to be appropriate to achieve the range and diversity within cancer survivors, hence helpful in identifying the most information rich cases to learn about issues fundamental to the purpose of the research (Suri 2011). The sample comprised adult cancer survivors who had

completed their cancer treatment. The details of the inclusion/ exclusion criteria are given in the methods section (4.4.1).

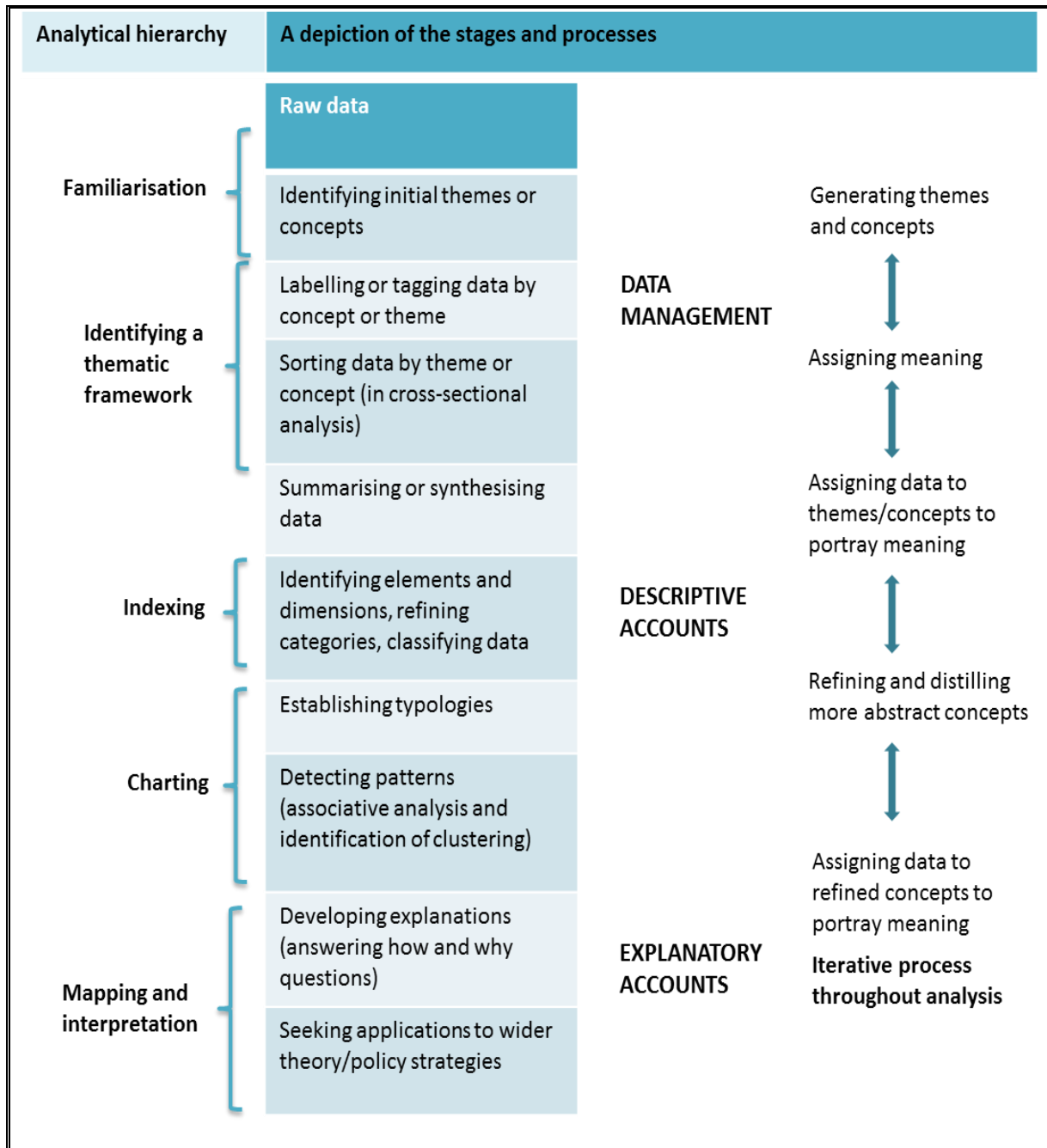
### ***Data analysis approach***

The Framework method was used in this study, which sits within a broad family of qualitative data analysis termed thematic analysis or qualitative content analysis. This method was developed by Ritchie and Spencer in the late 1980s in the UK (Ritchie and Lewis 2003) and is now being widely used in healthcare research, particularly where research builds from one phase to the other (Gale, Heath et al. 2013).

Thematic analysis was used to analyse the qualitative data in this study, which searches for common themes that emerge throughout the interview transcripts. Text was analysed paragraph by paragraph. Raw data were broken down into codes, clustered into categories and then built up into themes which were used to express the essence of the experience of cancer survivors during their journey (Gale, Heath et al. 2013).

This approach ensures integrity of data but allows a complete view of perceptions and experiences that answer the research questions while maintaining a rigorous analysis identifying a thematic framework, indexing, charting, and mapping & interpretation of the data. The analysis is described in detail under the corresponding section 4.4.7, explaining each stage along with the actual process undertaken in this study (Ritchie and Lewis 2003). A depiction of the analytical hierarchy is shown in Figure 4.1.

**Figure 4.1:** *The analytic hierarchy*; a depiction of the stages and processes involved in qualitative analysis



Adapted from Ritchie and Lewis, 2003; p-212

### 4.3 Study aims and objectives

- 1) Find out cancer survivors' views and perceptions about the role of physical activity in both the management of the symptoms of their disease.
- 2) Explore views of cancer survivors about various means of help and support including types of informational or educational materials available to help improve physical activity during their cancer journey.
- 3) Explore what helps or hinders the uptake of physical activity advice among adult cancer survivors?
- 4) Refine a physical activity promotional and maintenance intervention comprising evidence-based promotional messages developed from the literature and grounded in psychological theories of behaviour change; and also to translate the contents of these promotional messages into patient-centered, lay language.

### 4.4 Methods

#### 4.4.1 Population of Interest

##### ***Eligibility criteria***

In order to design an intervention for adults, the lower age limit was set at 18. Because age is not an accurate reflection of physical activity fitness or ability to exercise, and because a very modest level of activity has the potential to result in health benefits, this study did not impose an upper age limit.

Active curative intend cancer treatment completed within the previous six months

Any type of cancer

##### ***Exclusion criteria***

Close to death or without mental capacity to give informed consent

Cancer recurrence or requiring further treatment during the six months following treatment

Those with co-morbidities where physical activity would be contra-indicated, such as unstable angina or hypertrophic obstructive cardiomyopathy

People involved in other studies, if participation affects their ability or motivation to exercise.

##### ***Sampling frame***

A purposive sampling approach was employed to get an in-depth insight into the perspectives of patients with different cancer types (Ritchie and Lewis 2003). This selection criteria was thought useful to design and develop a physical activity promotional intervention that would be applicable to patients with any type of cancer. Invitation letters were sent

purposively to patients suffering from all types of cancers, of both genders, of all ages, and from as many socio-economic backgrounds as possible. This process was monitored weekly through the receipt of recruitment logs by the researcher sent by Health and Care Research Wales workforce team members who assisted with patient recruitment.

Four focus groups were planned with six to eight participants each. Such sample size has been described as sufficient to produce enough data to glean rich information regarding the research questions (Schultz, Dalton et al. 2011; Sagoe 2012). The intention was mainly to get an in depth learning about the experiences, attitudes, views and perceptions of cancer survivors about physical activity. This insight could then help explain the barriers as well as the facilitators to the uptake of physical activity advice. Hence, the 'richness' rather than 'amount' of data were deemed important, meaning that detailed patient accounts were important from study point of view rather than their total count (Carey 1995).

Though the provision was made to extend the sample size collection if the author felt some of the issues needed further exploration, data saturation was achieved (Guest, Bunce et al. 2006) by the end of the four focus groups originally planned so no further patients were recruited. This decision was facilitated through constant comparison of data (Glaser 1965), writing marginal remarks during transcript reading, keeping detailed field notes (Tuckett and Stewart 2004), post-interview meetings between moderator and the co-moderator to reflect recurring patterns, and the ongoing reading of literature. Back and forth reading of the data to recognise emerging as well as recurring themes and patterns in the data helped in the process of comparing and juxtaposing the experience of one person against the other in the data (Charmaz 1990; Cutcliffe and McKenna 2002). Once no new themes seemed to emerge, data saturation was considered reached and no further recruitment was then undertaken.

#### **4.4.2 Study Settings and Venues**

##### ***Settings***

The study was conducted at three main hospital sites across North Wales within Betsi Cadwaladr University Health Board (BCUHB): Northwest (Ysbyty Gwynedd and surrounding areas); Central (Ysbyty Glan Clwyd and surrounding areas); Northeast (Ysbyty Maelor Wrexham and surrounding areas).

##### ***Venues***

The venues for the interviews were chosen to be outside the hospital, across North Wales, in more naturalistic settings. The focus groups were organised in convenient geographic locations for the participants. Special consideration was given to the suitability of meeting rooms regarding spaciousness as well as ease of access with parking facilities. Refreshments were available at the start and during the discussion sessions, and the



environment was made as informal as possible to welcome the participants and make them feel comfortable for an open discussion within the groups.

Two out of four focus groups were conducted at the North Wales Centre for Primary Care Research, Bangor University in Wrexham, one in the Health and Care Research Wales's office in Abergele, and the last one in Bangor at the North Wales Organisation for Randomised Trials in Health, Bangor University.

#### **4.4.3 Study Set-Up**

##### ***Preparation of the study related documents***

Initial drafts of all study related documents including topic guide, participant invitation letter, participant information sheet, consent form and the reply slip were prepared and sent to the study management group and their comments and suggestions were incorporated.

##### ***Patient and Public Involvement***

In this study, cancer survivors were invited as 'lay researchers' through the Macmillan conference in November 2011, before the commencement of the study. They were asked about their willingness to participate nearer the time. One out of four invited was available at the given time. All study related documents prepared with the help of the study management group were sent to the lay researcher for her suggestions and comments. The feedback helped to refine these documents into more patient friendly versions and reduced the amount of technical information. The documents finalised for ethics submission with the lay researcher's help included the invitation letter, participant information sheet, consent form and reply slip. These study-related documents are presented in the Appendices G, H, I and J.

##### ***Development of the topic guide***

A topic guide was developed to address the research objectives (Ritchie and Lewis 2003), and was discussed within the study management group meetings (Appendix K). The detail about the topics of interest within the developed topic guide are given in the later section 4.4.5.

##### ***Ethics & regulatory approvals***

Ethical approvals were obtained from the School of Sport, Health and Exercise Sciences (SSHES) at Bangor University; and Wales Research Ethics Committee 4 (REC-4), reference number 13/WA/0025 on 01-03-2013 (Appendix L); and NHS Research and Development (R&D) approval from the internal review panel of Betsi Cadwaladr University Health Board, reference number IRAS ID 125654 on 25-03-2013 (Appendix M).

All of the study related documents were translated into the Welsh language after obtaining these ethical approvals.

### ***Pre-launch preparations***

The study was explained in person by the Bangor University researcher to the Health and Care Research Wales workforce team with the help of a procedural step by step guide. The invitation packs were delivered to the trial managers at Health and Care Research Wales within three hospitals in North Wales. The packs consisted of the following: an invitation letter, Participant Information Sheet (PIS), specimen consent form, reply slip and a prepaid envelop. Practical arrangements to conduct the focus groups were explained in the PIS. Patients interested in taking part were asked to complete and return the reply slip in the prepaid return envelope.

An Excel spreadsheet was developed in order for the Health and Care Research Wales workforce team members to send weekly updates about the study recruitment to the researcher at Bangor University. It was helpful to keep track of the purposive sampling, response rate and the recruitment challenges at any of the study setting. The expected date for the study commencement was communicated via email to the clinicians in the health board.

#### **4.4.4 Recruitment**

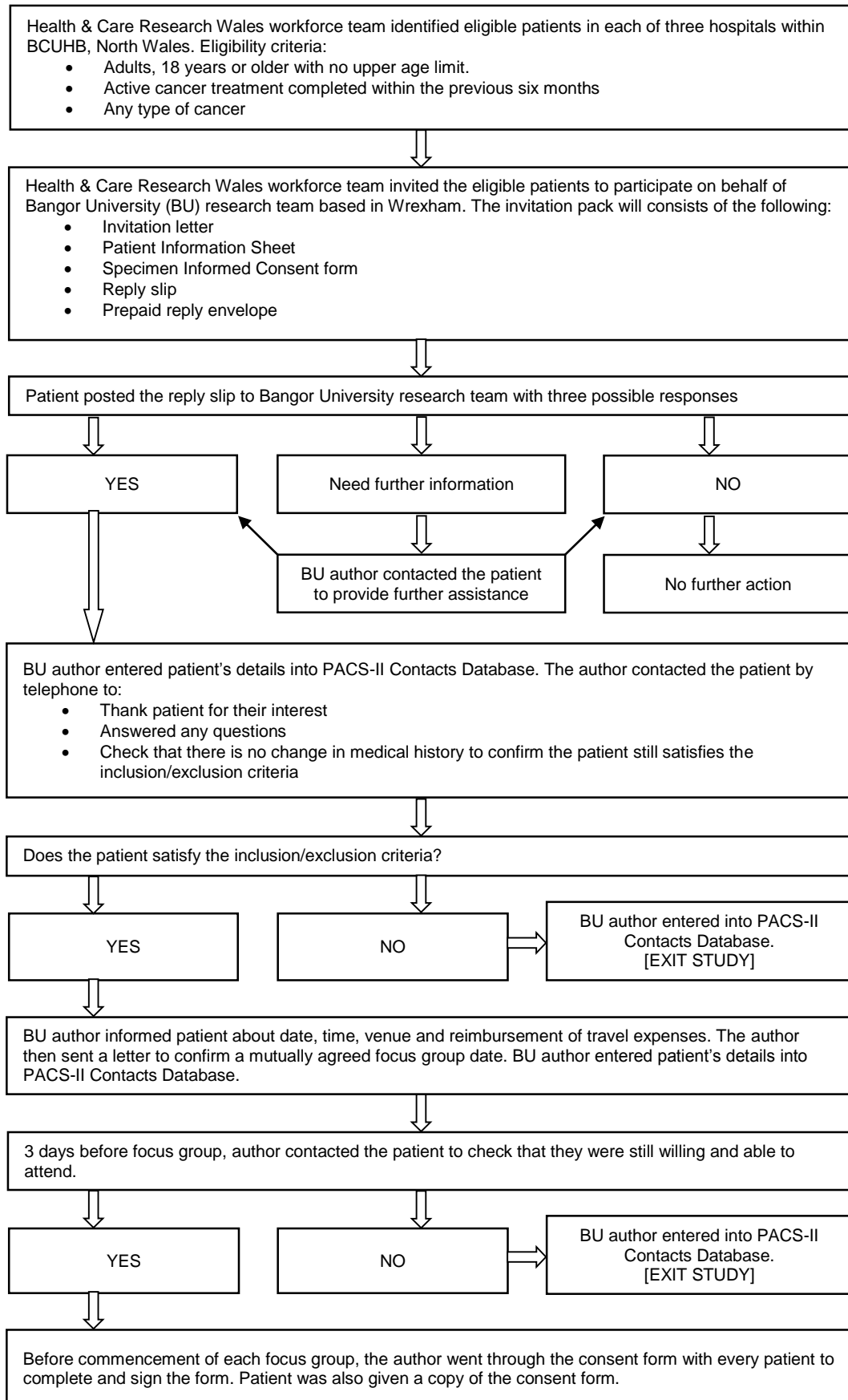
##### ***Screening***

Source data for screening of the eligible participants was the hospital written medical records within Betsi Cadwaladr University Health Board and were accessed through members of the Health and Care Research Wales workforce and the author who held an honorary research contract.

Adult cancer survivors were screened and identified in the oncology department's multi-disciplinary team meetings and from the daily listings of the oncology follow-up clinics, within six months of the completion of active cancer treatment. Inclusion was based on the eligibility criteria described earlier (section 4.3.1). Potential patients were invited by the members of Health and Care Research Wales workforce team and the author during their regular follow up consultations and were given the invitation packs to participate in a focus group discussion. Participants were allowed a period of reflection of at least 24 hours before sending the reply slip back to the author at Bangor University (Figure 4.2).

##### ***Sign up & confirmations***

The BU author contacted the patient via telephone upon receipt of the positive response. Participants were reassured that their participation, non-participation or withdrawal from the study would not affect their medical care. The date and venue was also discussed during this phone call. A week before the agreed date, a confirmation letter with directions to the venue, a free day parking permit and the travel expenditure claim forms were sent in the post.

**Figure 4.2:** Flow chart to explain the recruitment procedure of participants.

### **Recruitment challenges (April to Sep 2013)**

The study was launched in the first week of April 2013. Initially, the Health and Care Research Wales workforce team agreed to screen, identify and invite the eligible participants to the study, but recruitment was slow with the first patient only being recruited in June 2013. Only a few invitations were sent to the patients within these first eight weeks due to the competing commitments of other portfolio studies.

At this point the author requested an amendment to allow her to help the Health and Care Research Wales research nurses invite patients from the follow up clinics to speed up the recruitment process without disturbing the clinical nurse specialists' busy schedule. The target number of recruitment was achieved within ten weeks after adopting this strategy (Table 4.1). Total invitations sent out were 62: agreed 27; declined 13; non responders 22, with 67% response rate and 50% acceptance rate.

**Table 4.1:** Recruitment progress within six months

2013	Participants Invited		Non-eligible	Agreed to participate	Declined to participate	Non responders
	Health and Care Research Wales	Author (SN)				
April						
May						
June	5	1		3	3	0
July	4	22	4	13	1	8
Aug	4	21	2	9	6	7
Sep		5	1	2	3	0
Total in 6months	<b>13</b>	<b>49</b>	<b>7</b>	<b>27</b>	<b>13</b>	<b>15</b>

#### **4.4.5 Data Collection**

Focus groups were chosen as a data collection method for this study to capture adult cancer survivors' shared experiences of physical activity both in general and during their cancer journeys from diagnosis to treatment and beyond.

##### **Conduct of the focus group**

All four focus groups were conducted in North Wales, lasting approximately two hours each. Focus group venues were signposted clearly for easy participant access. Refreshments were provided during the interview sessions, and an honorarium (£10 high street gift vouchers) was offered at the end of each interview to acknowledge participants' effort to attend the interviews.

Formal introduction of the research team with acknowledgment of patients' participation was carried out before obtaining informed consent. Informal introduction of participants was performed after the consent process to make the environment conducive for

the discussion to follow. This also involved an introductory question to describe their experience of participating in a study like this.

All focus groups were moderated by the author and co-moderated by another senior member of the research team from the North Wales Centre for Primary Care Research (NWPCRC), Bangor University. The discussions were semi-structured using a predefined topic guide and were digitally recorded. The relevant points of discussion were also noted down by the co-moderator. Each focus group was followed by a post interview meeting of the interviewers, which was also recorded digitally, to reflect the views of the moderator and the co-moderator.

### ***Informed consent***

Informed consent was obtained from the participants before the start of each focus group (Sagoe 2012) confirming that their participation in this study was voluntary and they were eligible to withdraw at any time without affecting their medical care or legal rights.

Participants confirmed they heard and understood the information sheet. They were informed that the interview would be digitally recorded but these recordings would be anonymised, and used for the purpose of this research study only. The participants were also reassured verbally that all the information gathered, including note-taking and the digital recording of the group discussion, and the resulting data would be anonymised and kept confidential. It was also stated that these recordings would be destroyed at the end of the study.

### ***Overview of the research project***

A short overview of the whole project was given by the author to help the participants understand the wider research project.

### ***Topics of interest***

Participants were encouraged to discuss their views and experiences on the following broad areas:

Physical activity or exercise? (The definitions of physical activity and exercise were described in each focus group by the author and it was agreed to use physical activity as an umbrella term to include all sorts of exercises)

Physical activity and you (past and present)

Physical activity advice/education and you (what have you come across?)

The participants were also asked about their perceptions and attitudes on:

In general, what helps and hinders physical activity after a cancer diagnosis?

The role of physical activity education (what, how, who?)

Getting the message right; Rank purposes of messages

### ***Development of the interventional text messages***

The focus group participants also aided the development of the physical activity promotional text messages to be used as a proposed intervention for future research (chapter 7). Further detailed explanation of the role of focus group participants in the process of design and development of these messages is presented in chapter 6, section 6.2.3.

### ***Summary and close***

Each session included a closing summary by the moderator, inviting additional comments on any final points raised or expressed, hence welcoming any unattended queries or questions arising. The moderator thanked all of the participants at the end, turned off the recording, and gave them the gift vouchers as a gesture of appreciation for their time and effort to participate in the study. Post-interview discussions were held between the moderator and the co-moderator, after the participants were left, which were also tape-recorded separately.

#### **4.4.6 Data Management**

The interviews were audio recorded and then fully transcribed verbatim into the Microsoft Word. The post-interview discussions were also transcribed and incorporated into the group interview notes. The group interviews, reflective meeting notes along with hand written notes by the co-moderator during the interviews, lists with written comments and feedback by the patients were all considered for the purpose of analysis.

#### ***Data transfer and confidentiality***

The interview recordings along with post-interview researcher meeting recordings were downloaded onto Bangor University's secure network before being erased from the digital recorder, in line with the university's data protection policies and standard operating procedures. All data were anonymised and stored securely according to the Data Protection Act and Freedom of Information Act (Corti, Eynden et al. 2014). No participant was identified during the analysis, reporting or dissemination of any published material.

#### ***Data archiving***

A data archiving policy was drafted in line with Bangor University's data protection guidelines. It included details about the storage of the data after completion of the study with a pertinent audit trail to allow tracking of data handling steps i.e. from raw data to the final master dataset utilised for analysis. This draft formed part of the data management plan that also comprised the storage location of hard copy data. This archive of the original data, analysis and the data tracking file was accessible to authorised personnel of the research team at Bangor University (Corti, Eynden et al. 2014).

#### **4.4.7 Data Analysis**

The data were analysed using the framework method (Pope, Ziebland et al. 2000; Gale, Heath et al. 2013). All transcripts were initially read and coded independently by the author into categories, themes and sub-themes. Further analysis was conducted by regular discussions with a colleague who was a senior qualitative researcher (JH), who independently analysed the transcripts to confirm the emerging concepts, themes and sub-themes (Pope, Ziebland et al. 2000). Additional contributions to the data analysis were added from the main supervisor (NHW).

The five stages of this analysis approach are described in detail under the corresponding sections explaining the rationale behind each stage along with the actual process undertaken in this study (Ritchie and Lewis 2003).

##### **1. Familiarisation**

Familiarisation with the raw data using the interview recordings and transcripts was the first step of the thematic analysis and helped the author immerse herself in the data. It is a crucial activity to help researchers lay the foundation for the analytical structure that emerges in later stages. For this purpose, the interview recordings were listened to carefully, the anonymised transcripts were read and re-read and the hand written notes during the focus groups were examined. This immersion in the raw data helped to list key ideas and recurrent themes for the later stages of thematic analysis.

##### **2. Identifying a thematic framework**

This stage of analysis involved the identification of the concepts, and themes to examine and reference the data. The key questions were derived from the aims and objectives of the study; the reactions and impressions of the respondents were interpreted; and the repeated views, concerns and experiences of the participants were also analysed. These steps helped to manage the detailed index into manageable chunks for subsequent steps of the analysis (Pope, Ziebland et al. 2000).

During this stage, the anonymised data was coded into categories. Similar categories were combined together to generate preliminary themes to organise and understand the data (Ritchie and Lewis 2003). Attention was given to each line within the transcripts to pick up all of the participant's perceptions, views, and attitudes. Some initial themes and sub-themes were recognised during this stage, and were noted down. A senior qualitative researcher (JH) within the team independently performed this step and all documents were discussed in-depth. These drafts were discussed and modifications performed if required based on joint decisions. In other follow-up meetings the themes were merged through a process of comparing and contrasting where possible (Pope, Ziebland et al. 2000). The agreed draft

was presented to the management group and the feedback was addressed and incorporated where feasible.

### **3. Indexing**

Indexing involved systematic application of codes from the agreed analytical framework to all the data in the subsequent transcripts by annotating them with numerical codes from the index, usually supported by short text descriptors to elaborate the index heading. A single passage of text could sometimes cover a large number of different themes, each of which was then recorded, usually in the margin of the transcript (Pope, Ziebland et al. 2000). This stage was performed in two steps:

#### ***Step (i). Constructing an index***

All themes and subthemes emerged while reading the transcripts were listed and numbered to make a working index.

#### ***Step (ii). Labelling or tagging the data***

The author went back to each transcript to tag all of the data according to the developed index. This task was also accomplished in Word in the comments section in front of each line. Once finished, another researcher double checked this process to avoid any missing data for the next stage. This stage was important for the analysis purpose as data were transferred from the transcripts to working charts.

### **4. Charting**

A matrix was generated on a Microsoft Excel spreadsheet. The data were 'charted' into this matrix which involved summarising this data according to which category it belonged to from each transcript. The aim of this charting was to strike a balance between reducing the data and retaining the semantic and original meanings in which it was expressed. The chart also included references to illustrative quotations. This process resulted in the re-arrangement of the data according to the appropriate part of the thematic analysis to which they related so that a chart for each key subject area or theme could have entries from several respondents. Unlike simple cut and paste methods that group verbatim text, these charts contained distilled summaries of views and experiences emanating from a considerable amount of abstraction and synthesis (Pope, Ziebland et al. 2000). Following these principles, the key points of each piece of coded data were summarised and synthesised in a thematic chart, retaining the context and language in which they were expressed (Pope, Ziebland et al. 2000).

### **5. Mapping and interpretation**

The original research objectives as well as themes emerging from the data influenced the first stage of the thematic analysis. This process consisted of mapping the range and



nature of phenomena, creating typologies and finding associations between themes to provide explanations (Pope, Ziebland et al. 2000).

Thematic charts (Excel spread sheets) were constructed where the columns represented a theme or sub-theme and the rows denoted the participants, with individual cells representing the summarised data from the interview transcripts. This stage involved two further sub-stages including different steps.

### **A. Descriptive Accounts**

This sub-stage involved three key steps (Ritchie and Lewis 2003) which were executed as explained below:

**Step (i). Detection:** Detection involved segregating each column, representing one theme or sub-theme, from the thematic chart along with all the rows representing the participants to identify 'like material'. An additional column was added to note down detected relevance about participants' perceptions, views, attitudes, experiences and their behaviours.

**Step (ii). Categorisation:** Once the detection of 'like material' was complete, another column was added to assign labels or categories to these 'detections'. This step helped to get a more abstract or conceptual account of the data whilst still maintaining a clear link with the original raw data. None of the elements were ignored at this step.

**Step (iii). Typologies:** Creating typologies helped to form a strategy to serve three functions namely descriptive, classificatory and explanatory. The goal was to develop a set of distinct categories which were related to one another, and not subsidiary to each other. A strong familiarity with the data helped to identify the elements of this phenomenon and refined categories especially about the exercise behaviour of adult cancer survivors. The descriptive accounts defined and described the various types classified under one category within the typology.

### **B. Explanatory accounts**

This sub-stage helped to make comparisons and assess the consistency of the data with relevant theories (Ritchie and Lewis 2003). Concept maps were made of the categories identified in the descriptive accounts explained above.

**Step (i). Identifying links and associations:** The links were noticed and associations among the participants within each group and among other groups were identified. This step also identified the patterns in sub-groups of the sample. The theoretical framework was kept in mind while looking for the links and connections across the whole dataset. Cases that did not fit within the links were dealt separately.

**Step (ii). Seeking explanations:** This step involved interrogation of the data by asking 'why' questions linked to underlying psychological theories leading to the formulation

of case studies. These involved explicit statements or expressions presented by the participants, as well as inferred explanations by the author. Theoretical concepts or models of behaviour change theories were discussed in relation to the data, and explanations for these links were sought from similar studies and the wider literature.

#### 4.4.8 Trustworthiness of the qualitative data

Trustworthiness of the data is important throughout the process of qualitative research rather than only considering at the data analysis stage. A model comprising of four elements has been proposed to establish the validity, reliability and generalisability of the qualitative data. The elements to be considered in this model are credibility, transferability, dependability, and confirmability (Lincoln and Guba 1985).

The credibility of this study was enhanced by following step by step guidelines to analyse the data (Pope, Ziebland et al. 2000; Ritchie and Lewis 2003). Negative case analysis was also performed to enhance the rigor by re-examining every case, after the completion of initial analysis. The purpose was to establish that the emergent themes were applicable to all cases. There were no negative cases or disconfirmation of the analysis at the completion (Strauss and Corbin 1990; Padgett 1998). The detailed description of data analysis in the previous section demonstrates the reliability of this study. Reliability was further enhanced by involving a senior qualitative researcher within the team, who went through most of the steps till reporting of the results.

## 4.5 Results

There were four focus group discussions with 21 participants as described in table 4.2.

**Table 4.2:** Focus Group Participants

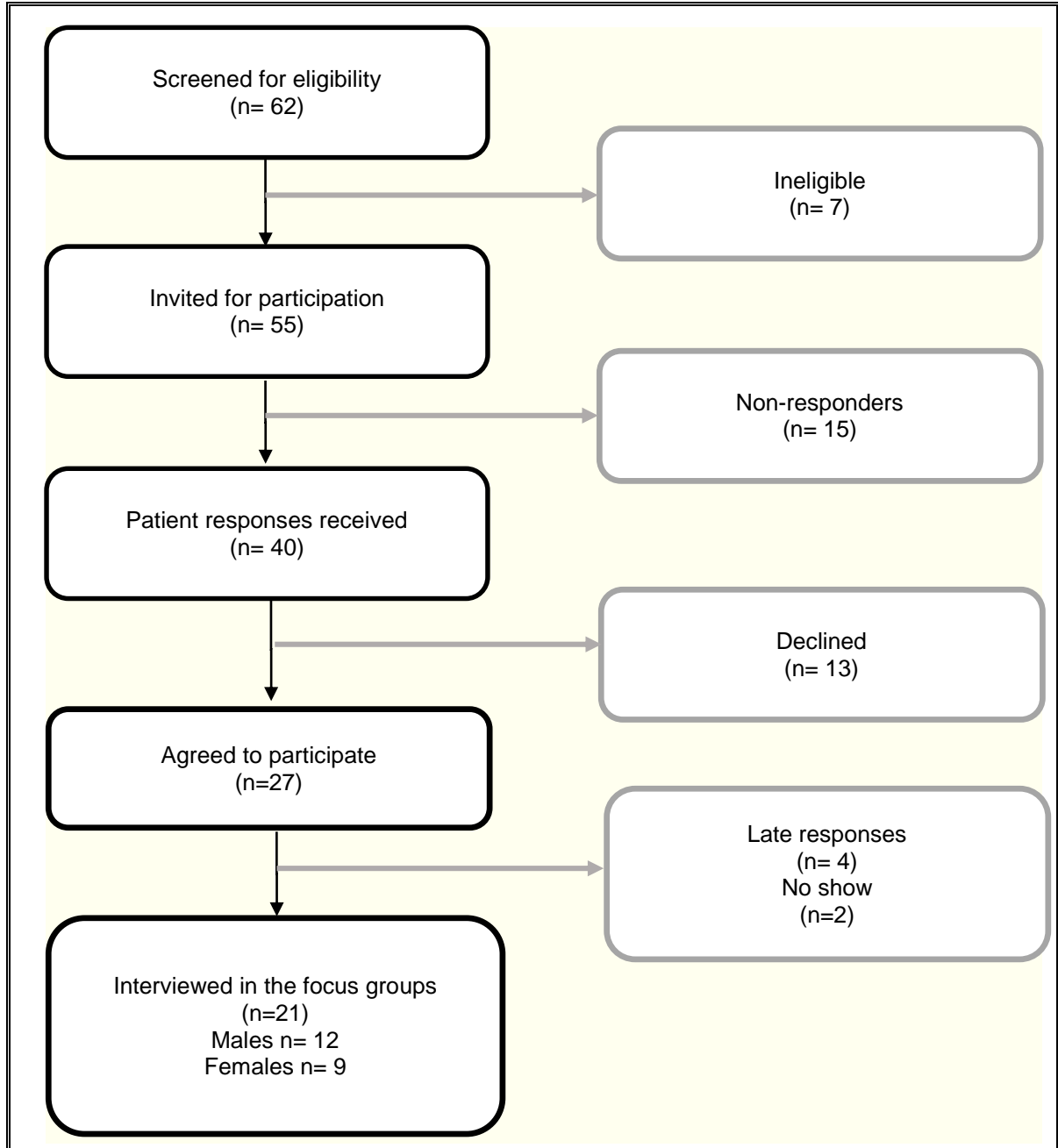
Date	Location	No. of Participants
25 <sup>th</sup> July 2013	Wrexham	6
15 <sup>th</sup> August 2013	Wrexham	6
6 <sup>th</sup> September 2013	Abergele	6
30 <sup>th</sup> September 2013	Bangor	3
<b>Total</b>		<b>21</b>

### 4.5.1 Sample Description

Sixty two patients were screened for eligibility during the recruitment window. Seven of these were ineligible. Of the 55 patients invited to participate, 15 did not respond; 13 declined by ticking the 'No' box on the reply slip but did not mention the reason; and 27 agreed to participate. Of the 27 agreed prospective participants, four responses were received later than the interview schedules, whereas two did not turn up on the day of the interview. Twenty one participants were interviewed in four moderated focus groups including

nine females with ages ranging from 42-85 years and twelve males with ages ranging from 57-84 years. The overall response rate was 72%, the acceptance rate was 68%, and the participation rate was 53% (Figure 4.3).

**Figure 4.3:** Recruitment flow diagram of the focus group participants



All participants were adult cancer survivors whose time since their cancer diagnosis ranged from 1-3 years and had finished their intended curative cancer treatment within last six months. The participants had a range of cancer types including head and neck, breast, lung, ovarian, prostate and colorectal. Participant characteristics including the cancer types are presented in Table 4.3.

**Table 4.3:** Characteristics of the final sample achieved (n=21) in four focus groups

Focus groups	Number of Participants	Identification codes	Gender	Age (years)	Cancer site	Time since the cancer diagnosis
1	1	1.1	F	48	Bowel/ Colorectal	2Y, 4M
1	2	1.2	F	76	Bowel/ Colon	1Y, 2M
1	3	1.3	M	77	Bronchus/ Lung	8M
1	4	1.4	M	74	Bronchus/ Lung	9M
1	5	1.5	F	42	Breast	1Y, 5M
1	6	1.6	M	83	Bowel/ Colorectal	1Y, 8M
2	7	2.7	M	68	Bowel/ Colon	10M
2	8	2.8	F	44	Ovarian	1Y, 8M
2	9	2.9	M	61	Rectum/ Colorectal	1Y, 3M
2	10	2.10	F	45	Breast	1Y, 11M
2	11	2.11	M	68	Larynx/ H&N	8M
2	12	2.12	M	70	Colon/ Colorectal	11M
3	13	3.13	M	66	Larynx/ H&N	3M
3	14	3.14	F	85	Breast	10M
3	15	3.15	M	73	Base of the tongue/ H&N	10M
3	16	3.16	F	46	Breast	1Y, 5M
3	17	3.17	M	60	H&N	10M
3	18	3.18	M	57	Prostate	1Y, 3M
4	19	4.19	F	72	Ovarian	1Y, 2M
4	20	4.20	M	84	Bladder	10M
4	21	4.21	F	53	Breast	10M

Key: Female (F), Male (M), Head & Neck (H&N), Years (Y), Months (M)

### **Patients' motivations for participation in this research**

This introductory question did not relate directly to the aims or objectives of the study but was an introductory question to explore cancer survivors' motives behind participating in this research study. The participants described both the inward as well as the outward looking motives behind their participation.

#### ***Inward looking motives***

They felt positive internally about taking part. The informal and open discussion during focus group interviews provided them with a platform to socialise in a group they described as 'people in the same boat'. For some, this was a chance to gain some knowledge and learn new skills which they could apply to themselves after completing their cancer treatment to keep themselves fit and lead a better life. Personal interest in research from their background led some to participate in this study. Some described that taking part

in activities like this could help them avoid the negative impact of the illness leading to isolation or psychological problems including depression.

### ***Outward looking motives***

Participation in a study like this gave them a feeling of being useful for other cancer survivors by helping in and being part of research that might result in strategies to help others cope with their disease better in the future. They knew to some extent that physical activity was important and its promotion could improve the quality of life of others, a perceived benefit of the research they were participating in.

### **4.5.2 Major themes of the study**

There were five major themes with 12 subthemes and 21 constructs (Table 4.4), reflecting participants' perceptions, attitudes and experiences towards physical activity in general. Furthermore, the discussions moved on to the physical activity advice during their cancer journey and also their views about planning ahead for its promotion and maintenance in follow-up care for cancer survivors.

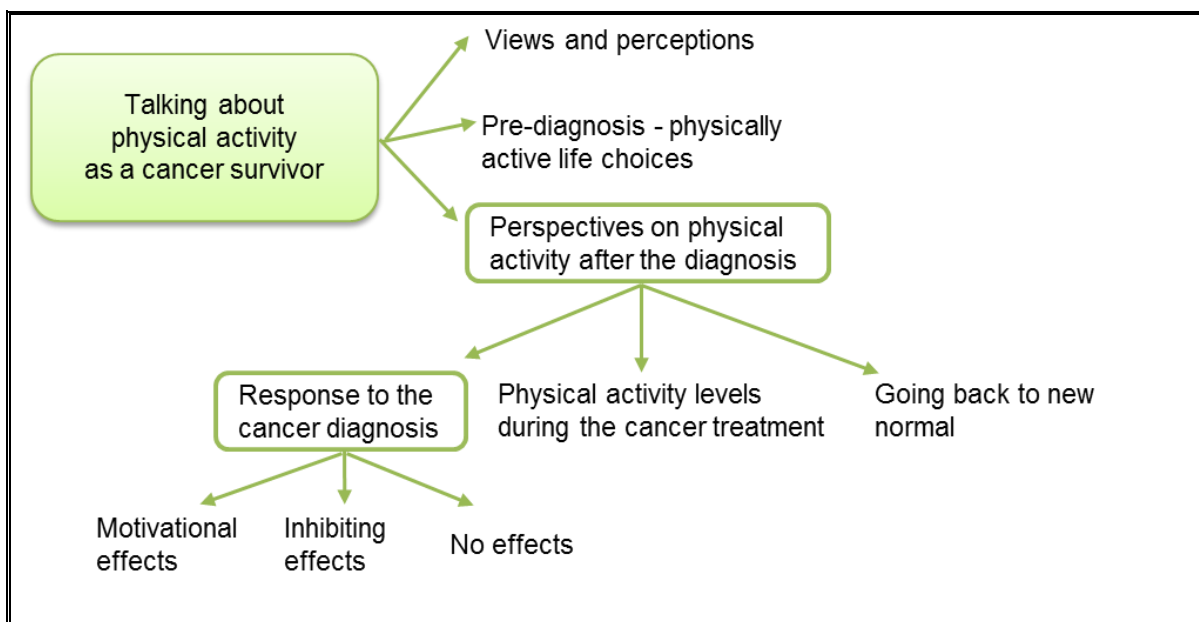
**Table 4.4:** Index: Experiences and views relating to the physical activity promotion for adult cancer survivors – a qualitative study

<b>THEMES</b>	<b>SUB-THEMES</b>	<b>CONSTRUCTS</b>		
<b>Theme 1. Talking about physical activity as a cancer survivor</b>	1.1	Views and perceptions about physical activity		
	1.2	Physically active life choices before the cancer diagnosis	1.2.1 Long-term active 1.2.2 Long-term sedentary 1.2.3 Retired from exercise 1.2.4 Work-related issues and exercising	
		1.3	Perspectives on physical activity after the cancer diagnosis?	
		1.4	Response to the cancer diagnosis	1.4.1 Motivational effect 1.4.2 Converted to exercise 1.4.3 Inhibiting effect 1.4.4 No effect
			1.5	Physical activity levels during the cancer treatment
	1.6		Going back to a new normal	
<b>Theme 2. Physical activity advice during the cancer journey</b>	2.1		Experiences of obtaining physical activity advice	2.1.1 Limited physical activity advice 2.1.2 Available resources within the locality 2.1.3 Seeking for physical activity advice <i>Requesting for physical activity advice</i> <i>Did not request advice</i>
		2.2	Concerns about physical activity advice	2.2.1 Information overload 2.2.2 Timeliness <i>Physical activity is not a priority</i>
		2.3	Personal readiness	
<b>Theme 3. Role of healthcare professionals in physical activity advice</b>	3.1	Acting as facilitators for physical activity advice	3.1.1 Face to face consultations 3.1.2 Tailored physical activity advice	
		3.2	Acting as barriers to physical activity advice	3.2.1 Lack of or conflicting physical activity advice 3.2.2 Uncertainty about physical activity guidelines 3.2.3 Inability to sign-post
	3.3		Who makes the best physical activity advisor?	
<b>Theme 4. Social interactions</b>	4.1	Role of family, friends and relatives	4.1.1 Overprotective relatives and friends 4.1.2 A sense of a responsibility for the family	
		4.2	Pet as a companion – a buddy	
<b>Theme 5. Acceptability of reminders or reinforcements</b>	5.1	Preferences about the reminders	5.1.1 Types 5.1.2 Time and frequency to intervene	
		5.2	Reinforcement as a continuing healthcare support	
<i>Total: 5 Themes</i>	<i>16 Sub-themes</i>	<i>22 Constructs</i>		

## Theme 1. Talking about physical activity as a cancer survivor

The first theme arising from the data was about participants' accounts of the nature and type of physical activities that they had been undertaking before and during their cancer journey. The main theme was then further broken down into subthemes based on the point of this journey at which a transition or a turn, either for better or worse, occurred: before their cancer diagnosis; how their physical activities were affected when they became aware of their cancer; what kind of physical activities were done, if at all, during their treatment; and how and when did they resume the physical activities on their active treatment completion (Figure 4.4). These subthemes are explained in further detail below:

**Figure 4.4:** Theme 1: Talking about physical activity as a cancer survivor



### Views and perceptions about physical activity

The beneficial effects of physical activity were discussed in terms of psychological and physical effects. Psychological benefits included: more energy, better mood, enhanced confidence leading to increased productivity at work, better sleep helping them to feel relaxed, with reduced stress of treatment and disease in their lives. Physical benefits were described as: improved weight control, the development of strong bones and muscles resulting in less arthritis pain, a healthy heart, and a lower risk of cancer or recurrence of cancer potentially leading to independent life.

### Physically active life choices before the cancer diagnosis

Many of the participants identified themselves as being very active before their cancer diagnosis. Swimming was one of the commonest type of physical activity, as well as walking, running, cycling, mountain biking and dancing. In addition, yoga, tai chi or other

types of stretching as well as breathing exercises were discussed. Many had been active in sports such as rugby, athletics, or cross country running. Some had been regular gym-goers who were on some type of physical exercise regime.

Apart from those engaging in intensive physical activity or sports, some participants regarded normal day to day work as the sole form of physical activity they were involved with. Doing house chores, outdoor work including gardening and shopping, and dog-walking were described as a common way of getting physically active among many in this group.

Few people reported having a sedentary lifestyle and the majority of the participants reported performing some form of physical activity ranging from very intense to a long walk. Depending upon the above mentioned patterns, the discussants were grouped into different categories given below.

### ***Long-term active***

Most of the participants described being physically active before their cancer diagnosis. They described their regular participation in different types of sport and leisure activities such as: swimming, walking alone or with a dog, hill walking, cycling, bowling, sequence dancing, gardening, rugby, tennis, cricket and going to the gym. Most of them did their own house work.

*“I was very active before my surgery and before my treatment. I was in the gym all the time and doing a lot of swimming” (FG 1, P 2).*

### ***Long-term sedentary***

Some participants never exercised and did not consider themselves to be physically active.

*“I don’t exercise at all. No, not when I was told about cancer. It didn’t make any difference to me at all” (FG 4, P 20).*

### ***Retired from exercise***

For others, a long time had passed since they had been active. They described doing different sorts of sports and exercises in their younger days and regarded this as a historic phase of their lives.

*“I did swim a lot in the past but I have not been to the swimming baths for years now” (FG 1, P 3).*

### ***Work-related issues and exercising***

Some participants regarded the nature of their jobs, long working hours, and travelling far away for work as the main reasons for not having enough time to do exercise or engage in leisure or other healthy physical activities. The choices of their physical activity were limited. A few of them seemed to have some physical activity while ‘dog walking’, while



others walked only during the lunch time. Some people reported walking about five to six miles on a weekly basis.

*“I haven’t exercised as much as I did before. A few years ago, I used to do quite a lot of swimming but I stopped doing that because again due to work” (FG 2, P 8).*

However, despite the long working hours, some people had been making efforts to be physically active.

*“I have always been very active despite having a sedentary job. I was going out for walks with the dog each day. I have always been naturally quite fit until this illness. I used to swim a lot as well” (FG 2, P 9).*

Some of the participants became more active after retirement as they could find more time to focus on healthy lifestyle activities.

*“Since I have been retired, I got into the habit of doing quite a lot of physical activity such as walking, hill walking, cycling, gym work and swimming. I live on my own, so I do my own housework and gardening as well” (FG 3, P 18).*

### **Response to the cancer diagnosis**

It was evident from the cancer survivors’ accounts that physical activity declined from the point they were diagnosed with cancer and remained so over a long period of time, limiting their ability to do any physical activity. Most of the participants expressed the frustration of the transition from being active to non-active in their survivorship phase. They quickly realised after the cancer diagnosis that they were unable to do what they used to do before. One of the participants reported that she did not do any physical activity at all since being diagnosed with cancer. In contrast to this response of becoming inactive after their cancer diagnosis, this event did have other effects as well depending on the individual’s attitude. Hence, these effect were divided into sub-categories as below:

#### ***Motivational effect***

This group includes those participants who described having been physically inactive before the cancer diagnosis and became active as the diagnosis motivated them to be physically active.

*“Coming out of my cancer treatment, I knew that I had to put myself in a better place to deal with anything else; I have gone from 12 months ago doing nothing to exercise” (FG 1, P 1).*

**Converted to exercise**

The cancer diagnosis acted as a turning point in the lives of some participants who started thinking about modifying their sedentary lifestyle towards being more physically active. Some had taken steps to becoming more active.

*“I have gone from 12 months ago doing nothing to exercise” (FG 1, P 1).*

**Inhibiting effect**

The participants of this group expressed a fear of damaging themselves by doing exercises and expressed their concerns.

*“Am I doing more harm or damage to my body by doing exercise?” (FG 4, P 21)*

**No effect**

Whereas for some participants the cancer diagnosis had no effect on their physical activity levels. Typically they were not physically active before their diagnosis and they were not thinking of becoming active after.

*“Cancer diagnosis had no effects on my physical activity levels, not for me” (FG 4, P 20).*

**Physical activity levels during the cancer treatment**

Cancer treatment is known to have serious side effects, which invariably have the potential to affect physical activity levels of the sufferers as well. This fact was highlighted by the discussants reporting reduced capacity to do any physical activity, mainly because of reduced stamina and energy leading to inability to do any work, physiological weakness, lack of concentration in the work, and losing balance such as required in during dancing, running etc. For many of them this had an inhibitory effect on their physical activity levels.

Whilst receiving chemotherapy, physical activity levels varied. Some reported being unable to do any physical activity because of fatigue.

*“I had six months of chemotherapy and I wasn’t well, not really and there was no way I could do exercise at that time” (FG 1, P 2).*

Whereas, others described attending the gym at least twice a week, or who tried to maintain their physical activity during their treatment but with less intensity, managing walks, swimming and other exercises. The progressive administration of chemotherapy weakened some who were active initially and during the early stages of chemotherapy.

*“I started to get fit again during treatment going through different chemotherapy sessions but then with the second lot it knocked me back again. When I had the cancer and the first chemotherapy, during the first chemotherapy I did manage to*

*walk probably about a mile most days until probably the last two lots where it had knocked me back then” (FG 2, P 8).*

### **Going back to a new normal**

Many cancer survivors reported that their ability after treatment was limited to a few chosen activities, especially soon after completing treatment. Nevertheless, most of the participants returned to physical activity within six months of finishing their cancer treatment, although at a lower level of intensity.

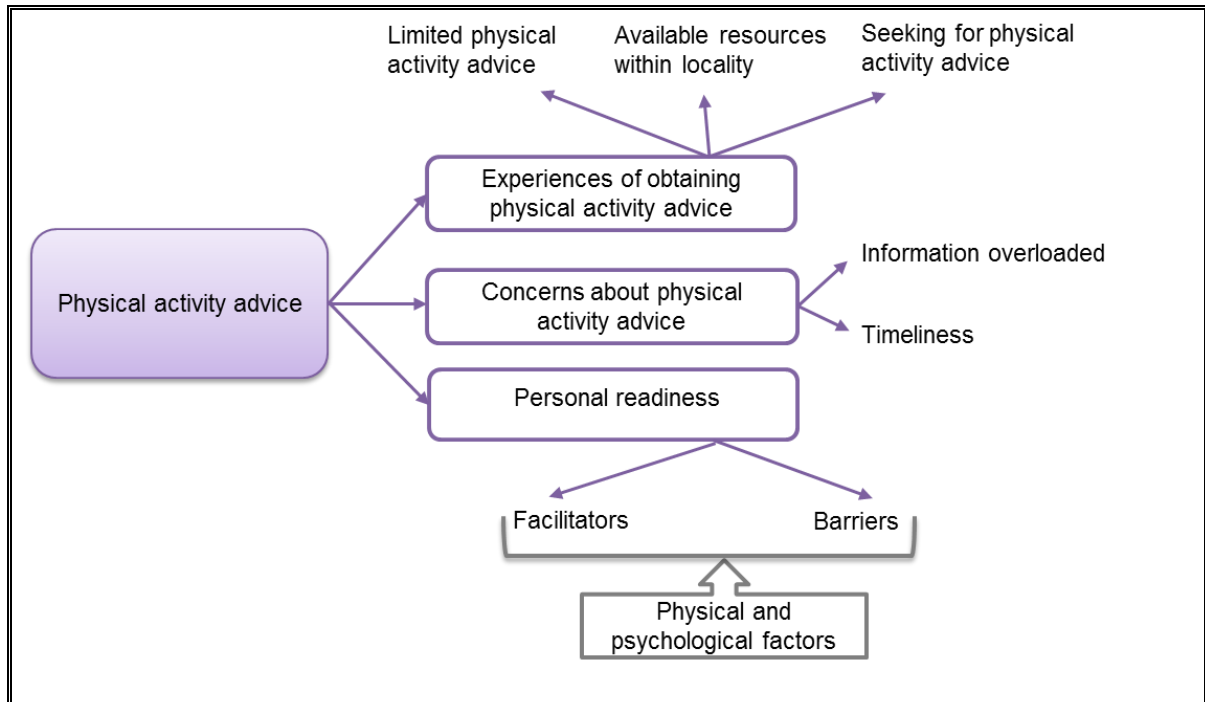
*“I am not as physically active yet as I used to be. I am doing a little of something every day such as walking and cycling. The difference is that if I was going for a walk previously I would have walked 15 miles but now I am pretty exhausted after 10 miles” (FG 2, P 10).*

Some participants wanted to take it slowly after finishing their cancer treatment, but they were keen to build up to higher levels of physical activity in the near future. Walking, doing household chores and gardening were reported to be some of the most common forms of physical activity to which cancer survivors gradually reverted as they finished their initial treatment.

*“The exercise I am doing now with walking and gardening, going round the shops with my wife, doing bits and bobs, housework. I quite fancy taking the swimming back up again” (FG 2, P 9).*

### **Theme 2. Physical activity advice during the cancer journey**

Physical activity advice was one of the major themes of the focus group discussion. There was a variety of experience of getting physical activity advice during their journey from diagnosis until the end of treatment (Figure 4.5). The subthemes are described below:

**Figure 4.5:** Theme 2: Physical activity advice during the cancer journey

### Experiences of obtaining physical activity advice

The three principal modes of physical activity advice for cancer survivors were verbal, written, or tailored. Leaflets were used as a common means of providing advice, but participants considered these leaflets untailored to their needs. Face-to-face verbal advice was preferred, followed by text messages, because participants could express their need for psychological support, apart from the reasons for physical activity per se. In the backdrop of these general descriptions, there were some specific issues that were brought to light and are described under sub-themes and sub-categories as below:

#### **Limited physical activity advice**

The majority of the participants did not get any advice about physical activity during their cancer journey. They received neither verbal nor written information of any kind.

*“I can’t recollect that anybody has ever given me advice on physical activity, not that I can think of and I’ve got a pretty good memory” (FG 1, P 6).*

A couple of them had the very basic post-surgical treatment related leaflets which were not specific about physical activity or exercise.

*“After I had my hysterectomy operation I had advice then on certain little bits of exercise I had to do because I couldn’t do very much and I got like a leaflet then but that was kind of more of a medical thing because it was following a big operation to start doing slight tummy exercises it was that basic” (FG 2, P 8).*

### **Available resources within the locality**

Some participants were signposted towards the available exercise referral resources by the clinical nurse specialists (CNS), which was regarded as very helpful.

*“Well a CNS [Clinical Nurse Specialist] from the Shooting Star Unit [healthcare setting] has got me on a course” (FG 2, P 12).*

### **Seeking for physical activity advice**

Although there was no instance reported of getting specific advice about physical activity in healthcare settings, most were interested in receiving advice during their cancer journey. There were two groups, those who requested advice and those who did not.

#### Requesting for physical activity advice

The participants of this group were keen to know what to do, when to do it, how much to do and for how long, but they did not get clear advice.

*“I asked the Consultant Oncologist if I could return to physical activity. I spoke to the Consultant Oncologist each time I had an appointment, which was about four times” (FG 3, P 18).*

#### Did not request advice

Some participants were overwhelmed by their daily chores and were not interested in seeking physical activity advice.

*“After my operation, I was told just to rest. I didn’t ask for any physical activity advice really” (FG 2, P 7).*

### **Concerns about physical activity advice**

#### **Information overload**

Some participants felt overwhelmed with the information leaflets that they received after their diagnosis and thought that further advice about physical activity would lead to information overload. They described being bombarded by information. They wished to concentrate on more important issues such as family matters, work related problems or treatment plans. They would prefer being given less information and only information essential for that phase of their cancer journey. They felt that if it was important it should be given prominence within the pile of documents handed over at the time of diagnosis or during their regular consultations.

*“It’s a bit confusing. When I was first diagnosed with cancer I was given books, it must have been about a dozen of them. You have leaflets from Macmillan and various literature on the operations, and it was just information overload really” (FG 2, P 9).*

### **Timeliness**

Opinions differed among participants about intervening with physical activity advice. Some expressed their concern that advice given at the time of their cancer diagnosis was inappropriate as the news of the diagnosis needed time to sink in. They felt that it would be better to wait until the next consultation when they would be ready to listen the treatment plan including physical activity advice.

*“When you are diagnosed with cancer your last thought is physical activity or exercise in any way. No you don’t think about that, you just think about will they get me better. It’s a selfish attitude but it is there” (FG 1, P 3).*

*“I think the earlier the better because once you start the chemotherapy you become less active as you go along but if you can be more active in the beginning that might help you” (FG 2, P 8).*

Some participants were keen to talk about physical activity during their cancer treatment. However, agreed that they should receive most physical activity advice at the end of their cancer treatment.

*“I think it [physical activity advice] should be after the treatment has finished as when everything is over and done with you feel that you can cope and come to terms with things” (FG 3, P 14).*

### **Physical activity is not a priority**

In the same way, some of the participants stated that because of the overwhelming nature of their cancer diagnosis; they could not think about being physically active as well. They did not prioritise being physically active.

*“You don’t concentrate on it [physical activity] yourself because when it is first diagnosed all you are thinking about is how am I going to get through this and how am I going to get better” (FG 2, P 8).*

For some of the participants, the main priority during their cancer treatment was completing a successful treatment plan rather than trying to be physically active during this time. Physical activity advice was not well absorbed during the cancer treatment by some of the participants. Successful treatment had a higher priority than being physically active.

*“I think when I was having treatment nothing was further from my mind than exercise. I think if I had that [physical activity booklet], then I would have probably put it away in the folder and then never looked at it again” (FG 2, P 9).*

## Personal readiness

The effects of physical activity advice on cancer survivors' behavioural modification seemed to be depended upon both psychological and physiological barriers and facilitators to the uptake of this advice.

Among these a positive mind-set and attitude; and knowledge about the current recommendations, such as what exercises to do at what time point, how much, for how long is sufficient, were considered helpful to act on the advice and perform recommended physical activities. Clarity and relevance of the advice was reported important whether individually sourced (motivation, active information seeking), or professionally advised (trusted source, consistent, and tailored). Social aspects of exercise such as encouragement (i.e. rewards, incentives, support by relatives/ friends/ family), and group exercises (exercise programmes such as Kick start or the National Exercise Referral Scheme) were deemed promising to facilitate the uptake of such advice.

*“Once I managed to push myself out or get myself out through the door and start doing things I felt more wide awake. I had it in my head that I wanted to become fit again...I found that physical activity, well exercise for me focuses my mind. Without it I would possibly just sit back and my head would be filled with all doom and gloom, and so it helps me to focus” (FG 1, P 1).*

*“Well I feel that it's knowing how much to do and what are you expected to do. I wanted to know that by doing more, would it mend more...you know what I mean...I kept on asking how much I do because I don't want to do any damage” (FG 4, P 21).*

*“You meet people when you go out don't you. There was something like a group of people doing the same thing, I think that would motivate you to go and do that thing” (FG 2, P 7).*

Barriers included psychological issues such as: anxiety and/or depression; uncertainty about the cancer journey emanating from the fear of recurrence or bad prognosis; lack of motivation or support due to absent or over-protective relatives, friends or family; unaddressed fear of harm from being physically active due to mixed messages, conflicting or lack of advice.

*“I am not physically active as I don't have strength. Fatigue is horrendous. I will say there is a lot of anxiety and fatigue, that's the worst thing for me” (FG 1, P 2).*

*“I still get tired after doing a bit of bowling and walking. It really takes it out of me and I can literally do nothing the next day. It is the fatigue that gets you the next day and I have to rest” (FG 3, P 13).*

*“One of the things that has influenced me is asking the medical people for advice on when to exercise, how much and so on. The thing that decides me which of those voices to listen to is the advice I get from somebody who should know more than I do about me” (FG 1, P 6).*

Barriers included the physiological aspects of the cancer journey such as: the effects of the cancer disease; or treatment related co-morbidities such as lethargy, nausea, and impaired immune system.

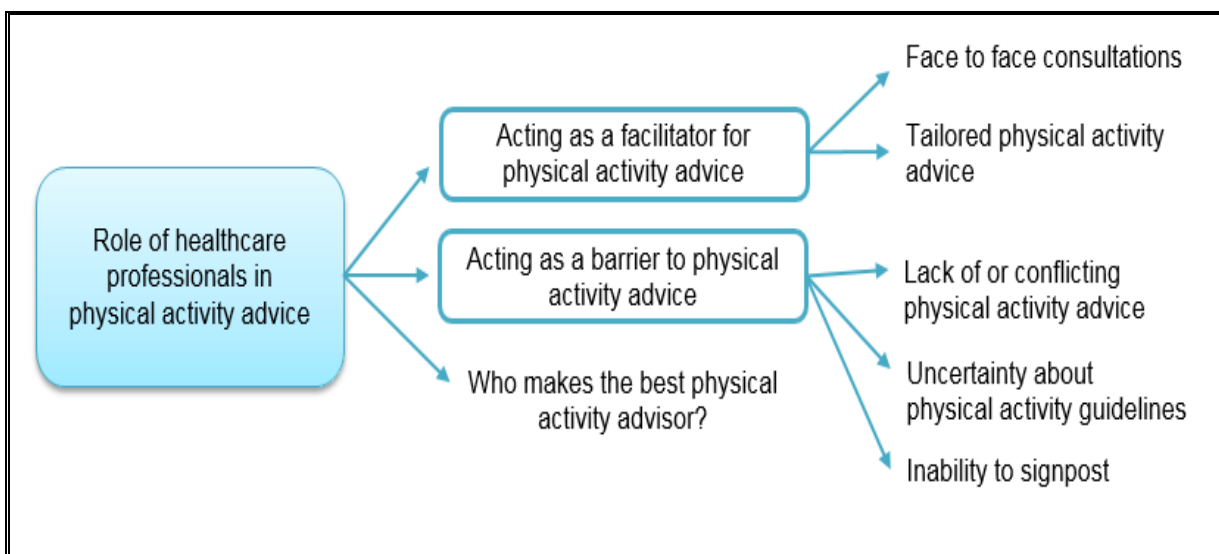
*“I will say there is a lot of anxiety and fatigue. I have not got the energy levels, that’s the worst thing for me” (FG 2, P 12).*

*“I have started exercise again but am realising my limitations very quickly. Since the treatment I have been walking but am now worn out after about an hour. It is surprising at how quickly you do fatigue” (FG 3, P15).*

### **Theme 3. Role of healthcare professionals in physical activity advice**

This theme reflected a vital role of healthcare professionals in physical activity promotion for cancer survivors. Advice from healthcare professionals could act as either facilitators or barriers (Figure 4.6).

**Figure 4.6:** Theme 3. Role of healthcare professionals in physical activity advice



#### **Acting as facilitators for physical activity advice**

Healthcare professionals can play a pivotal role to promote physical activity during their regular consultations by giving clear and concise advice to cancer survivors.

##### ***Face to face consultations***

There was a group of participants who preferred physical activity advice to be given face to face rather than in a booklet or over the phone.



*“I gain more benefit from talking to a human being than I do from the book because we are individuals. The opportunity to talk to an experienced person is the most useful thing of all” (FG 1, P 6).*

### **Tailored physical activity advice**

The majority of the participants preferred personalised advice. They felt that the physical activity advice should be targeted according to their need and ability to perform different exercises. There was a consensus that a one-size-fits-all approach should be avoided.

*“Everybody is different so you should get targeted advice depending on what you were capable of before and can do now” (FG 3, P 13).*

### **Acting as barriers to physical activity advice**

The physical activity advice could be disregarded if healthcare professionals gave inconsistent or conflicting advice.

### **Lack of or conflicting physical activity advice**

Most of the participants talked about the lack of physical activity advice from healthcare professionals. The findings were similar in earlier section of talking about their experiences of obtaining physical activity advice that there was a lack of it during their cancer journey.

*“I did not have any advice [about physical activity], not that I recall. It's not a discussion, I ever had about exercise” (FG 2, P 9).*

Some of the participants received conflicting physical activity advice from the healthcare professionals.

*“I asked two of the people in the hospital, is it OK if I start swimming again and one of them said that yes definitely and the other one said I think you better wait for another couple of months; so you know it is difficult” (FG 1, P 6).*

### **Uncertainty about physical activity guidelines**

The focus group discussions suggested a lack of knowledge among the healthcare professionals about the available physical activity guidelines for cancer survivors.

*“I went to the doctor to ask if I am doing fine with the exercise or doing more harm and the answer was: ‘I do not know’. He also said: ‘do not do too much pressure on joints’. I think they expect you to know and where to contact but where do you go to contact” (FG 4, P 21).*

*“I was told half an hour all week and that was it. Take it like 10 minutes each day you know and I thought right well I've been doing more than that anyway” (FG 2, P 10).*

These participants' perspectives on their healthcare professionals' lack of knowledge about physical activity guidelines was also seen to lead to healthcare professionals giving vague and unclear advice to patients.

*"My oncologist and other people kept saying don't overdo it, don't push yourself too much and that sort of thing. I was careful going back to exercise and asked for advice and they say, you can but don't push yourself and just take it easy" (FG 1, P 5).*

### ***Inability to sign-post***

It was also evident from participant accounts that there could be a lack of knowledge among many health professionals about the available resources to help and direct people interested in getting specialist physically active lifestyle advice during their cancer journey.

*"I felt that I needed something to help me get going so I went to my local leisure centre and asked them did they do it in Flintshire at Wrexham, and they said yes so I just asked them how do I get on it and they said go to your doctor but there is probably a 2-3 month waiting list" (FG 2, P 11).*

In conclusion, unclear or conflicting physical activity advice gave the participants quite negative thoughts about being active, which set in motion an inhibiting effect on their participation in exercise. It also developed the incorrect assumption to rest if they felt tired contrary to the evidence that physical activity could help in reducing fatigue rather than causing it.

*"I was told not to overdo it with physical exercise, no stretching or pulling. That's why I concentrate just on walking. When I had the operation, I was told not to overdo it, just to rest. It stopped me doing a lot I think as I was told to rest" (FG 2, P 7).*

### **Who makes the best physical activity advisor?**

There were several suggestions regarding who could be the advisors for physical activity. Participants suggested a clinical nurse specialist (CNS), a nurse with knowledge about oncology (Oncology Nurse), a 'knowledgeable person', a 'cancer buddy', or the 'healthcare team'.

#### ***Exercise / physical activity specialist***

The majority of the participants were interested in speaking to a trained person in physical activity advice and health promotion, who was dedicated to this task while being part of the healthcare team.

*"You need somebody to specialise, who you can trust and can tailor physical activity advice for you. That type of thing I would like as well" (FG 4, P 21).*

There seemed to be a concern about not having enough time with the medical specialists so it was thought not a good idea to have a medical specialist as a physical activity advisor. Whereas some participants were interested to have advice from the physiotherapists.

*“I think it [physical activity advice] should be given by a Physiotherapist or somebody who knows about the illness and fatigue” (FG 3, P 13).*

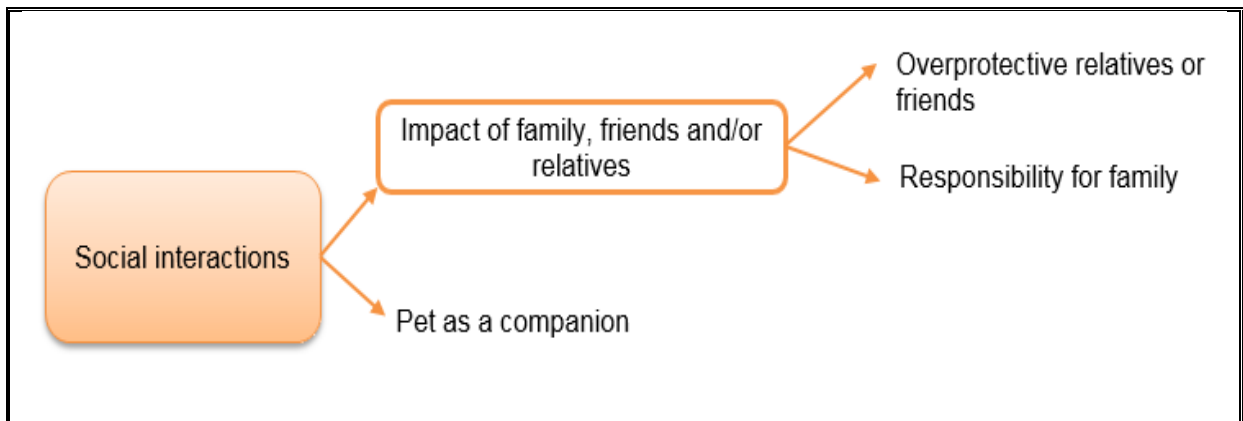
Others suggested volunteer service on physical activity advice or peer support.

*“A cancer survivor can help, who had the same experience” (FG 4, P 19).*

#### **Theme 4. Social interactions**

This theme reflected the social interactions within the lives of cancer survivors from the day of diagnosis till the end of their lives. The family, friends, and all other social circles play an important role which was explored under this theme (Figure 4.7).

**Figure 4.7:** Theme 4. Social interactions



#### **Role of family, friends and relatives**

Several participants regarded the role of their family and friends as supportive and understanding; but some described them as overprotective.

#### ***Overprotective relatives and friends***

An inhibiting effect on physically active was also experienced by some of the participants from their relatives and friends. They were advised during their lay consultations with them to rest and not to overdo it. Being overprotective did not help the participants to keep physically active.

*“I found with relatives because I was very much as soon as I realised that it was safe for me to jump in, I did, and I found that relatives actually wanted to pull me back sort*

*of reign me in. Their attitude to me having cancer was to sit back, relax and take it easy” (FG 1, P 1).*

### **A sense of a responsibility for the family**

Some of the participants shared their feelings about being responsible for their families, which became a reason for them to be receptive towards physical activity advice. They seemed to be keen to get knowledge about the physical activity recommendations to reap the beneficial effects.

*“You have got to be positive, I’ve got two kids” (FG 4, P 21).*

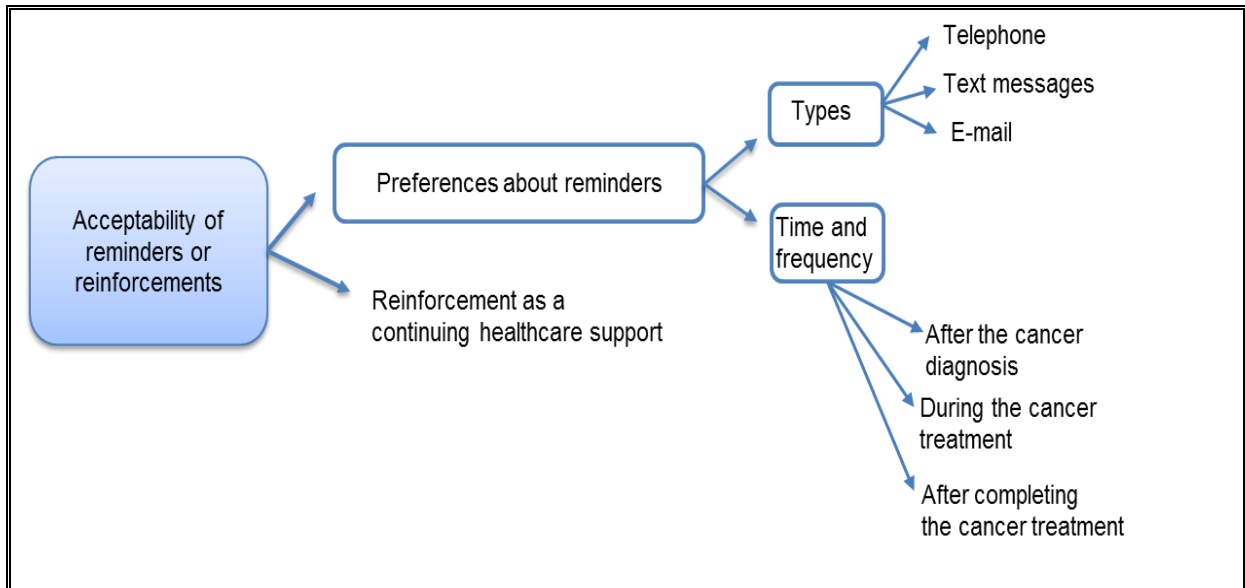
### **Pet as a companion – a buddy**

Companionship was cited as one of the strong factors in motivating people to develop a positive attitude towards life and come to terms with day to day challenges. The company of pets, dogs in most cases, was presented as an example of this behaviour. They were regarded as friends that filled the gaps of companionship that result while living alone. Activities performed together with pets, such as dog walking were considered to have a therapeutic effect which kept them going out regularly. Additionally, this gave them a sense of responsibility towards looking after their pet companions which further motivated them to do physical activity that they might otherwise have been avoided.

*“Oh yes and the dog looks at me like you are supposed to be taking me for a walk. I still have a dog, I still walk the dog” (FG 2, P 12).*

## **Theme 5. Acceptability of reminders or reinforcements**

This theme reflected the cancer survivors’ perceptions about the reinforcement of the message of being physically active by sending regular reminders often known as a ‘nudge’. Most of the participants expressed their need for a push to maintain their physical activity levels. The timeliness of the reinforcement was an important point raised during these discussions. Some of the participants were interested in getting a ‘nudge’ of physical activity advice during their cancer treatment with regular reminders after their treatment was completed, which would be focused on the maintenance of their physically active behaviour (Figure 4.8).

**Figure 4.8:** Theme 5. Acceptability of reminders or reinforcements

## Preferences about the reminders

### *Types*

Different modes of reinforcement were discussed. Some of the participants accepted the idea of sending regular text messages, whereas others were also interested in talking to someone over the phone. There were other participants who were interested in having both telephone and text prompts.

*“I think it would be better to speak to somebody in a phone call certainly after you finish the chemotherapy you can feel quite isolated. Somebody you can talk to about what you should be doing and the best place to go about it” (FG 2, P 8).*

However a few also expressed their interest in getting the reminders via email.

*“I would prefer computer actually...e-mail rather than text; you got the message there on the screen all the time and you can read it” (FG 4, P 20).*

### *Time and frequency to intervene*

As was discussed earlier under theme 2 about cancer survivors’ preferences about receiving physical activity advice, they preferred that reinforcement reminders should be after they have completed their treatment plan with healthcare team.

*“I think it should be after the treatment has finished as when everything is over and done with you feel that you can cope and come to terms with things” (FG 3, P 14).*

The most preferred frequency of reminder was once per week to keep them motivated.

*“Once a week should be the physical activity advice” (FG 1, P 2).*

## Reinforcement as a continuing healthcare support

With regards to the continuity of follow-up care, some participants felt that they had been left alone at the end of their treatment plan.

*“I noticed that ... Macmillan she phoned me after every chemo treatment how are you feeling and she sort of tabbed it...but when I am finished, she never phoned after...and I was thinking, maybe she is finished with, where I go after that now...and that’s a horrible feeling” (FG 4, P 21).*

There was a consensus among participants about getting continued support to maintain their physical activity levels after the cancer treatment was accomplished.

*“You need somebody to give you that nudge to think about it. When you come to the end of the chemotherapy perhaps a few weeks after you need that nudge again to get you going on a different programme (FG 2, P 8).*

## 4.6 Discussion

### 4.6.1 Summary of the Main Findings

Concern about optimum active cancer treatment and its (successful) outcome rather than physical activity was reported by majority of the participants as their priority after cancer diagnosis, which resulted in a lack of thought about maintaining a physically active lifestyle. Similarly, they also indicated that the period immediately after cancer diagnosis was not suitable for physical activity advice because of this stress. They preferred the advice to be offered during and after their cancer treatment, as they might be more receptive to it, in part because they would have come to terms with their condition while going through the management phase. Weekly reminders at the end of the cancer treatment were hailed as a way of keeping them motivated to stay active.

There were reservations about the inconsistent, unclear or conflicting advice they had been receiving from different members of their healthcare team. This led to the uncertainty about the timing, type and amount of exercise they should have been doing during treatment and recovery. Such ambiguities acted as barriers to exercise. Other barriers to positive reception of physical activity advice included psychological concerns emanating from uncertainty about the cancer journey, fear of recurrence or bad prognosis, lack of motivation or support, and unaddressed fear of harm from being physically active.

Conversely, where they received clear and in person advice tailored to their needs and circumstances, it acted as a motivational factor for them to engage in physical activity. Other facilitators for the uptake of physical activity advice as well as engaging/adopting an active lifestyle were positive attitude, knowledge about the current recommendations, social

aspects of exercise such as encouragement and support by relatives, friends and family, and group exercises where patients could meet up with other 'people in the same boat' with similar psychological or physical issues. Companionship provided by friends and family, and by pets to those who were alone, helped cancer survivors stay physically active by giving them a sense of responsibility towards others.

A few factors emerged as ambivalent and appeared to act as facilitators as well as barriers depending upon the context they were described in. Being active before the cancer diagnosis was one of the example, where the pre-diagnosis fitness levels dictated the post-treatment motivation. However, the treatment related morbidity including reduced energy levels resulted into frustration of not being able to perform the activities at similar levels. Family support was an important facilitator, but at the same time overprotective relatives acted otherwise by not allowing them to move about. Health professionals' advice was viewed as credible but in instances where the same advice contradicted with another member, this put the patients off and left them undecided or frustrated on what to do next or where to seek advice.

The theoretical constructs of Social Cognitive Theory used to develop the physical activity promotional intervention in this research project (chapter 3) were reflected by the participants. The possible techniques to reinforce the physical activity advice and the right time to intervene were gleaned from cancer survivor accounts which helped formulate the delivery plan of the developed intervention. As the participants appeared keen to get weekly reminders as reinforcement after treatment completion, various modes of delivery including telephone, text messages and email were discussed with the 'text messages' being favoured the most and chosen to be further developed in this project.

#### **4.6.2 Strengths and limitations**

All participants of the focus groups were enthusiastic about the discussion and the positive group dynamics generated new topics for discussion. This resulted in more in-depth discussion without one individual dominating the discussion. Face to face involvement allowed the moderator to take into consideration the body language, facial expressions, attitude of participants and the level of the conversation and assign meaning to non-verbal interpretation of the discussions.

The data collection approach was appropriate because it allowed wider coverage of the research question by generating rich data with originality, and also provided deeper insight in answering the research questions.

Management of large data sets is a common issue when analysing qualitative data. This was addressed in this study by use of the framework method of analysis. It was suitable

to achieve the desirable objectives to generate themes by making contrasts within and between participants of the focus groups.

Participants' personal interest in physical activity when invited to the study is likely to introduce bias. Although the invitations were open to all eligible patients, there is a possibility that their participation was based on their willingness to talk about physical activity.

Again setting the time frame for those participants who had finished their treatment in the last six months might mean that some participants may have lost interest in physical activities and may have affected their response and inputs into the focus group. If the time frame had been limited to those who had just finished their treatment, this might have provided a deeper insight as they might have been more interested to the physical activity advice as part of their cancer follow-up care.

Another limitation that might be considered for this study was the small sample size. However this sample was representative of the majority of the population covering a wide age range (42-85 years), both genders, a range of cancer types and a broader geographic area of North Wales including both the rural and urban patients. Hence, the population had fulfilled the aim of 'purposive sampling' (Patton 1990), as sample saturation (i.e., recruiting patients with a range of characteristics and experiences) was fulfilled. This became evident in the fourth focus group where no new themes appeared to emerge and therefore no further group discussions were arranged.

### **4.6.3 Comparison with the existing literature**

Our finding that patients in general were receptive to physical activity advice has been reported in a recent survey of lung cancer survivors (Philip, Coups et al. 2014) where the majority (regardless of stage) reported a desire to receive physical activity advice in face-to-face interaction with their physician in a cancer care centre. Similar were the findings reported in a recent review of such issues and concluded that clinicians should consider advising physical activity early, counsel against inactivity, and encourage physical activity in all stages to both the cancer patients and survivors (Bade, Thomas et al. 2015). Our findings complement these as the participants expressed interest in receiving the advice in person from the health professionals well aware of their medical condition and stage of disease/treatment so that they could tailor the advice accordingly.

Vigorous activities requiring energy expenditure of at least 3 Metabolic Equivalent of Task (MET)-hours per week or 4,000 kcal/week are reported to both reduce risk of developing cancer (Meyerhardt, Giovannucci et al. 2006) as well as reducing cancer recurrence and treatment related morbidity (Macmillan, DH et al. 2010). Swimming is classified as a vigorous physical activity (Kushi, Doyle et al. 2012) that can produce energy



higher than 3 MET-hours per week and has been found to reduce risk of adverse breast cancer outcome (Holmes, Chen et al. 2005).

Addressing misconceptions about the amount, extent or frequency of physical activity may need to be part of the physical activity advice as people sometimes do not consider walking as a form of physical activity. Speck et al. (2010) identified that brisk walking over a longer period among prostate cancer survivors was inversely related to mortality, although this was not statistically significant (Speck, Courneya et al. 2010).

Cancer survivors' described interesting accounts about the role of family members and/or friends during their cancer journey and how they influenced their attitudes and actions regarding physical activity and exercise. In this study it was noted that family members could be over protective of the cancer survivors. Lim (2014) noted that up until 2014 there was no study that identified how specific cultural contexts impact the cancer survivors to modify their behaviour (Lim 2014). Lim's observation coincides with the focus group discussion in which some survivors noted how family members could influence the choice of their physical activity in daily lives.

Strong evidence about the benefits of exercise and physical activity suggests that a healthy lifestyle during and after cancer is linked to better physical and psychological well-being, enhanced self-esteem, reduced treatment-related risks and recurrence leading to improved survival (Macmillan, DH et al. 2010). Despite this persuasive evidence, incorporating physical activity advice into routine care is proving to be challenging, and tailoring of the physical activity advice has been emphasised in a recent review by Macmillan (Campbell, Foster et al. 2011), the concerns that have also echoed in patients' accounts in our study. The importance of tailoring the advice is highly emphasised in light of the current evidence that exercise may not be feasible or sometimes safe (Rock, Doyle et al. 2012) during cancer treatment, so a plan that takes into account individual patients' condition and needs attains paramount importance. These findings have again reverberated in our study and the patients were vigilant enough to express the needs to tailored advice rather than something generic.

Physically active behaviour change is challenging to adopt and maintain (Marcus, Forsyth et al. 2000) and could be more so in cancer survivors due to the associated morbidity. However, the evidence suggests that regular reminders of physical activity advice might improve physical activity levels of those who receive them and have positive effects (Fisher, Williams et al. 2015) on the cancer outcomes. Our findings are in keeping with these as the majority of the survivors were of the view that regular weekly brief reminders may keep them motivated to remain physically active. The same study also found that small amount of physical activity advice given to patients regularly, is a finding that is further

confirmed by our findings. This is an interesting corroboration as the data sources although the study designs are different.

Reports from recent studies for both general adult populations (Compernelle, Vandelanotte et al. 2015) as well as cancer survivors (Coolbaugh, Raymond et al. 2015; De Cocker, Charlier et al. 2015; Heckman, Darlow et al. 2015) have shown that patients are in general receptive to the idea of receiving physical activity and/or other behavioural modification advice through the use of computer technology or electronic devices as far as it can be tailored to their needs. Similarly, GPs have also been shown to support such ideas, although there was resistance to the idea that such programmes can be adopted in the general practice and there were concerns about the challenges of educational level or older people that would need to be addressed if such self-regulation mechanisms were considered (Plaete, Crombez et al. 2015). In our study, many participants expressed interest in receiving the reminders through electronic means, indicating that these may be a useful adjunct to professional contact in keeping the patients motivated.

#### **4.6.4 Implications for future research**

There is a need to raise awareness among patients, and their families/ carers about the specificity of physical activity and exercise recommendations. Patients in general appeared to be cognisant with the general benefits of exercise but needed clarification on specific recommendations to reap the maximum benefits.

The need for the provision of physical activity advice during patients' cancer journey as part of their treatment plan was highlighted. Further, the need for this advice to be reinforced at the end of treatment to ensure maintenance of physically active behaviour was also emphasised.

Patients reported the physical activity advice from their caring health professionals as being inconsistent and conflicting, and wanted it to be tailored to their needs. Hence, there is a need to investigate the current practice of health professionals about the physical activity advice they offer to their patients. This has been assessed through an online survey of health professionals reported in chapter 5.

The benefits of exercise through professional referral (or prescription) were considered to be enhanced through continual emphasis and reminders. The strategy to achieve this has been proposed in the form of 12 weekly text messages developed in partnership with the focus group participants (Chapter 6). A pilot randomised trial protocol (Chapter 7, section 7.6.1) has been developed as an end product to this thesis which might

evaluate this intervention for its effectiveness and cos-effectiveness to be incorporated into locally existing initiatives to enhance their reach and effectivity.<sup>2</sup>

## 4.7 Conclusions

Cancer diagnosis is a major and distressing life event that can affect the physical activity levels of survivors both positively and negatively. Both social and professional support play a major role in their next course of action regarding adopting or maintaining a physically active lifestyle. Despite current evidence of the benefits of exercise for cancer survivors and local initiatives to support them to adopt a physically active lifestyle, there was either a lack of advice or inconsistent, conflicting advice from their treating teams contributing to a lack of physical activity uptake to the recommended levels for its beneficial effects. The next chapter further explores the issues highlighted through a survey of the health professionals regarding their knowledge and practices of physical activity advice and utilisation of existing services.

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**Chapter 5. Physical activity promotional attitudes and practices of health professionals to cancer survivors in North Wales: A questionnaire survey**

**Aim:**

To explore the knowledge, attitude and experiences of health professionals in relation to advising cancer survivors about physical activity

**Main findings:**

- Physical activity is beneficial for cancer survivors
- Their role is important in its promotion.
- They don't feel confident in their ability to advise their cancer patients about physical activity.
- Most don't encourage their patients to increase their physical activity.

## 5.0 Chapter summary

This chapter reports the findings of a questionnaire survey completed by 217 health professionals from primary, secondary and allied health disciplines. The rich dataset was analysed both quantitatively and qualitatively (based on free text comments). Results of the analysis were consistent with the patient perspectives that inconsistent physical activity advice described in the previous chapter, and also gave insight into health professionals' viewpoint about these issues.

In general, physical activity levels of health professionals, as measured by self-completed International Physical Activity Questionnaire (Craig, Marshall et al. 2003; Bauman, Ainsworth et al. 2011), either met or exceeded the recommendations for adults. However, the majority of health professionals were spending more time sitting than the UK's average. Some reported that their own activity levels did dictate their decision to offer or not to offer physical activity advice to their patients.

## 5.1 Introduction

Physical activity promotion has gained the attention of healthcare organisations around the world because of the high prevalence of physical inactivity among the general population and cancer survivors alike. The percentage of people physically active enough for it to be beneficial to their health in the general population is poor; 39% of men and 29% of women in England are active to the level recommended by the Department of Health (Department of Health 2004), whilst in Wales this drops to 37% for men and 24% for women. Whilst there is robust evidence to support the benefits of physical activity for people affected by cancer (Schmitz and Speck 2010; WHO 2010; Department of Health 2011), the effectiveness of strategies to achieve the increases in physical activity to acquire these benefits are yet to be understood (Hillsdon, Foster et al. 2005).

Numerous ways to promote physical activity among cancer survivors can be used (Fong, Ho et al. 2012; Mishra 2012; Mishra, Scherer et al. 2012). Interventions on a larger scale include the introduction and implementation of evidence-based policies and provision of appropriate and conducive environments for these policies to work, as well as mass media campaigns to educate individuals. Interventions at workplaces, and community, primary health care, and religious settings are examples of regional or local initiatives (WHO 2009). Recommendations from the National Institute for Clinical Excellence (NICE) have included the potential use of health

professionals to promote physical activity and the introduction of brief interventions in physical activity, which involve opportunistic advice and encouragement. They are commonly used in many areas of health promotion, and are delivered by a range of primary and community care professionals (NICE 2006). Similarly, cancer care providers can also play an active role in improving the long-term health of cancer survivors by opportunistically advising, referring and motivating patients to adopt physically active behaviours. Such actions on their part would require staying up-to-date with physical activity guidelines and the existing resources for professional and patient education (Demark-Wahnefried, Pinto et al. 2006).

The Department of Health (2011) published guidance encouraging local commissioning of physical interventions in primary care using an evidence-based behaviour charter model (Department of Health 2011). The National Exercise Referral Scheme (2010) in Wales directs someone to a service offering an assessment of need, development of a tailored physical activity programme, monitoring of progress and a follow-up. NICE advised that further research into the effectiveness of public health interventions is required, as the evidence to date is equivocal (NICE 2006). In Wales, structured physical activity provision through NERS is embedded within primary care. The Welsh Government published an evaluation of the NERS in 2012 which supported its long term effectiveness (Murphy, Edwards et al. 2012). The process evaluation of the scheme also demonstrated complex issues surrounding physical activity promotion in primary care and ranged from skills enhancement, the need to address ideological objections to paternalistic aspects of health promotion, personal physical activity levels affecting the promotional activities of health professionals and the uncertainties arising from ambiguous patient eligibility criteria for referral (Din, Moore et al. 2015).

All of these factors will also affect the physical activity advice given to cancer survivors especially in relation to the complex issues around the comorbidity arising from cancer diagnosis and treatment. Cancer survivors' perceptions and experiences about inconsistent and unclear physical activity advice during and after cancer treatment were described in the previous chapter. An online self-complete questionnaire survey was developed to provide an insight into health professionals' perspectives, attitudes and practices regarding physical activity promotion to cancer survivors in the context of their beliefs and knowledge about the benefits of physical activity for cancer survivors, current physical activity guidelines, and their awareness about the physical activity promotional services and campaigns in their areas of

practice. This survey was conducted across the whole continuum of cancer survivors' care from secondary to primary to follow-up care.

## 5.2 Study objectives

- 1) To describe the current practice of physical activity advice to cancer survivors during and after their treatment
- 2) To evaluate healthcare professionals' knowledge and beliefs about physical activity for their cancer patients
- 3) To evaluate healthcare professionals' awareness of exercise referral services in North Wales
- 4) To understand the physical activity levels of health professionals

## 5.3 Methods

### 5.3.1 Study Design

This study used a cross-sectional survey design to collect information to describe and compare the knowledge, attitudes and behaviours of health professionals towards physical activity in general and physical activity promotion to cancer patients in particular. Data from healthcare professionals in primary, secondary and community care were collected. A convenience non-probability sampling technique with an embedded snowballing element was used in this study to select the sample of respondents.

### 5.3.2 Questionnaire development

The literature was reviewed to find a standardised questionnaire that could address the study objectives but none was found that would fit the criteria. Hence, a questionnaire (Appendix N) was developed for this study in multiple steps as described below:

#### ***Evidence synthesis for initial draft***

This step comprised identifying the concepts related to the study objectives from a previous literature review (Douglas, Torrance et al. 2006). The main issues highlighted were health professionals' reluctance to advise physical activity stemming from a lack of knowledge and confidence about both the advice itself as well as existing referral services, and their own physical activity level dictating such behaviour.

***Incorporating evidence from the previous qualitative study***

The previous qualitative study identified issues amongst cancer survivors regarding receiving physical activity advice during or after their treatment. The main areas that were highlighted concerned 'receiving inconsistent and conflicting advice from different professionals involved in patients' care which produced the notion of health professionals lacking knowledge about physical activity advice; and 'health professionals' lack of awareness about the locally existing physical activity initiatives especially for cancer survivors'. These concepts were incorporated into the design of the questionnaire items.

***Incorporating questions about health professionals' awareness of locally existing schemes as part of the local health board and Macmillan audit***

The National Exercise Referral Scheme (NERS) is a Welsh Government funded scheme which has been developed to standardise exercise referral opportunities across all Local Authorities and Local Health Boards in Wales. The scheme targets people with a chronic disease or who are at risk of developing a chronic disease. Eligible patients are referred by health professionals to locally participating leisure centres which then assess the referred patients for programme suitability. If the patient is suitable, the exercise programme is tailored to patient needs. The Macmillan North Wales Physical Activity Project is another project that encourages cancer survivors to take part in physical exercise. Statements 5 to 9 of the questionnaire were designed to measure health professionals' awareness of these two schemes.

***Incorporating IPAQ as a measure of health professionals' own physical activity levels***

The International Physical Activity Questionnaire (IPAQ) instrument assesses walking, moderate and vigorous physical activities in the last seven days (Craig, Marshall et al. 2003) and was incorporated in the questionnaire as a measure of the health professionals' own current physical activity levels.

***Provision of free text box***

Open-ended questions inviting free-text comments are increasingly being used in surveys and can provide deeper insights into issues under scrutiny (Edwards, Roberts et al. 2002); identify areas for action, or initiate further investigation; and can help in the progression from documentation of the survey respondent to achieving quality improvement (Liu, Harris Ma Fau - Keyton et al. ; Riiskjaer, Ammentorp J Fau



- Kofoed et al.). Hence, a free text box was incorporated in the survey design to enable health professionals to express views about physical activity promotion, their perceptions about the beneficial effects of physical activity for their patients, and if they would like to share ideas they could not express while answering survey questions with limited response choices.

Qualitative data was analysed thematically to characterise the text (Riiskjaer, Ammentorp J Fau - Kofoed et al.). The data was read and re-read to collate similar topics of expressions. A matrix was then developed and data was summarised under those headings resulting into common themes, which were explained descriptively in the results.

### ***Feedback of the study management group***

Once all the required themes had been incorporated to fulfil the objectives of the study, the draft content was circulated to the study management group for their feedback on the content, language and layout of the questionnaire. The feedback was then assimilated, corroborated and incorporated to modify the questionnaire accordingly.

### ***Questionnaire piloting***

To assess content validity, the questionnaire was uploaded to the Bristol Online Surveys (BOS) website for in-house piloting within the North Wales Centre for Primary Care Research (NWCPCR), Bangor University. The link was emailed to 11 colleagues who had expertise in both clinical as well as primary research including questionnaire design. The content validity was assessed by nine of the eleven researchers. Along with methodologists, the group also included six academic health professionals: three GPs, an oncology consultant, an occupational therapist, and an oncology clinical nurse specialist. The three GPs had special research interests in musculoskeletal diseases, early diagnosis of cancer in primary care and safe cancer care during follow up respectively.

This expert panel had two weeks to assess and reflect on the content, layout and objectivity of the questions regarding their suitability to address the aims of the study. The panel's assessment helped appropriate adjustments to each item, and subsequently their recommendations and feedback were assimilated to finalise the questionnaire.

### ***Contents of the final questionnaire***

The questionnaire comprised four sections:

1. Demographic information on gender, professional responsibilities, and duration of practice in years
2. Questions about perceptions and attitudes towards promoting physical activity to cancer survivors as well as their day-to-day practice in this regard
3. Questions about their awareness of the various physical activity promotional campaigns and support services available in their areas
4. International Physical Activity Questionnaire (IPAQ) as a measure of their own current physical activity levels

A free text box to give the respondents a chance to share their experiences or views not covered by the questionnaire

The final questionnaire is available in Appendix N.

### **5.3.3 Choice of questionnaire administration medium**

The design and conduct of this survey was based on the latest recommendations to improve response rates. These recommendations include engaging health professionals through national and professional networks, providing incentives, and making the survey content as user friendly as possible (Edwards, Roberts et al. 2002; VanGeest, Johnson et al. 2007; Cho, Johnson et al. 2013). This study used an electronic mode of questionnaire access and completion due to the advantages offered by this survey method. Key advantages of using electronic surveys are their relative ease of implementation and the potential to conduct large-scale surveys whilst eliminating the costs associated with stationery, postage and administration (Wyatt 2000). Simple questionnaires are easy to construct and design and do not require sophisticated programming skills, and the cost and time implications of sending multiple e-mail invitations and reminders are negligible. Electronic surveys also allow tighter control of the order in which respondents see specific questions thus preventing respondents from returning to change their answers. Similarly, the option for mandatory responses can easily be incorporated in the design so that respondents cannot move to the next question until they have completed the previous question. This reduces the chances of having missing or incomplete data. Internet based surveys also allow simple automatic transfer of data into a database, thus eliminating the need for manual entry, hence avoiding potential human errors.

The host organisation, Bangor University, has a site licence for the Bristol Online Survey system which is widely used to design and administer online questionnaires.

### **5.3.4 Study participants**

The target population of interest was registered health professionals from the primary, secondary and allied health care disciplines involved directly or indirectly in the care and/or rehabilitation of cancer patients in North Wales, UK. These health professionals included general practitioners, practice nurses, community nurses, physiotherapists, occupational therapists, consultant oncologists, and clinical nurse specialists.

### **5.3.5 Ethical approvals**

This survey was conducted as part of an audit in collaboration with Betsi Cadwaladr University Local Health Board (BCUHB), Macmillan, and the Bangor University. After discussion by the clinical audit review panel, the survey was approved to progress as a registered audit and was not required to go through the regional ethics committee's approval process.

### **5.3.6 Sample size**

Considering the low response rates reported in internet based surveys of primary care staff (Aerny, Dominguez-Berjon et al. 2012), and the issues with electronic surveys such as server rejections, incompatibility with the host systems, and junk email filters (Wright 2005), a target sample of around 500 health professionals was chosen. A conservative estimate of the number of respondents from this sample, based on a response rate of 50%, was 250. Considering that 10% of the responses were likely to be incomplete, a number of approximately 225 complete responses were expected.

### **5.3.7 Participant recruitment**

A generic email was designed explaining the background of the research project and objectives of the survey. A link to the online questionnaire was placed at the end of the consent statements, with an explicit statement that clicking the link would take the respondent to the questionnaire page and would therefore imply that the respondent had given their consent to participate in the study.

Prospective health professional participants based at the Betsi Cadwaladr University Local Health Board (BCUHB) in North Wales, UK were invited by email. The email lists of relevant health professionals were obtained with approval from the BCUHB health board internal IT systems. Invitation emails were sent from an official BCUHB email address pertaining to the same organisation (NHS) to minimise the chances of the invitation being filtered into spam folders. A first reminder email was

sent three weeks later to the non-responders, with the second reminder was emailed three weeks following the first reminder.

All the data was collected anonymously and respondents did not have to enter any personal identifiable information.

### 5.3.8 Data manipulation

The questionnaire was designed to assess health professionals' attitudes to physical activity promotion in their routine clinical practice, their perceptions of their own knowledge and confidence in routinely advising physical activity, their awareness of locally existing physical activity initiatives (such as NERS or Macmillan's physical activity project) in general as well as for cancer survivors, and their own physical activity levels using the International Physical Activity Questionnaire (IPAQ) short form.

After all the data had been exported from the BOS tool to the statistical package used for data manipulation and analysis (STATA 11.0-<http://www.stata.com/>), individual items of the questionnaire were explored for any inconsistencies, missing data or non-responses. Where there were no or minimal responses to certain response options of a question, these were merged together to get a consistent and meaningful score for interpretation. The following is a brief description of the questions whose data were transformed for analysis purposes.

Questions 1-3: The responses were on a five point Likert-scale as:

strongly agree	agree	neither	disagree	strongly disagree
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At the data exploration stage, it was found that the responses were not distributed broadly and the predictor group (health professional roles) had many categories and subcategories which diluted the numbers in individual response groups. Hence, the first two categories (strongly agree/agree) and the last two disagree/strongly disagree) were merged together respectively to achieve three ordinal categories to reflect respondents agreement or disagreement to the question's statement.

In the demographic section of the questionnaire, data were collected regarding the health professionals' years of practice in their current professional role. These were then categorised into 'up to five years' 'between 6-10 years' 'between 11-15 years' 'between 16-20 years' and 'above 20 years' categories. The professional roles were categorised into primary care, secondary care, physical and

psychological rehabilitation teams, community support staff (Table 5.1); and other support staff who were not directly involved in day to day patient care but still played a part in the overall care process (Table 5.2).

Energy expenditure in Metabolic Equivalent of Task-minutes (MET-minutes) was calculated using the protocol devised and proposed by the IPAQ Research Committee (including the removal of outliers and truncation of maximum minutes of activity per day to 180 minutes). This allowed categorisation of participants into High, Moderate and Low activity groups (<https://sites.google.com/site/theipaq/scoring-protocol>). MET-minutes per week were also used as a continuous variable to analyse and compare values with the general population recommendations as well as similar populations.

Once the data had been cleaned and categorised appropriately, the analyses were performed according to the categories described above, with separate analyses performed in each domain.

### **5.3.9 Data Analysis**

The data were analysed using descriptive (frequency distribution) and analytic statistics and the results were reported according to the latest standards of reporting electronic healthcare research (Eysenbach 2004). Numbers and percentages of responses in the categorical or ordinal response categories in the dataset, males and females and self-reported physical activity were reported. The categorical outcomes i.e. health professionals' physical activity promotion 'beliefs' and 'practices', and their 'awareness of existing services' were statistically analysed using the Wilcoxon-Mann Whitney test; and the ordinal predictors 'professional role domain' and 'duration in practice' using the Kruskal Wallis test against the dichotomous predictor gender. The outcome variables regarding the health professionals' 'awareness' and 'utilisation' of physical activity referral services had dichotomous responses (Yes, No) and were analysed against all the categorical predictor variables in the dataset using Pearson's  $\chi^2$  statistics.

The IPAQ short form data was analysed as a continuous variable, where the duration of physical activity was calculated in the vigorous, moderate, walking and sitting categories as minutes of activity (or inactivity) per day. This data was also converted into minutes of activity per week and analysed as a categorical variable under vigorous, moderate and walking categories. The distribution of the IPAQ continuous data were summarised reporting the mean and standard deviation if normally distributed, or the median and inter-quartile range (IQR) if skewed.

Health professionals' self-reported physical activity levels in minutes of activity (or inactivity) per day as well as per week, and the energy expenditure calculated as MET-minutes per week were compared with the standard recommended levels for adults (WHO 2010) using one sample t-test.

Gender differences in these self-reported physical activity levels were computed using linear regression models. Unadjusted (crude) linear regression models were fitted in which only one predictor, gender, was included, and multivariable models in which all three of 'gender', health professionals' 'duration in practice', and their 'location of clinical practice' were included. Focus was on the multivariable analyses as primary. Where there was evidence at the 5% level of an association between physical activity levels and gender, tests of interaction were undertaken to explore if the relationships were affected by health professionals' 'duration in practice', and their 'location of clinical practice' categories. As the physical activity distributions were skewed, the linear regression results were validated by constructing bias-corrected accelerated bootstrap confidence intervals for the mean differences (regression coefficients) as these are robust to non-normality (Davison and Hinkley 1997). As the bootstrap confidence intervals were virtually the same as the regression model-based confidence intervals, results were reported from the latter analysis.

The association of levels of activity with the categorical predictors having more than two categories i.e. 'professional role domain' and 'duration in practice' were calculated using the one way analysis of variance (one way ANOVA). Post-hoc pairwise group comparisons were performed only where the relationships were statistically significant to find out the individual group effects using Studentised Range distribution technique through Tukey-Kramer statistics. Otherwise, only the p values are reported along with descriptive statistics.

Finally, the categorical variable weekly energy expenditure computed from MET-minutes per week depicting levels of physical activity as 'High, Medium and Low' was analysed against the categorical predictors using Wilcoxon-Mann Whitney for gender and Kruskal Wallis test for duration of practice and professional role category. Graphical presentation of the data was undertaken to clarify the results, wherever deemed suitable.

All data manipulation and analyses were performed using Stata 11.0 software (StataCorp 2009).

## 5.4 Results

### 5.4.1 Response rate

The questionnaire was available between November 2013 and March 2014 and the link was distributed via email to 496 healthcare professionals in North Wales; 217 responses were received (response rate of 43.75%).

### 5.4.2 Characteristics of the survey participants

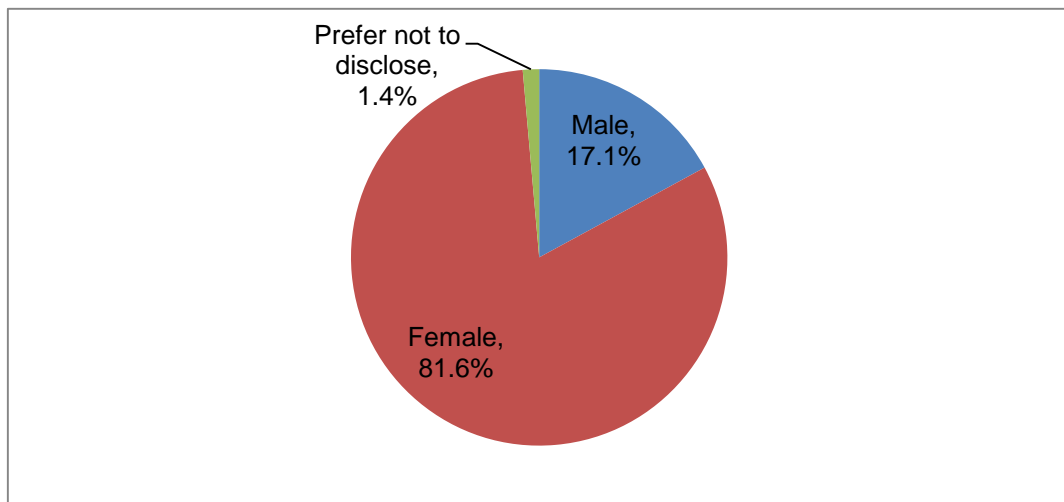
#### *Professional roles*

Table 5.1 presents the professional roles of the respondents and shows that the sample was reasonably representative of the professionals involved in patient cancer care and rehabilitation. These included 61 (28.1%) physiotherapists, 35 (16.1%) occupational therapists, 27 (12.4%) GPs, 27 (12.4%) clinical nurse specialists, 21 (9.7%) consultants, 11 (5.1%) community nurses and 9 (4.1%) practice nurses, and 23 (11%) others. The role as described in the 'others' category by the respondents was then, at the stage of grouping different professional roles into location of their practice, assigned to different groups (Table 5.2). When different health care respondent roles were grouped by their professional role domain, the representation by various groups was as follows: primary care 16.6% (36), secondary care 23.5% (51), rehabilitation teams 48.9% (106), community support teams 7.4% (16), and others 3.8% (8).

#### *Gender*

The majority of the participating health professionals were females; 17.1% were males and 1.4% did not disclose their gender (Figure 5.1). Table 5.1 presents the breakdown of health professionals' roles and their professional grouping by gender.

**Figure 5.1:** Gender Distribution of Participating Health Professionals





**Table 5.1:** Health professional roles by gender

Professional grouping	Total N (%)	Professional category	Gender		Total
			Male	Female	
Primary care	36 (16.6)	GP	13	14	27
		Practice nurse	0	9	9
Secondary care	51 (23.5)	consultant	14	7	21
		Clinical nurse specialist	0	21	21
		Oncologist	0	1	1
		Other	0	8	8
Rehabilitation team	106 (48.9)	dietitians	0	4	4
		OT	2	33	35
		Physio	4	57	61
		Other	0	3	3
Community support	16 (7.4)	Macmillan nurse	0	1	1
		Community nurse	0	11	11
		Other	1	3	4
Others	8 (3.8)	other	3	5	8

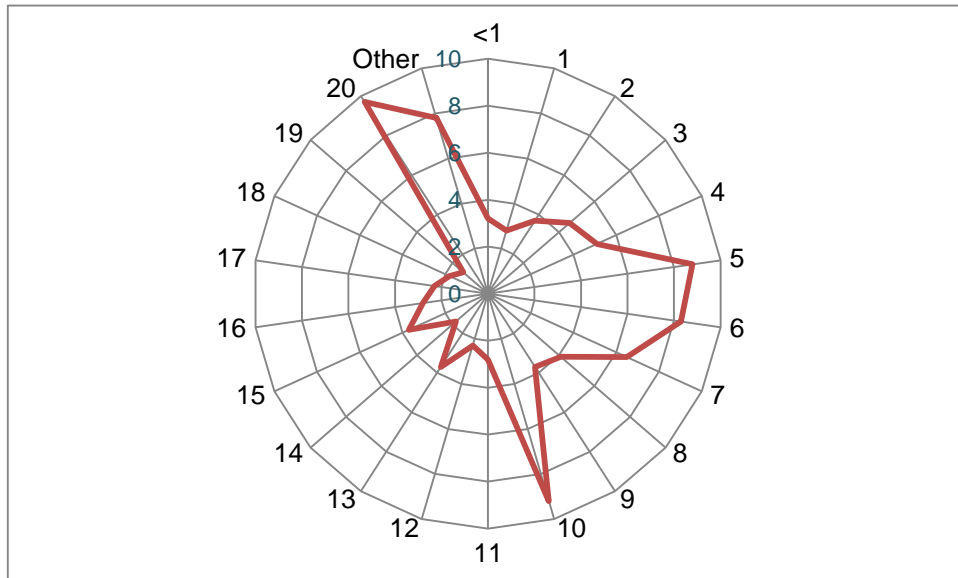
**Table 5.2:** Break-down of 23 'Other' category of HCPs' roles assigned to groups by gender

Number	Professional grouping	Health professional designation	Gender
1.	Secondary care	Health Improvement Practitioner	Female
2.	Secondary care	ANP	Female
3.	Secondary care	Ward Sister	Female
4.	Secondary care	Acute Oncology ANP	Female
5.	Secondary care	Psychological therapist / Psychiatric nurse	Female
6.	Secondary care	HCA	Female
7.	Secondary care	Liaison psychiatry team	Female
8.	Secondary care	Anaesthetic and ICM	Female
9.	Physical and psychological rehabilitation	Occupational Therapy Technical Instructor	Female
10.	Physical and psychological rehabilitation	Senior Occupational Therapy assistant	Female
11.	Physical and psychological rehabilitation	Technical instructor	Female
12.	Community support	Family support health visitor	Female
13.	Community support	Pharmacist	Male
14.	Community support	Exercise referral coordinator	Female
15.	Community support	Pharmacy technician	Female
16.	Other support staff	Therapeutic Radiographer	Male
17.	Other support staff	Medical Physicist	Male
18.	Other support staff	Executive Medical Director	Male
19.	Other support staff	Macmillan cancer information and support coordinators	Female
20.	Other support staff	Macmillan Information & Support Manager	Female
21.	Other support staff	Manager	Female
22.	Other support staff	Radiographer	Female
23.	Other support staff	Therapy Radiographer	Female

### ***Duration of service in the health care role***

The health professionals' service length varied between less than 1 year and over-20 years. The radar diagram in Figure 5.2 shows this distribution graphically.

**Figure 5.2:** Radar Diagram showing Health Professionals' Service Length



When categorised into quintiles of experience related their professional experience, it looks like as presented in Table 5.3.

**Table 5.3:** Years of experience of the health professionals in current role

<b>Years of experience in current role</b>	<b>Number</b>	<b>Percent</b>
Up to five years	61	28.1
6-10 years	69	31.8
11-15 years	31	14.23
16-20 years	39	17.9
Above 20 years	17	7.8
Total	217	100

### **5.4.3 Health professionals' perspectives on physical activity promotion**

Four questions, as shown in tables 5.4-a and 5.4-b, were used to determine health professionals' perspectives on physical activity promotion to cancer survivors during their routine care. The first two were designed to assess their beliefs about the importance of physical activity for cancer survivors as well as their perceptions about

the role of health professionals in promoting this; and the latter two about their confidence and practice in promoting physical activity to their cancer patients.

**Table 5.4-a:** Health professionals' perspectives on PA promotion to cancer patients during their routine care (n = 217)

Area explored	Responses n (%)				
	Strongly agree	agree	Neither	Disagree	Strongly disagree
1. Physical activity is beneficial for cancer survivors	151 (69.6)	64 (29.5)	2 (0.9)	0	0
2. It is important for healthcare professionals to promote physical activity among cancer patients	136 (62.6)	75 (34.6)	6 (2.8)	0	0
3. I have sufficient knowledge to advise cancer patients about physical activity	42 (19.4)	88 (40.5)	42 (19.4)	35 (16.1)	10 (4.6)

**Table 5.4-b:** Health professionals' perspectives on PA promotion to cancer patients during their routine care (n = 217)

Area explored	Responses n (%)			
	All patients	Some patients	Selected patients	None
4. I encourage cancer patients to increase their physical activity	30 (13.8)	115 (53.0)	45 (20.7)	27 (12.5)

Ratings for the statements in Table 5.4-a were collected on a five-point Likert scale from 1 to 5 (1 = strongly disagree to 5 = strongly agree). The frequency distributions of the responses obtained show that the majority 215/217 (99%) of respondents agreed about the beneficial effects of physical activity for cancer survivors, as well as the importance of promoting physical activity 211/217 (97%) among cancer survivors.

When it came to having sufficient knowledge (statement 3) to encourage patients to increase their physical activity (statement 4), there was a wider dispersion of responses with many responding neutrally 42/217 (19.4%) or not agreeing 45/217 (26%) to the notion that they had sufficient knowledge to advise physical activity to their patients. Many indicated that they advised physical activity to either some 115/217 (53%) or selected patients 45/217 (20.7%) only, and some did not advise physical activity at all 27/217 (12.5%).

When the data were analysed statistically according to the grouping variables (gender, location of professionals' practice and duration in practice), the Wilcoxon-Mann-Whitney test did not show any gender differences regarding their beliefs about the beneficial effects of physical activity for cancer survivors ( $p=0.22$ ), health professionals' role to promote physical activity ( $p=.96$ ) or having sufficient knowledge

about advising physical activity to cancer patients ( $p=0.16$ ). The  $\chi^2$  test also did not reveal any significant differences in the practice of encouraging patients to increase their physical activity ( $p=0.49$ ).

A Kruskal-Wallis test revealed that health professionals' duration in practice did not have any influence on their beliefs about the beneficial effect of physical activity for cancer survivors ( $p=0.19$ ), the importance of physical activity for cancer survivor's well-being ( $p=0.45$ ), their knowledge and confidence about advising physical activity to their patients ( $p=0.67$ ), or their practice of who they advised ( $p=0.67$ ). The same test revealed that their professional role domain did have significant influence on their belief that physical activity was beneficial for cancer survivors ( $\chi^2=12.644$  with 4 degrees of freedom,  $p=0.01$ ), and that health professionals had important role in promoting physical activity among their patients ( $\chi^2=17.958$  with 4 degrees of freedom,  $p=0.001$ ). An inspection of the distribution of these responses indicated that the groups working in rehabilitation teams such as physiotherapists or occupational therapists were more supportive of these ideas. Although, there were no statistically significant differences, a reasonable number from all categories disagreed with the statement that they had sufficient knowledge to advise physical activity to their patients. Similarly, only a few indicated that they encourage all of their patients to increase physical activity. These results are presented in Tables 5.5 & 5.6.

**Table 5.5:** Benefits of physical activity perceptions

Area explored	Respondents' category	Respondents' sub-category	Responses			P value	
			Strongly agree/ agree	Neither	Disagree/ Strongly disagree		
Physical activity is beneficial for cancer survivors	Gender	Male	36 (97.3)	1 (2.7)	0	0.22*	
		Female	176 (99.4)	1 (0.6)	0		
	Professional role domain	Primary care	36	0	0	0.01** $\chi^2=12.644$ with 4 d.f	
		Secondary care	51	0	0		
		Physical and psychological rehabilitation	105	1	0		
		Community support staff	16	0	0		
		Other support staff	7	1	0		
	Duration in practice	Up to five years	60	1	0	0.19**	
		5-10 years	69	0	0		
		10-15 years	31	0	0		
		15-20 years	39	0	0		
		Above 20 years	16	1	0		
	It is important for healthcare professionals to promote physical activity among cancer patients	Gender	Male	36 (97.3)	1 (2.7)	0	0.96*
			Female	172 (97.2)	5 (2.8)	0	
Professional role domain		Primary care	36	0	0	0.001**	
		Secondary care	51	0	0		
		Physical and psychological rehabilitation	102	4	0		
		Community support staff	16	0	0		
		Other support staff	6	2	0		
Duration in practice		Up to five years	58	3	0	0.45**	
		5-10 years	67	2	0		
		10-15 years	31	0	0		
		15-20 years	39	0	0		
		Above 20 years	16	1	0		

Area explored	Respondents' category	Respondents' sub-category	Responses			P value
I have sufficient knowledge to advise cancer patients about physical activity	Gender	Male	25 (67.6)	8 (21.6)	4 (10.8)	0.16*
		Female	102 (57.6)	34 (19.2)	41 (23.2)	
	Professional role domain	Primary care	22	9	5	0.89**
		Secondary care	31	11	9	
		Physical and psychological rehabilitation	62	17	27	
		Community support staff	10	5	1	
		Other support staff	5	0	3	
	Duration in practice	Up to five years	35	9	17	0.67**
		5-10 years	44	13	12	
		10-15 years	20	8	3	
		15-20 years	22	7	10	
		Above 20 years	9	5	3	

\*Wilcoxon-Mann Whitney test

\*\* Kruskal Wallis test

**Table 5.6:** Physical activity promotion activities

Area explored	Respondents' category	Respondents' sub-category	Responses				P value*
			All patients	Some patients	Selected patients	None	
I encourage cancer patients to increase their physical activity	Gender	Male	3 (8.1)	21 (56.8)	8 (21.6)	5 (13.5)	0.49
		Female	26 (14.7)	93 (52.5)	36 (20.4)	22 (12.4)	
	Professional role domain	Primary care	5	19	9	3	0.26
		Secondary care	5	32	7	7	
		Physical and psychological rehabilitation	17	49	27	13	
		Community support staff	3	11	1	1	
		Other support staff	0	4	1	3	
	Duration in practice	Up to five years	9	31	14	7	0.46
		5-10 years	12	36	9	12	
		10-15 years	2	20	9	0	
		15-20 years	5	19	9	6	
		Above 20 years	2	9	4	2	
		Total	30 (14)	115 (53)	45 (21)	27 (12.4)	

\*Pearson's  $\chi^2$  test

#### 5.4.4 Health professionals' awareness about physical activity promotional campaigns

Table 5.7 presents the results of questions 5-9. The majority (86%) of respondents were aware of the NERS and about half (49.5%) had heard of the cancer exercise pathway set up through the MacMillan physical activity promotional project. But, interestingly, at the time of completing the questionnaires, only 22.6% had referred cancer patients to NERS despite a high percentage of respondents indicating their awareness of such schemes. Nevertheless, the majority (94%) were happy to refer appropriate cancer patients to NERS as part of their role. However, just over one third of the respondents (33%) did not know that these services existed.

Pearson's  $\chi^2$  test revealed that awareness of the existing services had a significant relationship with gender and the professional role domain of the responding health professionals. Females were more aware than males ( $\chi^2$  1 d.f.=6,  $p=0.02$ ), and the rehabilitation team members along with community support staff such as physio- or occupational therapists as well as nurses were more aware of the schemes than professionals working in other disciplines, especially those in secondary care ( $\chi^2$  4 d.f.=9,  $p=0.05$ ). Similarly, rehabilitation team members had greater awareness about cancer patients' eligibility to be referred to these schemes than other disciplines ( $\chi^2$  4 d.f.=14,  $p=0.008$ ). There were no significant differences among the groups regarding their referral practices (whether referring or not) to these schemes: gender ( $p=0.15$ ), professional role domain ( $p=0.34$ ), and duration in practice ( $p=0.15$ ). Similarly, there were not significant differences in their willingness to refer or not to refer: gender ( $p=0.85$ ), professional role domain ( $p=0.51$ ), and duration in practice ( $p=0.29$ ). Regarding the awareness to the existence of Macmillan North Wales Physical Activity Project, females ( $\chi^2$  1 d.f.=7,  $p=0.01$ ), younger practitioners ( $\chi^2$  4 d.f.=14,  $p=0.006$ ) and community support staff ( $\chi^2$  4 d.f.=12,  $p=0.02$ ) were more aware than the other respondents.



**Table 5.7:** Awareness about the availability of services

Area explored	Respondents' category	Respondents' sub-category	Responses		P value*
			Yes	No	
5. I am aware of the National Exercise Referral Scheme	Gender	Male	27	10	0.02
		Female	156	21	
	Professional role domain	Primary care	35	1	0.05
		Secondary care	38	13	
		Physical and psychological rehabilitation	92	14	
		Community support staff	14	2	
		Other support staff	7	1	
	Duration in practice	Up to five years	54	7	0.29
		5-10 years	62	7	
		10-15 years	23	8	
		15-20 years	33	6	
		Above 20 years	14	3	
	Total		186 (86)	31 (14.3)	
6. I am aware that cancer patients can now be referred to the National Exercise Referral Scheme in North Wales	Gender	Male	21	16	0.22
		Female	119	58	
	Professional role domain	Primary care	17	19	0.008
		Secondary care	30	21	
		Physical and psychological rehabilitation	78	28	
		Community support staff	14	2	
		Other support staff	4	4	
	Duration in practice	Up to five years	40	21	0.48
		5-10 years	51	18	
		10-15 years	19	12	
		15-20 years	23	16	
		Above 20 years	10	7	
	Total		143 (66)	74 (34.1)	

Area explored	Respondents'	Respondents' sub-category	Responses		P value*
7. I have referred cancer patients to the National Exercise Referral Scheme	Gender	Male	10	27	0.51
		Female	39	138	
	Professional role domain	Primary care	7	29	0.34
		Secondary care	16	35	
		Physical and psychological rehabilitation	20	86	
		Community support staff	3	13	
		Other support staff	3	5	
	Duration in practice	Up to five years	13	48	0.15
		5-10 years	20	49	
		10-15 years	3	28	
		15-20 years	7	32	
Above 20 years		6	11		
Total		49 (23)	168 (77.4)		
8. I would be happy to refer appropriate cancer patients to the National Exercise Referral Scheme as part of my role	Gender	Male	35	2	0.85
		Female	166	11	
	Professional role domain	Primary care	34	2	0.51
		Secondary care	46	5	
		Physical and psychological rehabilitation	101	5	
		Community support staff	16	0	
		Other support staff	7	1	
	Duration in practice	Up to five years	58	3	0.29
		5-10 years	66	3	
		10-15 years	27	4	
		15-20 years	38	1	
Above 20 years		15	2		
Total		204 (94)	13 (6)		
9. I am aware of Macmillan North	Gender	Male	11	26	0.01

Area explored Wales Physical Activity Project	Respondents'	Respondents' sub-category	Responses		P value*
		Female	94	83	
	Professional role domain	Primary care	11	25	0.02
		Secondary care	28	23	
		Physical and psychological rehabilitation	51	55	
		Community support staff	13	3	
		Other support staff	4	4	
	Duration in practice	Up to five years	36	25	0.006
		5-10 years	41	28	
		10-15 years	13	18	
		15-20 years	13	26	
		Above 20 years	4	13	
	Total		107 (49.3)	110 (50.7)	

\* Pearson's  $\chi^2$  test

### 5.4.5 Assessment of health professionals' own physical activity levels

#### Description of various physical activities as reported by the participants

Table 5.8 presents the frequency distribution of respondents regarding their self-reported vigorous, moderate and walking activities per week as measured per day(s) of a week. The data shows that nearly three quarters reported doing vigorous physical activity (such as heavy lifting, digging, aerobics, or fast bicycling) every week. The activities ranged from one day to all seven days of the week. Most people (21%) reported doing vigorous physical activity on two days in a week. 46% (94) of the 203 respondents (14 did not reply) reported performing vigorous physical activities for less than one hour per week.

Regarding the moderate activities (i.e. carrying light loads, bicycling at a regular pace, doubles tennis, but excluded walking), the majority of professionals reported moderate activity two days per week of (22%). 17% reported performing moderate activity on 3 days per week. Similar to vigorous activity, most people (50%) reported moderate activity for less than one hour per week.

Regarding walking activity, over a third (39%) reported walking every day of the week for at least 10 minutes. However the number of people who did not report walking at least for 10 minutes a day was 125 (58%).

**Table 5.8:** Health professionals' frequency distribution regarding their physical activities during the week days

Number of days per week	Numbers (%) of respondents		
	Vigorous	Moderate	Walking (10 min/day)
1 day per week	33 (15.2)	33 (45.2)	10 (4.6)
2 days per week	46 (21.2)	47 (21.7)	23 (10.6)
3 days per week	39 (18.0)	37 (17.1)	26 (12.0)
4 days per week	12 (5.5)	16 (7.4)	25 (11.5)
5 days per week	18 (8.3)	11 (5.1)	28 (12.9)
6 days per week	7 (3.2)	3 (1.4)	13 (6.0)
7 days per week	4 (1.8)	22 (10.1)	85 (39.2)

### **Comparison with standard recommendations**

Table 5.9 presents the self-reported physical activity levels of health professionals using the IPAQ instrument. These levels were compared with the standard recommended levels for adults needed to benefit health (Department of Health 2011) using one sample t test. Overall, respondents' self-reported physical activity levels far exceeded the Department of Health recommendations and had statistically significant relationships in all the domains analysed i.e. total minutes of vigorous [Mean 75 (SD 64.9),  $p < 0.001$ ] per day + [Mean 239 (SD 347),  $p < 0.001$ ] per week and moderate activity [Mean 83 (SD 97),  $p < 0.001$ ] per day + [Mean 311 (SD 552),  $p < 0.001$ ]. Similarly, the energy expenditure using the MET-minutes per week [Mean 4111.2 (SD 3493.8),  $p < 0.001$ ] was significantly higher than the minimum standard recommendations.

One interesting finding was that despite the high levels of physical activity reported in all the domains, the health professionals reported sitting durations [Mean 444.1 (SD 309.5),  $p < 0.001$ ] per day significantly higher than those reported for the UK average (Mean 294 minutes per day for Males and 312 for females) (Department of Health 2010). Interestingly, the number of people who were not active enough to attain beneficial effects of physical activity was consistent with the levels of general population in Wales, where only 37% of men and 24% of women are active enough to benefit their health (WG 2014).

**Table 5.9:** Activity amount as measured by self-administered IPAQ

Total minutes of different physical activities	Number of respondents	Health professionals' self-reported Physical activity amount			Guideline daily physical activity recommendations in minutes	P value**
		Mean (SD)	Median	IQR		
Total minutes of vigorous activity per day	203	75 (75) [75.9 (64.9)]*	60	20-120	15	<0.001
Total minutes of moderate activity per day	217	83 (97) [68.4 (63.8)]*	50	20-120	30	<0.001
Total minutes of vigorous activity per week	203	239 (347) [200.6 (249.5)]*	120	0-300	75	<0.001
Total minutes of moderate activity per week	217	311 (552) [232.3 (313.2)]*	120	20-360	150	<0.001
Total MET-minutes activity per week	217	4111.2 (3493.8)	3026	1335-5742	500	<0.001
Total minutes spent sitting per day	217	444.1 (309.5)	360	240-540	300***	<0.001

\*Data truncated to 180 maximum minutes of activity per day

\*\*One sample t test

\*\*\*Minutes of sedentary activity as reported in one of recent government publications for UK adults

## **Comparisons within groups**

### ***Gender***

Statistical analyses of the continuous IPAQ data using univariable (minutes of activities against gender only) and multivariable (minutes of activity with gender, professional role domain and duration in practice in the model) regression showed that there were no significant differences in the amount of vigorous ( $p=0.74$ ), moderate ( $p=0.46$ ) or walking ( $p=0.39$ ) activities in minutes per day between males and females. Similarly, there were no significant differences between males and females when comparing minutes of activities per week as well as the energy consumption measured in MET-minutes per day as well as per week ( $p>0.05$ ). These results are presented in Table 5.10.

### ***Professional role domain***

Table 5.11 presents the one-way ANOVA analysis of the relationship of minutes/MET-minutes of activities within professional role domain. The analysis indicated that there were significant differences among the group sub-categories in the minutes of moderate activities per day ( $p=0.02$ ), minutes of moderate activity per week ( $p=0.01$ ), minutes of walking per week ( $p=0.03$ ), MET-minutes of moderate activity per week ( $p=0.01$ ), MET-minutes of walking activity per week ( $p=0.03$ ), and total MET-minutes per week ( $F(4,212) = 2.72, p=0.03$ ). As this analysis does not indicate which of the sub-groups had significant differences, a post-hoc analysis was performed. Whilst there was trends towards the rehabilitation group being more active, the Tukey's post-hoc test revealed that none of the differences between the sub-groups regarding total MET-minutes per week were significant (Tukey HSD test  $<2.72$ ).

**Table 5.10:** Activity amount as measured by self-administered IPAQ, by gender of respondents

Measures of physical activity	Gender	Number of respondents	Mean	SD	Median	IQR (25 <sup>th</sup> -75 <sup>th</sup> centiles)		Mean difference (95% CI)		P value*
								Crude	Adjusted*	
Total minutes of vigorous activity per day	Male	32	73.4	70.7	60	0	120	0.1	-2.6 (-32.2-26.9)	0.74
	Female	168	73.5	76.2	60	20	120			
Total minutes of moderate activity per day	Male	37	68.1	75.4	40	0	120	14.8	13.6 (-21.3-48.5)	0.46
	Female	177	82.9	97.5	50	20	120			
Total minutes of walking activity per day	Male	37	92.7	86.4	60	30	120	26.4	18.8 (-32.2-69.9)	0.39
	Female	177	119.2	146.0	60	30	150			
Total minutes spent sitting per day	Male	37	488.1	303.0	360	240	600	-51.4	-31.6 (-146.8-83.5)	0.43
	Female	177	436.7	312.3	360	240	480			
Total minutes of vigorous activity per week	Male	37	190.0	222.8	160	0	300	5.5	-1.7 (-93.2-89.8)	0.84
	Female	177	195.6	250.9	120	0	270			
Total minutes of moderate activity per week	Male	37	146.8	176.0	120	0	210	94.1	92.2 (-20.7-205.1)	0.26
	Female	177	240.9	324.1	120	30	360			
Total minutes of walking activity per week	Male	37	395.7	354.0	270	90	720	89.6	76.6 (-81.1-234.3)	0.10
	Female	177	485.3	442.1	300	120	840			
MET-minutes of vigorous activity per week	Male	37	1520.0	1782.7	1280	0	2400	44.7	-13.6 (-745.7-718.5)	0.84
	Female	177	1564.7	2006.8	960	0	2160			
MET-minutes of moderate activity per week	Male	37	587.0	703.6	480	0	840	376.6	368.8 (-82.8-820.4)	0.26
	Female	177	963.6	1296.3	480	120	1440			
MET-minutes of walking activity per week	Male	37	1305.7	1168.2	891	297	2376	295.8	252.8 (-267.5-773.2)	0.10
	Female	177	1601.5	1458.9	990	396	2772			
Total MET-minutes activity per week	Male	37	3412.8	2436.6	2970	1386	4532	717.1	608.1 (-652.6-1868.7)	0.48
	Female	177	4129.9	3559.6	3192	1293	5838			

\*Adjusted for 'professional's professional role domain' and 'years in practice' categories



**Table 5.11:** Relationships of minutes/MET-minutes of activities with HCPs professional role domain

Measures of physical activity	Health professionals' professional role domain	Number of respondents	Mean	SD	Median	IQR (25 <sup>th</sup> -75 <sup>th</sup> centiles)		P value*
Total minutes of vigorous activity per day	Primary care	27	83	100	60	0	150	0.23
	Secondary care	49	61	64	50	10	80	
	Physical and psychological rehabilitation	103	82	72	60	30	120	
	Community support staff	16	47	63	25	10	65	
	Other support staff	8	90	101	60	0	180	
Total minutes of moderate activity per day	Primary care	36	53	73	30	0	60	0.02
	Secondary care	51	72	92	30	0	120	
	Physical and psychological rehabilitation	106	104	109	60	30	120	
	Community support staff	16	62	63	35	30	85	
	Other support staff	8	45	70	0	0	90	
Total minutes of walking activity per day	Primary care	36	67	53	60	30	105	0.07
	Secondary care	51	121	130	70	40	150	
	Physical and psychological rehabilitation	106	138	169	90	30	180	
	Community support staff	16	77	104	30	20	105	
	Other support staff	8	150	108	160	40	240	
Total minutes spent sitting per day	Primary care	36	541	281	480	360	660	0.14
	Secondary care	51	368	254	300	240	480	
	Physical and psychological rehabilitation	106	450	340	360	210	540	
	Community support staff	16	452	312	360	255	510	
	Other support staff	8	405	254	300	240	600	
Total minutes of vigorous activity per week	Primary care	36	218	328	40	0	360	0.09
	Secondary care	51	129	153	60	0	180	
	Physical and psychological rehabilitation	106	240	251	180	40	360	
	Community support staff	16	163	286	40	15	150	
	Other support staff	8	135	153	90	0	270	
Total minutes of moderate activity per week	Primary care	36	151	240	60	0	225	0.01
	Secondary care	51	176	252	90	0	240	
	Physical and psychological rehabilitation	106	305	364	165	60	360	
	Community support staff	16	198	235	120	70	210	
	Other support staff	8	60	96	0	0	120	
Total minutes of walking activity per week	Primary care	36	308	277	225	80	420	0.03
	Secondary care	51	490	390	360	180	840	

Measures of physical activity	Health professionals' professional role domain	Number of respondents	Mean	SD	Median	IQR (25 <sup>th</sup> -75 <sup>th</sup> centiles)		P value*
	Physical and psychological rehabilitation	106	533	478	420	90	980	
	Community support staff	16	354	413	145	85	465	
	Other support staff	8	675	483	660	250	1120	
MET-minutes of vigorous activity per week	Primary care	36	1744	2621	320	0	2880	0.09
	Secondary care	51	1034	1227	480	0	1440	
	Physical and psychological rehabilitation	106	1918	2011	1440	320	2880	
	Community support staff	16	1305	2288	320	120	1200	
	Other support staff	8	1080	1224	720	0	2160	
MET-minutes of moderate activity per week	Primary care	36	606	959	240	0	900	0.01
	Secondary care	51	704	1007	360	0	960	
	Physical and psychological rehabilitation	106	1220	1456	660	240	1440	
	Community support staff	16	790	939	480	280	840	
	Other support staff	8	240	385	0	0	480	
MET-minutes of walking activity per week	Primary care	36	1018	915	743	264	1386	0.03
	Secondary care	51	1616	1287	1188	594	2772	
	Physical and psychological rehabilitation	106	1761	1578	1386	297	3234	
	Community support staff	16	1167	1364	479	281	1535	
	Other support staff	8	2228	1594	2178	825	3696	
Total MET-minutes activity per week	Primary care	36	3368	3430	1848	961	4140	0.03 (F(4,212) =2.72) HSD<2.7 2
	Secondary care	51	3354	2610	2772	1236	5130	
	Physical and psychological rehabilitation	106	4899	3802	3868	1704	7518	
	Community support staff	16	3262	3766	1680	991	4904	
	Other support staff	8	3548	1879	3732	2556	4473	

\*One way ANOVA with Tukey post-hoc statistics

**Duration in practice**

Table 5.12 presents the similar one-way ANOVA analysis of the relationship of minutes/MET-minutes of activities with health professionals' duration in practice. The only statistically significant relationship was between time spent sitting every day and the duration in practice [(F (4,212) =4.92, p<0.00). HSD: 1 vs 2= 0.409; 1 vs 3=5.17\*; 1 vs 4=1.72; 1 vs 5=0.27; 2 vs 3=4.76\*; 2 vs 4=1.31; 2 vs 5=0.68; 3 vs 4=3.45; 3 vs 5=5.44\*; 4 vs 5=1.99]. The results show that the practitioners with shorter duration in practice tend to spend less time sitting every day than the practitioners who have longer duration of practice. All the other domains did not have any significant relationship with any of the sub-groups in this category.

**Table 5.12:** Relationship of minutes/MET-minutes of activities with HCPs duration in practice

Measures of physical activity	Health professional s' duration in practice	Number of responden ts	Mean	SD	Median	IQR (25 <sup>th</sup> -75 <sup>th</sup> centiles)		P value*
Total minutes of vigorous activity per day	Up to five years	55	77	53	60	40	120	0.79
	5-10 years	67	77	85	40	20	120	
	10-15 years	29	80	70	60	30	120	
	15-20 years	38	69	82	60	0	120	
	Above 20 years	14	53	95	20	0	60	
Total minutes of moderate activity per day	Up to five years	61	79	85	50	30	120	0.17
	5-10 years	69	74	95	40	20	90	
	10-15 years	31	80	87	40	20	120	
	15-20 years	39	116	128	60	0	180	
	Above 20 years	17	58	76	40	0	60	
Total minutes of walking activity per day	Up to five years	61	125	139	60	30	150	0.62
	5-10 years	69	108	127	60	20	120	
	10-15 years	31	151	232	60	30	180	
	15-20 years	39	106	88	90	40	120	
	Above 20 years	17	103	97	60	40	120	
Total minutes spent sitting per day	Up to five years	61	385	211	360	240	480	(F(4,212) =4.92, p<0.00) HSD: 1 vs 3=5.17* 2 vs 3=4.76* 3 vs 5=5.44*
	5-10 years	69	406	283	300	240	480	
	10-15 years	31	650	406	480	300	1080	
	15-20 years	39	473	364	360	240	600	
	Above 20 years	17	371	226	360	240	420	
Total minutes of vigorous activity per week	Up to five years	61	222	213	180	60	300	0.94
	5-10 years	69	193	280	90	10	240	
	10-15 years	31	202	232	150	0	360	
	15-20 years	39	193	252	120	0	300	
	Above 20 years	17	173	290	40	0	180	
Total minutes of moderate	Up to five years	61	243	306	120	60	300	0.49

Measures of physical activity	Health professional s' duration in practice	Number of respondents	Mean	SD	Median	IQR (25 <sup>th</sup> -75 <sup>th</sup> centiles)		P value*
activity per week	5-10 years	69	197	289	90	0	180	
	10-15 years	31	220	267	100	10	360	
	15-20 years	39	305	389	180	0	420	
	Above 20 years	17	194	323	60	0	240	
Total minutes of walking activity per week	Up to five years	61	476	425	300	120	840	0.83
	5-10 years	69	433	440	240	90	720	
	10-15 years	31	525	481	420	80	1050	
	15-20 years	39	501	385	420	180	840	
	Above 20 years	17	531	474	300	180	840	
MET-minutes of vigorous activity per week	Up to five years	61	1773	1702	1440	480	2400	0.94
	5-10 years	69	1544	2236	720	80	1920	
	10-15 years	31	1613	1853	1200	0	2880	
	15-20 years	39	1541	2016	960	0	2400	
	Above 20 years	17	1384	2323	320	0	1440	
MET-minutes of moderate activity per week	Up to five years	61	972	1226	480	240	1200	0.49
	5-10 years	69	787	1154	360	0	720	
	10-15 years	31	879	1069	400	40	1440	
	15-20 years	39	1222	1556	720	0	1680	
	Above 20 years	17	776	1294	240	0	960	
MET-minutes of walking activity per week	Up to five years	61	1571	1402	990	396	2772	0.83
	5-10 years	69	1428	1451	792	297	2376	
	10-15 years	31	1731	1588	1386	264	3465	
	15-20 years	39	1652	1269	1386	594	2772	
	Above 20 years	17	1751	1565	990	594	2772	
Total MET-minutes activity per week	Up to five years	61	4316	3430	3525	1593	6594	0.86
	5-10 years	69	3759	3797	2460	1104	4758	
	10-15 years	31	4223	3054	4038	1386	6666	
	15-20 years	39	4414	3394	3119	1638	6558	
	Above 20 years	17	3911	3684	2580	1293	5598	

\*One way ANOVA with Tukey post-hoc statistics (only significant relationships shown)

Finally, the table 5.13 presents the minutes of activity converted into a categorical variable where the health professionals have been categorised into having a 'high' 'moderate' or 'low' activity per week based on the MET-minutes of energy expenditure per week. Wilcoxon-Mann Whitney test did not reveal any significant differences ( $p=0.52$ ) between males and females. Similarly, the Kruskal Wallis test did not show any significant differences ( $p = 0.46$ ) in the duration in practice group. But there was a significant difference ( $p = 0.01$ ) among the sub-groups of professional role domain category and the rehabilitation teams (physiotherapists/occupational therapists) appeared to be the most active sub-group.

**Table 5.13:** Self-reported physical activity levels of health professionals, categorised into High, Moderate and Low according to weekly energy expenditure as MET-minutes per week

Respondent categories	Respondent sub-categories	High	Moderate	Low	P value
Gender	Male	19	12	6	0.52*
	Female	99	57	21	
Experience in practice	Up to five years	39	17	5	0.46**
	5-10	33	27	9	
	10-15	19	7	5	
	15-20	21	11	7	
	Above 20	9	7	1	
Professional category	Primary care	13	16	7	0.01**
	Secondary care	23	23	5	
	Physical and psychological rehabilitation	73	20	13	
	Community support	7	8	1	
	Other support staff	5	2	1	
	Total	121 (55.8)	69 (31.8)	27 (12.4)	

\*Wilcoxon-Mann Whitney test

\*\* Kruskal Wallis test

#### 5.4.6 Integrating quantitative and qualitative findings of the survey

##### *Qualitative findings*

32 out of 217 respondents also inserted comments in the free text box that was provided for respondents to record any of their thoughts that might not have been addressed by the questions in the set response format. These provided interesting qualitative explanations to some of the quantitative survey findings. These were grouped into common themes to corroborate with the findings of the survey itself (Appendix O).

Most comments related to the fact that professionals in general support the idea of promoting physical activity as well as being active themselves, but various pressures on their time, such as meeting targets within specified time, competing family and other commitments and nature of job, all affect this behaviour leading to reduced levels of physical activity on their part:

*“I’m a GP - single handed and a single parent of 2 teenagers. I have no time nor energy to exercise” (General Practitioner, female, 14 years of experience).*

Physical activity promotion was strongly associated with practitioners own physical activity levels which if low might translate into not promoting it to their patients as a consequence:

*“I do think there may be a correlation between attitude to exercise of practitioner and enthusiasm in promoting exercise for others. Think we all need to exercise more and not just our patients!” (Liaison psychiatry team, female, 11 years of experience).*

The large majority were not aware of the physical activity promotional and referral campaigns in their areas of practice, but a few barriers to the utilisation of such services were expressed by those who were even aware of such services.

*“In my role the majority of people I come across would potentially benefit from exercise. Unfortunately I am rarely in possession of enough information to fill in the referral form to the NERS. I do however, always guide them towards asking their GP or CNS to do it for them” (psychological therapist / psychiatric nurse, female, 14 years of experience).*

## **5.5 Discussion**

### **5.5.1 Summary of the findings**

The health professionals demonstrated the belief that physical activity is beneficial to cancer survivors, and an equally strong belief that they have a specific role in promoting physical activity to cancer survivors. Contrary to this belief, whether or not they actually advised cancer survivors to undertake physical activity was not clear as there appeared to be an ambivalence in their responses when it came to actually advising their patients. Regardless of the enthusiasm for the beneficial effects of physical activity for cancer survivors, the opinions, represented by 33 types of professional roles, were diverse and divided when it came to advising patients about physical activity. The reason for this was not immediately discernible from the data.

The majority of professionals indicated that they lacked the appropriate knowledge, and hence, confidence in advising about the timing, type or amount of physical activity tailored to meet patients’ needs. Some of them did mention, in their free text accounts, that they utilised the brief advice techniques which were followed by referral or sign-posting to other specialised personnel who could then advise patients according to their needs and could tailor the programme (Din, Moore et al. 2015). This approach has been reported earlier as well where a high level of success was reported in incorporating brief advice into routine consultation without major disruptions (Albright, Cohen et al. 2000). NICE recent guidelines

also stress the use of brief physical activity advice in routine primary care consultations (NICE 2014).

Similarly one third of the respondents did not know that North Wales had two active schemes where they could refer their patients: the National Exercise Referral Scheme (NERS) and the Macmillan North Wales Physical Activity Project. These schemes provide specific support to cancer patients and survivors for their physical activity needs. Various factors could explain such discrepancies in the level of awareness among health professionals and the acclaimed impact reported for these schemes in published sources (Murphy, Edwards et al. 2012). It is not surprising given the fact that many of the 33 disciplines of health professionals who responded to this survey might not be directly associated with these two schemes, or their functionalities. Alternatively, it is possible that schemes are not known by their specific names as much as by their clinical and non-clinical functioning related to the patients.

### **Relevance to the theoretical constructs of the Social Cognitive Theory**

The survey was planned to determine the views of healthcare professionals about their role in physical activity promotional intervention. The results confirmed that they were aware of the beneficial effects of physical activity. They were also happy to refer or sign-post their cancer patients to the local physical activity promotional campaigns if a few barriers to this action could be addressed. Such action on their part might then provide a suitable environment for the cancer survivors to increase their physical activity levels, gain confidence and improve their self-efficacy (Chapter 4, section 4.6).

These findings can also be related to earlier phases of this project namely: complementing the theoretical underpinning for the development of physical activity behaviour change intervention for cancer survivors (chapter 6); and endorsement of cancer survivors' experiences about the role of health professionals in physical activity promotion (Chapter 4, section 4.5.2, Theme 3). The findings also highlight that health professionals are willing to act as facilitators to promote physical activity within their capacity if their concerns about the knowledge and skills enhancement could be addressed.

#### **5.5.2 Comparison with literature**

It has been argued that the cancer care providers can play a crucial role in improving the long-term health of cancer survivors by: being cognisant of opportunities to encourage health behaviours such as increased physical activity, exploring possibilities for any interventions that the patients can be amenable to, staying up-to-date with current physical activity guidelines and recommendations for cancer survivors as well as existing resources for professional and patient education, and participating in prevention research (Demark-Wahnefried, Pinto et al. 2006). Our results support this and other reports from earlier studies

which found that enthusiasm for giving physical activity advice was generally high among the primary care staff, but low levels of knowledge about current physical activity recommendations also exist (Douglas, Torrance et al. 2006). This is the case for both the general but specifically for cancer patients, leading to low confidence in recommending or advising physical activity to patients (Din, Moore et al. 2015). In the section where respondents described their own activity levels, data was captured for vigorous and moderate physical activity of a minimum 10 minutes duration. The results showed that the actual duration of vigorous and moderate physical activity extended over more than six hours per week for those who described taking vigorous activity, and over more than eight hours per week for some who described taking moderate activity. Speck *et al.* defined vigorous physical activity as exercising for more than or equal to three hours per week and their primary care study reported that those who were exercising actually had ambiguity as to what constitutes vigorous or moderate physical activity or exercise (Speck, Courneya et al. 2010). This uncertainty can potentially translate into either not advising or advising ambiguously to their patients about the amount their patients need to do to get meaningful benefit. Our study extends this finding to other health professionals in secondary and rehabilitation care of cancer survivors specifically.

Another finding reported that system barriers (such as time constraints) were not an issue in routinely advising about physical activity (Douglas, Torrance et al. 2006). This is contrary to what was evident in this study where this issue was still reported by a significant proportion of respondents and is consistent with other reports highlighting similar challenges of addressing personal, system and organisational barriers (Hebert, Caughy et al. 2012; Din, Moore et al. 2014; Din, Moore et al. 2015). The GPs specifically highlighted time constraints in addressing patients' primary complaints, albeit advising about physical activity, when it seems that physical activity advice is not a priority. This finding is also consistent with a recent qualitative component of a process evaluation (Din, Moore et al. 2015) of a randomised trial of National Exercise Referral Scheme in Wales (Murphy, Edwards et al. 2012). Otherwise, majority are receptive to the idea of physical activity promotion during their normal clinical duties, as has been reported earlier (Hebert, Caughy et al. 2012).

Physical activity levels of health professionals remain a significant barrier to routinely advising patients about exercise (Lobelo, Duperly et al. 2009; Din, Moore et al. 2014; Din, Moore et al. 2015) and this was also evident in the findings of this study. Although the physical activity levels of the health professionals in this study in general did meet or exceeded the latest recommendations, many of the respondents were not physically active to these recommended levels of physical activity required to stay healthy (Department of Health 2011), and the figures were similar to those of the general population of Wales, where only 37% of men and 24% of women are active enough to benefit their health (WG 2014). Secondly, despite the higher levels of the reported physical activity levels, the respondents



were actually spending more time sitting per day which was even greater than the UK's average for both men and women. This reaffirms the importance of North Wales Physical Activity Project which aims to improve the health, fitness and quality of life for cancer patients, as well as to educate clinical teams to facilitate a change in their behaviours, not only related to their actions within their job role, but also within their own lives by improving their own physical activity levels to benefit their health. This might help the Health Board by having a healthy workforce that works to promote healthy living and exercise to patients and the general public. Some of the respondents who commented in the free text box frankly expressed this stating different reasons for not being active and hence this then translated to not advising their patients about physical activity.

### **5.5.3 Strengths and limitations**

This is the first web-based healthcare professional survey encompassing both primary and secondary care as well as allied health disciplines to find out their knowledge, attitude and current practice related to advising cancer patients about physical activity during routine consultations. When conducting postal surveys, it is often possible to obtain a complete list of eligible health professionals in a given specialty or geographical location from which to sample. Internet technology to conduct surveys offers various advantages. In the UK, the establishment of an NHS e-mail and directory service for NHS staff raises the possibility of creating an 'e-phonebook' of electronic addresses of NHS health professionals from which researchers could recruit more representative samples for internet-based survey research. However, the technical and methodological challenges such as external validity, selection (invitation) and response biases of using this method should not be overlooked. General access to this information raises the spectre of electronic overload, which might well be of far greater magnitude than in postal surveys, with a resultant effect on response rates. We acknowledge the fact that the study sample might not be representative, hence akin to the risk of lacking external validity, in relation to both the original sample and a response bias. We tried to address this by sending reminders to non-responders to give opportunity to as many health professionals on our list as possible to participate in the study (Braithwaite, Emery et al. 2003). This resulted in a response rate almost similar to other internet (Braithwaite, Emery et al. 2003) and postal surveys (Mcavoy and Kaner 1996). The response rate to the survey was 43.8 per cent (217 responses out of 496 email requests) which is within reasonable limits of acceptability as reported closer to 50% in earlier similar surveys in similar populations (Braithwaite, Emery et al. 2003; Douglas, Torrance et al. 2006) though there is a great variability in response rates in different studies ranging from 4-96%. This was also closer to the estimated number that was calculated at the start of the study and the invitations sent accordingly.

During the piloting phase of the questionnaire content and design, Some key technical and methodological issues raised by internet-based survey research were tried to address, such as appropriate formatting to simplify data entry and clarification of possible responses wherever thought appropriate (Braithwaite, Emery et al. 2003). The complexity of visual design was considered to both facilitate and accommodate differences in respondents' computer hardware and software, different screen sizes they might use and the speed of loading in the web-browsers, and to avoid the possibility of data being submitted before the survey completion (Couper, Conrad et al. 2007). One limitation of this survey design was that there was no option to either print out or reply in the form of a hard copy or a postal survey for the non-responders (Braithwaite, Emery et al. 2003). This option might have increased the response rate but at the same time would have added to the complexity, cost and time required to complete the survey, and capture and analyse the data.

The respondent population in this survey was largely female which is interesting as earlier studies reported the opposite and males tended to have greater intention to use internet based tools (Braithwaite, Emery et al. 2003). Female doctors have been reported to be significantly underrepresented in earlier large scale UK-based web-based survey research (Potts and Wyatt 2002). It was not evident from this survey if this was a chance finding. The reasons could be manifold such as: gender differences in the number of workforce personnel at the time the survey was conducted as there are generally more females in the nursing and rehabilitation professions (physiotherapists, occupational therapists etc.); females might have been more keen to participate in the research; a demographic shift in the pattern of utilisation of internet based support tools; or incidentally more invitations being sent to females in the health care workforce. The email lists were anonymised and did not give any indication of the gender of the health care professionals being invited to participate in the survey and the information only came to light when the respondents completed the questionnaires.

It is important to acknowledge the issue related to the inherent weaknesses of using the Likert style scales. Such designs are subject to distortion because of several reasons such as: avoidance of using extreme response categories leading to central tendency bias; agreeing with the presented statements leading to acquiescence bias; and attempts on behalf of respondents to portray themselves or their organisation in a more positive light leading to social desirability bias (McLeod 2008).

#### **5.5.4 Future research and policy implications**

Health care professionals can play a pivotal role in physical activity promotion for cancer survivors. Their encouragement during regular consultation may influence their patients to adopt and maintain healthy lifestyle activities and could be achieved by repeatedly reminding them to stay physically active. This has been reflected in the National Institute for

Care Excellence guidelines (2006 & 2014) to include the potential use of health professionals to promote physical activity and the introduction of brief interventions in physical activity (NICE 2006; NICE 2014). Brief interventions involving opportunistic advice, discussion, and encouragement can commonly be used in many areas of health promotion, and can be delivered by a range of primary and community care professionals (NICE 2014).<sup>3</sup>

## 5.6 Conclusions

Health professionals were generally supportive of the idea of promoting physical activity and offering available specialist referral services to their patients but expressed a lack of knowledge, skill and confidence in doing so. There was also a lack of awareness about the availability of various organisational initiatives to support cancer survivors to take up and increase their physical activity.

In summary, the findings of this survey helped to finalise a component of the physical activity promotional intervention being developed in this project (Chapter 6, section 6.2.5, page 177). The aim was to discern health professionals' willingness to engage in physical activity promotion to cancer survivors and the issues surrounding such role. The contributory findings of this survey included that healthcare professionals were: willing to refer and direct their patients to NERS and other physical activity campaigns; keen to administer Macmillan's Move More Pack at the end of the active treatment of their patients; and enthusiastic to be part of physical activity promotional campaigns in general if supported well in their role. The survey highlighted that despite such enthusiasm, they were not utilising such available resources to their full potential, likely because of being unaware of such opportunities.

Training in physical activity advice-giving as part of their continuing professional development might be one way to accomplish the objective of incorporating physical activity promotion into routine follow up consultations, along with addressing the personal, organisational and system barriers such as skills enhancement, time management, guidance on identifying opportunities to offer advice or referral, hence helping them to avoid dependence upon subjective judgements of patient motivation (Albright, Cohen et al. 2000; Glasgow, Eakin et al. 2001; Douglas, Torrance et al. 2006; Din, Moore et al. 2014; Din, Moore et al. 2015).

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<sup>3</sup> This research was funded as a Postgraduate Research Scholarship from Cardiff University, but the organisation had no involvement in the study design, data collection and analysis, or thesis writing. This study was a collaborative work among the author, BCUHB, and Macmillan North Wales Physical Activity Project team. Special thanks to Joanne Garzoni (JG) of the Macmillan team and BCUHB for her help in the development of this study, emailing the questionnaire link from her official NHS working address to the prospective participants, and helping in analysing the data.

## **Chapter 6. Development of a behaviour change intervention**

### **Aim:**

To develop a behaviour change intervention to promote physical activity for adult cancer survivors using the MRC framework for development of complex interventions

### **Main findings:**

MRC framework for development of complex interventions:

- 1) Synthesising the evidence (Systematic review)
- 2) Identifying the appropriate theory (Social Cognitive Theory)
- 3) Modelling process (Researchers and PPI involvement) during the developmental process of the intervention

## 6.0 Chapter summary

This chapter describes the development of a behaviour modification and maintenance intervention targeting cancer survivors at the end of their active treatment.

Based on the theoretical framework developed in Chapter 3, twelve physical activity promotional messages (intended to be weekly text messages as part of a comprehensive promotional package) were developed from the Macmillan MoveMore pack. These were refined through patient and public involvement (PPI) by means of cancer survivor focus groups (Chapter 4) and cancer patient forum discussions (Chapter 6). The reporting of the whole process conformed to the revised Criteria for Reporting the Development and Evaluation of Complex Interventions (CReDECI 2).

### 6.1 Introduction

This chapter will describe the development and refinement process of a physical activity promotional intervention using weekly text messages as a reinforcement mechanism. The intervention aims to motivate cancer survivors to exercise by: providing them more information about the beneficial effects of physical activity, encouraging them to set realistic goals and working towards them, providing them with regular 'nudges' as a reinforcement mechanism to maintain physically active behaviour.

### 6.2 MRC framework for development of complex interventions

Complex interventions are widely used in research areas that have important health consequences including health services research, public health practice, and social policy. The research methods associated with complex interventions have evolved greatly in recent years, with the majority of the interventions comprising of more than one component, acting either independently or inter-dependently (Craig, Dieppe et al. 2008). Such interventions have several interacting components, and present certain evaluation, practical and methodological challenges, including the difficulty of standardising their design and delivery.

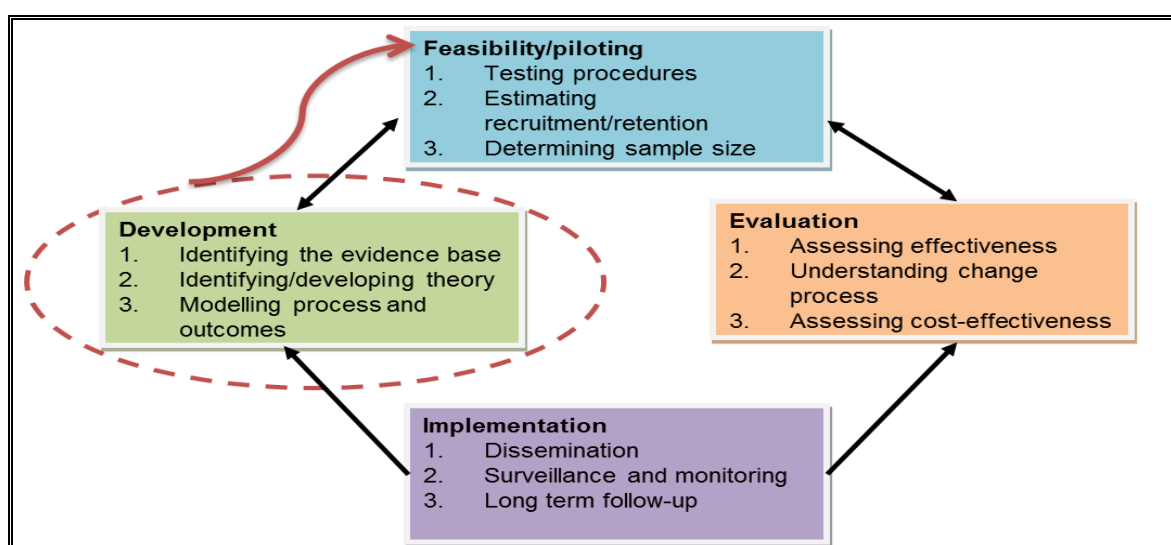
The quality of reporting the findings of an intervention along with the process adopted is important in clinical and non-clinical trials for transparency and trustworthiness (Begg, Cho et al. 1996). In 2006, the EQUATOR network (Enhancing the QUALity and Transparency Of health Research) was established to promote transparent and accurate reporting of research studies by providing 200 different guidelines for the reporting of various study types (The EQUATOR Network 2015). Similarly, the British Medical Research Council (MRC) published a framework for reporting in 2000, which came to be known as the MRC framework. Its scope was broadened subsequently in 2008 (Craig, Dieppe et al. 2008) to contain guidelines for the development, feasibility and piloting, evaluation, and long-term implementation of

complex interventions. These guidelines have been widely applied in healthcare sciences to develop behaviour change interventions (Anderson 2008; Craig, Dieppe et al. 2008).

Figure 6.1 presents the procedural phases and their interactions in the MRC's framework for complex intervention development. The intervention development phase of this framework was completed as the primary aim in this project, and comprises of three steps presented below:

1. Synthesising / identifying the evidence base
2. Identifying / developing appropriate theory
3. The modelling process and outcomes

**Figure 6.1:** Key elements of the development and evaluation process of MRC framework



Source: MRC framework - Craig, 2008

The following sub-sections will describe the application of these three steps in the development of the physical activity behaviour change intervention for adult cancer survivors as an outcome of this research project.

### 6.2.1 Synthesising/ identifying the evidence base

Findings of the systematic review (Chapter 2) highlighted the importance of reinforcement in the maintenance of physical activity behaviour change in adult cancer survivors.

### 6.2.2 Identifying/ developing an appropriate theory

Literature was reviewed to explore leading theories and models of behaviour change for their relevance to underpin the intervention development for this research project. This process resulted in the development of a theoretical framework based on all the theoretical constructs of Social Cognitive Theory (Chapter 3).

### 6.2.3 Modelling process of the intervention

Physical activity promotion for adult cancer survivors utilises different approaches including policy and environmental, informational such as campaigns, as well as social and behavioural (chapter 1, section 1.6). Patrick et al. showed that physical activity behaviour modification is likely to be successfully maintained over time if counselling and advice are integrated into existing healthcare initiatives (Patrick, Pratt et al. 2009). The evidence generated by Pavey and colleagues also indicates that coordinating clinical and community resources could be a better way for effective physical activity promotion (Pavey, Taylor et al. 2011). Van Sluijs et al. provided evidence that physical activity advice followed by telephone support can help to sustain long-term improvements in physical activity in chronic diseases (van Sluijs, van Poppel et al. 2005). Our systematic review (chapter 2) provided similar findings for the cancer population that physical activity advice with reinforcement can lead to a significant increase in levels of physical activity.

These literature findings guided this project in the development of a reinforcement component of a behaviour change physical activity promotional intervention that can be embedded in the already up and running physical activity promotional campaigns and initiatives in various healthcare settings. Such initiatives include the National Exercise Referral Scheme where patients can be referred during their cancer journey; and Macmillan's MoveMore pack which is aimed to be provided to all cancer patients at their diagnosis. The component developed in this research project consisted of reminders that can act as a nudge for cancer survivors to keep them active as much as possible and is proposed to be part of a comprehensive package of physical activity promotional intervention consisting of referral to the National Exercise Referral Scheme, provision of Macmillan's MoveMore pack and psychological theory based reminders or nudges to motivate the patients stay active.

Different reinforcement mechanisms were explored to complement the motivational objectives of the physical activity booklet within the Macmillan MoveMore pack as discussed earlier in Chapter 1, section 1.8 to develop a physical activity behaviour change intervention for cancer survivors. These are explained briefly below with regards to their implications for cost, resource and skills required for intervention delivery:

*Telephone reminders:* Evidence showed the effectiveness of telephone counselling as a reinforcement mechanism while promoting physical activity in cancer survivors (Chapter 2), and so this was the first consideration in this research project. Different aspects were explored while planning with regards to the skills required to deliver this intervention and the following were identified:

- A person skilled in behaviour change intervention delivery for patient motivation

- A person with good clinical skills to give advice about the issues related to physical activity for specific cancer types
- A cancer-specific exercise professional

Based on these, it was envisaged that this would neither be a low-maintenance nor a low-cost intervention to promote physical activity.

*Text messages:* The second option, which was considered and then accepted for this project, was the sending of regular motivational, reinforcement text messages (Joseph 2015). Recently, widespread use of technology-based platforms in the healthcare sector such as eHealth/ mHealth (electronic or mobile phone based) have created opportunities to address the current challenges of chronic disease management especially cancer. A few examples of such strategies currently being trialled or rolled out are in earlier cancer diagnosis (Kassianos 2015), diet, weight and physical inactivity management (Joseph 2015; Spark 2015; Wolvers 2015), and safer and acceptable cancer follow up (Dickinson, Hall et al. 2014). These platforms are designed to care and cure using different modes that include internet, social media, mobile phones, and text messages.

The delivery of this intervention would be automated by the CNS at the end of active cancer treatment, with messages sent at regular intervals to the specific contact and can be read at the person's convenience. However, one downside of this option is that it would not be available for people who are either unable, or uncomfortable with technology, or prefer not to use a mobile phone. Intervention acceptance could be measured in a feasibility trial and is proposed for future research as an outcome of this project (Chapter 7, section 7.6.1).

The recent concept of mHealth, as discussed above whereby mobile phone technology is being used as a medium to deliver various interventions for chronic disease management, has given rise to the development of 'text message based intervention' (Joseph 2015). This can be used as a strategy to promote and reinforce physically active behaviour in adult cancer survivors. The following sections will explain the developmental process of this proposed intervention.

### **Design and development of the messages**

#### ***Source of prospective messages***

As mentioned in Chapter 1, section 1.8, Macmillan Cancer Trust in the UK developed a physical activity promotional pack which included a physical activity booklet, goal setting diary and a pack of seeds to encourage gardening for cancer patients. This promotional pack is generic without any specification about the stage within the journey of a cancer patient. This means it can be used at any stage from the time of the cancer diagnosis until the end of the treatment or anytime later during follow-up care. This study used the physical activity



booklet within the Macmillan pack to extract the prospective physical activity promotional messages. The objectives of this process are listed below:

- To encourage people to start thinking about getting (more) active while considering making small changes to their lifestyle
- To tell them about the general health benefits of exercising and to encourage them to make a start, however small
- To explain the specific benefits of physical activity on mental health and wellbeing, and to encourage exercising as a social activity
- To encourage an increase in levels of physical activity and to persuade the maintenance of an active lifestyle in the future

### ***Selection criteria for the messages***

A draft list of physical activity promotional messages was developed focusing on the component mediators of physical activity behaviour change that were appropriate for adult survivors of cancer. The main focus was to consider the perceived benefits of physical activity for cancer survivors. The component mediators considered as the selection criteria for the messages included self-efficacy, beneficial effects of physical activity, identification and consideration of the facilitators of exercise and recognition of different ways to overcome the barriers to exercise. The selected messages were then arranged in a matrix according to the strategic objectives explained earlier.

Messages containing similar concepts were merged next after reviewing. The first consultation was with a senior researcher (MH), with following consultations with two other researchers (DP, BF) within the North Wales Centre for Primary Care Research (NWPCPR) team. Irrelevant, inappropriate or unclear messages were then either modified or rejected, and wording of the remaining messages was reviewed for clarity. The final list of 12 messages was arranged based on the aims of each week as given in the list below:

1. To persuade people to think about starting to be more active
2. To encourage them by saying, it's never too late to start being active
3. To get people to think about the type of exercise/activity they could do
4. To tell them about a health benefit of exercising
5. To persuade them that there is something they could do to be more active
6. To encourage them to make a start, however small
7. To explain the general health benefits of exercise
8. To explain the benefits of activity on mental health and wellbeing

9. To encourage exercise as a social activity
10. To emphasise the physical benefits of exercise
11. To encourage them to increase levels of activity
12. To persuade them to maintain exercise in the future and to wish them good luck

### ***Theoretical underpinning of the extracted messages***

Current emphasis has been to apply theory in the development of behavioural modification interventions to emphasise the effects of the theoretical constructs on the interventions, aimed at making them more effective (Pinto, Rabin et al. 2008). The theoretical constructs of the Social Cognitive Theory were considered to target adoption and maintenance of positive physical activity behaviour, to conceptualise the theoretical basis and the likely mechanism of action of the components of this intervention.

The selected messages based on the aims of 12 weeks were redefined, underpinned by theoretical constructs of the Social Cognitive Theory. In brief, the constructs included self-efficacy, outcome expectations and values, environment, self-control, behaviour capability, observational learning, reinforcements, emotional coping responses and the impediments.

### **Patient and Public Involvement**

Patient and public involvement (PPI) denotes research completed with or by patients and the public, rather than to, for or about them, thereby referring to an active partnership between researchers and patients and or the public during the research process. This confers patients and the public the ability to have a decision-making impact on one or more stages of the research process (Potts and Wyatt 2002). Public involvement is considered an indispensable part of the development of modern health and social care services. The idea is that the research that reflects the needs and views of the public is more likely to produce results amenable to improve health and social care.

Generally, three levels of public involvement have been recognised: consultation (where researchers seek the views of patients and the public on key aspects of the research); collaboration (an on-going partnership between researchers and patients and the public throughout the research process); and publicly-led research (where patients and the public design and undertake the research; where researchers are only invited to participate at the invitation of patients and the public). The level of patient/ public involvement is usually decided based on the objectives of the research study (Potts and Wyatt 2002).

### ***Refinement of the messages through patient and public involvement exercises***

The physical activity promotional messages were developed by the author of this thesis as part of PhD project's intervention development phase with substantial Patient and Public Involvement. This was an iterative process which involved four refinement exercises.

These are briefly described in the following passages with details of the venues and the stakeholders involved.

First refinement was undertaken by lay researchers recruited through regular monthly meeting of North Wales Cancer Patient Forum (NWCPF). The study overview was presented to 15 members who were present at one of their meetings to recruit the interested lay researchers. Four cancer survivors of head and neck, breast, prostate, and lung cancer agreed to participate. The initial draft of the 12 weekly physical activity motivational messages was sent in the post with pre-stamped envelopes for the responses to be sent back to the author at the North Wales Centre for Primary Care Research (NWCP CR), Bangor University. The participants were invited to comment on the content, language and understandability of the statements pertaining to each message. Suggestions were reviewed, discussed and then modifications were made in agreement with all those involved, taking care not to drastically change the meaning or scope of the messages regarding the underlying theoretical concepts that these messages were based on.

Once the lay researchers had agreed on the final iterations, and their comments were addressed, the refined draft of these physical activity motivational messages was piloted in-house. This second exercise involved team members at North Wales Centre for Primary Care Research (NWCP CR), Bangor University, which included professionals from different health care and academic disciplines such as GPs, nurses, therapists, and health care researchers. The same criteria of refinement was applied as explained above, suggestion or comments were addressed and the draft was revised. Six out of twelve messages were accepted without modification, whereas six were rephrased which are highlighted in table 6.1.

The third exercise for refinement involved cancer patients (end users/ consumers) which formulates an important step in intervention development phase of the MRC framework (Craig, Dieppe et al. 2008). This was undertaken in focus groups with cancer survivors who participated in the qualitative study of this project (Chapter 4). This included 21 cancer patients who had finished their active cancer treatment within last six months for different types of cancers (Chapter 4, section 4.3.1). The draft messages were presented to the groups and their opinions were invited regarding the need to reword/ rephrase the messages into lay language to facilitate understandability. They commented on the edited draft helping to refine and translate the messages into patient friendly language. Four out of twelve messages were accepted without modification, whereas eight were reworded to improve understanding without losing technical meaning or underpinning theoretical notions.

The fourth and final refinement of these interventional messages was performed by involving another mixed group of cancer survivors and/or their carers as well as health professionals attending Cancer Patient Forum meeting in North Wales. Eleven members who

were present on that day were invited verbally by the author after a formal presentation of the research project explaining aims and objectives. The process of refining these messages prompted the group to read and reflect. The probes were based on aims of each week systematically till last message on the 12th week. Group was requested to reflect on the messages keeping in view the underlying aims to capture their motivational effects.

A pre-defined form (Appendix P) was used to gather anonymised data in two sections: one asked about their gender, age, and role in that day's meeting; second was for the cancer survivors only about their cancer type, and information about their cancer journey. Pre-post envelopes were provided with forms to send their responses to this author if someone wanted to have additional time and wished to complete the form after the meeting. Majority of the participants agreed with the content and language of most of the messages. However, minor amendments were incorporated for three messages after feedback. The developmental process of these messages is presented in Table 6.1 with the highlighted areas depicting changes that were incorporated in each successive stage that involved researchers as well as patient and public.

**Table 6.1:** Example of the refinement process of the physical activity promotional intervention

	<b>Aims of each week</b>	<b>Initial draft with an input by lay researchers at NWCPF</b>	<b>Refined messages by NWCPDR</b>	<b>Refined message by cancer patient in focus groups</b>	<b>Further refinement by NWCPF</b>
1	To get people to think about starting to be more active	Being more active will help you get over your cancer treatment. Think about what sort of exercise you can do.	Being more active e.g. walking, gardening, etc. will help you get over your cancer treatment. Think about what sort of exercise you can do.	Group agreed	Group agreed
2	What stops you starting? It's never too late to start being active!	If you feel tired, physical activity can give you more energy. Set a goal to start this week with small steps.	Group agreed	Group agreed	Group agreed
3	To get people to think about the type of exercise/activity they could do	Plan what exercise you would like to do this week to fit in with your plans.	Group agreed	Think about what exercise you would like to do this week to fit in with your plans.	Group agreed
4	To tell them about a health benefit of exercising	Being physically active during the day helps you get a better night's sleep.	Being physically active during the day helps you feel better and get a better night's sleep.	Being physically active during the day helps you feel better.	Being physically active during the day helps you feel better and get a better night's sleep.
5	To persuade them that there is something they could do to be more active	Hard work, gardening or dancing are just as good as walking, cycling or swimming.	Energetic hard work, gardening or dancing are just as good as walking, cycling or swimming.	Breathing exercising, gardening or dancing are just as good as walking, cycling or swimming.	House chores, gardening or dancing are just as good as walking, cycling or swimming.
6	Encourage them to make a start, however small	Exercise will keep your heart healthy and help you to maintain a healthy weight. Keep it up!	Exercise and a balanced diet will keep your heart healthy and help you to maintain a healthy weight. Keep it up!	Group agreed	Group agreed
7	To explain the general health benefits of exercise	Even a small increase in daily exercise can help you recovery. Have you started yet? Great!	Group agreed	Even a small increase in daily physical activity can help your recovery. Have you started yet? Great!	Group agreed
8	To explain the benefits of activity on mental health and wellbeing	Keeping active may help to lift your mood. Carry on!	Keeping active may help to reduce stress and lift your	Keeping active may help to reduce tension and stress and lift your mood. Carry	Group agreed

	<b>Aims of each week</b>	<b>Initial draft with an input by lay researchers at NWCPF</b>	<b>Refined messages by NWCPDR</b>	<b>Refined message by cancer patient in focus groups</b>	<b>Further refinement by NWCPF</b>
			mood. Carry on!	on!	
9	To encourage exercise as a social activity	Exercise with a friend can be more fun and you can encourage each other. Keep going!	Group agreed	Being physically active with a friend/family can be more fun and you can encourage each other. Keep going!	Group agreed
10	To emphasise the physical benefits of exercise	Physical activity will make you stronger and help to look after your bones and joints.	Regular exercise will makes your muscle stronger and helps to look after your bones and joints.	Physical activity will make you feel fitter and help to look after your bones and joints.	Group agreed
11	To encourage them to increase levels of activity	Aim to get back to normal day to day activities and gradually increase daily exercise.	Group agreed	Aim to get back to normal day to day activities and gradually increase daily activities.	Aim to get back to normal day to day activities and gradually increase your level of physical activity.
12	To persuade them maintain exercise in the future and wish good luck	Remember staying active could help to keep you well. This is the last message, good luck for the future.	Group agreed	Group agreed	Group agreed

### 6.2.4 Outcome

Twelve weekly physical activity promotional text messages for adult cancer survivors were the end product of the whole exercise which are listed below:

- 1) Being more active e.g. walking, gardening, etc. will help you get over your cancer treatment. Think about what sort of exercise you can do.
- 2) If you feel tired, physical activity can give you more energy. Set a goal to start this week with small steps.
- 3) Think about what exercise you would like to do this week to fit in with your plans.
- 4) Being physically active during the day helps you feel better and get a better night's sleep.
- 5) House chores, gardening or dancing are just as good as walking, cycling or swimming.
- 6) Exercise and a balanced diet will keep your heart healthy and help you to maintain a healthy weight. Keep it up!
- 7) Even a small increase in daily physical activity can help your recovery. Have you started yet? Great!
- 8) Keeping active may help to reduce tension and stress and lift your mood. Carry on!
- 9) Being physically active with a friend/family can be more fun and you can encourage each other. Keep going!
- 10) Physical activity will make you feel fitter and help to look after your bones and joints.
- 11) Aim to get back to normal day to day activities and gradually increase your level of physical activity.
- 12) Remember staying active could help to keep you well. This is the last message, good luck for the future.

### 6.2.5 Criteria for Reporting the Development & Evaluation of Complex Interventions

Rothman (2000) described that the process of behaviour change entails both initiating and maintaining change (Rothman 2000). The developmental process (sections 6.2.2 to 6.2.4) of this intervention focused on the adherence and the maintenance aspects of physical activity promotion in cancer survivors by reinforcing them through regular reminders as text messages. The interacting components of the finalised intervention include current practice within local healthcare settings including the referral of cancer survivors to the National

Exercise Referral Scheme (NERS) and the Macmillan MoveMore pack to promote physical activity.

In recent literature, concern about lack of a standard reporting system has been highlighted. Lack of sufficient detail when reporting the interventions potentially limit the replication of the research findings into clinical practice. For example, Michie et al. (2009) reported that only 5 to 30 per cent of the reports have sufficient details for others to follow and replicate them. Similarly, these discrepancies lead to difficulties in the teaching, training and performance assessment of new practitioners, and transformation or reorganisation of healthcare processes (Michie, Fixsen et al. 2009). The relationship between the intervention and its outcome also suffer from the same issue with lack in procedural details being variously reported (Mitchell 1998; Rychetnik, Frommer et al. 2002).

Specific guidelines to report complex interventions were identified as missing as recently till 2012. Hence, CReDECI was developed between 2012 and 2015 (Möhler, Bartoszek et al. 2012; Möhler, Köpke et al. 2015). The reporting criteria according to the CReDECI-2 is 13 item list which has been used in this project to report the developmental stage of this intervention within the MRC framework (Table 6.2).



**Table 6.2:** CReDECI 2 checklist, 2015

Item	Reported on page
<b>First stage – Development</b>	
1	Description of the intervention’s underlying theoretical basis
2	Description of all intervention components, including the reasons for their selection as well as their aims / essential functions
3	Illustration of any intended interactions between different components
4	Description and consideration of the context’s characteristics in intervention modelling
<b>Second stage – Feasibility and piloting</b>	
5	<u>Description</u> of the pilot test and its <u>impact</u> on the definite intervention
<b>Description:</b> Chapter 7, section 7.6.1 <b>Impact:</b> To be tested	
<b>Third stage – Introduction of the intervention and evaluation</b>	
6	Description of the control condition (comparator) and reasons for the selection
7	Description of the strategy for delivering the intervention within the study context
8	Description of all materials or tools used delivery the intervention
9	Description of fidelity of the delivery process compared with the study protocol
10	Description of a process evaluation and its underlying theoretical basis
11	Description of internal facilitators and barriers potentially influencing the delivery of the intervention as revealed by the process evaluation
12	Description of external conditions or factors occurring during the study which might have influenced the delivery of the intervention or mode of action (how it works)
13	Description of costs or required resources for the delivery of the intervention
<b>N/A</b> To be explored in the proposed future research protocol of a feasibility randomised controlled trial	

The first four items in the CReDECI 2 checklist are related to the standard for describing the development of the intervention phase (Möhler, Köpke et al. 2015). These are listed and explained below in the context of the development of intervention phase based on the MRC framework mentioned earlier in section 6.2.

- 1) Description of the intervention’s underlying theoretical considerations
- 2) Description of all intervention components, including the reasons for their selection as well as their aims / essential functions
- 3) Illustration of any intended interactions between different components
- 4) Description and consideration of the context’s characteristics in intervention modelling

The Social Cognitive Theory was chosen as an appropriate theory based on the review of theories and models of behaviour change described in Chapter 3, section 3.5. In the perspective of Social Cognitive Theory (Bandura 2000), recognition of mediators of physical activity behaviour is important, especially as maintenance of a specific behaviour over a period of time requires an individual to adopt values and skills for targeted change, and experience self-determination. It further proposes that impediments faced by patients from personal and social factors, and relatedness in existing healthcare systems may help to internalise the regulation of health-related behaviours, and behaviour change will be better maintained (Williams, Deci et al. 1998). It is also important to understand what kind of behaviour to target and how to do this by analysing the techniques to change the behaviour. The discussions within the focus group interviews of cancer survivors (Chapter 4) also helped to understand the targeted behaviour depending on the constructs of Social Cognitive Theory. The possible techniques to reinforce the physical activity advice and the right time to intervene were also discussed with cancer survivors to help formulate the delivery plan of the developed intervention.

The final intervention comprised three components as listed below:

- Referral to the National Exercise Referral Scheme by the healthcare team.
- Physical activity booklet within MoveMore pack administered by the member of healthcare team
- Twelve text messages delivered weekly over three months through healthcare web-based system by the member of healthcare team

The various components of the intervention are designed to perform certain functions. For example, NERS is designed to target patients with chronic disease who can be advised by health professionals' advice, then identified and referred to a specialist facility where they can be assessed and an exercise programme designed to suit their individual needs. The physical activity booklet is designed to address patients' information needs regarding the side-effects of cancer related treatment, how to try to overcome these, sign-posting to other health care services that patients can contact if the need arises, and lastly sections to increase their awareness about the concept of physical activity, the types and role of physical activity in combating treatment related morbidity and the benefits of improved function and better quality of life. The goal setting diary is designed to give patients motivation and ownership of the recovery process. Finally, the weekly text messages are designed to help them maintain physical activity through constant reminders utilising the psychological principal of nudge (Thaler and Sunstein 2009), as well as their potential to increase patients' adherence by weekly reinforcement.

NERS is designed to motivate patients through health professional advice, referral to a subsidised service, assessment for suitability, tailoring and supervised activities to make it safe and appropriate for people's needs. The physical activity booklet within the MoveMore pack would also help people reflect on what they practice during NERS sessions. This booklet will also sign-post them to the local walk and sports groups, and other useful organisations if they need further help. Text messages would remind people to continue the modified behaviour by regular reminders and reinforcement so that the benefits of the initial NERS session/invitation can be internalised.

In summary, the theoretical constructs of Social Cognitive Theory would be utilised as mediators of behaviour change in cancer survivors to bring about efficient uptake of physical activity advice. Three interacting components of the proposed intervention are designed to lead to positive outcomes that can be measured with validated measures presented in Table 6.3.

In the context of the health care settings where this intervention is targeted, physical activity promotional campaigns for cancer survivors are already being in place across North Wales' healthcare settings. It includes the NERS in Wales, and collaborative physical activity promotional campaigns by the Macmillan and BCUHB. Wider roll-out as well as the addition of reminder messages to these campaigns may play an important role in improving the uptake and maintenance of physical activity behaviour among this population.

**Table 6.3:** Constructs of Social Cognitive Theory (SCT), relevance to physical activity promotion in cancer survivors, and components of the intervention

<b>Theoretical constructs of SCT</b>	<b>Relevance to cancer survivors for physical activity promotion</b>	<b>Components of the intervention</b>
Self-efficacy	Cancer survivor's confidence in his or her ability to adopt physically active lifestyle.	NERS + physical activity booklet + regular text messages
Outcome expectations and values	Expected results by the cancer survivors by being able to carry out prescribed physical activity, and the values that drive the cancer survivor in achieving the outcome (of regular physical activity prescribed).	NERS + physical activity booklet
Environment	Consists of facilitators from personal and social factors of the cancer survivors, and existing health systems in which they are a part of.	NERS
Self-control	Consists of goal-directed behaviour such as if the cancer survivor is planning for a future PA, or currently under a PA plan; and self-evaluation about the PA activity if under a PA routine.	NERS + physical activity booklet
Behaviour capability	Consists of the knowledge about the PA both before and after cancer treatment.	physical activity booklet
Observational learning	Consists of familiarity with any other cancer survivor who can be a role model to the respondent to bring a change in physical activity behaviour.	NERS
Reinforcements	Consists of an evaluation if the cancer survivor feels rewarded by performing PA activity.	Regular text messages
Emotional coping responses	Consists of an assessment of the sadness and worries associated with possibilities of failure to begin or to continue with the physical activity by the cancer survivors.	NERS + regular text messages
Impediments	Consists of impediments from personal and social factors of the cancer survivors, and existing health systems in which they are a part of.	NERS + physical activity booklet + regular text messages

### **6.3 Conclusion**

A thorough literature review of theories and models of physical activity behaviour change indicated that the Social Cognitive Theory had the most appropriate theoretical constructs underpinning the development of a physical activity behavioural modification and maintenance intervention. The maintenance component of such an intervention was then designed which comprised twelve weekly text messages that were extracted from Macmillan MoveMore pack. The content of these messages was then refined through patient and public involvement in different stages through focus groups and cancer patient forum. The focus groups, as presented in Chapter 4, had broader aims but also entailed the process of refinement and translating into patient centred language.

## **Chapter 7. Discussion, implications and conclusions**

## **7.0 Chapter summary**

This chapter concludes the thesis by highlighting the main findings of all the research methods used throughout the project following the MRC framework. This process culminated in the development of a physical activity behaviour change intervention for adult cancer survivors. This suggested intervention may be helpful in cancer patients' follow up care plan to reinforce the physical activity advice offered during and at the end of their active treatment. This can be accomplished by integrating this intervention into existing promotional services if found feasible in the proposed future pilot randomised controlled trial.

Irrespective of the feasibility of the aforementioned trial, this project has already had an impact on the current physical activity promotional campaigns in North Wales. Health and Well-being Clinics set up in partnership between BCUHB and Macmillan Cancer Support (Cancer Network Rehabilitation Advisory Group) took on board the findings of the focus groups and health professional survey to address both patient and health professional education/awareness needs regarding physical activity recommendations, and launched extensive knowledge and skills enhancement campaigns for both patients and the healthcare professionals.

## **7.1 Introduction**

This final chapter is structured to give an overview of this thesis by revisiting the aims and objectives and reflecting on how they were achieved. It highlights the significant findings of the overall project in light of the research questions posed at the outset. It will also bring to light the novel contribution of this work that fits into the contemporary context of the existing evidence, and its implications in practice. This is followed by an emerging impact story to highlight its unique contribution in improving health professionals' physical activity promotional practices to cancer survivors in North Wales. The chapter will conclude with a consideration of different approaches to take this research forward in future. Finally, it makes recommendations for further research, proposing a pilot randomised controlled trial to evaluate the physical activity promotional and reinforcement intervention developed in this project.

## **7.2 Background**

Every year around 19,000 people in Wales are diagnosed with cancer, which means 52 people every day (Cancer Research UK 2013). Improvements in early diagnosis, successful treatment of cancer, and progresses in follow-up care is resulting in an increased

number of people living beyond cancer (referred as cancer survivors in this thesis). The World Health Organisation estimates that one third of the cancer burden (newly diagnosed, active cancer diagnosed more than one year ago, cancers in remission, and cancers that have been cured) could be reduced by taking preventive measures to change lifestyle behaviours (including the improvement in diet, physical activity, and body weight) among cancer survivors (WHO 2010; WHO 2013).

Regular, optimum levels of physical activity can reduce treatment-related morbidity and improve quality of life in adult cancer survivors (Mishra 2012), but the levels of physical activity are low among this group (Stevinson 2014). Behavioural change interventions to promote physical activity are needed (WHO 2012). Different approaches have been proposed to promote physical activity (see Chapter 1, section 1.6 for more detail). Written educational information has shown favourable effectiveness resulting in improvement of self-management of certain types of chronic and progressive diseases (Payne, Wiffen Philip et al. 2012) including adult cancer survivors (Chapter 2). In the UK, Macmillan (the cancer charity) published an evidence based information booklet and workbook (MoveMore Pack) designed to promote physical activity in cancer survivors (Campbell, Foster et al. 2011). Their plan has been to offer this pack to all patients during their cancer journey as part of their Physical Activity Promotional Campaign where a physical activity champion was appointed in North Wales to assure patients' accessibility to these MoveMore Packs during their regular consultations.

### ***Aims and objectives***

The overall aim of this project was to design and develop an evidence based, theory driven behaviour change and reinforcement intervention to encourage the uptake and continuation of physical activity among adult cancer survivors. It was envisaged that this could support the messages given in the Macmillan physical activity booklet within the MoveMore Pack. The MRC framework for the development of complex interventions was used by adopting a stepped approach comprising of mixed methods (Craig, Dieppe et al. 2008). The detailed objectives were presented earlier in Chapter 1, section 1.9, and are listed below:

- 1) Conduct a systematic review
- 2) Conduct a literature review
- 3) Conduct a qualitative study**
- 4) Conduct a quantitative study
- 5) Develop a protocol for future research proposal



The first objective was achieved by synthesising the current evidence about the effectiveness of education materials for physical activity promotion in cancer survivors using a systematic review with meta-analysis presented in Chapter 2.

The second objective was achieved by exploring the literature for relevant behavioural change theories and models to develop the theoretical framework for this thesis as described in Chapter 3; and the specifically selected theory to underpin the physical activity behaviour change intervention developed in this project as described in Chapter 6.

Chapter 4 addressed the third objective by assessing cancer survivors' barriers and facilitators to physical activity in focus group discussions, as well as involving them as the service users in the development and refinement process of the intervention presented in chapter 6.

The fourth objective was achieved by finding out health professionals' physical activity promotional practices, their awareness of the physical activity guidelines and the referral services in their areas of practice using an online electronic self-complete questionnaire survey presented in Chapter 5.

The final objective was accomplished by developing a protocol for a feasibility randomised controlled trial based on the developed intervention presented in Chapter 7.

### **7.3 Significant findings, novel contributions and implications in practice**

This section will describe the novelty and what this thesis adds to the research field by presenting a summary of the findings resulting from this research project (Figure 7.1).

To the author's knowledge, the systematic review with meta-analysis conducted for evidence synthesis phase of this project to assess the effectiveness of physical activity education materials for increasing physical activity in adult cancer survivors is the first of its kind. Findings of this review indicated that physical activity education materials are helpful to increase physical activity levels in cancer survivors by a moderate amount of 30 minutes per week. Follow-up telephone counselling based on models of behaviour change was found to improve the adoption and maintenance of physical activity in the short term (Chapter 2).

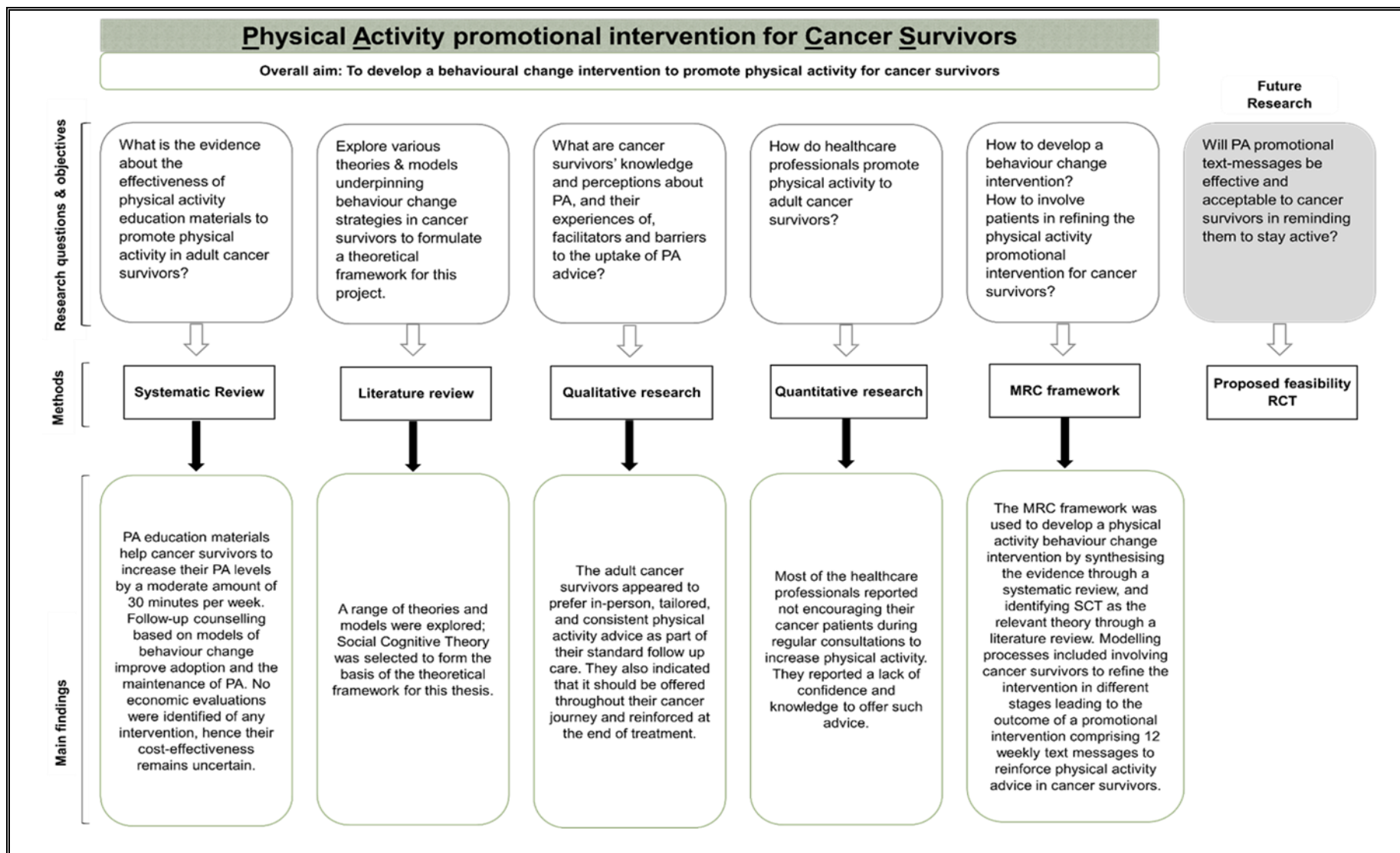
Theoretical framework was formulated through in depth exploration of the behaviour change theories and models used for physical activity promotion in cancer survivors leading to the choice of Social Cognitive Theory underpinning the framework for this project (Chapter 3).

Focus group interviews allowed an in-depth exploration of cancer survivors' knowledge and perceptions, their experiences of, and facilitators and barriers to the uptake of physical activity advice (Chapter 4). Results indicated that patients had positive perceptions about the beneficial effects of physical activity, but were uncertain about the extent, timing, duration and type of exercises to do at what point or stage in their cancer journey. This was further complicated upon inconsistent physical activity advice from health professionals, and was their major concern. They then perceived such conflicting advice as a lack of certainty about exercise recommendations on the part of health professionals.

Focus groups also facilitated patient involvement in modifying the text messages developed as part of the physical activity promotional and reinforcement intervention development for this project (Chapter 6). Their engagement assisted in refining and rephrasing these into patient centred messages ready to be evaluated in a randomised trial (Chapter 7).

Similar to the systematic review, the web-based service evaluation survey of health professionals regarding their practices of physical activity promotion to cancer survivors is also the first conducted in the UK. The results of this survey revealed that health professionals were encouraging limited number of their cancer patients to increase physical activity, during regular consultations (Chapter 5). This confirms the results of qualitative study. Despite citing lack of confidence and knowledge to offer such advice, the majority of health professionals appeared willing to be part of physical activity promotional campaigns for cancer patients if appropriately supported.

**Figure 7.1:** Research at a glance: Aims, objective, methods and significant findings of the research project



Findings of this project reported in this thesis have significant future implications in healthcare for both the health professionals who are involved in cancer care, and the researchers in the field of physical activity promotion for cancer patients.

This research highlights the issues raised by patients (e.g. lack of knowledge about physical activity guidelines), which they had not previously discussed at any forum because they had not yet been invited to raise their issues about physical activity advice. Similarly, focus group discussions also highlighted a gap at active treatment completion stage, where patients reported losing continuity of care and contact with care teams while transitioning into follow-up care (chapter 4). This seemed to produce anxieties and uncertainties leaving the patients wondering '*what to do next!*' (Female, 42 years, breast cancer survivor). Similar findings have recently been reported about this transitional phase during follow up care as a cause of concern among patients on completion of their primary cancer treatment (Guassora, Jarlbaek et al.). Therefore this study has implications for practice whereby patients' experiences of healthcare support during and at the end of their active cancer treatment can be improved.

On the other hand, this research also reveals some interesting findings related to health professionals' beliefs about the beneficial effects of physical activity for their cancer patients, and their role in its promotion. They acknowledged the importance of physical activity, and their role in its promotion to their patients. But their practices regarding this were inconsistent, which could be explained to some extent in the free text, qualitative data gathered from the survey (Chapter 5). The findings of this survey are consistent with the literature indicating that healthcare professionals are enthusiastic to promote physical activity but their consultation levels are low due to lack of knowledge about physical activity recommendations (Douglas, Torrance et al. 2006).

The willingness of the majority of healthcare professionals (Chapter 5) to engage in such activities can be channelled positively for patient benefit by knowledge and skills enhancement (i.e. continuing professional development, referral service awareness i.e. National Exercise Referral Scheme, and Health and Well-being Clinics) as well as some personal (i.e. physical activity levels) and system barriers (i.e. time constraints) could be addressed. Evidence shows high levels of success by incorporating brief advice into routine consultation without major disruptions (Hebert, Caughey et al. 2012). Healthcare professionals can act as facilitators to physical activity advice by: being cognisant of opportunities to encourage physically active behaviour, exploring possibilities for any interventions, staying up-to-date with current physical activity guidelines for cancer patients, and also being aware of the existing resources including physical activity promotion (Pinto, Frierson et al. 2005; Demark-Wahnefried, Pinto et al. 2006).

With regards to implications for patients, this research can bring improvement in patients' experience. The proposed promotional intervention may help to bridge the

transitional gap by sending them regular weekly messages. Continued follow-up care at the end of their active cancer treatment can minimise the anxiety by keeping patients motivated to carry on exercising. It may also give them a feeling of 'not been forgotten' while the transition takes place from secondary to primary/community care.

The above discussion concludes that the proposed three month post-treatment plan in the form of 12 weekly physical activity motivational text messages may have an impact on the current practice in near future after testing its acceptability and feasibility. Finally, the output of this research (the developed intervention) serves a novel contribution which may be affordable; not time consuming; and not needing clinical expertise. It is intended to minimise barriers to physical activity uptake, which can increase adherence to physically active lifestyle, resulting in relapse prevention that can lead to improved physical activity behaviour maintenance. This intervention can also contribute to improvement in physical activity promotional campaigns by its integration into the existing healthcare settings in North Wales.

## **7.4 Impact of this research project**

On changing the project direction at the launch of MoveMore packs by Macmillan as detailed in Chapter 1 section 1.8, it was important to manage two things: revision of the PhD project and building up a network with the local physical activity promotional initiatives.

The first point of contact was the Macmillan team who had developed the physical activity booklet. I approached their development manager (AC) of cancer support with an aim of developing a new campaign, and contributing to the existing campaigns. North Wales Physical Activity Promotional Campaign (NWPAPC) being run by Macmillan appointed a physiotherapist (JG) as Physical Activity Champion whose role was to raise awareness in the health board, support an education plan for site specific Clinical Nurse Specialists and other clinical professionals, be a point of contact for National Exercise Referral Scheme (NERS) exercise professionals, and to ensure that referral processes were running smoothly. Keeping in mind these roles, I started building up a team work by sharing and transferring the knowledge gained from the findings of different phases of my research at their regular meetings (see Appendix Q-i for dissemination resulting from this thesis and meeting agendas of the invited oral presentations).

The focus group findings in regards to inconsistent advice by the health professionals to cancer patients prompted me to develop and conduct an online survey of health professionals' practice, as well as their knowledge and beliefs about the beneficial effects of physical activity for cancer patients. At the same time, Macmillan expressed an interest in assessing behaviours, knowledge and confidence of clinical teams on advising physical activity to cancer patients, awareness of NERS which had by then included the cancer patients in their inclusion criteria for referral, and NWPAPC. This common interest was

discussed in one of their NWPAPC's regular meetings where I proposed the idea of developing an online survey, which would serve a dual purpose i.e. Bangor University's research project requirement for my PhD, and better targeting of Macmillan's promotional campaign. BCUHB was also interested in determining the behaviour of staff who had a pivotal role in physical activity promotion. So the survey turned out to be a joint venture of BCUHB, Macmillan and Bangor University, where I became a part of this audit team, who developed and piloted the questionnaire explained in Chapter 5.

This survey complemented focus group findings as well as highlighted a lack of health professionals' awareness and skills in physical activity promotion. The findings of this survey were presented in the evaluation report of the NWPAPC to inform the relevant parties. At the same time, a partnership between the BCUHB and Macmillan named Cancer Network Rehabilitation Advisory Group (CNRAG) was formed. Its role was to provide a forum where representatives from different clinical programme groups (CPGs) such as cancer, palliative medicine, clinical haematology, therapies and clinical support, surgery and dental, primary care and specialist medicine, as well as patient networks such as North Wales Cancer Patient Forum, hospices and 3<sup>rd</sup> party sectors could support patient care pathways. I was appointed as a consultant researcher from Bangor University on the panel of this rehabilitation advisory group (see Appendix Q-ii for CNRAG's Terms of Reference). The CNRAG then took on board the findings from the above mentioned two studies which helped them to set up a programme of ongoing one day events named 'Health & Well-being clinics in North Wales'. These events aim to cater for psychological and physiological needs of cancer survivors through active collaboration and advice of health professionals of different disciplines. Similarly, they aim to address health professionals' educational and skills enhancement needs especially for physical activity promotion to cancer patients.

It has been proposed in one of CNRAG's meetings that the survey could be re-run after health professional educational campaigns have been implemented. This survey can then be used as an evaluation tool by comparing the findings with the initial survey results to determine if health care professionals' physical activity promotional practices have changed subsequent to exposure to knowledge and skills enhancement sessions or workshops run by the NWPAPC.

Practice modification implementation resulting from the findings of the above-mentioned two studies encouraged the CNRAG to show interest in the developed intervention (the outcome of this research) to take it further through to a feasibility trial and then into their follow-up care plans for cancer survivors in the near future.

These examples provide evidence of the impact of this research in practice modification that occurred through input of this project's findings to the local health board and Macmillan physical activity promotional team.

## 7.5 Strengths and limitations of the overall approach

As is true for any research method, there are some strengths and limitations associated with each. A summary of these is presented below to highlight the main strengths and shortcomings of the mixed method approach used in this research project and have been then contextualised in later sections into how these can be done better in future if similar studies are conducted.

Over the past three decades, mixed methods research in healthcare is gradually increasing. Tariq and Woodman showed that in England, health services research classified as mixed methods was on the rise from 17% in the mid-1990s to 30% by the early 2000s (Tariq and Woodman 2013). Mixed methods research is appropriate for complex public health interventions, such as physical activity promotion, where different processes can interact to produce an effect (Craig, Dieppe et al. 2008). Recently, there has also been a growing recognition of the importance not only of the effects, but also of the processes involved in determining the effects of public health interventions (O'Cathain, Thomas et al. 2013).

Giddings (2006) conveyed rationale behind this increase in the use of the mixed methods by giving four more points to use a mixed methods approach: that it gives the opportunity to be more holistic, offers a broader understanding, can help to gain more certainty in the results, and can also enhance flexibility (Giddings 2006). This reasoning was also argued by Stange and Zyanski as:

“If the only tool researchers have is a hammer, they tend to see every problem as a nail” (Stange and Zyzanski 1989).

However, there are some disadvantages of mixing methods highlighted by Hess-biber (2010), that included a method-experience gap exists because most researchers tend to have expertise in one particular area (Hesse-Biber 2010). As a result of having lack of knowledge and skills, the researchers may have to step outside of their comfort zones and experiment blindly, without enough training and experience. Another limitation of mixed methods is how to evaluate the research quality as there is no universal criterion that exist and the ones in use are not appropriate (Tracy 2012). Cresswell and Garrett (2008) refer to mixed methods as a ‘movement’ indicating that it is a growing trend rather than an established methodology and add that growing pains are a natural outcome (Cresswell and Garrett 2008). Despite the challenges that have been identified, mixed method approach appear to be gaining popularity and researchers appear to be developing more adventurous ways of thinking. Brannen (2010) claims that using mixed methods research encourages researchers to think outside the box and is a practice that should be welcomed (Brannen 2010).

Thorough consideration based on the purpose of this research resulted in selection of the mixed method approach utilising the MRC framework for complex intervention development. In this research project leading to a PhD, the author used a theoretical lens as an overarching perspective while designing and developing the complex physical activity behaviour change intervention for cancer survivors at the end of their active treatment. This project's research design contained integration between both quantitative and qualitative components. The choice of mixed methods served as a learning curve during journey of the PhD, and the author became more open-minded and receptive to innovations. This lens provided a framework for topics of interest, methods for collecting data, and the outcomes by this research targeting much wider audiences. The *quantitative component* (systematic review and questionnaire) explored which strategies work for cancer survivors in order to rationalise the appropriate use of rehabilitation resources for safe follow-up care; whereas the *qualitative component* (focus groups) explored what being a cancer survivor means for people in terms of how they are able to function, how it impacts their self-esteem and decision making processes. It also tried to assimilate how these findings can be used to improve follow-up care strategies.

The systematic review employed standard review methods and searched a wide range of databases to improve rigor and reduce bias. The results of this review contributed valuable addition to the existing literature regarding physical activity promotion in cancer survivors.

Furthermore, survey was able to get responses from health professionals working in a wide range of specialties encompassing primary, secondary and allied health care disciplines. A rigorous method of questionnaire development was adopted involving practitioners of varying backgrounds and experiences. Further piloting was undertaken to ensure the feedback of professionals both involved in the development and otherwise was incorporated to make it user friendly. These processes helped to improve the relevance of the questionnaire to the aims of the project and ensured most pertinent data collection without overly burdening the respondents. The user friendliness and relevance of the questions along with an easy to follow user interface helped to achieve a response rate that was within reasonable limits compared to earlier similar surveys in similar populations (Braithwaite, Emery et al. 2003; Douglas, Torrance et al. 2006). This survey also had a large representation of female respondents which has been reported to be underrepresented in the previous studies (Potts and Wyatt 2002).

Participants of the focus group interviews were keen to discuss their experiences about physical activity advice during cancer journey, and their perceptions of the factors to help them keep motivated in future. The author has been on different qualitative research courses to learn about data collection and analysis techniques. These training activities helped during the conduct of focus groups in capturing in-depth patient perspectives because



the interviewer (the author) was successful in using probes and prompts that motivated patients to speak about their concerns with confidence. Hence, the author believes that we were able to collect sufficient data to answer the research questions and highlight patient views and experiences. Data analysis was undertaken in close consultation with another senior colleague to assure rigor and reliability of the findings. The sample comprised of good variation and breadth covering a wide range of age, both genders, cancer types, and a broad geographic area of North Wales, hence satisfying the requirement of sample variability in qualitative research to capture information from participants representing most backgrounds.

The author would like to acknowledge that there were some limitations to the methods used in this project. These are summarised below:

The systematic review identified only studies which were conducted in USA and Canada with largely white populations. Additionally, the targeted populations were only survivors of breast and prostate cancer. The findings were based on relatively small number of studies, with considerable methodological weaknesses probably resulting in insignificant differences among different interventions. Variability in study interventions and a wide variety of outcomes and measures reported made it a challenge for the author to pool the data due to such heterogeneity. Inconsistent follow-up data examining the effects of exercise was also an issue. There was also a lack of specificity about the types of exercises for different cancer patients limiting the applicability of findings to all adult cancer survivors.

The survey posed some technical and methodological challenges such as external validity, selection and response biases. The study sample may not be representative of the targeted population as there were more female responders in the nursing and rehabilitation services. The keenness of this group to participate in research might a phenomenon of underlying demographic shift in patterns of utilisation of internet based support tools, or incidentally more invitations being sent to females in the health care workforce. This aspect might warrant further exploration. Some results may have depicted the inherent weaknesses associated with Likert style scales resulting in central tendency, acquiescence, and social desirability biases (McLeod 2008).

Finally, the focus groups similarly posed some challenges including strict inclusion criteria such as the narrow time frame window of six months post active treatment when the patients could be invited to participate. Participants' responses might also have been influenced by their personal likeness or otherwise to be physically active. In depth focus group discussion generated large data set that posed some analytical challenges which were mitigated by the fact that the author had attended data management and analysis workshops as part of early researcher development programmes run by Bangor University as well as sought the help of a senior qualitative researcher when and if needed.

In summary, it is felt that the mixed method approach used in this thesis was appropriate to design and develop a complex intervention such as physical activity behaviour change for cancer survivors.

## **7.6 Consideration of different research approaches in the future**

The mixed methods research conducted during this project and reported in this thesis, in author's view, enhanced the knowledge base and improve understanding through significant contribution in the field physical activity and cancer survivors. The studies conducted can also be a stimulus for further investigation. As the change in physical activity behaviour in cancer survivors is a relatively new area, many questions also arose as a result. The author would like to highlight a few points, as part of lessons learned from this project and as the implications for further research, where things could be done differently or more comprehensively in the future studies.

Firstly, given the finding that patient education materials are helpful to increase physical activity levels in cancer survivors after their active treatment, the inclusion criteria of a future systematic review could be broadened to capture outcomes related to physical activity promotion after diagnosis and during cancer treatment. This may highlight different time points to be targetted and point to the right time to intervene in order to reap the beneficial effects of physical activity promotion throughout cancer journey, rather than only after treatment. Similarly, the need was felt to capture patients' perspectives during these time points and any issues highlighted would then need addressing. A review by Davies and colleagues (conducted by NCSI) concluded that physical activity advice should become part of routine clinical care of cancer survivors, not just on their treatment completion (Davies, Thomas et al. 2010). Hence, patient participation in focus groups should be considered right after their cancer diagnosis, during their treatment, and soon after finishing their active treatment in contrast to patients being recruited six months after their treatment completion as was done in the current study. Interesting patient related issues might be highlighted while sharing their experiences after diagnosis and during treatment. Their receptiveness to physical activity advice might be different at different time points (Rabin 2011), which warrants further exploration and might lead to different strategies of physical activity promotion tailored to individual stage or time point in their cancer journey.

Secondly, the potential role of health professionals in providing physical activity advice is worthy of further investigation. Free text narratives, though brief, hinted at some interesting health professional perspectives in addition to questionnaire data in the survey. These may be followed on with a qualitative study for indepth exploration of their perceptions about the issues highlighted in this study. This may be helpful to bring the pieces of the

jigsaw of 'who, what, how, when and where to promote physical activity' together to improve health professionals' participation in physical activity advice to their patients.

Finally, the end product of this research was a physical activity behaviour change intervention for adult cancer survivors that might require minimal time, skills and resources for successful implementation. It can be used as an inexpensive adjunct to the existing physical activity promotional campaigns in healthcare settings in Wales where the NERS and MoveMore packs are part of the usual current practice, hence has the potential of being seamlessly integrated into these existing initiatives.

### **7.6.1 A way forward: Protocol of a pilot randomised controlled trial**

Over the past decade, implementation is increasingly common for better research leading to inform decisions about health policies, programmes, and practices (Peters, Adam et al. 2014). It can help to explore what works, for whom, and in what circumstances thus enhancing the use of evidence within the design and delivery of health related interventions including physical activity promotion. A team of experts is running an implementation programme at Bangor University, and this author is keen to discuss the implementation strategy for the developed intervention that can be considered while refining the protocol for a future feasibility randomised controlled trial presented in the sub-section below.

This research completed the development phase of the MRC framework for complex interventions (Craig, Dieppe et al. 2008). As is true for any new intervention, it should be assessed for its effectiveness and cost-effectiveness in a randomised controlled trial. The next phase of feasibility/piloting was considered while planning the steps to move forward to promote physical activity in cancer survivors. The trial is designed to assess the acceptance of the intervention, the recruitment and retention rates, and is helpful to calculate sample size for full scale randomised controlled trial if found feasible.

The proposed protocol is presented below:

#### **Title: Study protocol for a randomised feasibility trial of physical activity promotional intervention for cancer survivors**

##### **Introduction**

Earlier diagnosis, both because of increased public awareness as well as improved technologies, and improvements in cancer treatments have resulted in a significant increase in the number of people living after cancer treatment, the cancer survivors. Whilst people are living longer with and beyond cancer, they are requiring long-term management of the disease related morbidity, consequences of the treatment and age related comorbidities (Campbell, Foster et al. 2011; Parry, Kent et al. 2011).

Regular physical activity has been found to show numerous health benefits in adult survivors of prostate, breast, colorectal and haematological cancers (Ingram, Courneya et al. 2006). These include, among others, better mental health; strong, healthy muscles, bones and joints; improved cardiovascular fitness; and improved function leading to greater independence (Pate, Pratt et al. 1995; Department of Health 2004). Healthy lifestyle behaviours including weight control and regular physical activity are also helpful in reducing treatment associated morbidity and improving quality of life in cancer survivors (Jones and Demark-Wahnefried 2006; Campbell, Foster et al. 2011) by improving their physical fitness, reducing the risk of recurrence and increasing survival (Thomas and Davies 2007).

Having a cancer diagnosis has been described as a "teachable moment" when cancer survivors may be more receptive to lifestyle change, including increasing their level of physical activity (Demark-Wahnefried, Aziz et al. 2005). Studies have suggested that interventions should focus on increasing self-efficacy for behaviour change (Pinto, Trunzo et al. 2002). A systematic review of physical activity guidelines for cancer survivors found that none were rigorously developed, evidence-based or underpinned by psychological theory (Humpel and Iverson 2005). A review published by Macmillan Cancer Support highlighted the importance of physical activity and offered a downloadable or mail order booklet (Campbell, Foster et al. 2011); but did not advise specifically on the type, intensity or duration of activity, neither did it give general nor specific safety precautions, suggested how to overcome barriers to exercise, or fully described the possible benefits.

Although the physical activity guidelines have been available since 2010, there is a need to provide cancer survivors with more education and information to encourage self-care (Department of Health 2007), using simple interventions to promote physical activity (NICE 2006). A range of options are available to inform them about physical activity, but the most effective approach is unclear particularly to affect long term adherence to exercise/physical activity. An intervention targeting the physical activity behaviour of cancer survivors was developed as a result of this PhD research project. The overall aim of this pilot study is to test the acceptability of the intervention, as well as feasibility for a future trial of effectiveness and cost-effectiveness of the developed intervention in a definitive Randomised Controlled Trial (RCT).

### **Study objectives**

- 1) To assess the acceptability of the developed intervention
- 2) To refine the logistics and mechanics of delivering the intervention
- 3) To explore the recruitment challenges
- 4) To observe the recruitment retention rate
- 5) To ensure that the randomisation is acceptable
- 6) To ensure that the outcome measures are collectable

- 7) To calculate the sample size for a definitive trial
- 8) To assess the feasibility of conducting a future definitive RCT with concurrent economic evaluation.

## **Methods**

### ***Study design***

This proposed feasibility study comprises second stage of the MRC framework for assessing the complex interventions (Bandura 2006), and as a future research proposal is being presented as an end product of the research project. It will be a randomised two-arm phase II feasibility trial, which will assess the acceptability and feasibility of weekly regular physical activity promotional text messages in addition to two components of usual care comparing with the usual care alone.

### ***Study Settings***

The study will be conducted at the three main hospital sites across North Wales within Betsi Cadwaladr University Health Board (BCUHB): North West (Ysbyty Gwynedd and surrounding areas); Central (Ysbyty Glan Clwyd and surrounding areas); North East (Ysbyty Maelor Wrexham and surrounding areas).

### **Population of interest**

#### *Inclusion criteria*

Any type of cancer

Adults, 18 years or older with no upper age limit

Curative intent active cancer treatment aimed for completion within six months

#### *Exclusion criteria*

Close to death

Lack of mental capacity to give informed consent

Patients living outside the jurisdiction of Betsi Cadwaladr University Health Board (BCUHB)

Cancer recurrence or requiring further treatment during the six months following active treatment

Those with co-morbidities where physical activity would be contra-indicated, such as unstable angina or hypertrophic obstructive cardiomyopathy (HOCM)

People involved in other studies, if participation affects their ability or motivation to exercise

Patients unable or not willing to use a mobile phone

Inability to read English or Welsh

### **Sample size**

It is estimated that 25% of the eligible patients who completed their active cancer treatment within last six months will be recruited from three hospitals in BCUHB. The participants will be randomised to either the text messages reminder or the usual care arm of the study, and the data will be collected at the baseline and three months. A total of at least 50 participants completing the trial, 25 in each arm of the study will be sufficient to fulfil the sample size requirements (Bandura 2001; Suri 2011) to estimate the standard deviation of the primary outcome (7-Day Physical Activity Recall). This standard deviation would then be used in the power calculation of a future definitive randomised controlled trial.

### **Study Arms**

#### ***Intervention – 12 weekly physical activity promotional text messages***

- Macmillan MoveMore pack administered by the clinical nurse specialists (CNS) at the end of the cancer treatment
- Referral to the National Exercise Referral Scheme (NERS) by the clinical nurse specialists (CNS)
- Weekly physical activity promotional text messages for 12 weeks

#### ***Control - Usual care to promote physical activity for cancer patients***

- Macmillan MoveMore pack administered by the cancer nurse specialists at the end of the cancer treatment
- Referral to the National Exercise Referral Scheme (NERS) by the clinical nurse specialists (CNS)

### **Outcome measures**

Data will be collected at baseline and three month follow-up. Outcome measure questionnaires will be completed by participants, assisted by healthcare professionals or a member of the research team who will be blind to treatment allocation. Participants will also be given the choice to complete validated versions in Welsh where they exist. As a phase II feasibility trial, the primary measure of interest will be patient recruitment, attrition and response rates. The outcomes will be collected in a variety of ways. Demographic data will be collected from patients and their records. Recruitment rates will be calculated by researchers from their screening and recruitment logs including information on the number of patients screened for eligibility, approached by the recruiters, the number who consented and where possible stating reasons for those who did not. The acceptability of randomisation will be recorded along with the number who withdrew after baseline assessment and/or

randomisation. The number of completed outcome measures at baseline and three month follow-up and the reasons for non-completion will also be recorded by the researchers.

The following demographic and condition-related clinical data will also be collected along with specific patient completed questionnaire data at the time of baseline measurements:

Date of birth (age)

Gender

Education levels

Living arrangements (alone or with a companion)

Type of cancer

Type(s) of treatment (chemotherapy, radiotherapy, surgery or a combination, hormone etc. (e.g. brachytherapy)

Time since the active treatment completion

### **Patient completed measures**

The intervention outcomes will be captured using a range of standardised patient reported outcome measures as reported below:

#### ***Physical activity***

##### *Seven Day Physical Activity Recall instrument (7-Day PAR)*

As a feasibility trial to promote physical activity in cancer survivors, the primary outcome of this study will be to assess the changes in physical activity levels at three months after the baseline, by administering the semi-structured interview 7-Day PAR (Marcus, Forsyth et al. 2000). It measure will assess duration, intensity, and frequency of the physical activity (Pereira M.A., FitzerGerald S.J. et al. 1997).

#### ***Psychological measures***

##### Behaviour change

The relationship of the constructs of Social Cognitive Theory selected for the development of this intervention as mediators of physical activity behaviour change in cancer survivors (Table 7.1). It explains the interaction among different components of the intervention and the outcome measures. The psychological mediators of change in this theory-based physical activity promotional intervention will be measured with the help of various behaviour change outcome measures described below:

##### *Self-efficacy for exercise*

Self-efficacy for exercise scale (Edwards, Roberts et al. 2002) will be used to assess the participants' confidence in his/her ability to adopt physical activity advice. The range is 0 to 90, where higher scores reflect more confidence in their capability to be physically active.

#### *Outcome expectations scale*

This 9-item scale (Edwards, Roberts et al. 2002; Wright 2005) will be used to rate respondents' level of agreement to different statements regarding exercise (e.g., "Exercise helps me feel less tired") to reflect their expectations that they might have to achieve from performing or not performing the exercise or activities.

#### *Physical activity enjoyment scale*

This 18-item scale (Eysenbach 2004; Wright 2005) will help to assess the participants' level of agreement with different statements regarding their feelings after doing an exercise (e.g., "I enjoy exercise").

#### *Social support for exercise questionnaire*

The social support for exercise survey (Davison and Hinkley 1997; Wright 2005), consists of 10-item questionnaire. It asks participants to rate their level of agreement on the given statements using 5 point Likert-scale, in regards to getting support for exercise from their family and friend.

#### Psychological well-being

##### *Hospital Anxiety and Depression Scale (HADS)*

This 7-item scale is designed to measure common symptoms of anxiety and depression in patients with physical health problems. Patients rate their symptom experience as definitely, sometimes, not much or not at all. The HADS was designed for use in the hospital setting but has been used successfully with the general population (StataCorp 2009). This measure will be used at baseline and at the three month follow-up assessment. The two sub-scales have a range of 0-21 with higher scores indicating increased anxiety or depression.

#### **Health economic measures**

##### *Client Service Receipt Inventory (CSRI)*

The CSRI questionnaire collects retrospective information about participants' use of health, social care and voluntary or charity services. This information will be combined with national sources of reference unit costs (Albright, Cohen et al. 2000; Department of Health 2010; WG 2014) in order to calculate health and social services costs for the economic evaluation. It will be administered at both baseline and the three month assessment.

##### *ICEpop CAPability measure for Adults (ICECAP-A)*



The ICECAP-A is used to measure capability of adults focusing on well-being rather than health to enable broader measures of wellbeing for economic evaluation (NICE 2014). The ICECAP-A measures five attributes of capability wellbeing including “stability”, “attachment”, “achievement”, “autonomy” and “enjoyment”. It will be administered at both assessments, baseline and the three month.

### **Quality of life measures**

#### *EuroQoL EQ 5-D*

This is a patient completed index of health related quality of life. EQ5-D (5L) gives a weight to different health states, and consists of five dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression (Braithwaite, Emery et al. 2003). Each dimension is having three possible responses that record three levels of severity (no problems, some/moderate problems and extreme problems). It will be used at baseline and at three month follow-up assessment to allow the calculation of quality adjusted life years (QALTs), using area under the curve method as part of the economic analysis.

### **Adverse events**

All adverse events (AEs) and serious adverse events (SAEs) will be recorded in this study. Adverse events will include: an exacerbation of a pre-existing illness; an increase in frequency or intensity of a pre-existing episodic condition; a condition (even though it may have been present prior to the start of our study) detected after participating in the study; and persistent disease or symptoms present at baseline that worsen during the study.

**Table 7.1:** Constructs of Social Cognitive Theory (SCT), relevance to physical activity promotion in cancer survivors, components of the intervention and the related psychological behaviour change outcome measures

<b>Theoretical constructs of SCT</b>	<b>Relevance to cancer survivors for physical activity promotion</b>	<b>Components of the intervention</b>	<b>Outcome measures</b>
Self-efficacy	Cancer survivor’s confidence in his or her ability to adopt physically active lifestyle.	NERS + physical activity booklet + regular text messages	Self-efficacy
Outcome expectations and values	Expected results by the cancer survivors by being able to carry out prescribed physical activity, and the values that drive the cancer survivor in achieving the outcome (of regular physical activity prescribed).	NERS + physical activity booklet	Outcome expectations
Environment	Consists of facilitators from personal and social factors of the cancer survivors, and existing health systems in which they are a part of.	NERS	PA enjoyment
Self-control	Consists of goal-directed behaviour such as if the cancer survivor is planning for a future PA, or currently under a PA plan; and self-evaluation about the PA activity if under a PA routine.	NERS + physical activity booklet	Self-regulation Self-efficacy
Behaviour capability	Consists of the knowledge about the PA both before and after cancer treatment.	physical activity booklet	Self-efficacy
Observational learning	Consists of familiarity with any cancer survivor and if or not inspired the cancer survivor (respondent) in following him/her as a role model.	NERS	Social support Social support
Reinforcements	Consists of an evaluation if the cancer survivor feels rewarded by performing PA activity.	Regular text messages	Social support
Emotional coping responses	Consists of an assessment of the sadness and worries associated with possibilities of failure to begin or to continue with the physical activity by the cancer survivors.	NERS + regular text messages	PA enjoyment
Impediments	Consists of impediments from personal and social factors of the cancer survivors, and existing health systems in which they are a part of.	NERS + physical activity booklet + regular text messages	Social support

## **Study set-up**

### ***Preparation of the study related documents***

Initial drafts of all study related documents including participant invitation letter, participant information sheet, consent form and the reply slip will be prepared by the researcher (SN) and sent to the study management group. Their comments and suggestions will be incorporated and the documents amended accordingly before being sent to the lay researcher.

### ***Patient and Public Involvement***

Patient and public involvement (PPI) refers to an active partnership between researchers and patients/ the public during the proposed research process (Potts and Wyatt 2002). The lay researchers will be invited through the North Wales Cancer Patient Forum with the help of their facilitator (Pat Evans). All study related documents will be sent to the agreed lay researcher for suggestions/comments. The feedback will be helpful to refine the documents into more patient friendly versions rather than the technical information. The documents finalised for ethics submission will include invitation letter, participant information sheet, consent form and a reply slip.

### ***Development of the Tele-form questionnaires***

The self-completed questionnaires will be prepared in electronically readable Teleform format to allow scanning of responses into a computerised database. There will be two sets of questionnaires, each in a single booklet to reduce the participant burden: one to be completed at the baseline before randomising the participants and the second at follow-up after three months.

### ***Ethics and Regulatory Approvals***

Ethical approval will be obtained from the Wales Research Ethics Committee 4 (REC 4) and the NHS Research and Development (R&D) from BCUHB. All of the study related documents will be translated into the Welsh language after gaining ethical approval.

### ***Indemnity***

Bangor University has appropriate Clinical Trials and Professional Indemnity insurance in place to cover the research team conducting the research. Members of NHS or Health and Care Research Wales staff helping with the study will have NHS contracts which would provide insurance cover for their work as we do not envisage they would be doing anything different than their normal day to day clinical duties.

### *Pre-launch preparations*

The study will be adopted as a portfolio study on the Health and Care Research Wales' website which will help to get their work force research team on board for recruitment of the potential participants. The study will be explained in person by the researcher from Bangor University to Health and Care Research Wales team with the help of a procedural step by step guide. The *invitation packs* will be delivered to the trial managers at Health and Care Research Wales within three hospitals in North Wales.

An excel spread sheet will also be developed for the Health and Care Research Wales team members to send weekly updates about the study recruitment to the researcher at Bangor University. It will be helpful to keep track of the response rate and the recruitment challenges at the study sites. The expected date for the study commencement will be communicated via email to the clinicians in BCUHB.

### *Study invitation packs*

The packs will consist of the following: an invitation letter, Participant Information Sheet (PIS), specimen consent form, reply slip and a prepaid envelope. Practical arrangements to conduct the pilot trial will be explained in the PIS. The contact details of the Bangor University's researcher co-ordinating the recruitment will be included. The participants will be encouraged to ask further information if they need. Patients interested to take part will be asked to complete and return the reply slip in the prepaid return envelope.

## **Recruitment Process**

### *Screening*

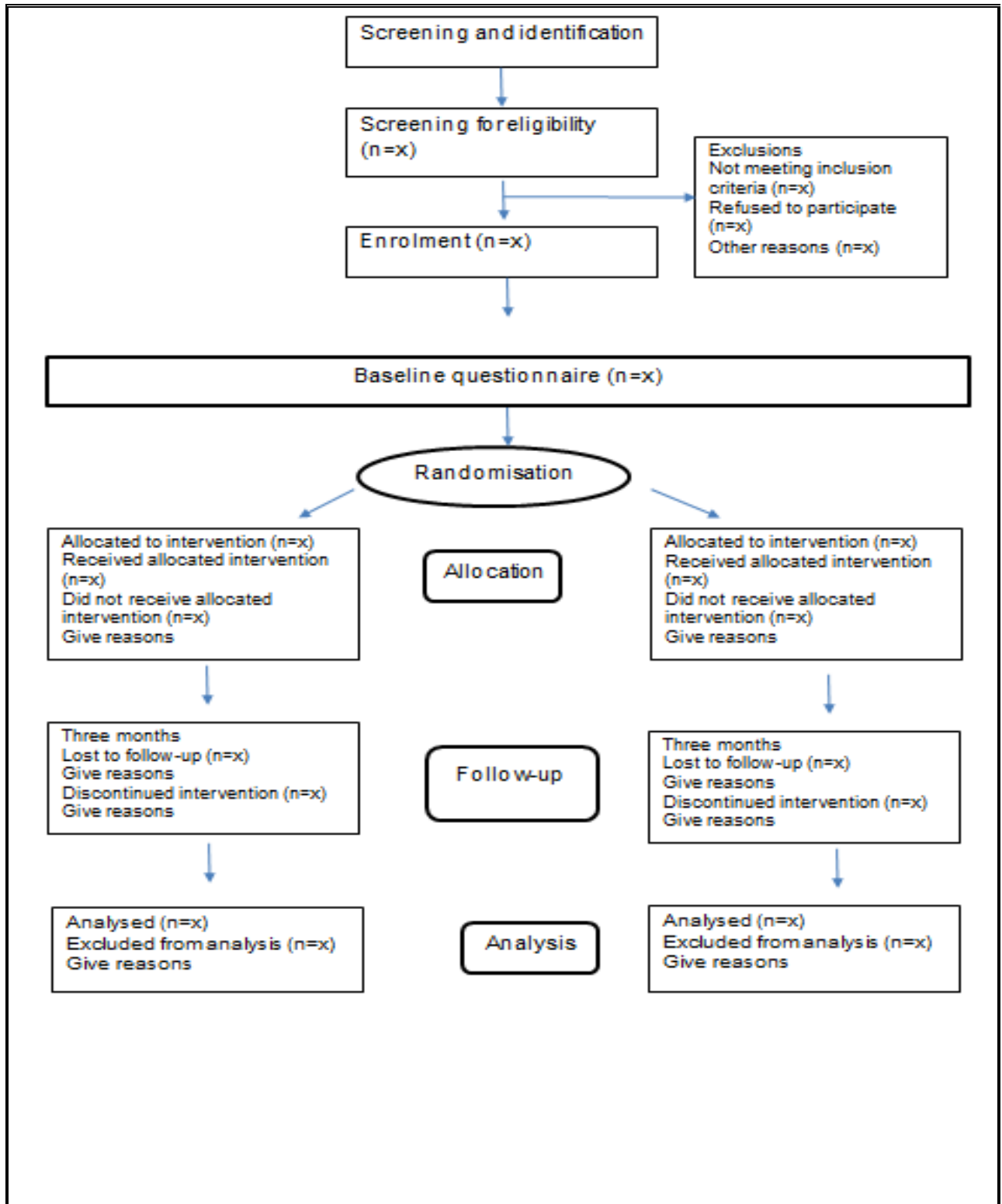
Source data for screening of eligible participants will be the hospital medical records within the Betsi Cadwaladr University Health Board (BCUHB) in North Wales. These will be accessed by research members of the Health and Care Research Wales and the Bangor University researcher who will have an honorary research contract with the BCUHB. Adult cancer survivors likely to finish their active cancer treatment within the next six months will be screened and identified for inclusion based on the eligibility criteria described earlier.

### *Invitation to participate*

Potential patients will be invited by the research members of Health and Care Research Wales team and the Bangor University researcher at the end of treatment within the respective treatment units of chemotherapy, radiotherapy and/or surgery. Patients agreeing to consider participating in the study will be given the **invitation packs**. Patients will be advised to reflect on the information for at least 24 hours before sending the reply slip to Bangor University research team (*Figure 7.2*). A postal reminder to send the reply slip back

to the Bangor University researcher will be sent two weeks later. No further reminders will be sent if the patient fails to reply after this period and their decision will be considered a refusal.

**Figure 7.2:** Flow chart explaining the patient recruitment procedure



### *Sign up & confirmations*

The Bangor University researcher will contact the patient via telephone upon receipt of a positive response. Participants will be reassured that their participation will be completely voluntary; they would be free to withdraw from the study at any time without giving any reason; and their withdrawal from the study will not affect their medical care. The consultation date in the follow-up clinics will be discussed, giving the participant an understanding of the protocol and so they allow some extra time on that day to give consent and fill out the baseline questionnaires.

### *Informed consent and baseline measures*

On the first consultation in the follow-up clinic after completion of cancer treatment, the agreed participants will be approached by the Health and Research Care Wales team or by the Bangor University researcher. Patients will be asked if they have any further questions or queries about any aspect of the study or if they need any further information. Once they agree to participate, informed consent will be obtained to confirm their voluntary participation in this study. Three copies of the consent form will be signed by the participant and the researcher, with each one retaining a copy and one copy being retained in the patient's medical records. All the patient's identifiable data and the consent forms will be stored in locked cabinets accessible only by the research team on the NHS premises.

Once the patients sign the consent forms, the baseline questionnaires will be completed in the presence of the recruiter. The baseline questionnaires will be returned to the research team at Bangor University.

### ***Randomisation***

Individual participant randomisation will be undertaken following the consent and completion of baseline questionnaires. Remote randomisation will be by an adaptive web based randomisation service managed by the North Wales Organisation for Randomised Trials in Health (NWORTH), which is an accredited trials unit. A computer generated random number sequence based on random permuted blocks of sizes 4, 6 and 8 will be used, stratified by cancer site and by hospital.

### ***Delivery of intervention***

#### *Control arm*

The recruiter (Clinical Nurse Specialist) will refer the participant to the National Exercise Referral Scheme (NERS) and will also flag up the physical activity booklet specifically in the MoveMore pack which will be given with the other cancer treatment completion information leaflets.

### *Intervention arm*

Participants in the intervention group will also be referred to the National Exercise Referral Scheme (NERS) along with specific emphasis on the physical activity booklet inside the MoveMore pack given with the other cancer treatment completion information. Additionally, the participant will also receive regular weekly physical activity motivational text messages for 12 weeks. Provision will be made to provide participants with a basic mobile phone if they are not users of one but are willing and capable of using it.

### ***Blinding***

Completion of outcome measures and data analysis will be performed blind to treatment allocation. This is a pragmatic study comparing a weekly text message based intervention and usual care, with usual care alone so it will not be possible to blind participants or their clinicians to treatment group allocation.

### ***Participant withdrawal***

All participants will remain on the trial until they withdraw consent, become unwell or physical activity becomes contra-indicated because of some other medical condition.

### ***Trial end point***

The trial will come to an end once the desired number of participants have returned the two completed questionnaires and they have been checked for validity.

### **Data Management**

A data management plan will be written to cover processes for auditing, patient protection, ensuring anonymity and monitoring quality. All the patient identifiable data as well as the consent forms will be stored on the NHS premises to ensure information protection and anonymity about their participation in the study. Outcome measure data will be stored on Bangor University premises in locked cabinets accessible by the research team only.

### *Data collection*

Two types of data will be collected during the course of the study. Firstly, patient screening for eligibility, willingness to be contacted by the research team to discuss participation in the study, and reasons for declining to participate. Secondly, patients who agree to participate in the study will complete questionnaires at two time points of the study, one at the baseline before being randomised and the second one at three months follow-up. The baseline data will be collected within the follow-up clinics on the day of their consultation. The follow-up questionnaire will either be at their regular consultations within the hospital settings or at the participants' convenient time and place.

### *Data transfer*

All participants' details will be anonymised and coded. The coded data will be recorded on an access database and will be assigned a unique trial code. Process of registration will be anonymised to ensure that outcome measurement and statistical analysis are performed blind to treatment allocation. All databases will be password protected and saved on secure university servers, accessible only by the research team conducting the trial.

### *Data sharing*

Specific dataset(s) will be shared with the members of the research group if and when required or formally requested using designated data request forms included in the data management plan. All data access requests will require chief investigator's (SN) approval. Data acquisition request forms and the dataset provided will be securely stored with details of the members making the request.

### *Data archiving*

A data archiving policy will be drafted in line with BCUHB's as well as Bangor University's data protection guidelines. This will give details about the storage of the data after completion of the study with a pertinent audit trail to allow tracking of data handling steps i.e. from raw data to the final master dataset utilised for analysis. This draft will form part of the data management plan that will also contain the storage location of hard copy data. This archive of the original data, analysis and the data tracking file will be accessible to authorised personnel of the N.WORTH only.

## **Data analysis**

### *Statistical analysis*

From population norms 30% of control group participants will have reached the public health guideline by 3 months after baseline. Group sample sizes of 25 in intervention group and 25 in control group achieve 80% power to detect a difference between the group proportions of 0.2. The proportion in intervention group is assumed to be 0.3 under the null hypothesis and 0.5 under the alternative hypothesis. The proportion in the control group is 0.3. The test statistic used is the two-sided Z test with pooled variance. The significance level of the test was targeted at 0.05. The significance level actually achieved by this design is 0.04.

### *Economic analysis*

Participants will be asked the type and frequency of contact with primary and secondary care health services during the trial period since they completed the initial questionnaires for this trial. This CSRI will be in Teleforms format, to be scanned into the trial



database. Unit costs will be obtained from national sources (Albright, Cohen et al. 2000) and local finance officers. Health economists at Bangor University will provide support for appropriate costing of services, analysis and presentation of cost data in manuscripts for publication.

### **Trial Management**

On a daily basis, the work of the study will be undertaken and coordinated by an experienced researcher based in Wrexham, North Wales. The researcher will be responsible to the chief investigator (CI) who will lead all aspects of the project, and take responsibility for ensuring adequate project management. These two will comprise the core research team and will hold monthly progress meetings to ensure that key milestones are being met. There will be quarterly Advisory Group meetings with the wider project team to ensure fidelity to the protocol and methodological soundness. An Independent Chair will be sought to ensure ongoing peer review. CI will maintain budgetary control and ensure the overall timely delivery of the research.

### **Dissemination Plan**

All publications and presentations relating to the study will be authorised by the Study Management Group. The main findings of the study will be submitted to leading international peer reviewed journals and presented at international conferences. Short project summaries, highlighting the main findings, will be disseminated to all stakeholders.

### **Discussion**

Physical inactivity is a major challenge and complexity of behaviour change is overwhelming in the literature. Proposal of the PACS feasibility trial will act as novel contribution to the follow-up care plans for adult cancer survivors, especially when the drive for physical activity promotional initiatives extends from the WHO (WHO 2010), DoH (Department of Health 2004; Department of Health 2011), local government health policies all the way to the charity sectors (Macmillan, DH et al. 2010; Macmillan Cancer Support 2011; Macmillan 2012).

This text message based intervention which is underpinned by the constructs of the Social Cognitive theory aims to modify physical activity related behaviour and improve adherence among cancer survivors. It is envisaged to be a useful, low maintenance, low resource hungry, amenable to be easily integrated adjunct to currently existing services, and can act as a novel contribution in this important area to improve cancer survivors' quality of life by helping them to reap the beneficial effects of physical activity.

This proposed feasibility trial will enable the researchers to assess the feasibility and acceptability of the intervention and to explore the recruitment challenges with concurrent

economic evaluation. The findings will inform the design of a phase III Randomised Controlled Trial for future research. The recruitment, attrition and questionnaire completion rates, together with the SD of the intervention outcomes will inform the estimation of the sample size for the future trial.

## **7.7 Conclusion**

This thesis has given an overview of the existing literature and suggests that cancer survivors are likely to benefit from engagement in physically active lifestyle behaviours. Furthermore, this thesis has raised patients' voice about their experiences of physical activity advice during their cancer journey. The concluding remarks of this thesis will be 'let the patient's voice bring the change'. The author would like to share the feelings of cancer survivors which were communicated during the focus group discussions. They expressed the feeling of 'left alone' after completing their supervised treatment plan, such as:

*"I felt like falling from a cliff on my last appointment with the consultant when he said, the results showed all clear at the end of the treatment so see you in three months' time. I said to myself, what's next?" (Female, 72 years, ovarian cancer survivor).*

The developed component of physical activity promotional intervention will be utilising a multi-pronged strategy: in the form of health professionals' involvement where they can deliver MoveMore packs to cancer patients; and can refer them to available resources such as National Exercise Referral Scheme (NERS); and the third developed component of 12 weekly text messages that can play a part in reinforcement of the physical activity advice by health professionals. Regular 'nudges' in the form of text messages, educational advice such as MoveMore Pack, and supervision via NERS is likely to help cancer patients to adopt and maintain a physically active life style. This thesis has provided a vehicle (the developed intervention) and a strategy (feasibility trial protocol) to test this hypothesis.

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## **Appendices**

## Appendix A: Original proposal PhD studentship advert by Cardiff University

### clinical epidemiology interdisciplinary research group

*'on the basis of scientific evidence...' Archie Cochrane*



CARDIFF  
UNIVERSITY  
PRIFYSGOL  
CAERDYDD

**IRG PhD STUDENTSHIP PROPOSALS 2010**

Research projects available for PhD students starting in 2010 are listed below.  
At least 3 Research Council and School of Medicine studentships will be awarded.

**TITLE:** Development of a decision support intervention for risk management options in familial breast/ovarian cancer

Effective risk management methods for women who are at high risk of breast/ovarian cancer are vital. However, complex clinical issues regarding the effectiveness and/or acceptability of prophylactic surgery and ovarian screening mean that these women face a dilemma regarding which risk management option to follow. The aim of this PhD study is to develop a preliminary decision support intervention (DSI) for women in the UK who are facing difficult decisions about risk management options in familial breast/ovarian cancer. The availability of a high-risk cohort and the close involvement of clinical collaborators on PsyFOCS (PI: Kate Brain) provide an ideal opportunity for further studies such as that proposed.

*Supervisor: Dr Kate Brain and Professor Glyn Elwyn*

**TITLE:** Development of a physical activity booklet for cancer survivors and its evaluation in a pilot RCT.

**Phase I:** Development of an evidence-based booklet for adult cancer survivors, encouraging physical activity and promoting autonomy, using systematic reviews and focus groups.  
**Phase II:** Pilot randomised controlled trial to evaluate the effectiveness of the new booklet compared with a general advice booklet:

- 1) To assess the feasibility of conducting a randomised controlled trial of the effectiveness of the new booklet.
- 2) To look for a difference in the proportion of participants who achieve a moderate level of physical activity.
- 3) To measure the difference in cancer related quality of life and readiness to change behaviour.

Cancer survivorship is a major initiative in the National Cancer Research Institute strategic plan for 2008-2013. Regular physical activity can reduce treatment associated morbidity and improve quality of life in cancer survivors. Physical activity level in the general population is low and the same or lower amongst cancer survivors. A common response to symptoms like pain, fatigue, nausea and depression is to rest and do less activity. This leads to reductions in muscle strength, functional capacity and ability to perform normal daily activities. The idea of exercising may also seem counter-intuitive to health care professionals who frequently advise rest and sleep. Simple interventions that promote physical activity in cancer survivors are needed.

*Supervisors: Dr Nefyn Williams and Prof Clare Wilkinson*

Full proposals can be viewed at: <http://www.cardiff.ac.uk/medic/irg-clinicalepidemiology/phdstudentships>  
To apply for more information on above proposals, please contact Angela Watkins email: [WatkinsA6@Cardiff.ac.uk](mailto:WatkinsA6@Cardiff.ac.uk)

## Appendix B: NISCHR study portfolio webpage



Ysgol Ymchwil  
Gofal Sylfaenol  
Cymru

WSPCR | Wales School  
for Primary  
Care Research

*Developing Excellence*

- Home
- News
- WSPCR Magazine
- Events
- Training and Development
- Funding Opportunities
- Research Themes
- Research Portfolio
- NISCHR RRGs
- Publications
- Leadership Team
- Advisors
- Useful Links
- Documentation and Resources
- Community Nursing Research
- Optometry Researcher Network
- Pharmacy
- Physio Research Network

**Title**  
Effectiveness and cost-effectiveness of patient education media about physical activity promotion among adult cancer survivors, using evidence synthesis and pilot randomised controlled trial (PhD studentship)

(Previous title: Development of a physical activity booklet for cancer survivors and its evaluation in a pilot RCT).

**Principal / Lead Investigator**  
Dr Sadia Nafees (PhD student)

**Co-Investigators**  
Dr Nefyn Williams, Professor Rhiannon T Edwards and Professor Clare Wilkinson (PhD supervisors)

**Type of study**  
Randomised Controlled Trial (Pilot)

**Summary**  
This PhD project aims to evaluate the effectiveness and cost-effectiveness of patient education media (PEM) about physical activity (PA) promotion among adult cancer survivors. It involves three stages: 1) systematic literature reviews to identify PEM and exercise interventions based on Psychological model based theories of behaviour change. 2) Focus groups to assess the acceptability of PEM 3) Pilot RCT comparing the exercise interventions & assess feasibility of Phase III RCT.

Group role / contribution

**Study sponsor**  
Bangor University

**Funder**  
BCUHB

**Total grant value**  
£17,150.00

**Start date**  
Mar/Apr 2013

**End date**  
Oct/Nov 2013

**Further Info**  
16 Nov 2012; Poster presentation of systematic review (Stage 1 of PhD project) at National Cancer Survivorship Initiative conference, London



## Appendix C: Search strategy for electronic database for systematic review

### Search strategy developed for Medline

MEDLINE (OVID) 1950 to June, week 03, 2011 searched on 18-06-2011

#### Search updated on 23-02-2014

- 1 exp neoplasms/
- 2 neoplasm\$.ti,ab.
- 3 (cancer\$ or neoplas\$ or malignan\$ or carcinoma\$ or sarcoma\$ or oncolog\$ or tumo?r\$).ti,ab.
- 4 ((carcinoma\$ or sarcoma\$ or blastoma\$) adj5 (fibro\$ or neuro\$ or medullo\$ or retino\$ or amelo\$ or lipo\$ or rhabdo\$ or osteo\$ or hepato cellular\$ or Schwann\$ or squamous or basal or adeno)).ti,ab.
- 5 (astrocytoma or glioma or Hodgkin\$ or leuk?emia or lymphoma or melanoma or mesothelioma or myeloma or non?melanoma or seminoma or teratoma).ti,ab.
- 6 or/1-5
- 7 Survivors/
- 8 Surviv\$.ti,ab.
- 9 or/7-8
- 10 6 and 9
- 11 exp Exercise/
- 12 exercise.ti,ab.
- 13 exp Exercise Therapy/
- 14 exercise therapy.ti,ab.
- 15 exp Exercise Movement Techniques/
- 16 Exercise Movement Techniques.ti,ab.
- 17 Physical Fitness/
- 18 Physical fitness.ti,ab.
- 19 physical activity.ti,ab.
- 20 (walk\$ or run\$ or jog\$ or swim\$ or cycl\$ or bik\$ or tai?chi\$ or tai?jj\$ or yoga\$ or weight?train\$ or resistance?train\$).ti,ab.
- 21 Human Activities/
- 22 human activities.ti,ab.
- 23 exp activities of daily living/
- 24 activities of daily living.ti,ab.
- 25 or/11-24
- 26 Patient Education as Topic/

- 27 patient education.ti,ab.
- 28 patient education handout/
- 29 patient education handout.ti,ab.
- 30 Pamphlets/
- 31 pamphlets.ti,ab.
- 32 exp Programmed Instruction as Topic/
- 33 Self Care/
- 34 self care.ti,ab.
- 35 Social Adjustment/
- 36 social adjustment.ti,ab.
- 37 exp Adaptation, Psychological/
- 38 adaptation, psychological.ti,ab.
- 39 (patient\$ adj5 (leaflet\$ or pamphlet\$ or hand?out\$ or book?let\$)).ti,ab.
- 40 or/26-39
- 41 economic evaluation.mp.
- 42 "Cost Allocation"/
- 43 Cost-Benefit Analysis/
- 44 "Cost Control"/
- 45 cost effective analysis.mp.
- 46 cost minimisation analysis.mp.
- 47 cost utility analysis.mp.
- 48 Health Care Costs/
- 49 health care finance.mp.
- 50 Economics, Medical/
- 51 social economics.mp.
- 52 quality of wellbeing.mp.
- 53 or/41-52
- 54 10 and 25
- 55 10 and 40
- 56 10 and 25 and 40 or 53
- 59 limit 56 to (humans and "all adult (19 plus years)")



## **List of electronic databases searched based on the search strategy developed for Medline, and adapted for them**

### **Search updated on 23-02-2014**

MEDLINE (OVID) 1950 to June week 03 2011 searched on 18-06-2011

OLDMEDLINE (OVID) 1947 to 1967 searched with updated searches on 23-02-2014

MEDLINE (R) In-process & Other Non-Indexed Citations searched on 18-06-2011

EMBASE 1980— June week 03 2011 Searched on 18-06-2011

EMBASE 1947—1979 Searched on 18-06-2011

EMBASE 1947—1973 Searched on 18-06-2011

Search updated on 23-02-2014 for EMBASE Classic 1947—1979

CINAHL – Cumulative Index to Nursing & Allied Health Literature 1982 to June week 03 2011 Searched on 18-06-2011

AMED (Allied and Complementary Medicine) 1985 to June week 03 2011 Searched on 18-06-2011

British Nursing Index and Archive 1985 to June week 03 2011 Searched on 18-06-2011

Health Management Information Consortium (HMIC) June week 03 2011 Searched on 18-06-2011

PsycINFO 1806 to June week 03 2011 searched on 18-06-2011

Inspec 1969 to 2011 June week 03 2011 searched on 18-06-2011

THE COCHRANE LIBRARY All databases June week 03 2011 searched on 18-06-2011

SIGLE 1980-2005/03 searched on 18-06-2011

Web Of Knowledge all Databases [SCI-Exp & SSI, BIOSIS Previews (With Human Studies Restriction) and ISI Proceedings]—All Time Span to June week 03 2011 Searched on 18-06-2011

## Appendix D: Quality assessment of each included study for systematic review

### Risk of bias tables of each included study for systematic review of primary studies

a) Basen-Engquist, 2006

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Low risk	Minimization (adaptive method of randomisation) to balance a number of covariates.
Allocation concealment (selection bias)	Unclear risk	Insufficient information to permit a clear judgement.
Blinding of participants and personnel (performance bias)	High risk	Pragmatic RCT comparing a lifestyle intervention with usual care.
Blinding of outcome assessment (detection bias)	Low risk	Staff conducting assessments was blinded to treatment allocation.
Incomplete outcome data (attrition bias)	High risk	Drop-outs/withdrawals 51/60 (15%), 8 withdrew after randomisation, 1 died. No method for handling missing data.
Selective reporting (reporting bias)	Low risk	No selective reporting
Other bias	Low risk	None

b) Demark-Wahnefried, 2002

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Low risk	Random assignment using software
Allocation concealment (selection bias)	Low risk	Allocation concealment remote and concealed
Blinding of participants and personnel (performance bias)	High risk	Pragmatic RCT comparing tailored info with non-tailored info
Blinding of outcome assessment (detection bias)	Unclear risk	Unclear whether telephone interventions or physical measurements performed blind
Incomplete outcome data (attrition bias)	Low risk	All included in intention to treat analysis, last observation carried forward
Selective reporting (reporting bias)	Low risk	24/543 lost to follow-up
Other bias	Low risk	None

## c) Demark-Wahnefried, 2006

<b>Bias</b>	<b>Authors' judgement</b>	<b>Support for judgement</b>
Random sequence generation (selection bias)	Low risk	Block randomisation
Allocation concealment (selection bias)	Low risk	Performed by statistician with no patient contact
Blinding of participants and personnel (performance bias)	High risk	Pragmatic RCT comparing two alternative information strategies
Blinding of outcome assessment (detection bias)	Unclear risk	Not repeated if telephone interventions or physical examinations performed blind
Incomplete outcome data (attrition bias)	Low risk	22/182 (12%) drop outs, repeated measures analysis allow for missing values
Selective reporting (reporting bias)	Low risk	?
Other bias	Low risk	None

## d) Pinto, 2005

<b>Bias</b>	<b>Authors' judgement</b>	<b>Support for judgement</b>
Random sequence generation (selection bias)	Unclear risk	No detail given
Allocation concealment (selection bias)	Unclear risk	No detail given
Blinding of participants and personnel (performance bias)	High risk	Pragmatic RCT comparing counselling with contact control group
Blinding of outcome assessment (detection bias)	Unclear risk	No detail given
Incomplete outcome data (attrition bias)	Low risk	Missing data 4/43 in counselling group handled by baseline measurement carried forward
Selective reporting (reporting bias)	Low risk	Wide range outcomes reported
Other bias	Low risk	None

## e) Vallance, 2007

<b>Bias</b>	<b>Authors' judgement</b>	<b>Support for judgement</b>
Random sequence generation (selection bias)	Low risk	Computer generated random list
Allocation concealment (selection bias)	Low risk	Sealed envelopes concealed from project co-ordinator
Blinding of participants and personnel (performance bias)	High risk	Pragmatic RCT of printed material compared with pedometer and standard recommendation
Blinding of outcome assessment (detection bias)	Low risk	Self completed outcome measures
Incomplete outcome data (attrition bias)	Low risk	Drop outs analysed using linear mixed models analyses
Selective reporting (reporting bias)	Low risk	Broad range outcomes
Other bias	Low risk	None

## f) Yuen, 2007

<b>Bias</b>	<b>Authors' judgement</b>	<b>Support for judgement</b>
Random sequence generation (selection bias)	Low risk	Computer-generated random sequence
Allocation concealment (selection bias)	Unclear risk	Insufficient information to permit a clear judgement.
Blinding of participants and personnel (performance bias)	High risk	Pragmatic RCT, comparison of two different kinds of exercises with usual care
Blinding of outcome assessment (detection bias)	Unclear risk	Insufficient information to permit a clear judgement
Incomplete outcome data (attrition bias)	High risk	Drop-outs/withdrawals 7/29 (24%), details are not reported. No details about handling the missing data.
Selective reporting (reporting bias)	Low risk	The outcome measures used were reported well within the study
Other bias	Low risk	None

### Appendix E: Outcome measures used in each study with their effectiveness

Study ID	Outcomes reported					
	Physical activity	Physical performance	Quality of life	Psychological	Diet/BMI	Pain/Fatigue
<b>PA education material vs usual care</b>						
Basen-Engquist 2006						
Demark-Wahnefried 2007						
Yuen 2007						
<b>PA education material + Telephone counselling vs usual care</b>						
Demark-Wahnefried 2006						
Pinto 2006						
<b>PA education material + PA advice vs PA advice only</b>						
Vallance 2007						
<b>PA education material + PA advice + Pedometer vs PA advice only</b>						
Vallance 2007						
<b>Key:</b>	PA Education materials were more effective than the control(s)		There was no difference between PA Education materials and control(s)		Did not report this outcome	

## Appendix F: Set of 83 theories identified as Behaviour Change Theories

This list of 83 behaviour change theories occurs in the work of Michie and her colleagues. The relevant publications come in slightly different titles as follows:

- Michie S, West K, Campbell R, Brown J, Gainforth H. (2014), *An ABC of Behaviour Change Theories*, London, UK: Silverback Publishing.
- Michie, S. (2014), *ABC of Behaviour Change Theories*, Silverback Publishing.
- Michie, S., West, R., Campbell, R., Brown, J. and Gainforth, H. (2015), *ABC of Behaviour Change Theories (Behavior Change): An Essential Resource for Researchers, Policy Makers and Practitioners*, Silverback Publishing

- (1) Action Theory Model of Consumption (Bagozzi)
- (2) Affective Events Theory (Weiss & Cropanzano)
- (3) Aids Risk Reduction Model (Catania et al.)
- (4) Behavioural-Ecological Model of Adolescent Aids Prevention (Hovell et al.)
- (5) CEOS Theory (Borland)
- (6) Change Theory (Lewin)
- (7) Classical Conditioning (Pavlov)
- (8) COM-B System (Michie et al.)
- (9) Consumption as Social Practices (Spaargaren & Van Vliet)
- (10) Containment Theory (Reckless)
- (11) Control Theory (Carver & Scheier)
- (12) Differential Association Theory (Sutherland)
- (13) Diffusion of Innovations (Rogers)
- (14) Ecological Model for Preventing Type 2 Diabetes in Minority Youth (Burnet et al.)
- (15) Extended Information Processing Model (Flay et al.)
- (16) Extended Parallel Processing Model (Witte)
- (17) Feedback Intervention Theory (Kluger & DeNisi)
- (18) Focus Theory of Normative Conduct (Cialdini et al.)
- (19) General Theory of Crime (Gottfredson & Hirschi)
- (20) General Theory of Deviant Behaviour (Kaplan)

- (21) Goal Directed Theory (Bagozzi)
- (22) Goal-Framing Theory (Lindenberg & Steg)
- (23) Goal Setting Theory (Locke & Latham)
- (24) Health Action Process Approach (Schwarzer)
- (25) Health Behaviour Goal Model (Maes & Gebhardt)
- (26) Health Behaviour Internalisation Model (Bellg)
- (27) Health Belief Model (Rosenstock)
- (28) Health Promotion Model (Pender et al.)
- (29) I-Change Model (De Vries et al.)
- (30) Information-Motivation-Behavioural Skills Model (Fisher & Fisher)
- (31) Information-Motivation-Behavioural Skills Model of Adherence (Fisher et al.)
- (32) Integrated Theoretical Model for Alcohol and Other Drug Abuse Prevention (Gonzalez)
- (33) Integrated Theory of Drinking Behaviour (Wagenaar & Perry)
- (34) Integrated Theory of Health Behaviour Change (Ryan)
- (35) Integrative Model of Behavioural Prediction (Fishbein)
- (36) Integrative Model of Factors Influencing Smoking Behaviours (Flay et al.)
- (37) Integrative Model of Health Attitude and Behaviour Change (Flay)
- (38) Integrative Model of Factors Influencing Smoking And Attitude And Health Behaviour Change (Flay et al.)
- (39) Model of Pro-Environmental Behaviour (Kollmuss & Agyeman)
- (40) Motivation-Opportunities-Abilities Model (Ölander & Thøgersen)
- (41) Needs-Opportunities-Abilities Model (Gatersleben & Vlek)
- (42) Norm Activation Theory (Schwartz)
- (43) Operant Learning Theory (Skinner)
- (44) Precaution Adoption Process Model (Weinstein & Sandman)
- (45) Pressure System Model (Katz)
- (46) PRIME Theory (West)
- (47) Problem Behaviour Theory (Jessor)
- (48) Prospect Theory (Kahneman & Tversky)
- (49) Protection Motivation Theory (Rogers)
- (50) Prototype Willingness Model (Gerrard et al.)
- (51) Rational Addiction Model (Becker & Murphy)
- (52) Reflective Impulsive Model (Strack & Deutsch)

- (53) Regulatory Fit Theory (Higgins)
- (54) Relapse Prevention Model (Marlatt & Gordon)
- (55) Risk as Feelings Theory (Lowenstein et al.)
- (56) Self-Determination Theory (Deci & Ryan)
- (57) Self-Efficacy Theory (Bandura)
- (58) Self-Regulation Theory (Kanfer & Gaelick)
- (59) Six Staged Model of Communication Effects (Vaughan & Everett)
- (60) Social Action Theory (Ewart)
- (61) Social Action Theory (Weber)
- (62) Social Change Theory (Thompson & Kinne)
- (63) Social Cognitive Theory (Bandura)
- (64) Social Consensus Model of Health Education (Romer & Hornik)
- (65) Social Development Model (Hawkins & Weis)
- (66) Social Ecological Model of Behaviour Change (Panter-Brick et al.)
- (67) Social Ecological Model of Walking (Alfonzo)
- (68) Social Identity Theory (Tajfel & Turner)
- (69) Social Influence Model of Consumer Participation (Dholakia et al.)
- (70) Social Learning Theory (Miller & Dollard)
- (71) Social Norms Theory (Perkins & Berkowitz)
- (72) Systems Model of Health Behaviour Change (Kersell & Milsum)
- (73) Technology Acceptance Model 1, 2 & 3 (Davis; Venkatesh & Davis; Venkatesh & Bala)
- (74) Temporal Self-Regulation Theory (Hall & Fong)
- (75) Terror Management Theory (Greenberg et al.)
- (76) Terror Management Health Model (Goldenberg & Arndt)
- (77) Theory of Interpersonal Behaviour (Triandis)
- (78) Theory of Normative Social Behaviour (Rimal & Real)
- (79) Theory of Planned Behaviour (Ajzen)
- (80) Theory of Triadic Influence (Flay & Petraitis)
- (81) Transcontextual Model of Motivation (Hagger et al.)
- (82) Transtheoretical Model of Behaviour Change (Prochaska & DiClemente)
- (83) Value Belief Norm Theory (Stern et al.)



## Appendix G: Patient invitation letter

### Physical Activity promotion among adult Cancer Survivors (PACS-II)

Dear .....

We are a Bangor University research group and would like to invite you to take part in a focus group discussion. This research study is for an academic qualification and is part of the chief investigator's PhD. We would like to hear about your views and experiences about the best way to encourage exercise in patients who have completed their cancer treatment. This group discussion will help us to develop a better way of encouraging physical activity and determine the acceptability of providing these messages. It will also help us to explore why some people are more physically active than others.

Please find a Participant Information Sheet attached which provides further details of the study; however you are under no obligation to take part.

**If you would like to take part:**

Please complete the attached reply slip and return it to us in the enclosed FREEPOST envelope. A researcher will then contact you.

**If you would like more information:**

Please either complete the attached reply slip indicating this and return it to us in the enclosed FREEPOST envelope, and a researcher will then contact you; or you can ring the researcher on 01978 726079.

**If you do not wish to take part**

We would be grateful if you would complete the attached reply slip indicating this and return it to us in the enclosed FREEPOST envelope. Please be assured that this will not affect the care you receive.

As a reminder, the researcher will contact you to discuss your willingness to participate in this study in two weeks' time.

Many thanks.  
Yours sincerely

Dr Sadia Nafees  
Chief investigator  
North Wales Centre for Primary Care Research  
Bangor University  
Tel: 01978 726079  
Email: [s.nafees@bangor.ac.uk](mailto:s.nafees@bangor.ac.uk)

**ATTACHED:** Patient Information Sheet, reply slip and FREEPOST envelope.

## Appendix H: Participant Information Sheet

### PARTICIPANT INFORMATION SHEET

#### Physical Activity promotion among adult Cancer Survivors (PACS-II) Study

##### **What is the purpose of the study?**

We want to ask cancer survivors about the best way to promote physical activity which is known to be beneficial. This research study is for an academic qualification and is part of the chief investigator's PhD.

##### **Why have I been invited to take part?**

We are asking a number of adult cancer survivors who have recently (or within last six months) finished their active cancer treatment to help us find different ways to encourage uptake of physical activity.

##### **Do I have to take part?**

Taking part in this study is entirely voluntary.

##### **What will I be asked to do if I decide to take part?**

If you agree to take part, a researcher will contact you via telephone and you will be invited to join a focus group. You will be offered a choice of date, time and location according to your convenience; your travel expenditures will be reimbursed. Before the start of the interview, you will be asked to sign a consent form (specimen enclosed) and given a copy to keep. The Bangor University researcher will lead the focus group discussion with input from another researcher. It will be a structured group conversation following a topic guide which will help us to cover all study related issues. The focus groups will be run in English. The group discussions will be tape-recorded and hand-written notes will also be taken. The audio recording will allow the discussion to be accurately transcribed and analysed by the researchers. The focus group will be held at university venues at three places in North Wales and you will be asked to join the nearest. The meeting will be relaxed, in a comfortable environment with light refreshments and will last no longer than 90 minutes.

##### **What are the possible disadvantages and risks of taking part in the study?**

We do not foresee any disadvantages or risks to you taking part in the focus group. However if any concerns arise, please let us know so that we can try to put things right. You can either speak to the researcher or the study supervisor, Dr Nefyn Williams (By telephone: 01978 727430, or by e-mail: nefyn.williams@bangor.ac.uk), or you may prefer to contact the cancer nurse specialist or key worker involved in your follow-up care.

##### **How do I stand to benefit from the study?**

There are no direct benefits to you as a participant. However, the study results will help us to understand how we can promote physical activity to increase awareness about its benefits. We will reimburse your travel expenses and will also provide refreshments during the meeting.

##### **Will my taking part in the Study be kept confidential?**

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2.

##### **What if I decide not to take part or withdraw later?**

If you decide not to take part, this will not affect the care you receive. You can also withdraw your consent at any stage without giving a reason. If you do withdraw, all data relating to you already collected with your consent will be used in the study. No further research procedures relating to you will be carried out.

**What if there is a problem?**

We do not foresee any circumstances where you come to harm by participating in this focus group. Any complaint about the way you have been dealt with during the study or any harm you might suffer will be addressed.

If you are unhappy about any aspect of your participation, we would ask you to tell us about this in the first instance, so that we can try to resolve any concerns and find a solution. Our contact details are below. However, if you are still unhappy or dissatisfied about any aspect of your participation, then you can contact the Concerns Team at Betsi Cadwaladr University Health Board (BCUHB, Ysbyty Gwynedd, Penrhosgarnedd, Bangor, LL57 2PW. Tel: 01248 384194, email: concernsTeam.bcu@wales.nhs.uk).

**Will my taking part in this study be kept confidential?**

All information you give us during the interview will be kept strictly confidential and secure. It will not be used for anything other than this research. Any information which leaves our research unit will have your name, address and any other identifiable information removed. It will not be possible to identify you in any report or publication of the study. If you join the study, data collected for the study will be looked at by authorised persons from the research team. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

**What will happen to the results of the Research Study?**

A copy of the final report of the study will be available from the Research Team. You will not be identified in any report or publication.

**Who is organising and funding this research?**

This research project is fully funded by Betsi Cadwaladr University Health Board (BCUHB) and is organised by Bangor University.

**Who has reviewed this Study?**

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed by other researchers in the Bangor University and by North Wales Research Ethics committee (Central & East).

**Where can I get further information?**

For more information or to discuss any concerns about this study, please feel free to contact:

Dr Sadia Nafees  
 Chief Investigator, PACS  
 North Wales Centre for Primary Care Research  
 Bangor University, Gwenfro Unit 4-7  
 Wrexham Technology Park  
 Wrexham, LL13 7YP  
 Telephone: (01978) 726079  
 E-mail: s.nafees@bangor.ac.uk

**What do I do now?**

Please express your decision on the enclosed reply slip either yes, no or need further information and send us back in the provided FREEPOST envelope. The research team will respond as per your decision.

*Please take your time to decide whether you would like to be part of the Study*

## Appendix I: The consent form

PID -

### CONSENT FORM

#### Physical Activity promotion among adult Cancer Survivors (PACS)

**Name of the researcher: Dr Sadia Nafees**

Please initial box

- |    |   |  |
|----|---|--|
| 1. | I confirm I have read and understood the information sheet dated 25/02/2013 (version 5) for the above study and have had the opportunity to ask questions.                    | <input style="width: 40px; height: 25px; border: 1px solid black;" type="checkbox"/> |
| 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. | <input style="width: 40px; height: 25px; border: 1px solid black;" type="checkbox"/> |
| 3. | I agree to take part in the above study.  | <input style="width: 40px; height: 25px; border: 1px solid black;" type="checkbox"/> |
| 4. | I agree to allow the interview to be tape recorded on the understanding that it will be kept confidential and only used for this research project.                            | <input style="width: 40px; height: 25px; border: 1px solid black;" type="checkbox"/> |

Name of Patient \_\_\_\_\_

Signature of Patient \_\_\_\_\_

Date \_\_\_\_\_

Name of Person taking consent: \_\_\_\_\_

Signature of person taking consent \_\_\_\_\_

Date \_\_\_\_\_

**Contact details: DR SADIA NAFEES, Chief investigator**

**Telephone (01978) 726079 E-mail: s.nafees@bandor.ac.uk**

**WHEN COMPLETED - ONE COPY TO PARTICIPANT, ONE COPY TO RESEARCHER FILE,  
AND ONE COPY TO PATIENT'S MEDICAL NOTES**

## Appendix J: The reply slip

### REPLY SLIP: Physical Activity promotion among adult Cancer Survivors (PACS-II)

Please return in the enclosed FREEPOST envelope. Please tick as appropriate:

- I would like to take part in the above mentioned Study. ....
- I would like more information about the Study. ....
- I would prefer not to take part in the Study. ....

Contact Details: NAME

ADDRESS

POSTCODE

TELEPHONE NUMBER

MOBILE NUMBER

EMAIL ADDRESS

PREFERREF TIME TO BE CONTACTED

## Appendix K: Topic guide for the focus groups

### TOPIC GUIDE for Focus Groups (PACS-II)

#### Physical Activity promotion among adult Cancer Survivors

##### Ice-breaker

Introduction of the interviewer(s), background and brief explanation of the process; what and why are we doing this? How long the interview might take? Encourage everyone to participate and express their views.

1. Experiences of physical activity (PA) advice or education material following cancer treatment

Have you had any experience or heard of PA advice or educational material?

If yes (Prompts):

Type (flyer/booklet/electronic/web-based)

Source (family, friends/health professionals/community workers/charities)

Event when you came across the PA advice (After cancer diagnosis, during treatment or post-treatment care)

Perceived benefits/disadvantages/shortfalls

2. What other forms of physical activity advice do you think should be available and why?

(Prompts options)

Audio/Video/Web-based/Applications for hand held devices (smart phones/tablets, etc.)

3. Experiences of physical activity/exercise

Did you do any form of exercise prior to the illness?

If yes:

How much (For example, 1-2 hours per week)

Type (walking/cycling/swimming/gym)

Location (Home/Park/gym)

Structured/under-supervision or alone

What do you think are good ways of encouraging physical activity?

Prompts (Explore different areas)

Rewards/incentives

Personal coach

Friends or family

Social network

What do you think are the obstacles to being more physically active?

Prompts (Explore different areas)

Environmental factors (Weather)

Issues of access (Local availability of facilities/Transport)

Cost – Price for gym, etc.

Social factors (Busy schedule/Local support/Loneliness/No encouragement by instructor/Personal stress of some kind)

Personal factors (Not interested in the programme/activity/Pain or discomfort when exercising/Self-conscious about my appearance)

4. Follow-up telephone counselling/support

If yes:

By whom would you like to receive a call; a physiotherapist, clinical nurse specialist, key worker or by another cancer survivor.

If no:

What could be the reason?

5. Tailored text messages to encourage exercise

## Appendix L: Approval letter from the Research Ethics Committee 4

Part of the research infrastructure for Wales funded by the National Institute for Social Care and Health Research, Welsh Government.  
Yn rhan o seilwaith ymchwil Cymru a ariannir gan y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd, Llywodraeth Cymru



**North Wales REC (Central & East)**  
G1/G2 Croesnewydd Hall  
Croesnewydd Road  
Wrexham Technology Park  
Wrexham LL13 7YP

Telephone : 01978 726377

E-mail : [tracy.biggs@wales.nhs.uk](mailto:tracy.biggs@wales.nhs.uk)

Website : [www.nres.nhs.uk](http://www.nres.nhs.uk)

01 March 2013

Dr Sadia Nafees  
Research Assistant  
Cardiff University  
NWCS, Gwenfro Unit 6/7  
Wrexham Technology Park  
Wrexham  
LL13 7YP

Dear Dr Nafees

**Study title:** Physical Activity promotion among adult Cancer Survivors (PACS-II): Focus Groups  
**REC reference:** 13/WA/0025  
**Protocol number:** GWBETJJ6X  
**IRAS project ID:** 87103

Thank you for your letter of 26 February 2013, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Mrs Tracy Biggs, [Tracy.Biggs@wales.nhs.uk](mailto:Tracy.Biggs@wales.nhs.uk).

### Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

### Ethical review of research sites

#### NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

#### Non-NHS sites

### Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Cynhelir Cydwethrediad Gwyddor Iechyd Academaidd y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd gan Fwrdd Addysgu Iechyd Powys

The National Institute for Social Care and Health Research Academic Health Science Collaboration is hosted by Powys Teaching Health Board





Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

*Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.*

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

#### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter		16 January 2013
Covering Letter		14 February 2013
Covering Letter		25 February 2013
Evidence of insurance or indemnity		09 July 2012
Interview Schedules/Topic Guides	2	12 December 2012
Investigator CV		23 January 2013
Investigator CV		
Letter of invitation to participant	3	12 February 2013
Other: Reply slip	2	12 December 2012
Other: Letter from funder		08 December 2011
Other: REC Unfavourable decision letter		07 September 2012
Other: Response to REC unfavourable letter		20 December 2012
Participant Consent Form: Focus Group	2	12 December 2012
Participant Information Sheet	5	25 February 2013
Protocol	3	10 December 2012
REC application	3	21 January 2013
Response to Request for Further Information		14 February 2013
Response to Request for Further Information		26 February 2013

#### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

**After ethical review**Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

13/WA/0025	Please quote this number on all correspondence
------------	--

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project.

Yours sincerely

*T. A. Biggs.*

P

Professor Alex Carson  
Chair

E-mail: [tracy.biggs@wales.nhs.uk](mailto:tracy.biggs@wales.nhs.uk)

Enclosures: "After ethical review – guidance for researchers"

Copy to: Huw Roberts, Bangor University  
Mrs Lona Tudor Jones, BCUHB

## Appendix M: Approval letter from the NHS Research and Development from the BCUHB



Ymchwil a Datblygu  
Bwrdd Iechyd Prifysgol Betsi Cadwaladr  
Ysbyty Cymuned Treffynnon, Ffordd Helygain, Treffynnon,  
Sir y Flint CH8 7TZ

Research & Development Office  
Betsi Cadwaladr University Health Board,  
Holywell Community Hospital  
Halkyn road, Holywell, Flintshire CH8 7TZ

Dr Sadia Nafees  
NWPCR - Bangor University  
Gwenfro Unit 4-7  
Wrexham Technology Park  
Wrexham  
LL13 7YP

**Ein cyf/Our ref:** LTJ  
**Eich cyf/Your ref:**  
**Fon/Tel:** 01352 718382  
**Gofynnwch am/Ask for:** Lona Tudor Jones  
**E-bost/Email:** [Lona.tudorjones@wales.nhs.uk](mailto:Lona.tudorjones@wales.nhs.uk)  
**Dyddiad/Date:** 25.03.2013

### PRIVATE & CONFIDENTIAL

Dear Dr Sadia Nafees

**Re: Physical Activity promotion among adult Cancer Survivors (PACS-II)**  
**Ref: 13/WA/0025 (IRAS ID 125654)**

The above research project has been reviewed by the Research Governance Panel / Internal Review Panel on 22<sup>nd</sup> March 2013 at Ysbyty Glan Clwyd Hospital.

I have pleasure in confirming that the Internal Review Panel has approved the study to proceed at BCUHB – Betsi Cadwaladr University Health Board (note NISCHR CRC staff will only be involved to identify patients)

The study should not commence until the Ethics Panel reviewing the research has confirmed final ethical approval (favourable opinion and no objection to Site Specific Assessment).

As part of the regular monitoring undertaken by the Research Governance Panel you will be required to complete a short progress report. This will be requested on a six monthly basis. However, please contact me sooner should you need to report any particular successes or problems concerning your research. Whilst the Health Board is keen to reduce the burden of paperwork for researchers failure to produce a report may result on withdrawal of approval.

All research conducted at Betsi Cadwaladr University Health Board must comply with the Research Governance Framework for Health and Social Care in Wales (November 2001). An electronic link to this document is provided on the Health Boards R&D web pages. Alternatively, you may obtain a paper copy of this document via the R&D office.

Attached you will find a set of approval conditions outlining your responsibilities during the course of this research. Failure to comply with the approval conditions will result in the withdrawal of the approval to conduct this research at the Betsi Cadwaladr University Health Board.

If you would like further information on any other points covered in this letter, please do not hesitate to contact me. On behalf of the Panel, may I take this opportunity to wish you every success with your research.

Yours sincerely

  
\_\_\_\_\_

 Dr D A Parker  
Director R&D

## Appendix N: Final questionnaire of healthcare professionals



### Macmillan N.Wales Physical Activity Project for Cancer Survivors: (PACS-III-a)

#### Physical Activity for Cancer Survivors

1: Physical activity is beneficial for cancer survivors.

strongly agree	agree	Neither	disagree	strongly disagree
----------------	-------	---------	----------	-------------------

2: It is important for health care professionals to promote physical activity among cancer patients.

strongly agree	agree	Neither	disagree	strongly disagree
----------------	-------	---------	----------	-------------------

3: I have sufficient knowledge to advise cancer patients about physical activity.

strongly agree	agree	Neither	disagree	strongly disagree
----------------	-------	---------	----------	-------------------

4: I encourage cancer patients to increase their physical activity.

strongly agree	agree	Neither	disagree	strongly disagree
----------------	-------	---------	----------	-------------------

#### National Exercise Referral Scheme

5: I am aware of the National Exercise Referral Scheme.

Yes	No
-----	----

6: I am aware that cancer patients can now be referred to the National Exercise Referral Scheme in North Wales.

Yes	No
-----	----

7: I have referred cancer patients to the National Exercise Referral Scheme.

Yes	No
-----	----

8: I would be happy to refer appropriate cancer patients to the National Exercise Referral Scheme as part of my role.

Yes	No
-----	----

9: I am aware of Macmillan North Wales Physical Activity Project.

Yes	No
-----	----

### Information about you.

10. What is your professional role?
- 10.a: If you selected Other, please specify:
- 10.b: Years of experience in your current role
- 10.b.i: If you selected Other, please specify:
- 10.c: What is your gender?

### Physical activity and you

11. During the last 7 days, on how many days did you do VIGOROUS physical activities like heavy lifting, digging, aerobics, or fast bicycling? Think about only those physical activities that you did for at least 10 minutes at a time.

12. How much time in total did you usually spend on one of those days doing VIGOROUS physical activities?

- 12.1: Please select a number under hours and minutes, even if its 0.
12. 1.a: Please select a number under hours and minutes, even if its 0. – Hours
- 12.1.b: Please select a number under hours and minutes, even if its 0. – Minutes

13: Again, think only about those physical activities that you did for at least 10 minutes at a time. During the last 7 days, on how many days did you do MODERATE physical activities like carrying light loads, bicycling at a regular pace, or doubles tennis? Do not include walking.

14: How much time in total did you usually spend on one of those days doing MODERATE physical activities?

- 14.1: Please select a number under hours and minutes, even if its 0.
- 14.1.a: Please select a number under hours and minutes, even if its 0. – Hours
- 14.1.b: Please select a number under hours and minutes, even if its 0. – Minutes

15: During the last 7 days, on how many days did you WALK for at least 10 minutes at a time? This includes walking at work and at home, walking to travel from place to place, and any other walking that you did solely for recreation, sport, exercise or leisure.

16: How much time in total did you usually spend WALKING on one of those days?

- 16.1: Please select a number under hours and minutes, even if its 0.
- 16.1.a: Please select a number under hours and minutes, even if its 0. – hours
- 16.1.b: Please select a number under hours and minutes, even if its 0. – Minutes

17: During the last 7 days, how much time in TOTAL did you usually spend sitting on a week day?

17.1: Please select

17.1.a: Please select – Hours

17.1.b: Please select – Minutes

**Suggestions or comments**

18: If you have any further comments please provide in the box below.

## Appendix O: Free text comments at the end of the online healthcare professionals' survey

### Qualitative accounts given by health professionals

<b>Competing commitments</b>	
I don't do as much exercise as I would like because of being full time. The last 7 days have been particularly busy, so no time to walk, which I usually do at the weekends. Also, since our dog died in the summer, I have not had the same incentive to walk as I had before.	Lack of time and motivation to exercise
Job has changed so now more office based and lots of time driving in the car has meant a huge rise in amount of time sitting	Nature of job limiting activity
Doing this survey has made me realise how much I do sit in a day as my role involves sitting with clients or sitting typing at a computer.	Nature of job limiting activity
I am currently pregnant therefore the amount of exercise I do at the moment is less than what I would usually do. On average I would previously engage in vigorous exercise twice a week for an hour each time.	Family commitments limiting activity, otherwise active
For question 16/17, not clear, is it total of hours for all the week or one day specific?  With small children, the only time I do sit is either in car or at work, but no time for any other exercise!	Nature of job and family commitments limiting activity
Harder to get out cycling in the winter evenings, more active in the summer. Patients would face the same problem.	Environmental conditions (weather) limiting activity, same perception about patients
I'm a GP - single handed and a single parent of 2 teenagers. I have no time nor energy to exercise.	Nature of job and family commitments limiting activity
Given the Government's wish to extend our hours in general practice further it will leave even less time for activity	Nature of job and policy change limiting activity
Would love to do more exercise but unable to fit it in!	Nature of job limiting activity
Less active than usual because of acute injury!	Health limiting activity
Job involves sitting at desk for about 12 hours each day. Would love to have more time for exercise	Nature of job limiting activity
I have a role as a professional but I am a cancer survivor and only found out about this programme through training provided to me as a professional last week. I also have disabled dependant to care for at home. Fitting in "proper" exercise is very difficult. I would not be allowed time off from work to attend any NERS type sessions.	Unaware of the referral criteria for NERS Nature of job and family commitments limiting activity
I am more than happy to discuss exercise as part of a GP consultation, unfortunately the time allotted to patients is increasingly pressurised. 10 minutes to address the patients agenda, my agenda and all the other things we are now expected to do, make it very difficult to achieve it at all and provide the perfect service which we are now increasingly expected to do. It would be possible if much more was invested in primary care in its widest definition. I would be very happy to support an expansion of community physio and exercise services generally	Supportive but time pressure in GP practice
I run 4 or 5 times a week when on leave - I was on leave last week. Can't usually find the time otherwise.	Time constraint to do exercise

<b>Lack of awareness of physical activity guidance and/or referral schemes</b>	
I find the exercise questions too limiting. My job is active but not sure how much of the time I am vigorously or moderately exercising and I have put 4 hours sitting on a week day but I have considered this to be during work hours. Could well have under or over estimated. I have found the work that Jo has done valuable but it is only the tip of the iceberg where exercise and cancer is concerned.	
In my role the majority of people I come across would potentially benefit from exercise. Unfortunately I am rarely in possession of enough information to fill in the ref form to the NERS. I do however, always guide them towards asking their GP or CNS to do it for them.	NERS aware but unable to refer because of job commitments Opportunistic promotion
I cannot answer question 4 as I don't see cancer patients, however, if I did I would	No cancer patients but would promote
I would like more guidance about who I should be referring to NERS and what considerations etc. there are for cancer patients for exercising etc.	Lack of knowledge about NERS referral criteria
I keep active before and after work as tend to do a lot of sitting and report writing/interviews/driving at work.	active
difficult to work out the different varieties of exercise i.e. aerobic , pre aerobic and moderate and also the specific times spent as it may vary from day to day and is also work dependent	Unaware of type and amount of guidance exercise
do exercise 6 times weekly various activities	active
It is important to consider all co-morbidities before referring to NERS not just their presenting condition - in this case cancer- such as blood pressure, cardiac & respiratory status.	Unaware of the referral criteria for NERS
I'm not sure what the last question meant, sorry	
I have never referred patients with a cancer diagnosis to the exercise referral scheme. I think this is because they either do not present to the GP as they are under secondary care. Additionally if they do present to me then it is for other reasons and I have therefore not thought of or not felt it necessary to promote exercise during such consultations,	GP not referring as thinks cancer is managed by secondary care
I do not work with any patients with cancer. I am a children's OT working in the community mainly with children with dyspraxic difficulties.	No cancer patients
Last week was not representative of my usual week due to Christmas holidays!	
I cycle to work daily 5 and 1/2miles approximately each way	Active-cycle to work
promoting exercise is so important	supportive
I do think there may be a correlation between attitude to exercise of practitioner and enthusiasm in promoting exercise for others. Think we all need to exercise more and not just our patients!	HPs level and promotion correlate
The last 7 days are not 'typical' in that I spent 4 days at a medical conference!	Usually active
I believe that many of these patients have much reduced reserve, and need to take their time with exercise. I generally advise that they keep moving, but do things at a slow pace to start, to avoid problems. For example, I did too much too soon after a laparotomy for bowel cancer, and then started yoga and pilates at 6 weeks post-op; I first developed a wound infection and later an incisional hernia, which I put down to too much exercise too soon.	Exercise but with caution
I am assuming that housework constitutes moderate physical activity, e.g.: vacuuming, dusting, changing bedding and doing washing.	
With regards to question 4, I don't often see cancer patients.	



## Appendix P: Developmental process of physical activity promotional messages

### Physical Activity for Cancer Survivors (PACS)

Evaluation of the physical activity motivational intervention



Thank you for your time (Please write and/or tick the appropriate boxes below)

#### Section A

Gender: Male  Female

Age: \_\_\_\_\_

Your role in today's meeting: Cancer survivor  Carer

Health care professional  Others  If others, please describe \_\_\_\_\_

#### Section B For cancer survivors ONLY

Cancer Type: \_\_\_\_\_

Information about your cancer journey:

- a) Month & Year of diagnosis
- b) Are you still under treatment? Yes  No
- c) Time since completed the treatment

*Please give us your suggestions on the developed 12 weekly physical activity motivational messages for cancer survivors. Thank you!*

Aims	Suggested message by the researcher	Refined message by the cancer survivors in focus groups	Suggested modification by members of the North Wales Cancer Patient Forum
1. To get people to think about starting to be more active	Being more active e.g. walking, gardening, etc. will help you get over your cancer treatment. Think about what sort of exercise you can do.	Group agreed	Group agreed
2. What stops you starting? It's never too late to start being active!	If you feel tired, physical activity can give you more energy. Set a goal to start this week with small steps.	Group agreed	Group agreed

Aims	Suggested message by the researcher	Refined message by the cancer survivors in focus groups	Suggested modification by members of the North Wales Cancer Patient Forum
3. To get people to think about the type of exercise/activity they could do	Plan what exercise you would like to do this week to fit in with your plans.	Group agreed	Group agreed
4. To tell them about a health benefit of exercising	Being physically active during the day helps you <b>get a better night's sleep.</b>	Being physically active during the day helps you feel better.	Being physically active during the day helps you feel better and get a better night's sleep.
5. To persuade them that there is something they could do to be more active	<b>Energetic hard work, gardening</b> or dancing are just as good as walking, cycling or swimming.	Breathing exercising, gardening or dancing are just as good as walking, cycling or swimming.	House chores, gardening or dancing are just as good as walking, cycling or swimming.
6. Encourage them to make a start, however small	Exercise and a balanced diet will keep your heart healthy and help you to maintain a healthy weight. Keep it up!	Group agreed	Group agreed
7. To explain the general health benefits of exercise	Even a small increase in daily <b>exercise</b> can help you recovery. Have you started yet? Great!	Even a small increase in daily physical activity can help you recovery. Have you started yet? Great!	Group agreed
8. To explain the benefits of activity on mental health and wellbeing	Keeping active may help to reduce tension and stress and lift your mood. Carry on!	Group agreed	Group agreed
9. To encourage exercise as a social activity	<b>Exercise</b> with a <b>friend</b> can be more fun and you can encourage each other. Keep going!	Being physically active with a friend/family can be more fun and you can encourage each other. Keep going!	Group agreed
10. To emphasise the physical benefits of exercise	Physical activity will <b>make your muscles stronger</b> and help to look after your bones and joints.	Physical activity will makes you feel fitter and help to look after your bones and joints.	Group agreed
11. To encourage them to increase levels of activity	Aim to get back to normal day to day activities and gradually increase daily <b>exercise.</b>	Aim to get back to normal day to day activities and gradually increase daily activities.	Aim to get back to normal day to day activities and gradually increase your level of physical activity.
12. To persuade them maintain exercise in the future and wish good luck	Remember staying active could help to keep you well. This is the last message, good luck for the future.	Group agreed	Group agreed

## Appendix Q-i: Disseminations from the thesis

### Publications

#### *Drafts completed*

1. Effects of physical activity promotional education materials among adult cancer survivors: a systematic review with meta-analysis (Need to update the searches and submit the manuscript to a potential journal).
2. Physical Activity for Cancer Survivors (PACS): study protocol for a randomised feasibility trial of physical activity promotional intervention for cancer survivors

#### *In preparation*

1. Role and effects of theories and models of behaviour change towards physically active lifestyle
2. Cancer survivors' perceptions about physical activity; facilitators and barriers to uptake physical activity advice: a qualitative study
3. Physical activity promotional attitudes and practices of health professionals to cancer survivors in North Wales: A questionnaire survey

### Public involvement/media

#### *Oral presentations in the UK*

- |           |  |
|-----------|--|
| July 2015 | International Festival of Public Health UK 2015, Manchester                              |
| Nov. 2014 | First annual audit Cancer Clinical Programme for Governance (CPG) Symposium, North Wales |
| June 2014 | INSPIRE, NWCPDR, Wrexham   |
| Mar 2014  | South West Society for Academic Primary Care, Bristol                                    |
| Nov 2013  | Wales Health Economist Group, Cardiff  |
| Oct 2013  | Post Graduate Research (PGR) Symposium, Bangor University                                |

#### *International oral presentations*

- |          |   |
|----------|---|
| May 2013 | Psychiatry & Behavioural Sciences, Stanford University, San Francisco |
|----------|---|

#### *Invited oral presentations in the UK*

- |           |  |
|-----------|--|
| Jan. 2015 | North Wales Cancer Patient Forum meeting, Gwersyllt                  |
| Sep. 2014 | All Wales Physical Activities project, Steering Group meeting, Powys |
| Mar. 2014 | Cancer Network Rehabilitation Advisory Group meeting, North Wales    |

#### *Poster presentations in the UK*

- |          |   |
|----------|---|
| Sep 2015 | Research showcase Bangor University and BCUHB, Bangor         |
| Nov 2013 | Wales Health Economist Group (WHEG) Meeting, Cardiff          |
| Oct 2013 | Post Graduate Research (PGR) Symposium, Bangor University     |
| Jan 2013 | British Psychosocial Oncology Society Conference, Southampton |
| Nov 2012 | National Cancer Survivorship Initiative Conference, London    |

#### *International poster presentations*

- |          |   |
|----------|---|
| May 2013 | Psychiatry & Behavioural Sciences, Stanford University, San Francisco |
|----------|---|

Social media: **Twitter**

Tweet by North Wales Cancer Patient Forum on 18<sup>th</sup> Sep 2015

The screenshot shows a Twitter notification interface. At the top, it says 'Twitter / Notifications'. The notification is from 'N Wales Cancer Forum' (verified) dated Sep 21. The tweet text reads: 'Welcome, it's my pleasure. 'In order to care & cure, we need to interact with patients''. Below the tweet, it shows it has 1 favourite and was posted at 3:00 p.m. on Sep 18, 2015. A reply from 'Sadia Nafees @NafeesSadia' is visible, dated Sep 18, with the same text: 'Welcome, it's my pleasure. 'In order to care & cure, we need to interact with patients''. The interface also shows a 'Trends' sidebar on the left with topics like #Empire, #theqinitiative, #PopelnDC, Eid Mubarak, #diversenhs, Mecca, and #LifelsWhy. On the right, there are 'Who to follow' suggestions including LymphomaResearch, SCPHRP, and Macmillan Coffee.

The poster about summary of the PhD project was retweeted by others in Oct 2015

LinkedIn








The screenshot shows a LinkedIn post by Sadia Nafees (@NafeesSadia) from October 1, 2015. The post title is 'Team work .... Journey of the PhD project! @NWCPGR Poster presented at the Research showcase, @BangorUni'. The main content is a poster titled 'Physical Activity promotional intervention for Cancer Survivors'. The poster includes a quote: 'Get active, feel good! What helps to promote physical activity?' and states that the World Health Organisation estimates that one third of the cancer burden could be reduced by taking preventive measures. The poster is divided into four quadrants: Systematic Review, Theoretical underpinning to develop an intervention, Quantitative study - online questionnaire, and Qualitative study - Focus groups. It also includes a 'Developmental process of the physical activity promotional intervention' and 'Future research directions - Feasibility randomised controlled trial'. The post has 4 retweets and 1 favourite.

This is a duplicate of the LinkedIn post shown in the previous block, featuring the same text and poster content.

## Meeting agendas

### Cancer Network Rehabilitation Advisory Group (CNRAG) Cancer CPG Cancer Rehabilitation, Health and Well Being Group

**When is it:** Wednesday 26<sup>th</sup> March , 2.30-4.30pm  
**Where is it:** Ron Smith, NWCTC, YGC, & MDT Meeting Room,  
 Shooting Star Unit, WMH, Alaw Seminar Room, YG  
 VC Dial up: 51 8826

Item	Subject	
1	Welcome, Introductions and Apologies	
2	Minutes and matters arising from previous meeting	 CNRAG Minutes 31.01.14.docx   CNRAG TOR Final.doc
3	Effectiveness and cost-effectiveness of physical activity promotion among adult cancer survivors. Dr Sadia Nafees, PhD Student and Researcher, Bangor University,	
4	Feedback from visit to Velindre Cancer Centre (JG/PP)	
5	Directory of Therapy Services and Hospices	 Copy of Cancer rehab Nightingale Hos
6	Developing an education strategy for staff not specialising in cancer	 csp_so_your_patient _has_cancer.pdf
7	A Cancer Rehabilitation MDT: How could it work in BCU?	 DRAFT Rehabilitation MDT North Wales Car
8	Referral Pathway to access cancer rehabilitation services: A holistic needs referral form? (Examples of some referral forms attached)	 7 Key Questions.doc   Referral form CENTRAL BCUHB SPC
9	Any other business	

**Next meeting: Thursday 26<sup>th</sup> June, 2.30-4.30pm**

Venues: Ron Smith Seminar Room, YGC. Alaw Seminar Room, YG. TBA, WMH.

Cancer Network Rehabilitation Advisory Group (CNRAG)  
Cancer CPG Cancer Rehabilitation, Health and Well Being Group

**2014-2015 Meeting Dates**

Date	Time	Venue
Wednesday 1 <sup>st</sup> October 2014	3.00 – 4.00pm	MDT Meeting Room, Shooting Star Unit, Wrexham Physics Seminar Room, YGC Alaw Seminar Room, YG
Thursday 29 <sup>th</sup> January 2015	2.30 – 4.00pm	MDT Meeting Room, Shooting Star Unit, Wrexham Ron Smith Seminar Room, YGC Alaw Seminar Room, YG
Thursday 30 <sup>th</sup> April 2015	2.30-4.00pm	MDT Meeting Room, Shooting Star Unit, Wrexham Ron Smith Seminar Room, YGC Alaw Seminar Room, YG
Wednesday 19 <sup>th</sup> August 2015	2.30-4.00pm	MDT Meeting Room, Shooting Star Unit, Wrexham Ron Smith Seminar Room, YGC Alaw Seminar Room, YG

VC dial up number for all meetings **51 8826**





# Fforwm Cleifion Rhwydwaith Canser Gogledd Cymru North Wales Cancer Network Patient Forum

## North East Wales Locality Group

Tuesday March 24<sup>th</sup> , 2.00 – 4.30pm

Gwersyllt Community Resource Centre, Wrexham

## AGENDA

1.	<b>Welcome, introductions and apologies</b>	
2.	<b>Appointment of Locality Group Chair / Vice Chair</b>	
<b>MINUTES AND MATTERS ARISING FROM PREVIOUS MEETING</b>		
3.1 3.2 3.3 3.4 3.5 3.6 3.7 3.8 3.9 3.10	<ul style="list-style-type: none"> <li>▪ Acceptance of Minutes</li> <li>▪ Chair / Vice Chair appointment</li> <li>▪ Mason ward</li> <li>▪ Macmillan Information and Support service</li> <li>▪ Key worker update</li> <li>▪ Support for head and neck patients</li> <li>▪ Shooting Star waiting area</li> <li>▪ Cancer awareness campaigns</li> <li>▪ <b>Interventions to promote physical activity (Dr Sadia Nafees)</b></li> <li>▪ Written information for patients at the end of treatment</li> </ul>	 \\ rypa1srvnas0001.cyr
<b>BUSINESS</b>		
4.	<b>Macmillan Palliative Care Team – your views on new project</b> Theresa Richards, Macmillan End of Life Care Facilitator	
5.	<b>News from members, including:</b> <ul style="list-style-type: none"> <li>• Manchester conference</li> <li>• Centralisation of breast surgery</li> <li>• Bowel cancer support group</li> </ul>	
6.	<b>CPF news updates</b> <ul style="list-style-type: none"> <li>▪ Communication group</li> <li>▪ Website page for North East Group</li> </ul>	 \\ rypa1srvnas0001.cyr
7.	<b>Any other business</b>	
8.	<b>Close and date of next meeting: Tuesday May 22<sup>nd</sup> 2015</b>	

## Appendix Q-ii Collaborative work

### Betsi Cadwaladr University Health Board Terms of Reference

#### **Cancer, Palliative Medicine and Clinical Haematology Clinical Programme Group Cancer Rehabilitation, Health and Well Being Group**

<b>1. Scope</b>	The Cancer CPG Cancer Rehabilitation, Health and Well Being Group will function as the Cancer Network Rehabilitation Advisory Group (CNRAG) and provide support and where necessary advice and direction to other groups/forums already developed for example Cancer Key Worker Implementation and Quality Assurance Group, Specialist Interest Groups.
<b>2. Remit</b>	<p>To provide a forum where representatives from the Cancer, Palliative Medicine and Clinical Haematology CPG, Therapies &amp; Clinical Support CPG, Surgery and Dental CPG, NWCPF, Hospice, and Primary Care and Specialist Medicine CPG can support the patient pathway.</p> <p>Key Objectives:</p> <p>1). To act as the North Wales Cancer Network's primary source of opinion on issues relating to cancer rehabilitation and to influence funding of cancer rehabilitation services.</p> <p>2). To develop and facilitate the implementation of a North Wales Cancer Network <b>Rehabilitation Service Development Strategy</b>, that links to national work and takes into account the needs of patients and carers needs throughout the cancer experience by:</p> <ul style="list-style-type: none"> <li>- Undertaking a baseline assessment of rehabilitation services, including workforce and equipment across BCUHB as a measure of current service provision</li> <li>- Agreeing BCUHB cancer site specific rehabilitation pathways in line with national work</li> <li>- Developing a cancer rehabilitation service specification</li> <li>- Developing a service needs assessment based on differences between the baseline mapping work and service specification</li> <li>- Developing a workforce, training and education strategy to support the service specification</li> <li>- Providing a rehabilitation section for each locality's cancer services directory</li> </ul>
<b>Chair Vice Chair</b>	Joanne Garzoni Mark Hall



<b>Membership</b>	<p>Physiotherapy- <b>Lizzie Evans</b>  Occupational Therapy - <b>Ann Stananought</b>  Speech and Language Therapy – <b>Sue Kirk</b>  Dietetics- <b>Jane Power/Cherry Vickery</b>  Acute Nursing- Manon Williams  Community Nursing- <b>Emma Groves/Louise Pickering</b>  NWCPF Representative- <b>Pat Evans</b>  Hospice Representative – <b>Helen Fisher/Debbie Gilman</b>  Health and Social Care Facilitator, 3<sup>rd</sup> sector – <b>Not filled presently</b>  <b>Research – Dr Sadia Nafees</b>  User representative – <b>Not filled presently</b>  Social Worker – <b>Not filled presently</b>  Pharmacy- <b>Not filled presently</b>  Psychological Care – <b>Jilly Wilcox Jones</b>  Macmillan Information Facilitator – <b>Amanda Coathup</b>  Specialist Palliative Care – <b>Mark Hall</b>  Lymphodema – <b>Tracey Tate</b>  Macmillan Development Manager- <b>Ann Camps</b></p>
<b>Secretary</b>	The minutes and actions from the meetings will be circulated to Steering Group members within one month of the meeting.
<b>Attendance</b>	The group may co-opt additional persons to attend at any time should there be a need for specific knowledge or expertise. These persons will be recorded as being 'in attendance'.
<b>Quorum</b>	5 members of the group must be present to hold a meeting to include the Chair or Vice Chair. This membership should be representative of each discipline.
<b>Frequency</b>	Meetings will be held bimonthly during 2014
<b>Authority</b>	The Group is authorised to implement the Welsh Government Cancer Rehabilitation Standards.
<b>Accountability</b>	The group will be accountable to the Person Centred Care Strategic Steering Group, and the Cancer CPG Board to provide an overview of cancer rehabilitation, health and well-being activity.
<b>Reporting Arrangements and Key Working Relationships</b>	<p>1.1 The group will report to the Cancer CPG Board and Therapies &amp; Clinical Support CPG to ensure effective communication with all relevant stakeholders.</p> <p>1.2 The Group will work in partnership with all constituent organisations and bodies across the North Wales Cancer Network. These include BCUHB, voluntary organisations, social services and other relevant agencies.</p> <p>1.3 The primary area of concern for the Group will be cancer management and other cancer-related issues, including living with and beyond cancer as covered by the <b>NICE Guidance, Supportive and Palliative Care for Adults with Cancer (2004)</b>, the <b>WG's Cancer Delivery Plan</b>, the <b>National Cancer Survivorship Initiative (NCSI)</b> and the <b>National Standards for Rehabilitation of Adult Cancer Patients</b>. Integration with wider NHS/Department of Health policy initiatives and other developing policies are important as well as links with other non-cancer rehabilitation services.</p> <p>1.4 Briefing notes of all meetings will be produced and will be circulated to members of the Cancer CPG Cancer Rehabilitation, Health and Well Being Group. Outcomes, actions arising and the discussion notes will be formally approved at the monthly meetings.</p> <p>Notes will be placed on Cancer CPG Sharepoint site.</p>
<b>Communication</b>	Cancer Clinical Programme Group and Cancer Rehabilitation, Health and Well Being Group will ensure appropriate communication systems are in place to enable feedback from the Group to be shared with the staff across North Wales