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Understanding the Importance of Therapeutic Relationships in the Development of Self-Management Behaviours After Cancer Rehabilitation: A Qualitative Mixed-Methods Study.

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of the requirements for Professional Practice Doctorate

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Abstract

This Professional Practice Doctorate research explored the importance and impact of therapeutic relationships in the development of sustainable self-management behaviours during cancer rehabilitation. This research aimed to evidence the need to preserve person-centred cancer rehabilitation. It aimed to protect local services from organisational pressures to rationalise rehabilitation through standardised, protocol driven practice.

Therapeutic relationships are an important aspect of multi-disciplinary healthcare practice. However, they receive inversely proportionate attention in the research literature. Where research exists, it has often focused on elements of the relationship, rather the entire relationship. This is likely reflective of the complexity of therapeutic relationships.

This research was undertaken in three phases alongside clinical practice. An integrative literature review was completed in parallel to semi-structured interviews, and a Modified Delphi Technique.

The results confirmed the underlying assumption that the local cancer rehabilitation service was effective in supporting the development of self-management behaviours. Participants perceived professionals' characteristics and behaviours to be a significant barrier or enabler to the development of therapeutic relationships. Therapeutic relationships were found to have significant roles or functions at different stages of cancer rehabilitation. On completion of cancer rehabilitation, the dissolution of therapeutic relationships was not consistently well managed by professionals, resulting in residual dependency or alienation. Poor participant experiences of previous therapeutic relationships may explain poor early engagement in rehabilitation, protracted rehabilitation duration and poor self-management outcomes.

These findings provide insight for decision-making around cancer rehabilitation service design and workforce skills development. This research sets the foundation for future studies to measure the impact of therapeutic relationships on self-management outcomes. These insights could also inform the design and evaluation of learning opportunities for professionals, optimising the management of therapeutic relationships. Future research would focus on how to support professionals to meet the long-term needs of people affected by cancer and other LTCs.

Declaration and Statements

DECLARATION

This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

Signed ... [redacted]... (candidate)

Date ...01/09/2020...

STATEMENT 1

This thesis is the result of my own investigations, except where otherwise stated. Where correction services have been used, the extent and nature of the correction is clearly marked in a footnote(s).

Other sources are acknowledged by footnotes giving explicit references. A bibliography is appended.

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I hereby give consent for my thesis, if accepted, to be available for photocopying and for inter-library loan, and for the title and summary to be made available to outside organisations.

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Glossary and Abbreviations

Abbreviation (if applicable)	**Term in full**	**Working Definition (if applicable)**
AHP	Allied Health Professional	Includes up to 14 distinct professions e.g.: Art Therapists, Dietitians, Drama Therapists, Music Therapists, Occupational Therapists, Operating Department Practitioners, Orthoptists, Osteopaths, Paramedics, Physiotherapists, Podiatrists, Prosthetists & Orthotists, Diagnostic & Therapeutic Radiographers, Speech & Language Therapists. Have professional titles which are recognised and protected by law; and are registered the Health and Care Professions Council.
AOS	Acute Oncology Service	Services which aim to meet the acute cancer-related or cancer treatment related problems quickly, often in secondary care settings.
CR	Cancer Rehabilitation	Cancer rehabilitation attempts to maximise patients' ability to function, to promote their independence and to help them adapt to their condition. It offers a major route to improving their quality of life, no matter how long or short the timescale. It aims to maximise dignity and reduce the extent to which cancer interferes with an individual's physical, psychosocial and economic functioning. Rehabilitation in cancer can be preventive, restorative, supportive and palliative.
	Expert	A person who is very knowledgeable about or skilful in a particular area.
H&CRW	Health & Care Research Wales	Is a national, multi-faceted, virtual organisation funded and overseen by the Welsh Government's Division for Social Care and Health Research. It provides an infrastructure to support and increase capacity in research and development and runs a number of funding schemes. It aims to generate and support excellent research to improve the health and care of people in Wales across a range of conditions and settings.
ILR	Integrative Literature Review	Please see Chapter 2 for details.

IRAS	Integrated Research Application System	Electronic system for ethics applications and research permissions.
LREC	Local Research Ethics Committee	Committee responsible for assessing ethics application.
LTC	Long-Term Condition	Also known as chronic condition.
MDT	Multi-Disciplinary Team	Healthcare team of individuals from different professions.
ModDT	Modified Delphi Technique	Please see Chapter 3 for details.
MSCC	Metastatic Spinal Cord Compression	Acute oncological emergency.
NHS	National Health Service	UK wide publicly-funded health service.
OT	Occupational Therapy / Therapist	An allied health professional who helps people overcome or adjust to disability resulting from illness, ageing or accident in order to participate in everyday tasks, roles and occupations.
PABC	Person affected by cancer	Also known as person who has received diagnosis of cancer.
PCC	Person Centred Care	Please see Chapter 1 for details.
PPD	Professional Practice Doctorate	Doctoral route where research is embedded in practice.
PPI	Patient & Public Involvement	Patient Experience and Evaluation in Research (PEER) Group is the Swansea University group responsible for providing patient and carer perspectives into the early stages and throughout research in health and care.
-	Rehabilitation Participant	A person who takes part in rehabilitation, seeking to make the most of their potential to live well before, during or after a cancer diagnosis.
-	Rehabilitation Provider	In the context of the local cancer rehabilitation setting, and this research; rehabilitation providers included: AHPs (including Dietitians, Occupational Therapists, Physiotherapists, Speech &

		Language Therapists, Therapeutic Radiographers). AHPs and nurses working in a Lymphoedema service. Exercise professionals working in the community and third sector.
R&D	Research & Development	Health Board based team responsible for supporting research.
RCOT	Royal College of Occupational Therapists	Is a registered charity which acts on behalf of all members of the British Association of Occupational Therapists (BAOT). They promote the profession, meet the professional needs of OTs in the UK, set professional standards and represent the profession nationally and internationally.
SDT	Self Determination Theory	Please see Chapter 1 for details.
SSI	Semi-Structured Interview	Please see Chapter 3 for details.
SM	Self-Management	A period of transition during which cancer rehabilitation participants, their families and professionals work in partnership to support the development of knowledge, skills and confidence. Self-Management results in being able to make informed healthcare decisions and adopt or adapt healthy lifestyle behaviours. Enabling people to live well with or after their cancer.
TR	Therapeutic Relationship	A shared personal connection and effective working partnership, undertaken with self-awareness and vigilance of impact, between participant and professional in a healthcare setting.
-	Third Sector	Charitable organisations who provide practical and emotional support for people with significant healthcare conditions. These organisations may also have political influence and also programmes for investing the start-up funding of developmental healthcare roles to influence service improvement.
UKOTRF	United Kingdom Occupational Therapy	A division of the Royal College of Occupational Therapists (RCOT) launched to support and increase research capacity within the profession.

	Research Foundation	

Chapter One: Introduction

This thesis has been submitted in fulfilment of the requirements for a Professional Practice Doctorate (PPD). The research questions underpinning this PPD were generated from observations in clinical practice. The PPD consisted of three research projects, which included an Integrative Literature Review (ILR), Semi-Structured Interviews (SSI) and a Modified Delphi Technique (ModDT).

These three research projects were all related to, and carried out during, my previous clinical role as an Advanced Practitioner Occupational Therapist (OT) in a cancer rehabilitation setting. My role has changed since the beginning of this PPD journey. Most of the analysis and thesis writing took place after I moved into a strategic Allied Health Professionals (AHPs) leadership role in the Wales Cancer Network (WCN). Where the preliminary results of this PPD were used to inform the development of strategic cancer rehabilitation priorities.

During the latest stages of thesis preparation, my role changed again. In April 2020 I started as Head of AHP Transformation with Health Education Improvement Wales (HEIW). At the time of submission, I anticipate the learning from this PPD will be invaluable in shaping a transformative conversation across a wider rehabilitation context.

1.1 Introduction to Chapter One

This chapter aims to establish a foundation for this PPD research by:

- Introducing the research aim and objectives.
- Introducing the changing cancer landscape. Including an overview of the:
    - Changes in cancer incidence,
    - Impact of the consequences of cancer or its treatments, and
    - Implications of these for cancer survivorship and rehabilitation.
- Introducing cancer rehabilitation. Including:
    - Description of the local service,
    - Working definitions of the key concepts of cancer rehabilitation, self-management and therapeutic relationships.

- Introducing the policy context in which this research took place.
- Describing the structure of this thesis to aid navigation.

1.1.1 Thesis Aim and Rationale

The cancer rehabilitation evidence base has expanded with investigations into the effectiveness of different clinical interventions. This PPD research sought to look beyond effectiveness or outcomes of rehabilitation interventions. It aimed to understand the unique role that therapeutic relationships play in the complex process of participants transitioning towards self-management (SM). Understanding how therapeutic relationships effect behaviour change may be more beneficial long-term, than focusing on what interventions to include in cancer rehabilitation.

This thesis presents PPD research which aimed to protect therapeutic relationships, a complex component of healthcare interaction. It sought to enhance professional understanding of the role therapeutic relationships play in improving clinical outcomes through supporting SM behaviour change.

To understand the importance of therapeutic relationships and their impact on long-term behaviour change after cancer rehabilitation, this research was approached from the cancer rehabilitation participants' perspective. This recognises the participants' responsibility for making and sustaining lifestyle change for long-term health and wellbeing. And reflects the changing nature of 'cancer' as more people survive their cancer diagnosis.

Participant involvement and practice-based research are two threads which will be discussed throughout this thesis. These threads were clear at the outset of this PPD study and helped shape the design and conduct of the research reported in this thesis.

This thesis presents a three phase programme of PPD research which explored participants' perceptions of the importance and impact of therapeutic relationships on their development of SM outcomes during cancer rehabilitation. The PPD aims were broken down into research questions which related to:

- Participants' experiences of the barriers and enablers of therapeutic relationships,
- Participants' perceived importance or relevance of therapeutic relationships,

- Potential mechanism through which therapeutic relationships might influence the SM process or outcomes.

The research questions which were used to inform the ILR are presented in Section 2.1.3. The research questions which informed the SSI and ModDT are presented in Section 3.2.

Over the last ten years the National Health Service (NHS) in Wales has faced greater challenges to manage increasing demands on service whilst simultaneously delivering cost savings. This has resulted in subsequent organisational pressure to adopt rationalised pathways and protocol-driven practice. These pathways offer the benefits of predictable cost and uniform provision of practice (Imison, Sonola, Honeyman, & Ross, 2014). The policy context is explored further in Section 1.4.

Self-management behaviours are increasingly important for empowering people who are learning to live with the consequences of disease or treatment after a cancer diagnosis. Therapeutic relationships may be integral to the development of these SM behaviours. By demonstrating the value of therapeutic relationships, this PPD aimed to add weight to the argument to protect person-centred models of practice, and reinforce the need to configure services according to local need (Imison et al., 2014).

1.1.2 Key Concepts Relevant to this Study

A glossary of terms, working definitions and abbreviations have been collated and can be found before this opening chapter for ease of reference. Some of the key concepts within this thesis are complex and do not all have the benefit from clinical consensus around definition. A concept map demonstrating the inter-relationships between the concepts integral to this PPD can be found in Appendix 1. These concepts include:

- Cancer survivorship (Section 1.2.3)
- Cancer rehabilitation (Section 1.3.1)
- Self-management (Section 1.3.2)
- Therapeutic relationships (Section 1.3.3)

How these concepts are applied within clinical practice may vary depending on local interpretation. It is for these reasons, that it was deemed important to provide clarity around how these concepts have been defined, interpreted and applied within the context of this PPD research. Each definition is accompanied by a brief discussion around how these definitions were decided upon and can be found in the relevant sections listed above.

In addition to the key concepts, throughout this PPD research, and this thesis, there are other terms which I would like to introduce. The first is ‘healthcare or rehabilitation participant’, which has been used to identify those people who took part in either healthcare services or cancer rehabilitation. This term recognises that participants were not passive recipients of therapeutic interventions. Subsequently, the term ‘research participant’ has been used in preference to ‘research respondent’, or ‘subject’, for the same reason.

These terms replace the common identifiers used for participants in healthcare and rehabilitation including ‘patient’, ‘service-user’, ‘consumer’, or ‘client’. Although the last three identifiers claim to underpin person-centred care, it was felt that they did not adequately reflect the active participation with which people engaged in either the local cancer rehabilitation service or this PPD research study. Neither did these terms reflect the reciprocal nature of therapeutic relationships.

Throughout this chapter, the working definition for each of the four key concepts will be presented alongside the background, historical and policy contexts underpinning this PPD research.

1.2 Introduction to the Changing Cancer Landscape

The following describes a brief overview of the changing trends that have taken place within the cancer landscape over the past ten years. This overview includes a summary of cancer incidence and prevalence, a discussion relating to the consequences of cancer or its treatment and an introduction to concept of cancer survivorship.

The background to cancer rehabilitation is resented in Section 1.3. This overview aims to describe how cancer rehabilitation had already adapted in response to changes in cancer. It also offers suggestions as to how the most recent trends might affect the future provision of cancer rehabilitation. The local cancer rehabilitation service was established in line with the emerging cancer rehabilitation evidence base and relevant policy. A brief description of the local service model in Section 1.3.4, aims to provide an orientation to the practice-based context where this PPD research was conducted.

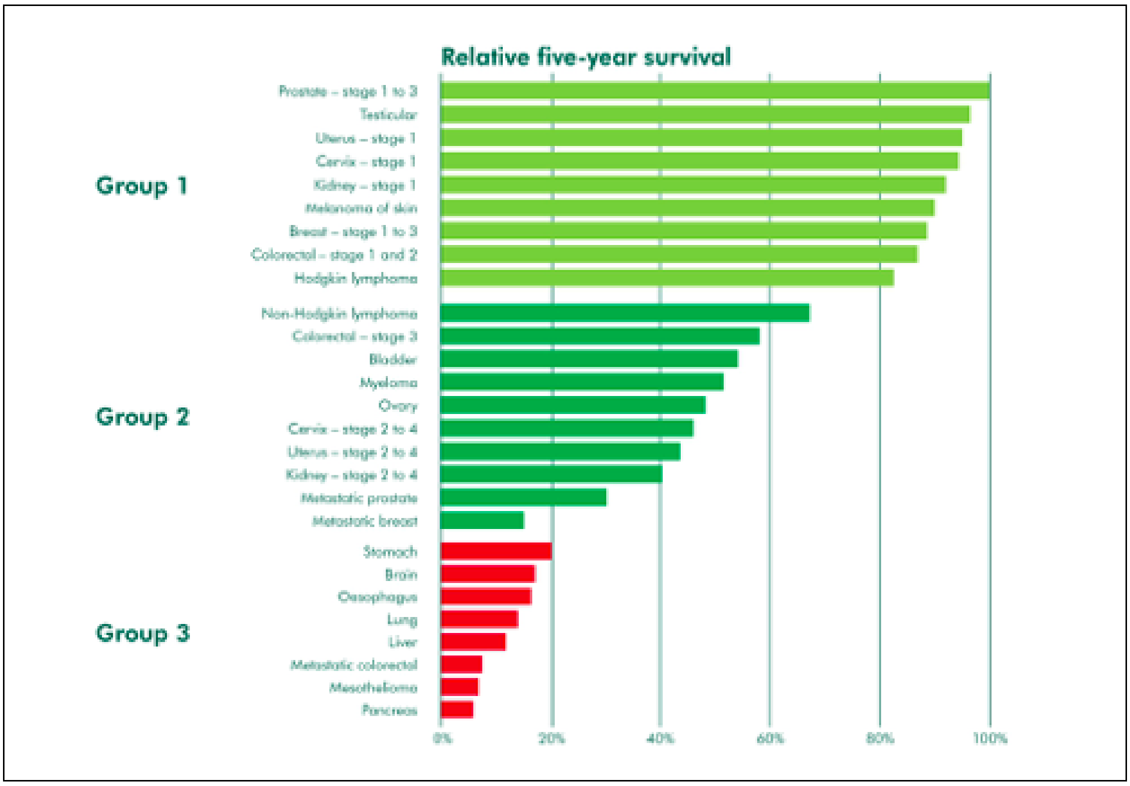
1.2.1 Background to Cancer Incidence and Prevalence

The rising incidence of cancer is a global challenge, with predictions of 68% increase in people diagnosed with cancer worldwide by 2030 (IARC, 2014). In recent years, the estimated incidence has risen from one in three, to one in two people born after 1960 in the United Kingdom (UK), now being likely to develop cancer at some point in their lifetime (Cancer Research UK, 2014a). In Wales, there were over 19,000 new diagnoses of cancer registered in 2015, representing a 10% increase in incidence from the previous decade (Welsh Cancer Intelligence & Surveillance Unit, 2016). This trend is predicted to continue through to 2035 in the as the population ages (Smittenaar, Petersen, Stewart, & Moitt, 2016). As the number of people diagnosed with cancer rises, so will the potential need for cancer rehabilitation services as more people survive their cancer treatment(s).

As a result of improvements in screening programmes and increasingly effective cancer treatments, five-year survival rates have nearly doubled, in some populations, over the past forty years. The picture in Wales is variable, reaching over 90% chance of 5-year survival for some across tumour sites. However, there is approximately 50% chance of successfully achieving five-year survival, across all tumour sites (Cancer Research UK, 2014b).

Cancer survivorship is complex construct and is discussed in more detail in Section 1.2.3. McConnell, White, and Maher (2015), proposed that there were three broad categories of cancer survivorship (See Figure 1). Many of those people in Group 1, with the highest relative 5-year survival, may expect to live for decades. The people in Group 2, may most closely resemble non-cancer Long-Term Conditions (LTC) populations. And for those people in Group 3, survival is often of short duration.

Figure 1. Three Categories of Cancer Survivorship



The impact, or the consequences, of the disease and or its treatments will also vary for each group, resulting in different demands on cancer rehabilitation, palliative care and wider support services. Increases in the survivorship population, especially Group 2, has the potential for this population’s needs to go unmet if dedicated cancer rehabilitation services are not available, or place existing cancer rehabilitation services under pressure to meet the rising demand of the long-term consequences of cancer which characterise this group.

1.2.2 Consequences of Cancer and Cancer Treatments

As cancer survival improved, the need to describe the impact of a cancer diagnosis and associated treatments on the health and wellbeing of individuals was prioritised by the National Cancer Survivorship Initiative (Department of Health, Macmillan Cancer Support, & NHS Improvement, 2010). The phrase ‘consequences of cancer or its treatments’, describes a wide range of short-, medium-, long-term, or late-onset effects of either the disease or its treatments. Many of which are distressing and can affect a person physically, emotionally, and socially. These consequences do not necessarily refer to acute treatment side effects, or peoples’ needs associated with end of life care.

The cancer survivorship population is heterogenous in terms of the impact of cancer or its treatments on health and quality of life. This is because the range of treatments is diverse and prescriptions differ depending on disease type, site, stage and individual health status (Cancer Research UK, 2019). Some of the consequences include, fatigue, physical disability, changes to body image due to severe scarring or disfigurement, altered ability to communicate, incontinence or sexual dysfunction. The impact of any of these consequences can include loss of life roles, social isolation and financial hardship. Also, there is an increased risk of developing a subsequent cancer, or other health condition which may present after a significant delay. For some people receiving certain anti-cancer treatments there is also a higher risk of post-treatment cardiac complications (Macmillan Cancer Support, 2013b).

Survivorship is not a straightforward, post-treatment phase. It is a complex time when people are learning to live with the, often unexpected, after-effects of their disease or its treatments (Macmillan Cancer Support, 2013b). Whilst estimating the number of people who will experience consequences of their cancer or treatment remains a challenge, some trends have been reported. For example, Bennett et al. (2016), identified that cancer related fatigue may affect up to 90% of people with a cancer diagnosis.

There is an additional factor to make the experience of cancer more challenging for many. Parkin, Boyd and Walker (2011), estimate up to 40% of cancers are related to lifestyle factors including poor diet, and inactivity. Both of which are contributory factors for several non-cancer LTCs. Findings from a Macmillan Cancer Support (2015) report, suggest that approximately 70% of people diagnosed with cancer are living with at least one concurrent LTC.

Global trends in obesity, ageing, and multi-morbidity compounds the challenge faced by cancer survivors, when coping with the physical, emotional and social consequences of their cancer or its treatments. Healthcare organisations will need to consider adapting their approach to meeting the needs of the cancer survivorship population, if they are to continue to be able to do so into the future. This highlights the importance of the cancer survivorship agenda, which aims to encourage healthcare professionals to view cancer survivorship through a LTCs lens

(Department of Health et al., 2010). The following explores this complex concept of cancer survivorship in more detail.

1.2.3 Cancer Survivorship

Cancer survivorship is a complex and evolving concept in multi-disciplinary cancer practice. There has been increasing need for multi-disciplinary research to understand how we can better support the health and wellbeing of people affected by cancer (PABC), as more people survive their diagnosis (Feuerstein, 2007). The following discussion intends to illustrate the complexity surrounding the definition of cancer survivorship and provide a context-specific definition of the participant cohort relevant to this PPD research (Khan, Rose, & Evans, 2012).

Defining cancer survivorship is complex and has been approached predominantly from two perspectives. The first is a temporal approach, based on identified time points on the treatment pathway when survivorship starts and stops. Common starting time points include the end of active treatment, or five years post diagnosis (Khan, Rose, et al., 2012). It has been less easy to identify a definition for the end point of survivorship, assuming that there is one. Truant, Kohli, and Stephens (2014, p. 169), identified literature which described survivorship lasting for the “remainder of one’s life”. However, Khan, Rose, et al. (2012), suggest that people receiving end of life care are excluded from the survivorship cohort by many researchers and authors.

The second perspective appears to adopt a conceptual approach which relates to a phase of the cancer pathway. In this view, survivorship is used as a collective name for cohorts of individuals who have had a wide range of cancer experiences. For example, survivorship might be seen to include any and all individuals who are symptom-free but would benefit from preventative support to reduce the risk of recurrence or subsequent disease. Survivorship might also be individuals who need to learn to live with the long-term consequences of their disease or treatments. Individuals who need to manage the impact of a late-onset consequence of their cancer or treatment might also be considered cancer survivors. Finally, the family or friends of someone diagnosed with cancer are sometimes also described as cancer survivors (Aziz & Rowland, 2003; Hebdon, Foli, & McComb, 2015).

Both approaches pose challenges, one of which is the risk of alienating PABC who do not identify with, or meet the eligibility criteria described by these two perspectives (Khan, Harrison, Rose, Ward, & Evans, 2012). The vision defined by the National Cancer Survivorship Initiative included “those who are undergoing primary treatment, those who are in remission following treatment, those who are cured, and those with active or advanced disease” (Department of Health et al., 2010, p. 21). This is the definition used by the local rehabilitation service in practice as it was inclusive of the wide range of people who accessed the local rehabilitation service. This offered an inclusive view of survivorship which informed the following working definition used throughout this research:

> *Any phase of care when people who have received a diagnosis of cancer, are learning to live with the consequences of their disease and/or its treatments; or when people are working towards defining a new normal for their future. This is irrespective of the length of their prognosis or the presence, absence or severity of their disease.*

Family and informal caregivers were not included in this working definition. Whilst family and friends are important in supporting cancer rehabilitation participants, their role and influence on rehabilitation outcomes, SM and survivorship is complex and was outside the scope of this research.

Within the context of this PPD research, cancer survivorship was viewed as a mind-set, or a state of participation, activation or empowerment relevant to a therapeutic encounter. It was not seen as a phase of care or a clearly defined cohort with strict criteria. This approach embraced the potential for the partnership between healthcare participants and professionals to share responsibility for care planning and provision.

Cancer rehabilitation supports the diverse physical, emotional and social needs of cancer survivors, making the most of participant motivation, capability and opportunities to self-manage all stages of the cancer pathway (Michie, van Stralen, & West, 2011). In the context of this PPD research, it was seen as being ideally placed to support people to make the necessary adjustments to the consequences of cancer or its treatments. Cancer rehabilitation offers a vehicle through which a person-centred approach to meeting survivorship needs could be available, at all stages of the cancer pathway.

Cancer rehabilitation is also an ideal environment to introduce SM of pre-existing LTCs, and support people to identify lifestyle changes that can reduce their risk of subsequent or recurrent disease. More detail regarding SM is presented in Section 1.3.2. In doing this, cancer rehabilitation is a practical step away from traditional care models which may have fostered participant dependency upon professionals (Palumbo, 2016). The following Section 1.3 explores cancer rehabilitation and related key concepts in more detail.

1.3 Introduction to Cancer Rehabilitation and Related Concepts

As described in Section 1.1.2 the key concepts relating to the PPD research reported in this thesis can be complex because of their lack of consensus and inter-relatedness (Appendix 1). The purpose of this section is to provide some clarity around these concepts and how they have been interpreted in the context of this PPD research. A description of the local cancer rehabilitation service and its place in the wider health setting aims to orientate this research, recognising that, at the time that this PPD research commenced, dedicated cancer rehabilitation services were not common in Wales.

Section 1.3.1 starts with a discussion of cancer rehabilitation including the working definition used in this research. Section 1.3.2 explores how SM fits into the cancer rehabilitation and cancer survivorship agendas. Section 1.3.3 explains the potential role of therapeutic relationships in supporting SM during cancer rehabilitation and how the definition has been interpreted for this PPD research. Section 1.3.4 presents an overview of the local service and its place within the wider health setting.

1.3.1 Cancer Rehabilitation

Cancer rehabilitation refers to a complex set of interventions, tailored to meet the needs of individuals who experience a decline in their physical or psychosocial ability to undertake daily activities or life roles at any point following a diagnosis of cancer (Craig et al., 2008; Korstjens et al., 2008). Pearson and Twigg (2013), defined cancer rehabilitation by highlighting its key features. These features included the use of a multi-disciplinary approach, meeting the functional impact of cancer as the focus for treatment, and the goal to optimise participation in daily life.

Their definition was based on guiding principles of rehabilitation highlighted by Dietz (1980), who introduced four cancer rehabilitation approaches. These include preventative rehabilitation which aims to prepare people with a cancer diagnosis for treatment (Li et al., 2013; Morris et al., 2009; van Weert et al., 2008). Restorative rehabilitation aims to facilitate recovery after cancer treatment (van Weert et al., 2008). Supportive rehabilitation aims to balance making the most of individuals' potential as they learn to adapt to residual functional limitation (De Lisa, 2001). Palliative rehabilitation aims to reduce the impact of symptoms and support people to optimise quality life as they approach end of life care (National Institute for Health & Care Excellence, 2004).

In the UK, cancer rehabilitation has been more closely aligned with palliative care than oncology services (National Institute for Health & Care Excellence, 2004). There is a level of congruence between the philosophy of palliative care and cancer rehabilitation. Many of the outcomes, interventions and tools used in the optimisation of function, improvement of wellbeing and quality of life may also be similar to both settings. However, the rehabilitative intent, the way in which the tools are used and the approach adopted by professionals from each speciality may be very different (Silver et al., 2015).

The National Cancer Survivorship Initiative (Department of Health et al., 2010), raised the profile of cancer rehabilitation outside of the palliative care context. This work highlighted the potential for rehabilitation to prepare people for cancer survivorship (Foster et al., 2014). Where the role of rehabilitation for other non-cancer services, such as stroke, cardiac and pulmonary conditions, appears to have been better understood. There has been more service development than in cancer despite equal need for rehabilitation.

This lack of parity of esteem for cancer rehabilitation also recognised that a predominantly palliative, post-treatment approach to cancer rehabilitation was not the best placed to prepare the increasing cancer survivorship population (Robb & Davis, 2015). The authors called for a transformational shift in health and social care practice. Their vision sought to inspire the development of services which embed a person-centred, holistic approach to cancer rehabilitation. They recognised the need for this transformation to be underpinned by a robust evidence base (Robb & Davis, 2015).

The last decade has seen an increase in research evidence exploring the use of rehabilitation programmes across the cancer pathway (Mewes, Steuten, Ijzerman, & van Harten, 2012; Oldervoll, Kaasa, Hjermstad, Lund, & Loge, 2004; D. A. Scott et al., 2013; Silver & Baima, 2013; van Weert et al., 2010). This burgeoning evidence base suggests that cancer rehabilitation offers a clinically effective way to meet the needs of the cancer survivorship population, demonstrating both physical and psychosocial benefits (Mewes et al., 2012; Oldervoll et al., 2004; D. A. Scott et al., 2013; Silver & Baima, 2013; van Weert et al., 2010). However, defining a framework which describes optimal service provision models, evidence-based interventions, and timing of cancer rehabilitation along the cancer treatment pathway, for maximum impact, remains work in progress (Gamble, Gerber, Spill, & Paul, 2011). The gap between the evidence base and service provision was evident at the time this PPD research commenced (Silver et al., 2015).

The evidence base was increasingly supportive of two particular shifts in practice. The first was a move towards earlier rehabilitation intervention, adopting a preventative approach to cancer rehabilitation known as prehabilitation. It was not within the scope of this thesis to explore prehabilitation in any detail beyond acknowledging the emerging evidence base recommending a move away from historic reactive restorative practice (Li et al., 2013; Silver & Baima, 2013). The second was to increasingly aim to support the development of participant SM as a key outcome of cancer rehabilitation. Self-management is a key concept related to this PPD research and will be discussed in more detail in Section 1.3.2.

1.3.1.1 Defining Cancer Rehabilitation

The following definition of cancer rehabilitation, published in the national cancer rehabilitation standards for Wales, was adopted by the local cancer rehabilitation service. It was also accepted as a comprehensive representation of cancer rehabilitation for use in this PPD research.

> *"Rehabilitation attempts to maximise patients' ability to function, to promote their independence and to help them adapt to their condition. It offers a major route to improving their quality of life, no matter how long or short the timescale. It aims to maximise dignity and reduce the extent to which cancer interferes with an individual's physical, psychosocial and economic functioning'…'Rehabilitation in cancer can be preventive, restorative, supportive and palliative" (Welsh Assembly Government, 2010, p. 5).*

This definition adopts the foundation of cancer rehabilitation published by the Guidance for Supportive and Palliative Care National Institute for Health & Care Excellence (2004), whilst recognising the complexity of need, and importance of adopting different approaches to rehabilitation, as described by the model of cancer rehabilitation published by Dietz (1980). Supporting cancer rehabilitation participants to make the most of their potential, at any point on the cancer treatment pathway, and self-manage their condition long-term, were the primary aims of the local cancer rehabilitation service. The following section explores the concept of SM in more detail.

1.3.2 Self-Management

Self-management is a term often used alongside words like education, programme or support, to denote structured, time-limited programmes designed to help people to learn to live well with a LTC. These programmes provide disease-related education, promote active self-monitoring and teach people to become proficient in self-care skills e.g. medication administration (Lorig, 2003). This psycho-educational approach to teaching people with LTC, including cancer, the knowledge and skills to help them to manage their conditions (Department of Health, 2001), may or may not occur within a rehabilitation setting (Korstjens et al., 2008).

A second view of SM refers to the impact of collaborative partnerships between healthcare professionals and participants. The partnership allows for the individualisation of support that enables healthcare participants to make informed decisions, adapt their behaviour and manage their health and wellbeing (de Silva, 2011). This approach suggests that SM might be more accurately considered an outcome of cancer rehabilitation, not an intervention.

Of these two views of SM, the second was closest to the approach adopted by the local cancer rehabilitation service. The remainder of this section aims to describe some of the tensions surrounding SM and its application in practice. It presents a working definition of SM to clarify how the concept was interpreted and applied within this PPD research.

The dual use of the term self-management, referring to both a portfolio of techniques and tools, and an outcome of a vital shift in the participant-professional relationship (de Silva, 2011), is likely to contribute to the lack of clarity around the concept.

Interventions which focus on the development of self-efficacy, have shown greater promise for long-term benefits for people living with LTC, compared with those which focus on education, skills development and self-monitoring (McCorkle et al., 2011).

There is an underlying assumption in the SM paradigm described by (Boger et al., 2015), that most people with a LTC are confident and capable to manage their condition most of the time. This suggests that interaction with healthcare professionals should only occur if there is a change in either the condition, or the person's ability to manage it. Foster, Brown, Killen, and Brearley (2007), remind professionals that SM is a dynamic process, through which people learn to negotiate a state of optimal living, striking a balance between the diagnosis and daily life. There are similarities between SM and cancer rehabilitation in respect to the dynamic nature of change. These authors caution professionals to avoid attaching value judgements to SM. There is a delicate balance to be achieved between promoting lifestyle behaviour change which supports health and wellbeing and enabling a person to live life their way.

1.3.2.1 Defining Self-Management

For the purpose of this PPD research, the following working definition of self-management has been informed by the discussions above.

> *'A period of transition during which cancer rehabilitation participants, their families and professionals work in partnership, to support the participants' development of knowledge, skills and confidence, to make informed healthcare decisions, and adopt or adapt healthy lifestyle behaviour, to enable them to live well with or after their cancer'.*

1.3.2.2 Models of Self-Management

Koch, Jenkin, and Kralik (2004), describe three models of SM. These include medical, self-agency and collaborative models of SM. The first model, medical self-management, can be described as often occurring soon after diagnosis, when people have much to learn about their condition. The self-management aspect of this model is reflected through compliance with professionally devised treatment plans and recommendations. This model is largely professionally led and allows little accommodation for individual context.

The second model, self-agency, can be described as the ownership some people take over healthcare decision making, which creates habits and routines to create order and cope with LTCs. At times, this model sees people choosing not to accept professional recommendations, being selective in information sharing with professionals, and actively researching latest developments in the management of their condition. This model reflects the lived experience of the LTC, and the internal locus of control held by the person experiencing it. However, it risks a person making poorly informed decisions if they do not feel able to engage in effective partnerships with healthcare professionals if the need arises. The overall aim is not to reduce the overall contact between people with LTCs and healthcare services, but to create a more proactive partnership which reduces the need for crisis intervention (de Silva, 2011).

The third model, collaborative self-management, can be described as utilising a partnership between professional and participant, to make the most of the person's actual (self-agency), and perceived (self-efficacy) ability to input into designing and managing their own care (Bandura, 2000). The collaborative model reflects the complementary contributions from both professionals and participants. It is congruent with the aims and objectives of cancer rehabilitation and provides scope within the model for people to choose not to accept professional advice or guidance. The collaborative model was the closest description of self-management that was implemented in the local cancer rehabilitation service.

van de Bovenkamp and Dwarswaard (2017), suggest that SM is not a dichotomy, and is best viewed along a sliding scale. They propose that individuals will personalise how they engage in SM. Personalisation includes selecting the type behaviour changes and the extent or level to which they change, so that their results aligns with their beliefs and values. Participant ownership over this personalisation of SM may be a key consideration for understanding what influence therapeutic relationships might have on rehabilitation outcomes.

Findings from the most recent national patient experience survey indicate that there is room to improve the therapeutic relationship between healthcare professionals and PABC in Wales (Quality Health, 2014). This suggests that not only will participants need to learn how to engage in more collaborative partnerships, but a significant adjustment to how therapeutic interactions are conducted by healthcare professionals will also be required (Jones, Livingstone, & Hawkes, 2013).

Lorig and Holman (2003), suggest that there are five core skills required for effective SM. These include, problem solving, informed decision making, use of resources, translating decisions into actions and active participation in therapeutic relationships. Implicit in this discussion around SM skills is an expectation that rehabilitation participants may need to engage in a process of lifestyle behaviour change. The following presents a brief overview of the relevance of behaviour change theory within the SM context.

1.3.2.3 Behaviour Change

Behaviour change is a challenging speciality in health, which aims to reduce the impact of health risk behaviours that contribute to poor health or disease. At times, it can be difficult to discern if behaviour change is the process or the outcome of an intervention (National Institute for Health & Care Excellence, 2014). The speciality is underpinned by a complex theoretical landscape which describes the intrinsic and extrinsic factors which can either reinforce or undermine behaviour change (Davis, Campbell, Hildon, Hobbs, & Michie, 2015).

As discussed earlier in Section 1.3.2, not all SM requires behaviour change. However, for those people whose lives might be enriched by adopting change in their lifestyle, making behavioural change is part of the SM process. Health behaviour change is a dynamic process, whereby participants' fundamental psychological needs are considered instrumental in achieving sustainable change (Ryan, Patrick, Deci, & Williams, 2008).

Self Determination Theory (SDT), proposes that for behaviour change to be successful, a person must feel that their psychological needs for autonomy, competence and relatedness must all be addressed. It is for this reason that SDT was used to inform the theoretical foundation for this PPD research. One of the three psychological needs, relatedness, the fundamental human need to relate to others was interpreted as encompassing the participant-professional connection in practice (Deci & Ryan, 2012). How this concept of relatedness correlates with the therapeutic relationship is described in Section 1.3.3.3. A more detailed discussion around SDT is presented in Chapter 3.3.3.

In this discussion, therapeutic relationships have been described as either a key skill, or pivotal part in the process of successfully supporting the development of SM after cancer. Like SM, there are a range of views regarding the definition of therapeutic relationships. There is also debate around the mechanism through which they might support SM outcomes including lifestyle behaviour change. The following section explores therapeutic relationships in more detail and presents a working definition.

1.3.3 Therapeutic Relationships

The term ‘therapeutic relationship’ appears in nursing, medicine, psychotherapy, rehabilitation and OT literature, reflecting its applicability across a range of healthcare professions and settings. Therapeutic relationships are complex constructs, their impact is not well understood. However, they are believed to improve participant engagement in treatment (Bonsaksen, Vollestad, & Taylor, 2013), and influence treatment outcomes (Gelso, 2014), and are the cornerstone of person-centred care (McCormack & McCance, 2006). A more detailed discussion of person-centred care will follow in Section 1.4.1.

The therapeutic relationship is perceived as fundamental to OT practice. Ideally built through a reflexive process whereby healthcare professionals consciously engage personal attributes and behaviours to develop therapeutic relationships with participants. It is seen as the crucial process through which therapy is made relevant and meaningful to the individual, that behaviour change is enabled, and therapeutic outcomes facilitated (Finlay, 2004). In addition to achieving goal-related physical rehabilitation outcomes (Hall, Ferreira, Maher, Latimer, & Ferreira, 2010), additional key benefits of adopting this approach in practice, is the potential to facilitate the development of confidence and self-esteem by reducing anxiety (Holmqvist, Holmefur, & Ivarsson, 2013).

‘Therapeutic relationship’ is a term which appears to be used interchangeably with professional, or nurse-patient relationships (Dowling, 2006; Hill, Paley, & Forbat, 2014), caring relationships (McCormack & McCance, 2006), physician-patient relationships (Emanuel & Emanuel, 1992), therapeutic, helping or working alliances (Martin, Garske, & Davis, 2000), therapist-patient relationships (Hall et al., 2010), and intentional relationships (Bonsaksen et al., 2013; Taylor, 2008). It is also important to make a distinction between therapeutic relationships and therapeutic-use-of-self (TUOS).

1.3.3.1 Therapeutic-Use-of-Self

As therapeutic relationships are more than working alliances, they are also greater than the sum of therapeutic tools and techniques employed by a healthcare professional to facilitate change (Gelso, 2014). Although there is interface between therapeutic relationships and therapeutic-use-of-self, the constructs are different. This section aims to briefly highlight these differences at a high level, to clarify the scope of therapeutic relationships within this research.

An OT is required to develop an awareness of the impact of their own personal characteristics and behaviours on their therapeutic relationships. The therapeutic-use-of-self sees the professional's deliberately manipulate these characteristics and behaviours to effect change during the therapeutic process (Holmqvist et al., 2013). There are three intentions of the therapeutic-use-of-self.

The first is the creation of trust. The second is guiding rehabilitation participants to take control over their treatment by supporting self-awareness and setting realistic goals. The third is facilitating emotional adjustment to changing circumstances (Holmqvist et al., 2013; Taylor, Lee, Kielhofner, & Ketkar, 2009). This has been interpreted as the 'professional self' being consciously used as a tool or technique, to be used if and when clinically appropriate. The therapeutic-use-of-self is another construct which is not always well defined, but it has been considered both a process and an outcome of OT and is largely dependent on the therapeutic relationship (Solman & Clouston, 2016).

This brief overview of therapeutic-use-of-self has been provided for two reasons. The first is to help clarify the concept of what is, and is not, included under 'therapeutic relationships'. The second is to provide some background detail to support the decision to amend the integrative literature review (ILR) search strategy after the 'a priori' protocol had been published. Further detail regarding the changes made to the ILR are discussed further in Chapter 2.2.

1.3.3.2 Model of Therapeutic Relationships

Gelso (2014), presents a comprehensive model of therapeutic relationships in psychotherapy, which describes three key components. The first provides a foundation, known as the 'real' relationship between professional and participant. This represents the personal connection between the two parties and is determined by the extent to which their regard is genuine. This connection has been described as the chemistry between professional and participant (Wåhlin, Ek, & Idvall, 2009), and can be characterised by a sense of fellowship and compassion.

The second is the catalyst to successful outcomes, known as the 'working alliance'. This is a practical collaboration, a dynamic interaction, characterised by shared decision making, goal setting, and treatment plan negotiation. This aspect of the therapeutic relationship is believed to be most effective if it embraces tension between professional and participant and uses the restorative process of overcoming fractures in the alliance as a mechanism for driving change.

The final component is known as 'transference and countertransference', where professionals and participants transfer prior experiences of relationships onto the therapeutic relationship. This is a particularly complex aspect of the model, which requires the professional to be alert to, and skilled in, managing the impact of both transference and countertransference, to ensure these do not lead to the detriment of healthcare or rehabilitation interaction.

1.3.3.3 Defining Therapeutic Relationships

Definitions of therapeutic relationships often reflect the collaborative nature, the positive affect, and mutual agreement between professional and participant, with respect to setting treatment goals, plans and desired outcomes (Hall et al., 2010; Heins, Knoop, & Bleijenberg, 2013; Martin et al., 2000). These authors appear to explore the component characteristics of Gelso's real relationship in greater detail, studying the impact of trust and communication on health outcomes, quality of life, self-efficacy and treatment adherence. Whether these definitions fall short of providing a comprehensive picture of therapeutic relationships, is not the purpose of this discussion. However, exploring models from different healthcare sectors has demonstrated that the minimum features required for therapeutic relationships include a shared personal connection, an effective working partnership and professional self-awareness. For the purpose of this PPD research, the following working definition of the therapeutic relationship was informed by the discussion above.

A shared personal connection and effective working partnership, undertaken with self-awareness and vigilance of impact, between participant and professional in a healthcare setting.

This definition reflects the concept of relatedness which is one of three fundamental psychological needs, alongside autonomy and competence, described by Self Determination Theory (SDT). Relatedness has been called the “medium or vehicle for change” (Ryan et al., 2008, p. 3). It is a compatible descriptor for the therapeutic relationship within SDT.

In Section 1.3.2 the therapeutic relationship was described as playing a significant role in supporting the transition towards SM of LTCs, including cancer. Cancer rehabilitation was described as an ideal opportunity to support individuals to either maintain or adopt SM behaviours across the whole cancer pathway in Section 1.3.1. This PPD research aims to explore the importance therapeutic relationships in the development of SM, from the rehabilitation participants’ perspective.

This section has presented a summary of the key concepts relevant to this PPD research. It has attempted to identify the inter-relationships between these concepts and identify some of the tensions around implementing these concepts in practice. The following section provides an overview to the local cancer rehabilitation service where this PPD research took place.

1.3.4 Local Cancer Rehabilitation Context

This PPD research was undertaken in a local cancer rehabilitation service, within a Health Board which also hosted one of three regional cancer centres in Wales. The service was provided by an integrated team of Occupational Therapists and Physiotherapists. It was based on an acute oncology / haematology ward within the hospital which housed the cancer centre.

The team held responsibilities for the inpatient and outpatient provision of rehabilitation services for all adult residents of the local Health Board who had been affected by any cancer site, of any stage, across the entire treatment pathway. The service had never been commissioned to provide rehabilitation for children. It provided both individual and group rehabilitation interventions, modelled on other LTCs rehabilitation service models. Some group interventions were held on the hospital site, others were provided in partnership with local leisure providers. The service could be accessed via either professional or self-referral. A diagram representing the service model is included in Appendix 2.

The local cancer rehabilitation service was first established in 2008, following developmental funding from a cancer charity in Wales. The service evolved using an evidence-based approach. As described above, the cancer rehabilitation evidence base was growing rapidly. However, there was a lot to learn from the wider LTCs rehabilitation models. The service not only evaluated and implemented recommendations from research. But, it participated in generating new knowledge by supporting research activities in practice (McNamee, 2016; McNamee, Rance, & Fitzsimmons, 2012).

Anecdotal feedback from participants who attended annual fundraising events suggested that participants continued to self-manage following their completion of cancer rehabilitation. However, at the time that this PPD research commenced, no follow up studies exploring long-term adherence to SM behaviour change had been undertaken locally. This PPD research, therefore, worked on an assumption that the local service was successful in supporting sustainable SM behaviours. This assumption will be discussed further in Chapters 5.2 and 8.1.1.

It was as a result of this research-practice partnership that the service became aware of Self Determination Theory (SDT). Having appreciated how SDT could inform changes in practice, SDT would also help to shape the PPD research presented in this thesis. Further discussion regarding how this decision evolved is presented in Chapters 2.4.3 and 3.3.3.

The service worked with local participants as partners and prioritised their feedback and experiences to inform the service evolution. This partnership working grew from a culture of person-centredness that was embedded in practice. Working with rehabilitation participants as partners in service improvement consolidated this culture within the fabric of the service (Wilkinson, 2014a).

The team provided education, training and peer support for non-cancer specialist colleagues within the host Health Board, and for colleagues in nearby Health Boards. The team endeavoured to support the Acute Oncology Service (AOS), especially in the acute management of metastatic spinal cord compression (MSCC). It also aimed to provide early intervention rehabilitation, also known as prehabilitation. However, neither of these services received dedicated funding and were therefore subject to ad hoc cover as workforce availability, skills mix, and caseload demand allowed.

Within the local Health Board, specialist palliative care services were available for PABC and other life-limiting conditions. This did not preclude people with advanced disease from accessing the cancer rehabilitation service. Several of the group interventions, including Adapted T’ai Chi and hydrotherapy were particularly effective in supporting people to learn to adapt to, or live with their advanced disease. There was little duplication between the rehabilitation and palliative care services.

For the purpose of this research, when describing ‘rehabilitation professionals’, this refers to the healthcare professionals responsible for providing the local cancer rehabilitation service, where this research took place. These professionals most frequently included Occupational Therapists, Physiotherapists, Dietitians, and Speech and Language Therapists. In the local context, there was close working between the cancer rehabilitation team, the lymphoedema service, community-based exercise professionals and third sector (charity) support agencies. Due to the complex nature of cancer rehabilitation, this wider group of professionals have been considered as rehabilitation professionals within the scope of this research.

At the time this PPD research commenced, there was a growing awareness of cancer survivorship, recognition of the need for cancer rehabilitation and an appetite within the local cancer rehabilitation service to learn from other LTCs rehabilitation models. The policy context in which this PPD research took place was also conducive to the development of services which aimed to support SM. The following section provides an overview of the policy context which surrounded this PPD research. In particular the two key shifts towards person-centred care and co-production of services with participants as experts.

1.4 Policy Context

There are several key drivers with the health care policy context that have been relevant to this research. The first and perhaps most influential document called for Welsh healthcare services transformation through the adoption of Prudent Healthcare (Bevan Commission, 2014; Longley, Chucha, Llewellyn, & Bowen, 2017). The four principles of Prudent Healthcare include providing co-produced person centred care (PCC), which aims to reduce inequality and unwarranted variation. It seeks to prioritise those with the greatest need and create a healthcare environment in which service providers work to the top of their licence, or ‘do that which only they can do’.

In the climate of financial austerity which preceded this research, there was a challenge to prevent the interpretation of these principles from resulting in rationalisation of service provision. There was a tension between the person-centred philosophy of the policy context and translation of policy into operational implementation of the Prudent principles. The challenge was to preserve the relationship between healthcare professionals and healthcare participants (Andrews & Butler, 2014; Bevan Commission, 2014; Bradley & Willson, 2014). Conversations which ought to have strived to raise the standard of care, often resulted in standardisation, or the provision of a standard set of interventions, which allowed little or no personalisation of care (Imison et al., 2014).

There was significant policy shift around the early stage of this PPD research, with the publication of the Social Services and Wellbeing Act (Welsh Government, 2014), and the Wellbeing of Future Generations Act (Welsh Government, 2015). With these publications came a clearer mandate to ensure that healthcare maintained its focus on being personalised, coordinated and enabling (Health Foundation, 2014). Person-centred care is discussed in more detail in Section 1.4.1.

Cancer rehabilitation was included for the first time in the 2016-2020 Cancer Delivery Plan (Wales Cancer Network, 2016). Cancer rehabilitation services have made some progress since the beginning of this PPD research, but largely remain under-developed in Wales. The introduction of the Single Cancer Pathway (SCP) (Crosby, 2017), offered an opportunity to shift perceptions away from historic views of cancer rehabilitation as an optional extra. The need for meaningful research to underpin and support the inclusion of cancer rehabilitation into the cancer pathway as an essential service, was now even more crucial. As was the need for evidence to protect the principles person-centred care in a pathway which might be placed at risk of being translated into standardised protocol-driven practice.

Towards the end of this PPD process, two significant publications were to frame this research and reinforce the importance of co-producing healthcare services. The first was A Healthier Wales (Welsh Government, 2018), which presented a whole systems vision for a transformed health and social care system, with the needs of people at its centre. The second was the AHP Framework for Wales (Welsh Government, 2020), which described the potential contribution that AHPs might make towards the transformed future vision described in A Healthier Wales. These two documents embodied the philosophy of prudent and person-centred care and articulated how these might be achieved in practice. As described earlier in this chapter, my role changed throughout the duration of this PPD research. Together, the changes in policy context and my learning from this PPD research would become tools to influence change. Opportunities for change are discussed in Chapter 8.3. The common thread through all of these policies is person-centred care, which is explored in detail in in the following section.

1.4.1 Person-Centred Care

As described in the previous section, this PPD research took place during a time in which Welsh health policy increasingly sought to place people and their needs at the centre of care. Person-centred care has become a widely used term within healthcare in the UK. Its position in Welsh healthcare policy is highly valued. This is evidenced by its place in all Welsh Government Health Delivery Plans, of which cancer is one example (Wales Cancer Network, 2016).

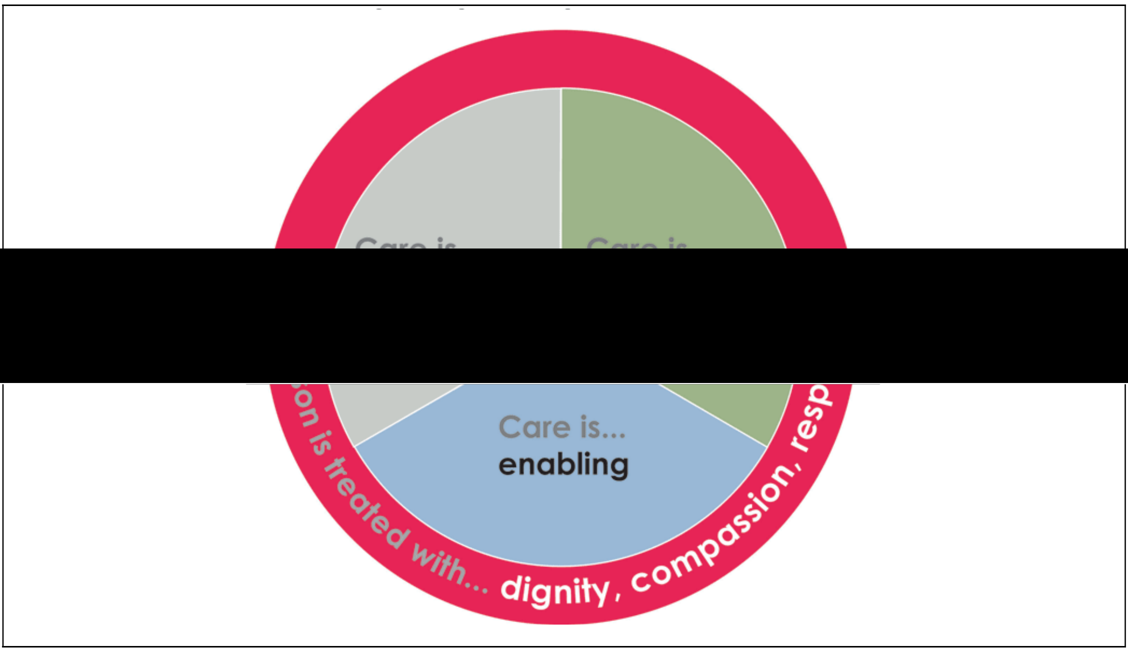
The term is often used inter-changeably with patient- or client-centred care. Throughout this thesis, the term ‘person-centred care’ is used, to ensure consistency in my language between clinical practice and this PPD research. It may also aims to encourage other healthcare professionals to focus on the person at the centre of healthcare interactions.

Macmillan Cancer Support (2013a, p. 3), defines person-centred care as “ensuring that the needs of the person living with cancer are always at the heart of how services are planned, not the needs of the service providers. It means treating people with sensitivity and compassion and ensuring that their care is holistic in its planning and delivery. This care goes beyond the clinical to address wider social, financial, emotional, practical, psychological and spiritual concerns".

There is a risk that operationalising person-centredness into a list of concerns, or an assessment framework of holistic domains, may result in person-centred care being seen as an intervention. Person-centred care is more than an intervention. It requires that healthcare professionals practice in an empathetic and non-judgemental manner. When this PPD research journey started, there appeared to be a tension between the person-centred ideology embedded in policy and organisational pressures to standardise and homogenise practice in order to meet increasing resource restrictions. This translated into a risk that person-centred care would become a set of interventions, rather than an approach that truly values the partnership between healthcare professionals and participants (Wolf et al., 2017).

The Health Foundation (2015), presents four principles of person-centred care which include approaching individuals with dignity, compassion and respect; offering care which is personalised and coordinated; which enables people to use their own strengths and abilities to live as independently as possible, fulfilling their vision of a meaningful future. These principles are presented in Figure 2. In clinical practice, I used the Health Foundation's principles. They not only reflect the nature of the type of healthcare interactions valued personally and professionally, but they also describe expectations of what PCC could look like without being prescriptive. These principles allow for individuals at different levels of abilities to engage, at an appropriate level. When discussing PCC in this thesis, it is this Health Foundation definition and principles of the concept being referred to.

Figure 2. The Health Foundation: Person Centred Care



[redacted]

To achieve true PCC, professionals must surrender their identity as the only 'expert' in the relationship and allow care to be negotiated according to the unique needs and situation of each individual, and their ability or inclination to direct their own goals and targets (Health Foundation, 2015; Potempa, Butterworth, Flaherty-Robb, & Gaynor, 2010). This introduces the concept of the 'expert patient'.

1.4.2 Expert Patient

The Merriam-Webster Dictionary (2015), defines an expert as one who has skill or knowledge because of what they have been taught or what they have experienced. In healthcare, there has been a shift in perceiving that experts are not only those involved in the development and delivery of healthcare services, but also those who have become experts in learning to live with long term conditions. Sohl, Birdee, and Elam (2016), suggest that professionals are experts in healthcare from a disease perspective, whereas participants are experts in their experience of living with a disease.

The expert patient initiative was set up in recognition that the management of LTCs could not continue to harness only half of the resources available in the healthcare interaction (Department of Health, 2001). Identifying people living with LTCs as experts was the first step towards re-shaping healthcare services. This led to arming people with the knowledge, skills and confidence to self-manage their conditions and lead more meaningful lives. This notion of expert patient encompasses a reclamation of responsibility or ownership over the maintenance of one's health and wellbeing. Which requires a handover of the management lead role from professional to the person living with the LTC (Koch et al., 2004). This shift in healthcare relationship is a core component of empowering people living with LTCs, including cancer, to actively manage the consequences and day-to-day impact of their conditions.

The principles of person-centred, prudent healthcare were adopted and embedded in the design and delivery of the local cancer rehabilitation service. Section 1.2.5 provided an overview of the local service model and its interface with the wider cancer and healthcare context. In the context of this PPD research, the rehabilitation participants held an expert role that complemented the expertise of the rehabilitation professionals. The success of the therapeutic relationship hinges on an assumption that the partnership between healthcare professionals and participants is collaborative, with each party bringing knowledge and skills to the interaction.

The following section will explore some of the complexities around key concepts that are relevant to this PPD research.

1.5 Thesis Structure and Signposting

This thesis is divided into eight chapters. This chapter has provided an introduction to the changing cancer landscape, and key concepts relating to this research including cancer survivorship, cancer rehabilitation, SM and therapeutic relationships. It also presented the clinical and policy context in which this PPD research took place.

Chapter Two presents a critical review of the evidence base concerning therapeutic relationships in cancer rehabilitation and the development of SM behaviours.

Chapter Three presents an overview of the study design, research methodology and data collection methods used in this research.

Chapter Four will introduce the research participants.

The findings from this PPD research will follow, exploring the results from two phases of data collection. The first presents the findings from semi-structured interviews (Chapter Five), and the second presents the findings from a Modified Delphi Technique, undertaken in two rounds (Chapter Six).

Chapter Seven explores the mechanisms used to facilitate reflexivity throughout this research. It also contains reflections on my experience of undertaking a PPD and my development as a practitioner-researcher.

Finally, Chapter Eight revisits the research presented in this thesis. It presents a discussion of these findings and their contribution towards better understanding how therapeutic relationships influence SM outcomes after cancer rehabilitation. This chapter also discusses the strengths and weaknesses of this PPD research. It identifies opportunities for contributions to scholarly discourse, to informing policy and practice, and the future research agenda.

1.6 Summary

This chapter has introduced the aim and rationale behind this PPD research. It has introduced the research topic by exploring the background and identified changes that have taken place across the cancer landscape over the past decade. It has also explored the transition that cancer rehabilitation has made alongside cancer, and in response to the survivorship agenda.

Key concepts from practice and the policy context relevant to this research, including SM, therapeutic relationships and PCC have been defined. Their complexity and inter-relationships have been described, as have working definitions for the key concepts relevant to and used in this PPD research. This chapter has presented an overview of the thesis structure and provided signposting to subsequent chapters where further detail relating to this PPD research will follow. Chapter Two will present the rationale, methods and findings from the first phase of this PPD research, an Integrative Literature Review (ILR).

Chapter Two: Integrative Literature Review

The ILR was the first of three phases of research within this PPD research. It was initiated prior to, and completed alongside, the second and third phases of the PPD research. This allowed the literature to help guide the SSI and ModDT, but also enabled the emerging research findings to inform the interpretation of the ILR analysis.

The ILR is presented separately from the subsequent PPD research activities to help to provide structure to the thesis. The aim of this chapter is to provide a summary of the extent to which the impact of therapeutic relationships on SM behaviour change had already been researched and reported in the cancer rehabilitation literature. To this end, the ILR was guided by five questions, described in Section 2.1.3.

2.1 Introduction to Chapter Two

This chapter introduces the Integrative Literature Review (ILR) and outlines the rationale the and structure of the ILR. In the Section 2.2, the ILR methods are described including the search strategy. This section also presents an overview of the criteria for inclusion, data organisation, methods of quality assessment and data extraction. This is followed by the presentation of the findings from the ILR in Section 2.3.

In addition to answering the four review questions, the ILR had the potential to offer insights into the complex concept definitions. Any changes to the working definitions used in this PPD research, as a result of the ILR findings are discussed in Section 2.4. The chapter concludes with a summary of the strengths and limitations of the ILR and presents the rationale for the next phases of the PPD research presented in this thesis.

2.1.1 Rationale for Integrative Literature Review

Integrative literature reviews (ILR) are a preferred method for research into emerging topics that may either have a limited evidence base or include contradictions or discrepancies between what is seen in practice and what is reported in the literature (Torraco, 2016). It was anticipated that there would be a narrow evidence base relating to therapeutic relationships associated with SM and cancer rehabilitation.

Integrative literature reviews also have the potential to illuminate complex concepts, and draw connections between these concepts, theory and healthcare practice (Whittemore & Knafl, 2005). In the opening chapter (Sections 1.2 and 1.3), working definitions of the relevant concepts involved in this PPD research were presented. These definitions were used to inform the ILR search strategy.

The ILR approach offered the opportunity to be able to collate and synthesise data from a broad range of research methodologies. Integrative literature reviews may also combine data from policy, and theory. The ILR offered a flexibility that other systematic approaches to reviewing the literature couldn't offer (Whittemore & Knafl, 2005).

2.1.2 Organisation and Structure of Integrative Literature Review

To build rigour into the ILR process and facilitate high quality reporting, the ILR was designed following the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) statement (Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group, 2009). The process of undertaking the ILR followed the recommendations by Whittemore and Knafl (2005). Their recommendations describe four stages including problem identification, literature search, data evaluation, data analysis and presentation.

Torraco (2016), added detail to this process by advising reviewers to structure the ILR from one of three perspectives. The first perspective was to structure the review from a temporal perspective. This is where the historic development of the topic would be described, and the literature presented in a chronological sequence. The second perspective was to arrange the literature according the methodological similarities. The third perspective would present the ILR from a conceptual approach. This would adopt a thematic structure to identify the key topics from within the research papers.

For this ILR, the papers were assessed for quality according to their methodological approach. However, the ILR findings were organised and analysed according to the key concepts relevant to the wider programme of PPD research, as outlined in Chapter 1.3. The methods and findings from this ILR aimed to collate and synthesise the available evidence in response to the following research questions.

2.1.3 Review Questions

The purpose of this ILR was to answer the following questions:

- What contribution can the literature make to the definition of 'self-management' and 'therapeutic relationships'?
- To what extent have therapeutic relationships been researched in relation to supporting self-management outcomes following cancer rehabilitation?
- Does the literature identify the role that therapeutic relationships play in enabling the development of self-management behaviours during cancer rehabilitation?
- Does the literature report cancer rehabilitation participants' experiences of therapeutic relationships?
- Does the literature report barriers to and facilitators of therapeutic relationships in cancer rehabilitation?

2.2 Methods

Early during the problem identification stage of the ILR process, an 'a priori' protocol was written and published (Wilkinson, Rance, & Fitzsimmons, 2015), in line with best practice (Sharif, Janjua-Sharif, Ali, & Ahmed, 2013; Sharma & Oremus, 2018). This protocol proposed to search the impact of 'therapeutic-use-of-self' (TUOS) on cancer rehabilitation outcomes, SM, or behaviour change. However, there was too little literature relating to TUOS and its impact on cancer rehabilitation outcomes, SM, or behaviour change, to be able to proceed with this term. There were no papers identified that could answer the research questions using TUOS as a search term.

In consultation with the information specialists based in the libraries at Swansea University and the Local Health Board, the academic supervisory team, and rehabilitation participants, it was agreed that 'therapeutic relationship' would replace 'therapeutic-use-of-self' (Reflective Journal Entry 01/03/2015).

This minor adaptation to the search strategy altered the focus of the research very slightly but enabled the research to proceed as the two concepts were closely related. A brief discussion of the concepts is presented in Chapter 1.3.3.1. Further detail regarding the impact of this change is described later in this chapter (Section 2.5). The following describes the subsequent development of the search strategy used to inform this ILR.

2.2.1 Search Strategy

Following this amendment early in 2015, the revised search strategy (See Table 1), using ‘therapeutic relationships’ was refined through preliminary testing of search terms in Applied Social Sciences Index and Abstracts (ASSIA). The search strategy was then implemented in ASSIA for the period January 2003 to February 2015, adapted and undertaken in the following databases for the same timeframe:

- Cochrane Library
- Cumulative Index for Nursing and Allied Health Literature (CINAHL)
- Medical Literature Analysis and Retrieval System Online (MEDLINE)
- Psychology Information (PsycINFO)
- Web of Science

In July 2018, the original search strategy was repeated across all databases listed above for the period January 2003 to July 2018. An automatic search was established in Pubmed via National Center for Biotechnology Information (NCBI), at the United States National Library of Medicine (NLM). This search highlighted new papers which may have met the search strategy. Automatic monthly email alerts were sent to the principal researcher from February 2015 to the time of thesis submission. Papers identified by the automatic search alerts after July 2018 have been included in the Chapter Eight Discussion.

The search strategy employed a combination of controlled vocabulary, medical subject headings, keyword terms implemented with truncation. The Boolean operator ‘OR’ was used between search terms, and the Boolean operator ‘AND’ was used to combine search topics. The search topics and associated search terms can be found in Table 1. The limitations placed on this search strategy included a requirement that studies must involve adult human populations and may have been conducted in any country as long as the report was published in English.

Table 1. ILR Search Terms

Search Topic	**Search Terms and Key Words**
Cancer	Cancer*, oncology, malignancy, neoplasm, carcinoma, tumour, tumor

Chronic disease	Long term condition*
Self-management	Self-manage*, self efficacy, self care, behavior* change*, patient-empower*, patient participation
Cancer survivorship	Cancer surviv*
Cancer Rehabilitation	Rehab*, Cancer rehab*, occupational therap*, physical therap*, Exercise therap*, Exercise*, physical activit*, lifestyle* intervention
Therapeutic Relationships	Therapeutic relations*, therapist character*, coach*, therapeutic alliance, patient-professional relations*, professional-patient relations*

Integrative Literature Reviews include grey literature alongside primary studies and literature review papers. Examples of grey literature include conference proceedings, service reports, policy and guidance documents, unpublished theses and books. These sources were included in the ILR if identified by the search strategy or hand searches (Whittemore & Knafl, 2005).

The Allied Health Evidence Database, which hosts PEDro and OTseeker, repositories for critically appraised topics and unpublished research projects; and EThOS, an online repository of doctoral e-theses, were searched to identify any research not yet published. Hand searching of reference lists from retrieved articles was also undertaken to complete the search. The literature search strategy was documented as it developed to reduce the risk of bias from inconsistencies in search terminology and to facilitate study replication (Whittemore & Knafl, 2005).

2.2.2 Inclusion and Exclusion Criteria

Following the removal of duplicate records, all of the titles and abstracts of retrieved articles were assessed by the principal researcher with respect to the criteria for inclusion in the review described in Table 2. Once this initial assessment was complete, two members of the academic supervisory team (DF and JR), reviewed half of the papers each to confirm the preliminary decisions regarding eligibility for inclusion in the review.

All of the references which were recommended for exclusion following preliminary assessment for eligibility, were reviewed by a second member of the academic supervisory team (DF), to confirm their exclusion from the review. A discussion between the principal researcher and the academic supervisory team took place for a small number of papers which appeared to meet the inclusion criteria, from their title and abstract. Reasons for inclusion or non-inclusion in the review were recorded.

Table 2. Inclusion and Exclusion Criteria

Inclusion	**Exclusion**
Population:	
• Adults aged 18+ • Current or previous diagnosis of cancer – any tumour type, any tumour stage. • Allied health professionals working with adults affected by cancer in a rehabilitation context.	• Children and adolescents (aged < 18 years). • Adult survivors of childhood or adolescent cancer diagnoses.
Setting:	
• Inpatient, outpatient or community rehabilitation or Occupational Therapy or self-management programme for cancer.	• Cancer screening programmes. • Rehabilitation for long term conditions other than cancer will be coded as 'LTC' as reason for exclusion from initial search. This will allow for inclusion in subsequent search strategies in the event that cancer-related articles are insufficient for analysis.
Intervention:	
• Interventions identified as relevant to 'therapeutic relationships', or correlates of 'therapeutic relationships' including professional-patient relations, therapist characteristics or connectedness. • No restriction will be made on whether interventions are carried out in group and/or individual formats.	• Interventions designed to increase knowledge or technical healthcare skill development, including education, cognitive behavioural therapy, motivational interviewing, mindfulness or other correlate of behaviour change interventions not directly relating to 'therapeutic relationships'. • Non face-to-face interventions including written, web-based or telephone interventions.
Control / Comparison:	
• Interventions identified as information delivery, education, cognitive behavioural therapy, motivational interviewing, mindfulness or other correlate of behaviour change interventions not relating to 'therapeutic relationships'.	
Outcome:	

Primary Outcomes: • Behaviour change reflecting self-management, self-efficacy, confidence, or self-care. Secondary Outcomes: • Characteristics of ‘therapeutic relationships’ identified as being effective in behaviour change. • Psychosocial outcomes including quality of life and functional performance.	• Increased knowledge or technical healthcare skill development.
Context:	
• Published between 2003 and 2018. • There will be no restrictions placed on the country where studies were conducted as long as the written outcome has been published in English.	• Published prior to 2003. • Studies published in a language other than English. • Ongoing studies if not complete at time of review will be coded as ‘ongoing’ as reason for exclusion to allow for inclusion in future review updates.
Study Design:	
• Original study or review paper. • Quantitative research including randomised controlled trials, quasi-experimental studies, and observational studies. • Qualitative research including descriptive and exploratory studies. • Items of grey literature including policy and clinical guidance documents, books, opinion pieces and dissertations.	

2.2.3 Data Organisation and Management

All references and full text papers obtained from the search strategy in 2015, the follow up search in 2018 and monthly search alerts were added to an electronic library using Endnote X7/X9 reference management software. All referencing for this ILR and throughout the thesis complies with the APA 6th Referencing Guide (Swansea University, 2018).

All of the titles and abstracts of retrieved articles were transferred and presented in a Microsoft Excel spread sheet. These were collated and categorised into those recommended for inclusion, and those to be excluded. This format enabled data sharing with the academic supervisory team. It also reduced duplication of data recording during data assessment and extraction.

2.2.4 Quality Assessment

When undertaking an ILR, assessing the quality of papers from diverse methodologies can be complex (Whittemore & Knafl, 2005). It was anticipated that the ILR search strategy would retrieve a range of papers reporting original studies using different methodological approaches, review papers, and other data sources. The 16-item Quality Assessment Tool for Studies with Diverse Designs (QATSDD), is a tool designed to enable the quality comparison of papers employing qualitative, quantitative and mixed methods design (Sirriyeh, Lawton, Gardner, & Armitage, 2012).

The QATSDD is increasingly being used within healthcare. It supports the analysis and reporting of literature reviews relating to complex topics which seek to synthesise data from different theoretical perspectives. It has also been used in allied health professional research where research evidence is limited and made up of studies from a range of research designs (Del Piccolo & Finset, 2018; Graham-Clarke, Rushton, Noblet, & Marriott, 2018; Sanzo et al., 2016). While the QATSDD may not offer the specificity that other quality assessment tools may, it has been useful tool for facilitating discussion when the relevant research studies cross different disciplines and methodologies. The QATSDD was described as a good tool to begin reviewing papers from diverse methodologies, if the research team had expertise in both qualitative and quantitative research design (Fenton, Lauckner, & Gilbert, 2015). It was for these reasons that the QATSDD was deemed compatible with the ILR philosophy and method. And subsequently selected for use in this study.

The 16 items of the QATSDD do not assess the quality of research study results. Rather, they address the consistency, clarity and organisation of reporting study results (Fenton et al., 2015). Each item is rated on a four-point Likert scale (0 = no detail in paper, to 3 = full details described). The assessment tool was accompanied by a matrix which outlined pre-defined criteria to assist scoring for each item. Of the 16 items, 12 were relevant to both qualitative and quantitative studies. There were two items which were specific to qualitative or quantitative studies. The quality of each study is presented as a percentage.

This ILR included qualitative studies which employed focus groups and interviews. It also included quantitative studies reporting Randomised Controlled Trials (RCT) and systematic literature reviews including other integrative literature reviews. As the QATSDD does not assess the quality of review papers, a second tool was required. The Assessment of Multiple Systematic Reviews (AMSTAR), is a tool which enables the quality assessment of literature reviews for papers presenting both randomised and non-randomised controlled trials (Payne, Wiffen, & Martin, 2012; Pieper, Mathes, & Eikermann, 2014). The use of these tools together has been shown to be effective in streamlining the quality assessment and reporting of integrative literature reviews (Macgregor, Wathen, Kothari, Hundal, & Naimi, 2014).

The AMSTAR framework has been used by some healthcare publications as a tool to engender readers' confidence in the reported results of systematic reviews (Dahm, 2017). Authors of systematic reviews are also being encouraged to undertake self-assessment using AMSTAR prior to publication, in an effort to improve the quality of reporting of systematic reviews (Sharma & Oremus, 2018). AMSTAR was used to assess the quality of all review papers included in this ILR. It was also used to shape the discussion of the results of this ILR.

The principal researcher (WW) assessed all studies using the QATSDD and AMSTAR tools. The findings of these assessments were presented to the academic supervisory team (DF and JR). Where there were any disagreement in the scores, these were resolved via discussion. No papers were excluded from the study based on the quality assessment. It was felt that their findings may still offer value to the conceptual analysis, and synthesis of priorities for future research. Especially in light of the small number of papers retrieved by the search. Adopting this perspective is congruent with the ILR methodology (Whittemore & Knafl, 2005).

Overall, the quality of the literature was moderate to high. Eleven of the fifteen papers scored moderate to high on their respective tools (Browall, Koinberg, Falk, & Wijk, 2013; Dunne et al., 2018; Dwarswaard, Bakker, van Staa, & Boeije, 2016; Kaplan, Greenfield, & Ware, 1989; Lee, Twinn, Moore, Jones, & Leung, 2008; B. Murray & McCrone, 2014; Schulman-Green et al., 2012; Schulman- Green, Jaser, Park, & Whittemore, 2016; Thorne et al., 2005; van de Bovenkamp & Dwarswaard, 2017; Wood, Connors, Dogan, & Peel, 2013). The most frequently identified methodological issue with these papers was the lack of explicit discussion around user-involvement in the study design. Other issues included a lack of detail relating to recruitment and sample size, funding arrangements, an ‘a priori’ protocol, discussion of potential publication bias, theoretical framework or description of excluded papers.

Four of the fifteen papers scored low on their respective tools (Ackerman & Hilsenroth, 2003; McCorkle et al., 2011; Phillips-Salimi, Haase, & Kooken, 2012; Schnur & Montgomery, 2010). Methodological issues included authors not providing sufficient details relating to the use of an ‘a priori’ protocol, clarity as to the authors’ intention around the inclusion of grey literature, or detail relating to the quality assessment method and results. The details of the quality assessments of the included papers are presented for AMSTAR (Appendix 3a) and QATSDD (Appendix 3b).

2.2.5 Data Extraction and Analysis

A data extraction tool was designed using a Microsoft Excel spreadsheet. The principal researcher (WW), populated the spreadsheet with key information from the included papers including study design, population characteristics and key findings. The spreadsheet was shared with the academic supervisory team (DF and JR) to confirm the accuracy of the data (see Appendix 4 for a table of included papers).

Descriptive statistics were carried out using Microsoft Excel to answer the first ILR question relating to the extent to which therapeutic relationships had been researched in a cancer rehabilitation context. These included the number of papers retrieved, research design and population characteristics. The findings of which are presented in the following ILR results section.

Answering the remaining review questions became the lens through which the review data was viewed in order to maintain focus and reinforce the boundaries that would shape the conceptual analysis. Key data items were identified in relation to research contexts, description of interventions, relevant theoretical frameworks, and population characteristics. Within the findings of each study the data were coded according to the key concepts relating to this research. Namely therapeutic relationships and their impact on the development of SM behaviours, participant experiences of therapeutic relationships and any identified barriers or facilitators to therapeutic relationships. As it was not always obvious from the study titles, it was noted whether therapeutic relationships were an intervention, or an outcome of the research reported. This data was then simplified and organised into matrix using Microsoft Excel to facilitate analysis and synthesis (see Appendix 5).

Once all of the data was arranged in the matrix, it was critically examined to extract the main concepts and inter-relationships. The data was used to inform key concept definitions. There were two aims during this process. The first was to determine the extent to which the data answered the review questions. The second was to establish whether there was congruence or discrepancy between study findings (Torraco, 2016). This process produced a clearer understanding of the role that therapeutic relationships play in the development of SM behaviours. It also identified the priorities for the next phase of the research.

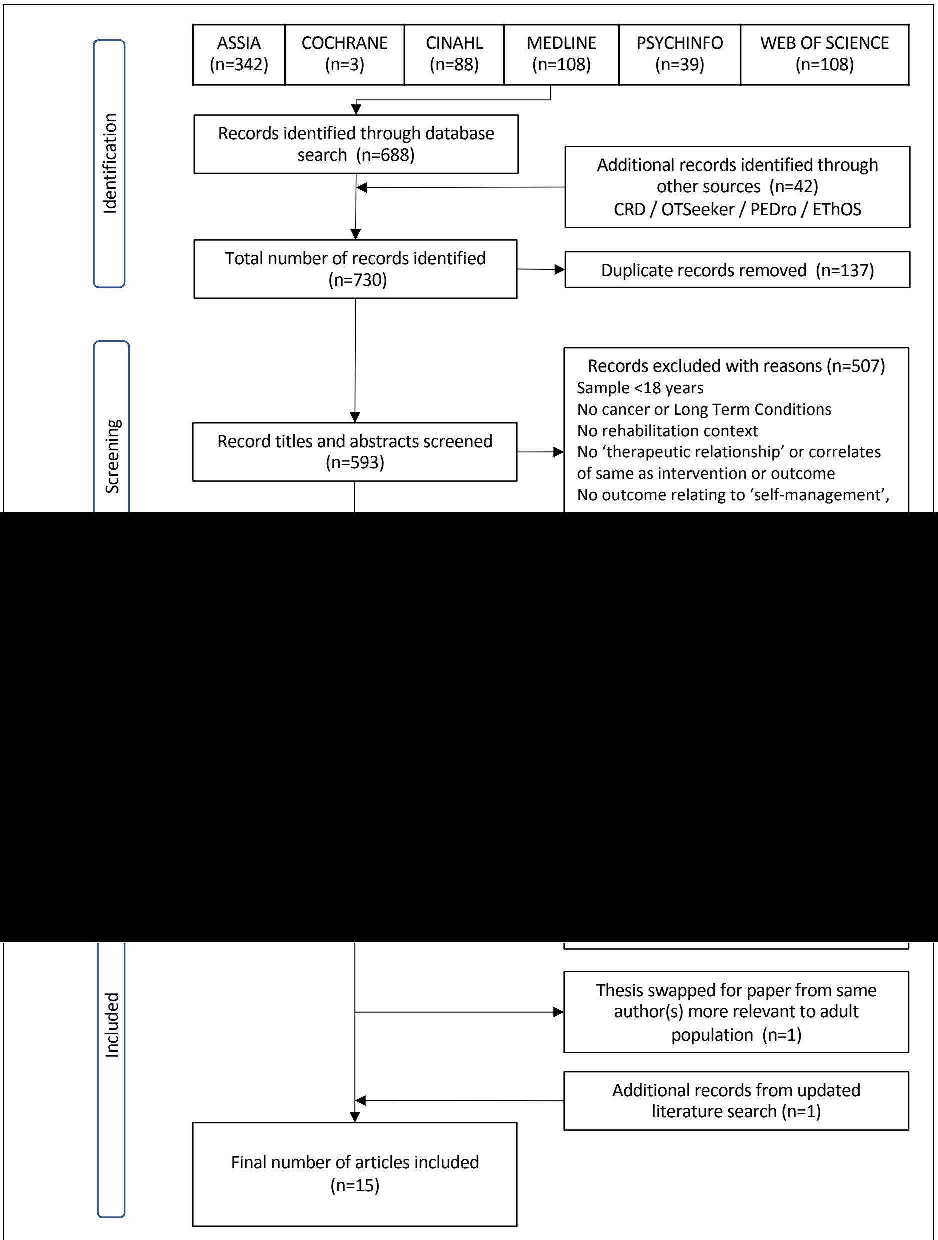
Progress updates relating to the critical analysis and synthesis of the literature were discussed with the academic supervisory team. Using supervision in this way, offered the opportunity for sense-checking when the data appeared unconvincing or incomplete. Being able to articulate the logic, critical thinking, and conceptual reasoning used in this forum was congruent with ILR methodology (Torraco, 2016).

2.3 Integrative Literature Review Results

2.3.1 Summary of Included Studies

In total, fifteen papers were identified as being eligible for inclusion in the ILR as per the criteria described (Section 2.2.2: Table 2). Figure 3. provides an overview of the papers yielded from each stage of the review process.

Figure 3. ILR PRISMA Flow Diagram



[redacted]

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). *P*referred *R*eporting *I*tems for *S*ystematic Reviews and *M*eta- *A*nalyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

A summary of the included papers is presented in Appendix 4. This summary includes a concise description of research methods, theoretical framework and analytical approach, research context, sample characteristics, and whether therapeutic relationships were a focus of the intervention, or an outcome of each study.

Of the fifteen papers, two were identified following a hand search of the reference lists of retrieved papers. Following discussion with the academic supervisory team, it was agreed for these papers to be included the review, despite not meeting all of the PICO criteria, in recognition of the potential contributions they could make to the discussion (Supervision Record: 21/09/2018).

The first, a seminal work by Kaplan et al. (1989), predated the search criteria by twenty years. The paper was selected for having been instrumental in informing the research agenda around therapeutic relationships and SM outcomes in medicine (Ha & Longnecker, 2010).

The second paper was a publication written by the same author as a thesis identified by the search strategy. The thesis focused on the needs of adolescents and young adults (Phillips-Salimi, 2009), and therefore did not meet the ILR inclusion criteria. The subsequent publication presented a concept analysis of connectedness in provider-participant relationships and was relevant to adult populations (Phillips-Salimi et al., 2012).

2.3.2 ILR Research Methods and Theoretical Frameworks

Of the final papers included n=8 reported systematic-style reviews including:

- Integrative Literature Reviews n=3,
- Qualitative Meta-syntheses n=3, and
- Systematic Reviews of Quantitative studies n=2.

The remaining papers reported primary research, of which:

- n=6 reported qualitative studies, and
- n=1 reported a quantitative study.

Please see Table 3 for more details.

2.3.3 ILR Research Context

Over half of the included studies were undertaken in the USA (n=8), with two from the Netherlands, and one each from Canada, Hong Kong, Sweden, the UK and a collaboration between the UK and Ireland. Nine of the papers were published towards the end of the search interval, between 2012 – 2018. Five of the SM papers were authored by two groups of researchers, one based in the USA, the other in Europe.

Despite therapeutic relationships being a core skill of many healthcare professions including OT, the impact of therapeutic relationships has not received a corresponding level of attention in research (Schnur & Montgomery, 2010). The authors' professional background has been summarised in Table 3. The greatest proportion of research was generated from a nursing perspective. It is of note that there were no papers identified by the review search strategy, which addressed therapeutic relationships, from an OT perspective.

Table 3. Professions Undertaking Research Reported in Included Papers

Professional Perspective	No. of Papers N= (%)
Nursing	6 (40%)
Multi-Disciplinary Team e.g. Nursing – Medicine Nursing – Psychology Psychology – Palliative Care	3 (20%)
Medicine	2 (13.5%)
Health Policy / Behavioural Sciences	2 (13.5%)
Psychology / Psychotherapy	1 (6.5%)
Physiotherapy / Rehabilitation	1 (6.5%)

Due to the variation in detail reported by the included papers, it was not possible to identify all settings in which the studies took place. However, where described, the settings included cancer-specialist and non-cancer specialist settings in both primary and secondary care. Data was collected from inpatient and outpatient populations, from state funded and private healthcare organisations.

2.3.4 ILR Population Characteristics

It was not possible to identify the population characteristics for four of the included papers. Of these, two reported sample characteristics for a sample with one or more LTC, which may have included cancer (McCorkle et al., 2011; Schulman- Green et al., 2016). The third paper presented a concept analysis of connectedness in the context of patient-professional relationships (Phillips-Salimi et al., 2012). The fourth paper presented a review of therapist characteristics and their impact on therapeutic relationships (Ackerman & Hilsenroth, 2003).

Eleven papers reported the sample characteristics, including sample size, age, sex, and diagnoses, relating to PABC. Where the sample characteristics were not described, the original research papers were hand searched in an attempt to identify them. Where sample characteristics were reported across the eleven papers, the findings related to approximately n=7000 PABC (Browall et al., 2013; Dunne et al., 2018; Kaplan et al., 1989; Lee et al., 2008; McCorkle et al., 2011; B. Murray & McCrone, 2014; Schnur & Montgomery, 2010; Schulman-Green et al., 2012; Schulman- Green et al., 2016; Thorne et al., 2005; van de Bovenkamp & Dwarswaard, 2017). Where these papers reported a mean age for PABC, these ranged from 47 to 70 years. The total age range was 18 to 94 years. Where described, there was representation of up to nine different tumour sites. The number of tumour sites represented within this review may have been higher than this. However, several authors reported solid tumours, oncology with symptoms, advanced cancer, or cancer, when describing their research populations.

Although it was not possible to present all of the population characteristics for the studies included in the ILR. It has been possible to demonstrate that the papers which informed the ILR reflect diverse populations made up from various tumour sites, disease stages, and demographics. This will help to facilitate the discussion in Chapter Eight and inform the extent to which the findings presented in this thesis can be generalised.

2.4 Response to Review Research Questions

The following findings are presented according to the five review questions described earlier in this chapter. Please see Appendix 3-5 for summaries of papers included in ILR.

2.4.1 Contributions to Concept Definitions

The two key concept definitions, presented in Chapter One, which had the potential to be refined through the ILR process, were ‘self-management (SM)’ and ‘therapeutic relationships’. There was some overlap between therapeutic relationships and SM in almost all of the papers.

Nine included papers reported research which focused on therapeutic relationships, or aspects of therapeutic relationships within the research design. These included the impact of therapeutic relationships, therapist attributes, communication or trust on clinical outcomes in cancer or LTCs. Another approach was to explore the complexity of SM interventions including the role of therapeutic relationships. A third focus was via a concept analysis of ‘connectedness’.

The remaining six included papers reported research which focused on SM. These papers did not explore therapeutic relationships as part of the study design. They yielded results which highlighted either the role of therapeutic relationships or their impact on the process through which SM skills are learnt and integrated in daily life. Or they identified barriers and enablers to the development of therapeutic relationships or SM.

The following briefly summarises how these concepts were represented by the papers included in ILR. Any trends or tensions represented in the literature are described. Information which could be used to refine these concept definitions is highlighted.

2.4.1.1 Self-Management

The definition of self-management (SM) was largely consistent across the six papers whose research focus was SM in LTCs including cancer (Dunne et al., 2018; Dwarswaard et al., 2016; McCorkle et al., 2011; Schulman-Green et al., 2012; Schulman- Green et al., 2016; van de Bovenkamp & Dwarswaard, 2017).

Half of these papers (Dwarswaard et al., 2016; Schulman-Green et al., 2012; Schulman- Green et al., 2016), referenced the definition of self-management published by Richard and Shea (2011). There were three common features between these definitions of self-management. These include the active participation of the individual and their family, community and professionals in partnership. The need for participants to be aware and manage the treatments, symptoms and the physical, psychosocial, cultural and spiritual consequences of their condition. The aim for the participant to adopt lifestyle change which contributes to their health and wellbeing.

McCorkle et al. (2011), developed their definition of self-management around the foundation work of Lorig and Holman (2003). Dunne et al. (2018), and van de Bovenkamp and Dwarswaard (2017), cited a range of sources in their development of a concept definition. These definitions considered SM to be a collection of tasks which a person undertakes as way of negotiating their disease, emotional adjustment and engagement with life roles.

The key tension in these ILR papers related to the perspective from which SM was viewed. The first saw SM from the disease perspective and focused on medical outcomes of SM interventions. The second adopted a more holistic, person-centred perspective which shaped SM around a person seeking to live their best life. Not only is there a lack of consensus in definition, these perspectives are opposing in nature. This creates a tension which may likely contribute to the continued ambiguity around the desired outcomes of SM and pose challenges to implementing SM in practice (Van de Velde et al., 2019).

Two papers discussed the mechanism through which SM behaviours are developed. Schulman-Green et al. (2012), identified that there are three processes that people undertake to achieve SM. These include focusing on illness needs, activating resources, and living with a chronic illness. These authors do not elaborate on how the therapeutic relationship then supports SM. Dwarswaard et al. (2016), present a model which describes the types of support required by people learning to self-manage LTCs. Within this model they highlight the importance of partnerships with professionals. This will be explored in further detail in Section 2.5, as this paper offers insights relevant to one of the four research questions which framed the ILR.

2.4.1.2 Therapeutic Relationships

Of the nine papers who reported findings relating to therapeutic relationships, it was not clear that there was a consistent definition or description used. All authors who discussed therapeutic relationships as the focus or outcome of their research concurred that therapeutic relationships are complex constructs. The authors used language like “a primary bond” (Kaplan et al., 1989, p. S125), and “a universal value” (Thorne et al., 2005, p. 894), to denote their important but imprecise nature.

The definitions, or discussions, of therapeutic relationships in three of the ILR papers reflected all three components of Gelso’s (2014), tripartite model of therapeutic relationships (Browall et al., 2013; Lee et al., 2008; Thorne et al., 2005). As discussed in Chapter One, these include the personal connection, the working alliance, and both parties’ prior experiences of interpersonal relationships.

Two of the included papers described the therapeutic relationship as being synonymous with the therapeutic alliance or working alliance (Ackerman & Hilsenroth, 2003; Schnur & Montgomery, 2010). Three papers explored the impact of individual components of the therapeutic relationship including locus of control and communication (Kaplan et al., 1989), development of trust (B. Murray & McCrone, 2014), or healthcare professionals' personal attributes and skills (Wood et al., 2013), on healthcare outcomes.

Whilst the concept analysis of connectedness, undertaken by Phillips-Salimi et al. (2012), did not address the role of therapeutic relationships in SM specifically. It was the only paper to highlight that interpersonal connections are reliant on the extent to which each individual needs or wants to connect with another. This highlights a fundamental assumption, common to all of the papers that discussed therapeutic relationships. This assumption is that all healthcare participants must want, or need, a relationship with their healthcare professional. The extent to which the participants' need for connectedness might pose a barrier or facilitator to effective therapeutic relationships is explored further in Section 2.5.2.

The concept definitions presented by the papers included in the ILR, confirmed the complexity and potential for ambiguity of both 'self-management' and 'therapeutic relationships'. The definitions presented in the ILR papers did not indicate significant amendments to the working concept definitions presented in Chapter One.

2.4.2 To what extent have therapeutic relationships been researched in relation to supporting self-management outcomes during cancer rehabilitation?

There continues to be little research reporting the impact, or role, of therapeutic relationships in supporting SM outcomes in a cancer rehabilitation context. The ILR search strategy yielded over 590 papers relating to SM in cancer or other LTCs. Only fifteen of these papers met the inclusion criteria in a broader LTCs context. Of these, only two papers reported studies which had taken place within cancer rehabilitation.

There were three types of paper which were not included in the ILR. The reason for not including the following types of studies was because the ILR aimed to, as close as practicable, identify research which reflected the delivery mode and clinical model employed by the local service. The ILR also aimed to identify the impact of therapeutic relationships on SM, not specific SM treatment tools.

The first type of paper excluded included those which explored the impact of specific interventions on SM. Examples of such interventions included motivational interviewing (Bishop & Jackson, 2013; Linden, Butterworth, & Prochaska, 2010; G. Scott, 2010a, 2010b), cognitive behavioural therapy (CBT) (David et al., 2016; Eseadi et al., 2017; Tummers, Knoop, van Dam, & Bleijenberg, 2012), and coaching (Oliveira, Sherrington, Amorim, Dario, & Tiedemann, 2017; Park & Chang, 2014; Wagland, Fenlon, Tarrant, Howard-Jones, & Richardson, 2015). Whilst these tools and interventions were integrated into the local cancer rehabilitation service, they were used as participant need indicated, rather than being part of a standardised package. The focus of this study was on the impact of the therapeutic relationship on SM behaviour change, rather than an exploration of the efficacy of the SM intervention itself.

The second type of paper which was excluded, related to those which reported on ‘self-management’ as an intervention, rather than a change in personal behaviour. These included studies which explored the effectiveness of SM interventions, including structured psycho-educational programmes. These papers did not largely report SM as an outcome of wider healthcare interventions (Aoun, Osseiran-Moisson, Collins, Newton, & Newton, 2009; Fenlon & Foster, 2009; Quinn et al., 2017).

The third type of excluded paper reported the outcomes of SM interventions or programmes which were delivered using technology, including telephone, telemedicine and web-based applications (Aoun, Osseiran-Moisson, Shahid, Howat, & O'Connor, 2012; Hammersley, Cann, Parrish, Jones, & Holloway, 2015; Hawkes, Pakenham, Chambers, Patrao, & Courneya, 2014; Partridge et al., 2015). The reason for this decision was to reduce the risk that the findings from the review would be incompatible with the local service provision.

2.4.3 Therapeutic Relationships: Role in Developing Self-Management Behaviours

The most frequent result of therapeutic relationships related to supporting participants to build confidence, to feel empowered and regain, or retain, control of their health-related decision making. This finding was reported by seven of the fifteen papers (Ackerman & Hilsenroth, 2003; Dwarswaard et al., 2016; Kaplan et al., 1989; Lee et al., 2008; Phillips-Salimi et al., 2012; Thorne et al., 2005; Wood et al., 2013).

Dwarswaard et al. (2016), suggested participants require three types of support in order to self-manage LTCs. These included instrumental, psychosocial and relational support. The authors proposed that relational support was central to, and underpinned, the provision of both instrumental and psychosocial support elements. The relationships which contributed to the development of SM included not only partnership working with professionals, but also recognised the importance of relationships within family, social networks and interactions with peers.

Whilst it was not the intention of this ILR to identify a theoretical model. This finding was resonant with the fundamental human psychological need for competence, autonomy and relatedness described by Self-Determination Theory (SDT) (Deci & Ryan, 2012). There was congruence also with the recognition of the dynamic nature of SM. Self-Determination Theory reinforces the premise that not all people will have the same SM need, which drives home the importance of a personalised approach (Wood et al., 2013). Further detail relating how SDT has informed this research is described in Chapter 3.3.3.

This raises the question of whose view of SM is best? There is an argument that SM should be de-medicalised and tailored using a ‘best fit for the person’ approach to enable them to live their best life. This approach would need to consider the person’s values, beliefs, and available resources within their own life context. The following section explores the idea of participant ownership over their SM goals in more detail.

2.4.3.1 Self-Management Ownership

van de Bovenkamp and Dwarswaard (2017), identified the professional-patient relationship, including frictions and their implications, as significant influencers of SM. This includes the extent to which professional and participant share common beliefs and values relating to SM. They urge professionals to be mindful of their own beliefs and values around SM and adapt to the needs and abilities of the people they are working with; in order to navigate the tensions where differences in participants’ opinion arise. The difference between professional and participant beliefs and values are important in determining the level and type of SM behaviours that are adopted.

The authors describe the potential for conflict to arise from this difference in perspectives, which may also impact on the shape of SM in practice. This links with the need for professionals to be more aware of readiness for change, and motivation models (Prochaska, 2008). These models may guide professionals to understand their participants better, through using therapeutic relationships, and as a result, modify their approach as required and tailor interventions appropriately.

There were two suggestions from the literature as to how therapeutic relationships influence SM outcomes. The first considers the impact of timing of therapeutic relationships and their influence on SM. Lee et al. (2008), describe the importance of both parties agreeing their roles in the therapeutic relationship, early in the clinical interaction. This was perceived as reflecting that participants were listened to, cared for, and respected for their equal power in the relationship.

The impact of this early connection included building trust, adherence with treatment, development of coping skills, reduced perception of vulnerability and increased locus of control. These authors reinforce the need to avoid assumed roles, for participation in therapeutic relationships to be effective. Phillips-Salimi et al. (2012), build on these findings, suggesting the impact of timely connectedness results in participants' developing higher self-esteem; enhanced psychosocial and emotional adjustment. They propose that this allows them to develop adaptive interpersonal skills, which results in improved health status and wellbeing, and diminished risk-taking behaviours.

van de Bovenkamp and Dwarswaard (2017), argue that there is a balance that needs to be reached between viewing SM exclusively as medical condition management or viewing SM as enabling people to live their best life. The most interesting aspect of this finding is that it contradicts the 'all or nothing' perception of SM. It starts to interpret SM as a continuum of choices that people living with LTCs must make, in order to balance their health and wider needs. This underlines the importance of healthcare professionals modifying their approach, enabling individuals to adopt ownership of certain aspects of their SM. Recognising that people may be selective in which aspects of their healthcare they self-manage and which aspects they prefer to defer to others including family members, community partners or healthcare professionals (Schulman-Green et al., 2012).

2.4.3.2 Informed Non-Compliance

Where non-compliance with SM recommendations was reported in the ILR papers, there was an implied sense of participant failure. Dunne et al. (2018, p. 49) report that reasons for avoidance of SM included participants' return to learned behaviour patterns, which included "negative behaviours", including non-attendance at hospital appointments, alcohol or tobacco consumption, in order to cope with situational stressors. Wood et al. (2013, p. 504), echo this challenge of overcoming lifetime habits and add participants' views suggesting that "the need for practice, effort and concentration" is also prohibitive. van de Bovenkamp and Dwarswaard (2017), describe professional perceptions of participants being uncooperative, without first understanding the social context, and available resources to self-manage surrounding the person.

The statements "not self-managing optimally" and "vary in the ability to develop effective coping strategies" used by Schulman-Green et al. (2012, p. 142), denote that their view at the time was that the fault for failure lay with the participant. However, in their later paper, they present a more complex picture of the factors influencing SM. They reconceptualise these factors as being less concrete than "present or absent", suggesting instead that these factors would better suit being perceived as existing on a continuum (Schulman- Green et al., 2016, p. 1483). This resonates with the view presented later in this chapter (Section 2.4.5) relating to influencers of therapeutic relationships having the potential to be either positive or negative, and present at differing degrees.

This concept of graded integration of SM includes both the level to which individuals choose to adapt their behaviour and the choice over which behavioural adaptations they choose to adopt. These choices are often guided by individuals' available resources, environment and social context (Schulman-Green et al., 2012; Schulman- Green et al., 2016). Perhaps this is the point at which SM and cancer rehabilitation have the greatest potential to, together, support the development of SM.

Through the shared decision-making process, and person-centred goal setting inherent in cancer rehabilitation, the concerns relating to participant volition and ownership might be managed. The rehabilitation process seeks to support the development of new skills and behaviours, offering a supportive environment for practice and rehearsal. This may be instrumental in replacing harmful coping mechanisms with more effective, less harmful alternatives. A greater appreciation of individuals' experiences will be pivotal to understanding this process better. The following section outlines the participant experiences described by the literature included in the ILR.

2.4.4 Therapeutic Relationships: Cancer Rehabilitation Participants' Experiences

All fifteen papers included in the ILR reported research samples which were either made up of PABC or included cancer as part of a population affected by a range of LTCs. Of these, participant experiences of therapeutic relationships were identified in eleven papers.

Seven of these eleven papers explored the concept of the therapeutic relationship as their primary focus (Ackerman & Hilsenroth, 2003; Browall et al., 2013; Kaplan et al., 1989; B. Murray & McCrone, 2014; Phillips-Salimi et al., 2012; Schnur & Montgomery, 2010; Thorne et al., 2005). Two papers explored the experiences of PABC in the context of cancer survivorship and/or SM (McCorkle et al., 2011; van de Bovenkamp & Dwarswaard, 2017). Only two papers reported peoples' experiences of therapeutic relationships in a cancer rehabilitation context (Lee et al., 2008; Wood et al., 2013).

These last two papers shared three key themes which impact on participants' experiences of therapeutic relationships. The first of these suggested that participants were sensitive to professionals' personal attributes and qualities, which were reflected through their attitude and conduct. The second was the value associated with professionals who integrated their knowledge and skills with intuition and instinct into their practice. The third, reflected participants' awareness of professionals' behaviour as it conveyed genuine interest in participants as individuals. How professionals then managed the balance of power during working partnerships were seen as influential on the development of therapeutic relationships. The authors of the remaining papers presented results which supported these findings. A summary of ILR papers can be found in Appendix 4 and 5. The following section describes these themes in more detail.

2.4.4.1 Personal Attributes and Qualities

Participant perceptions of healthcare professionals' personal attributes and qualities were presented to some extent in all ten papers which reported findings relating to therapeutic relationships (See Appendix 5). These authors present participants' descriptions of professional attributes or characteristics which could be collated into two broad themes, namely professional attitudes towards the healthcare relationship, and their conduct during the healthcare relationship.

There was greatest consensus across the papers in relation to the impact of professional attitude on the development of therapeutic relationships. Twelve papers reported personal qualities conveyed through professional interactions including warmth, friendliness, empathy, sympathy and a caring attitude as important. Other professional attributes described by individual papers included honesty, sincerity, trustworthiness and moral comportment.

Professionals' conduct, including their portrayal of interest, effort and enthusiasm in their role was described as contributing to the development of therapeutic relationships. To a lesser extent, other aspects of professional conduct including being respectful towards healthcare participants, having a flexible or adaptable working style, being perceived as open and transparent by healthcare participants, or being constant were also attributed to influencing therapeutic relationships (Ackerman & Hilsenroth, 2003; Browall et al., 2013; Dwarswaard et al., 2016; Lee et al., 2008; B. Murray & McCrone, 2014; Phillips-Salimi et al., 2012; Thorne et al., 2005; van de Bovenkamp & Dwarswaard, 2017).

2.4.4.2 Knowledge and Skills

The ILR papers identified a range of professional knowledge and skills which could be viewed as being either the tools and techniques relevant to the healthcare professional role or the application of instinct and intuition in the course of fulfilling a professional role.

Professional knowledge and competence with technical skills were identified in five papers, as having an impact on the development of therapeutic relationships. However, of all of the skills, tools and techniques available to healthcare professionals, ten papers described communication skills as one of the most influential tools or skills involved in developing therapeutic relationships. This included communication, which was described as being active and bi-directional, during which tone of voice was perceived as important. Healthcare participants feeling that they were being listened to by healthcare professionals, was a specific skill highlighted in six papers.

Eight papers explored professionals' integration of instinct or intuition into the therapeutic relationship as important. Examples of this include professionals being sensitive to cues during interaction and interpreting these appropriately, professionals being emotionally engaged within therapeutic encounters so that participants feel their own investment is reciprocated and professionals being attentive to the healthcare participants' experience of the therapeutic interaction.

2.4.4.3 Professional Behaviours

Professional behaviours were described in thirteen ILR papers. These differed from the professional attributes discussed earlier in terms of describing behaviours which reflected the adoption of a person-centred approach healthcare interactions and willingness to work in partnership with healthcare participants.

Person centred care was described in eight papers. Examples of person-centred behaviours included avoiding paternalistic interactions such as the exclusive use of prescriptive interventions and restricting participants' personal responsibility for their own health and wellbeing. In contrast, person-centred behaviours incorporated viewing healthcare participants as individuals, getting to know them and tailoring support to their unique needs and circumstances. Healthcare participants were clear that behaviours which conveyed a focus on disease, treatment, or medical records was likely to be counter-productive to therapeutic relationships. Personalisation of healthcare interventions included agreeing treatment goals that had been formed in a co-productive manner.

Partnerships between healthcare professionals and participants were described in ten ILR papers. Largely this was discussed from the perspective of determining agreed roles within the therapeutic relationship, determining and maintaining a power balance during active involvement in decision making, which is acceptable to both parties. Ackerman and Hilsenroth (2003), highlighted that identifying and repairing ruptures in the partnership was important to the development and maintenance of dynamic therapeutic relationships. Browall et al. (2013), reinforces the importance of this partnership including careful consideration of family members and their needs.

The impact of therapeutic relationships has the potential to be both positive and negative, depending on a participant's perception of the experience. The following explores how personal preferences and perspective can influence how barriers and facilitators to therapeutic relationships are interpreted.

2.4.5 Therapeutic Relationships: Barriers and Facilitators

The professional attitudes, attributes and behaviours represented in the ILR papers appeared to have had the potential to act equally as facilitators and/or barriers, to the cultivation and maintenance of therapeutic relationships (Ackerman et al., 2001; Phillips-Salimi et al., 2012; Thorne et al., 2005; Wood et al., 2013). There appeared to be three conditions which influenced whether therapeutic relationships might succeed or fail. These included the compatibility between professional and participant. The authenticity with which both parties approached the interaction. The impact of time on or timing of the interaction. These are discussed below.

2.4.5.1 Compatibility

Schulman- Green et al. (2016), proposed that attributes, attitudes and behaviours exist on a continuum. All having the potential to positively or negatively influence the development of therapeutic relationships. Whether the impact of professional attitudes, attributes or behaviours were positive or negative seemed to have been dependant on expectations around the type and level of participant involvement in healthcare and interpersonal communication styles (van de Bovenkamp & Dwarswaard, 2017).

This introduces the importance of understanding the interpersonal boundaries of the individuals involved (Phillips-Salimi et al., 2012). Boundaries can be subjective, objective, with both psychological and physiological dimensions. They are contextually dependent and therefore be at one time stable and at another changeable. It is important to avoid the assumption that every person has the motivation and desire for connectedness, in the same manner, and to the same level as each other.

Gaining a true sense of what people felt their experience of relationships with healthcare professionals were like was present in 60% of papers which described a sense of ‘being known’ (Thorne et al., 2005). This incorporated the sense that care was tailored to individual needs (Wood et al., 2013). This suggests that to some extent, professionals need to develop two key skill sets. The first is an acute level of awareness which enables them to read and interpret the behaviour of healthcare participants. The second is the malleability within their behaviour and communication style to adapt to the needs of each individual with whom they interact.

2.4.5.2 Authenticity

Within the ILR literature there appeared to be conflicting messages, alternating between healthcare professionals’ being adaptable to participants’ needs and also being able to maintain authenticity in the expression of their own emotions. Kaplan et al. (1989), noted that genuine expression of affect by professionals resulted in better health outcomes. This included expression of negative affect; as anger and frustration were denoted as sincere expressions of concern and conveyed a message of care. But Lee et al. (2008), countered this finding by saying that negative affect such as lack of sympathy and inattentiveness to participants’ feelings was counter-productive to therapeutic relationships.

None of the included papers addressed this tension explicitly. Professional anxieties around managing this tension are not new. Aranda and Street (1999), suggest that limiting therapeutic relationships, or maintaining a ‘professional’ persona were strategies used for managing professional anxieties. The importance of negotiating authenticity within an adaptable relationships style, is considered by some, as essential for building therapeutic relationships (Yedidia, 2007). Hechinger, Mayer, and Fringer (2019), propose that being adaptable and maintaining authenticity need not be mutually exclusive. These papers which describe this tension were not written from an OT or rehabilitation perspective. It would be beneficial to explore whether this tension is perceived to exist within cancer rehabilitation during later phases of this study.

The way that messages were conveyed by professionals, significantly influenced the participants’ interpretation of the message. Negative emotions and behaviours might be perceived as placing the therapeutic relationship at risk of friction or rupture and result in professionals concealing all negative emotional expressions. However, the importance of the navigating therapeutic relationships, incorporating both positive and negative affect, was echoed by (Ackerman & Hilsenroth, 2003). They suggested that ruptures and repairs in the working alliance were to be expected in practice. How the professional uses personal qualities such as affirming, understanding and nurturing to positively influence the development and maintenance of the therapeutic partnership is key. They raise the question, perhaps it's not important what professionals do, but how or when they do it?

2.4.5.3 Time and Timing

Time or timing, in relation to therapeutic relationships or SM was discussed in half of the papers. The concept of time was described in relation to either a timepoint in the treatment pathway, or the amount of time allocated to an interaction. Time allocation included the frequency of interactions, or duration of interactions (either singular or episodes of care) with healthcare professionals (B. Murray & McCrone, 2014; Schulman- Green et al., 2016).

Whilst largely represented in the papers in relation to SM rather than therapeutic relationships, the aspect of time concerned the timing of the interaction, in relation to the phase of the cancer continuum. (McCorkle et al., 2011), propose that different phases of treatment set the context for individual preferences for engaging with SM. They suggest that SM is critical across all phases of the treatment continuum. However, they advised that the implementation of SM strategies may be more difficult for people when the burden of treatment is high. The authors observed an increase in participant passivity in SM when they felt physically or emotionally challenged.

In contrast to this opinion, Schulman- Green et al. (2016), proposed that the impact of time, or the different phases of the cancer pathway, is important on the development of therapeutic relationships or SM. But not because of treatment burden or participants feeling overwhelmed. They argued that professional behaviours, such as investing time, and offering regular contact, and offering timely, practical, anticipatory advice, would improve the likelihood of SM recommendations being adopted.

Browall et al. (2013), suggest that there was a moment at first contact with healthcare professionals that people make a judgement as to how they will be treated. This suggests that there is a narrow window of opportunity for healthcare professionals to build trust and confidence. The impact of not taking this opportunity is that people might feel their needs are not important to the healthcare professional, and subsequently disengage from the relationship.

Of the papers which explored themes relating to time. None considered the concept of time from the participants' perspective. The value of time to a person with a long-term, and potentially life-limiting condition can take on new meaning. This might result in people being disinclined to accept delayed or rushed interactions as worthy of their time. This would likely impair the development of the therapeutic relationship, and subsequently pose a challenge to professionals supporting the development of SM behaviours.

2.5 Strengths and Limitations

The ILR did appear to be the most suitable review method for this study. Even having revised the search terms proposed in the 'a priori' protocol, the sample yielded by this revised strategy was still small. The ILR enabled the review to draw on a wider range of primary and secondary research papers reporting studies which used qualitative, quantitative and mixed methods designs. The iterative nature of the ILR allowed for this amendment (Cooper, 1982).

There were benefits and risks to the use of working definitions to shape an ILR (Russell, 2005). While avoiding the definitions of key concepts from being too narrow protects against impaired findings which don't accommodate new information from the review process, there is also a risk that not defining the operational definitions enough can lead to misinterpreting the study findings by overlooking important details. However, it may not be unexpected for operational definitions, or their inter-relationships to change as a result of the ILR. One of the key aims of the ILR was to avoid simply re-writing a summary of existing knowledge, it sought to challenge and extend the concepts and conceptual frameworks (Torraco, 2016).

There is an inherent bias throughout this review which resulted from the approach adopted. Randolph (2009), recommends researchers clearly articulate their perspective and associated biases when reporting their ILR. It was not possible to approach this review from a truly neutral perspective. Reflections on this lack of neutrality can be found in Chapter 7.4 and actions taken to mitigate bias during data analysis are presented in Chapter 8.5.3.

The tension between theory underpinning therapeutic relationships in practice (Finlay, 2004; Taylor, 2008), and rationalised approaches to service design was introduced in Chapter 1.4 as a key driver for this research. This tension continues to place therapeutic relationships at risk of being de-prioritised by healthcare systems under pressure (Imison et al., 2014; Kaplan et al., 1989). Despite policy in the UK, and specifically in Wales, being supportive of PCC, there appears to be a delay, or disconnect, between the generation of research findings and impact on practice.

With only one paper from the UK being included in the ILR, this raises the question of whether the findings from other countries could be generalised to the UK. One issue, in particular, needs to be taken into consideration. This relates to the comparison of healthcare systems. Several of the healthcare systems where the reported research was undertaken, were not directly equivalent with the NHS in the UK. The key difference being the participants from other nations having participated in healthcare systems where care is either wholly or partly private (i.e. participant-funded). Some might argue that taking ownership and responsibility for the cost of rehabilitation would indicate a higher level of volition and motivation for SM. This potentially reflects a different state of mind to participants who access NHS rehabilitation.

This integrative literature has started to describe the interface between therapeutic relationships and SM. One of the challenges facing this topic is the lack of a clear consensus in definition of therapeutic relationships. None of the papers, which focused on therapeutic relationships in this review, identified Gelso’s (2014), model of therapeutic relationships. It is likely that this is because these papers pre-dated the growth in research into SM, in which therapeutic relationships play a role, which appears to have emerged after 2012. Whilst this growth in evidence supports an association between the two concepts, there is little evidence to suggest a causal relationship between effective therapeutic relationships and SM. This review yielded a small sample of papers, and as a result, the findings have been interpreted conservatively.

2.6 Summary

This ILR was the first of three phases of PPD research to be reported in this thesis. The findings presented by this ILR suggest that therapeutic relationships may act as the mechanism through which professionals can support cancer rehabilitation participants to develop SM behaviours. The healthcare professional role was highlighted by participants as being pivotal in therapeutic relationships and SM.

As Yedidia (2007, p. 42), states “an illness episode for [healthcare professionals] is a routine part of their working day, while for [participants] it is a unique, often traumatic event”. This suggests that healthcare professionals might take a lead in the development of therapeutic relationships, initially, with a view to handing over ownership of their SM over time. There appears to be increasing need for professionals to be more self-aware. There were outstanding questions relating to the impact of time or timing on the development of therapeutic relationships and SM. Professionals’ time was explored within the ILR papers, but the value of healthcare participants’ time was not explored.

The ILR revealed that there was a greater level of consensus regarding the definition of SM than there was around the definition of therapeutic relationships. Where therapeutic relationships were described, they were perceived as being as unique as the individuals who were involved in developing and maintaining them. Professional attributes, knowledge and skills and behaviours may have the potential to be either a facilitator or a barrier to the development of therapeutic relationships, depending on the people they’re working with and the circumstances surrounding the interaction.

There was a tension alluded to in the ILR findings relating to how professionals negotiate the tension between adapting their style of approach to suit individuals, whilst maintaining their authenticity during healthcare interactions. There was very little addressing this topic within the ILR papers, and further reading uncovered very little with which to explore this topic to any level of satisfaction. This is a tension that predominantly relates to professionals. However, it would be beneficial to understand how important professionals’ adaptability and authenticity are to rehabilitation participants.

There were opposing views within the ILR papers surrounding the definition of SM. The first saw SM as compliance with professional recommendations, which was at odds with the PCC, ‘expert patient’ agenda promoted by healthcare policy in Wales throughout the duration of this PPD research. The second saw SM as laying on a continuum. Healthcare participants should own the responsibility for their SM and behaviour change outcomes. They should have the autonomy to decide to engage with recommendations in a way and to a level that was congruent with their beliefs, values and resources. This might be called the de-medicalisation of SM. This continuum approach to this would appear to offer a practical solution to what has historically been viewed as a compliance, non-compliance dichotomy.

Given the complexity of this research topic, ILR methodology was employed to offer the greatest chance of identifying relevant research. However, so few studies met the ILR criteria, and even fewer reported studies undertaken within a cancer rehabilitation setting. The evidence presented, lacked sufficient detail regarding the tensions and observations described in this chapter to support local services to protect therapeutic relationships in practice and thereby resist service rationalisation and standardisation.

With healthcare services at increasing risk of service rationalisation, this PPD research was timely. The second and third PPD research activities sought to build on these ILR findings, providing a means to explore how this mechanism influenced clinical outcomes in more detail. These activities would use local cancer rehabilitation participants’ experiences of therapeutic relationships to explore the extent to which therapeutic relationships, influenced SM behaviour change.

Chapter Three provides an overview of the methodology for these subsequent two phases of PPD research.

Chapter Three: Research Design and Methodology

3.1 Introduction to Chapter Three

The integrative literature review presented in Chapter Two identified areas of tension around therapeutic relationships and SM. The first included the role of therapeutic relationships in supporting SM, which incorporated the concept of ownership over SM and negotiating informed participant non-compliance. The second included understanding the barriers and facilitators of therapeutic relationships and the challenge for professionals to navigate participant expectations in relation to time, adaptability and authenticity.

This third chapter will present an overview of the PPD research design and methodology which shaped the second and third PPD research activities. This will include the research aims and objectives, philosophical and theoretical foundation which underpins this research, an exploration of the research process including the sampling and recruitment strategy and a brief description of the data collection tools. This chapter also includes a brief discussion around the methods of data management and analysis. Ethical considerations associated with this research are explored.

3.2 Research Aims and Objectives

In addition to the aims outlined for the ILR in Section 2.1.3. There were two aims of this PPD research. The first was to gain a greater understanding of how participants of a local cancer rehabilitation service experienced therapeutic relationships. The second was to understand the role that therapeutic relationships played in their ability to develop SM behaviours. To address these aims, the following specific research questions were defined:

- How do cancer rehabilitation participants describe their experiences of therapeutic relationships?
- Can cancer rehabilitation participants identify barriers and facilitators for effective therapeutic relationships, based on their experiences?
- What aspects of cancer rehabilitation do participants perceive as most important and/or relevant to their own circumstances?
- How important are therapeutic relationships, during cancer rehabilitation, for supporting sustainable self-management behaviour change?
- What impact on rehabilitation or self-management outcomes (if any) did rehabilitation participants attribute to their therapeutic relationships with local providers?

3.3 Research Approach Process and Design

The PPD research presented in this thesis was guided by the process described by Crotty (1998). This process asks the researcher to consider the methods and methodologies most appropriate to answering the research questions(s). Then challenges the researcher to justify their decision-making through exploration of the theoretical and philosophical context in which the research is to take place.

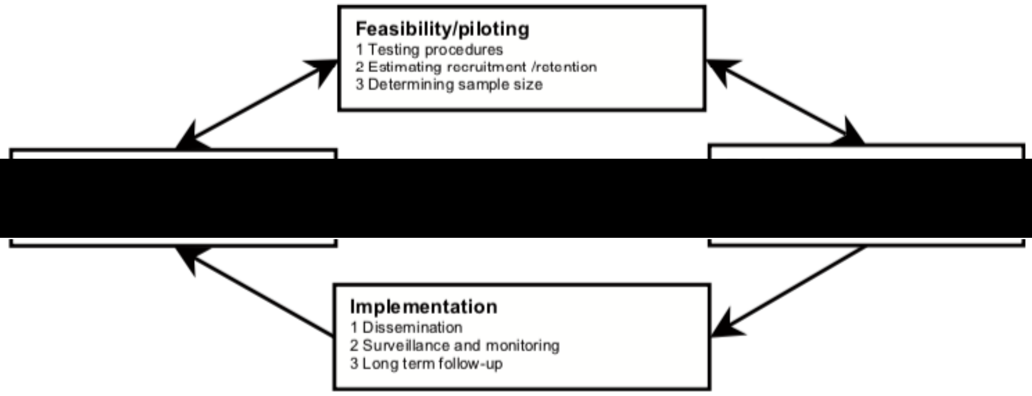
A group of expert rehabilitation participants worked in partnership throughout the planning of this research. They suggested that two considerations be incorporated in the decision regarding the selection of data collection methods (Fox, Martin, & Green, 2007). The first was to consider the practicalities of having to go somewhere in order to participate in the research and all of the logistics travel entails, including cost and access to transport, parking, time away from work and family responsibilities. The second was the risk that less confident participants may be forced to consensus by stronger personalities, if a face-to-face group technique was selected. In light of these considerations, the research process and data collection methods are introduced in overview below. This relationship with the expert rehabilitation participants is discussed in more detail in Chapter 7.4.

There were three key factors which influenced the approach to this research. The first was to adopt a philosophical framework which accommodated cancer rehabilitation as a complex intervention. The second, was to ensure this philosophical framework reflected the valued role of rehabilitation / research participants' involvement in shaping the research design. The third, was to select suitable theoretical models to support the data collection methods and data analysis processes throughout the research.

3.3.1 Researching Complex Interventions

In Chapter One, the complexities of cancer rehabilitation were explored, and how it provides an example of a complex intervention. The following explores how the Medical Research Council's (MRC) model for Developing and Evaluating Complex Interventions (2006), informed the research design (See Figure 4).

Figure 4. Medical Research Council Model for Developing and Evaluating Complex Interventions



[redacted]

The MRC framework offers four phases for developing and evaluating complex interventions. In this framework it is advised to approach the development of complex interventions in a manner which builds upon the evidence base and relevant theoretical perspectives, ahead of systematic approach to pilot, exploratory and definitive evaluation. The MRC advise that while it is helpful to consider each of these phases as a guide for defining the objectives of research studies, these phases are not rigid and they may not need to be completed in a pre-determined linear or even cyclic sequence (Medical Research Council, 2006). This allows for investigators to return to earlier phases of enquiry even after a complex intervention has been implemented.

The PPD research presented in this thesis sought to understand more about a clinical service which had already been implemented. To this end, the research focused on the development and evaluation phases of the MRC framework. The ILR sought to develop a more thorough understanding the relevant evidence base. Subsequent research activities aimed to evaluate the impact of one aspect of rehabilitation, i.e. therapeutic relationships, within an existing cancer rehabilitation service.

This PPD research did not seek to assess the clinical effectiveness of therapeutic relationships or undertake an analysis of cost-effectiveness. Local service evaluation activities separate to this research have been implemented for this purpose. Instead, it aimed to understand the impact of therapeutic relationships on the change process which takes place during cancer rehabilitation. The logic model in Appendix 6 presents the inter-relationships between the different PPD research activities presented in this thesis (Hayes, Parchman, & Howard, 2011).

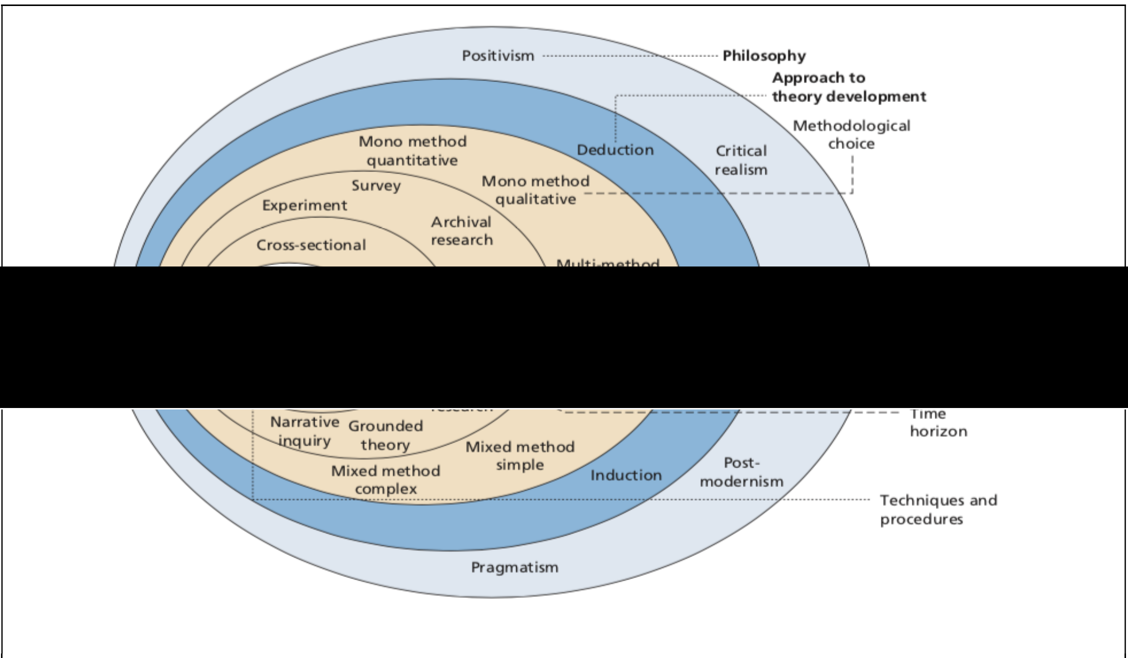
3.3.2 Philosophical Framework

Research philosophy describes a framework of beliefs and assumptions about the creation of knowledge. There are three types of assumptions which inform research question development, guide data collection methods and frame how the results are interpreted (Saunders, Lewis, & Thornhill, 2009). These include epistemology, ontology and axiology. Epistemology is concerned with how knowledge is created, obtained, and deemed to be reasonable and acceptable to a clinical community and ontology relates to the nature of reality. Axiology, incorporating reflection and reflexivity, considers the impact of the researcher, their values and ethics on the research process (Eastwood et al., 2017). A full discussion of the axiological aspects of this research can be found in Chapter Seven. The following section will briefly outline the epistemological and ontological foundations which underpin this research.

3.3.2.1 Epistemological and Ontological Approach

Crotty (1998), describe the challenges faced by novice researchers when trying to find the language to articulate the philosophical foundation for their study as terms are not always well organised and at times, terms seem to be used interchangeably. To overcome this, Saunders et al. (2009), use the analogy of a research ‘onion’ to illustrate the process researchers undergo in order to describe the philosophical foundations of their research (see Figure 5). This model was used to guide the philosophical design of this research.

Figure 5. Research ‘Onion’



[redacted]

Source: © 2015 Mark Saunders, Philip Lewis and Adrian Thornhill

This study was concerned with understanding the experiences of individuals within a specific context. This accommodated the subjectivist perspective that what was perceived as true or right for one person, may not be for another. However, it also aspired to the objectivist values towards theory development and maintaining a high level of research rigour. It aimed to achieve this through robust and replicable methodological design, viewed through a lens of pragmatism. Any tensions which might arise between objectivist and subjectivist research findings will be considered in Chapter Eight.

Pragmatism is was one of five research philosophies (see Figure 5), which offered the opportunity to balance the rigour of objectivist research with the subjectivist nature of contextual experiences. Saunders et al. (2009), cautions novice researchers to avoid considering the use of pragmatism when the challenge of understanding other paradigms becomes too great.

The following three research philosophies were considered, but ruled out, when planning this PPD research. The first was a positivist empirical design. The research questions did not lend themselves to experimental hypothesis-testing. The second was an interpretivist approach. Whilst the use of a case study may have resulted in deep understanding of a rehabilitation participant’s ethics and values. There would be limitations to understanding how this one perspective reflected the needs of a diverse cancer rehabilitation population (Kazi, 2003). The third was action research approach, which had previously been used within the local service, but this PPD research did not aim to achieve a change in practice (Kemmis & McTaggart, 2000).

Pragmatism can be a powerful tool for interpreting mixed methods (Glogowska, 2011). When combined with a subjectivist approach to understanding participants' perspectives, pragmatisms offers a deeper insight into how complex interventions produce outcomes (Kazi, 2003)Adopting a pragmatic approach to research design aimed to close the gap between research and practice, ensuring the research findings could be used to effect change in the clinical setting. The following section explores how pragmatism was used to shape this research.

3.3.2.2 A Pragmatic Approach to Research Design

Pragmatism aims to navigate the dichotomy of qualitative and quantitative research, supporting both deductive and inductive approaches to research. It does this by proposing that any research design which helps the researcher to learn more about the phenomenon which they set out to understand is more important than adherence to paradigmatic rules. Pragmatism embraces uncertainty in research, and encourages researchers to be flexible and adaptable in their research (Feilzer, 2010). Pragmatic research aims to enable action or change as a result of the practical application of ideas and knowledge generated by research (Saunders et al., 2009). It is not wedded to the generation of 'truth' but seeks to understand phenomena within the ambiguity of the real world.

The pragmatic perspective mirrors the valued role of theoretical frameworks as a guide, rather than a directive, for OT practice. Occupational Therapy theory is seen to provide a roadmap for practitioners, which helps to structure thought processes, provide signposting, and enable them to support participants to navigate the physical, psycho-emotional and social consequences of their disease or its treatments (Fleming, 1994). Fleming argues that much of this theoretical knowledge is poorly articulated by practitioners but is shared with rehabilitation participants through action within everyday clinical encounters. The very nature of rehabilitation, as a complex intervention, compounds the challenge for practitioners to describe the theoretical foundation upon which they build their rehabilitation practice. This link between practice and PPD research offers insights and value to the research findings that may not have been achieved through a traditional PhD route. In Chapter Seven, I present reflections on how my practitioner role influenced the research and how my role as a novice researcher influenced my practice.

Cryer (2005) suggests that, in research, a pragmatic approach to matching the research paradigm to the aspect of the complex intervention being studied, may overcome the risk of forcing a study to fit an incompatible research paradigm. Pragmatic research design recognises that there is no single view of the world and embraces the potential for multiple realities. Pragmatic research embraces the opportunity to work with multiple methods but does not mean that multiple methods are always employed. Pragmatism does not dictate the use of specific research methods but promotes method selection which facilitates relevant data collection that advances reliable, credible and sound research (Saunders et al., 2009; Weaver, 2018).

Glogowska (2011), presents a strong argument for the use of a pragmatic research paradigm incorporating mixed methods in healthcare research. Pragmatism accommodates the complexities of humans, health, and the services that provide care. This allows research to be more person-centred. This was one of the key strengths of the pragmatic research paradigm. It enabled the person-centred practice, which was highly valued, to be carried over, and reflected throughout this PPD research.

It was anticipated that adopting a person-centred approach to this research would open up the opportunity to explore the range and uniqueness of individual' perceptions. Not only was it important for the research to hear stories from a group who represented the different disease, demographic, and socio-cultural backgrounds of the local cancer rehabilitation population. It was congruent with the local cancer rehabilitation service's philosophy of person-centred service provision and service design as outlined in Chapter 1.2.4. It was an intuitive response to place cancer rehabilitation participants at the centre of a research study about their experience of cancer rehabilitation and the importance of their relationships with professionals on their rehabilitation outcomes (Wilkinson, 2020).

Morgan (2014), presents a discussion of the difference between the process and philosophy of the pragmatic paradigm. He challenges researchers to recognise the philosophical influences within the pragmatic paradigm and consider how these impact on the wider research context and community. By doing this, researchers might better understand and articulate not only the *outcome* of research decision-making, but also the *reasons* researchers made their decisions and the *impact* of their decisions. This approach has given this PPD research a level of freedom to evolve in response to the needs of the participants, the restrictions of the clinical environment and skills of the principal researcher.

Understanding the theory behind how interventions influence behaviour change in practice has been highlighted as a priority for health researchers (Davis et al., 2015). As described in Chapter 1.3.4 the local cancer rehabilitation service was introduced to Self-Determination Theory (SDT), while supporting prior research activities. This PPD research was underpinned by the theoretical assumptions shaped by Self-Determination Theory (SDT), and the OT practice model, Occupational Performance Model - Australia (OPM-A), which was used to guide clinical reasoning in the local cancer rehabilitation service.

The explicit use of theoretical frameworks in the development of behaviour change interventions has the potential to improve their effectiveness (Michie et al., 2011). Behaviour change theories including Transtheoretical Model (TTM) (Prochaska, 2008), and the Capability, Opportunity and Motivation Behaviour change model COM-B (Michie et al., 2011), aim to provide a framework for tailoring rehabilitation and SM interventions to the individuals’ readiness for change and their wider context within which change needs to take place.

On closer examination of theories of motivation and behaviour change, SDT appeared to offer a better fit for this PPD research than the behaviour change theories. There were three key reasons for this decision. First, SDT was sighted on supporting healthcare outcomes which aligned well with rehabilitation outcomes. Second, it was congruent with the OPM-A, the OT theory which underpinned my practice. Third, SDT was more explicit in terms of the importance of relatedness in supporting individuals to engage in behaviour change. The following sections explore both SDT (Section 3.3.3) and the OPM-A (Section 3.3.4) in more detail.

3.3.3 Self-Determination Theory

Self-Determination Theory (SDT) is a theory of human motivation which proposes that people have three fundamental needs. These include competence, autonomy and relatedness. Competence considers the development of knowledge and skills. Autonomy reflects the extent to which a person has control over their decisions and actions. Relatedness pertains to the intra- and inter-personal connections that people have within their social environment. Within this framework, relatedness (potentially identifiable as the therapeutic relationship), may be considered a key mechanism by which behaviour change can be achieved (Ryan et al., 2008).

There is growing evidence supporting the application of SDT in healthcare (Ng et al., 2012; Ryan et al., 2008; Silva, Marques, & Teixeira, 2014). Competence and autonomy, although part of the complex interplay between a person and their internal and external environmental contexts, were not the focus of this PPD research (Deci & Ryan, 2012). Ng et al. (2012), called for more research into the mechanisms that effect health behaviour change. It is for this reason, that the study focused on the impact of relatedness and its potential to be the ‘mechanism’ through which behaviour change can be facilitated.

Self-Determination Theory (SDT), offered a language with which the concept of therapeutic relationships could be operationalised (Silva et al., 2014). This operational framework was used to provide a structure with which to support the collection and analysis of data throughout this research. The SDT also provided a way to link cancer rehabilitation with existing behaviour change research by exploring the role that human motivation plays in the development of SM outcomes and to what extent therapeutic relationships, if any, influence this process.

Boger et al (2015) highlight therapeutic relationships with healthcare professionals, as part of a broader positive network, as a fundamental element in providing effective SM support. This relationship can promote knowledge, skills, development of identity and independence commonly associated with optimal SM outcomes. It can be a key feature in people feeling enabled to manage their own care.

Behaviour change interventions have been identified as one of the most promising ways of supporting SM in healthcare (de Silva, 2011), However, the development of interventions for SM is complex. They need to take into account the individuals’ situation and readiness for change (National Institute for Health & Care Excellence, 2014). Whilst behaviour change is achieved by some in the short term, not all programmes result in long term, sustainable behaviour change. Davis et al. (2015), presented evidence which suggested that there is inconsistent use of theoretical foundations in the development of behaviour change interventions. This raises the question as to whether the lack of theoretical foundation may have reduced the effectiveness of the interventions.

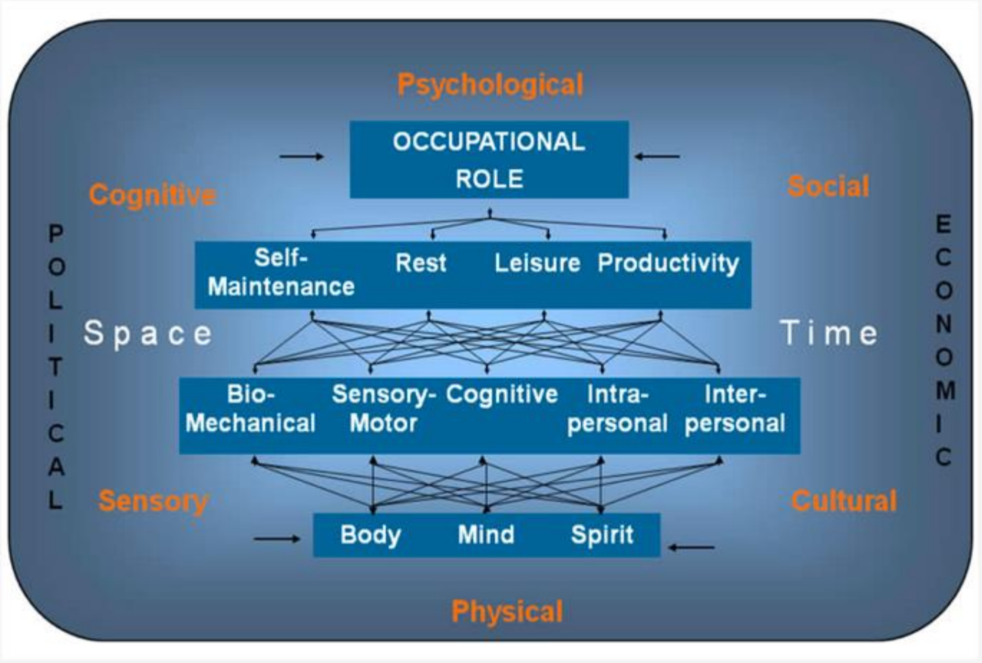
3.3.4 Occupational Performance Model – Australia (OPM-A)

Whilst the OPM-A was the theoretical framework which shaped my clinical practice, it was important to identify a theoretical framework for this PPD which could appeal to a wider range of healthcare professionals.

There is congruence between SDT and OT theoretical models in terms of their aim to facilitate enablement, ownership, through internal motivation. The OPM-A (Ranka & Chapparo, 1997a, 1997b), embeds motivation as an aspect of the intra-personal performance component within a complex interplay between an individual's internal and external physical, sensory, cultural and social environment, their activities of daily living and life roles (See Figure 6).

There is common ground between OPM-A and SDT in terms of four broad assumptions. These include the premise that people have fundamental needs for connection within themselves, and with their wider environmental context. It is accepted that human motivation can be influenced and thereby change behaviour. The social context or environment and how a person connects with it has the potential to be a catalyst for this change. Both theories acknowledge that the interplay between contributory factors is both complex and unique to each individual (Deci & Ryan, 2012; Ranka & Chapparo, 1997a).

Figure 6. Occupational Performance Model – Australia



3.4 Overview of Methods

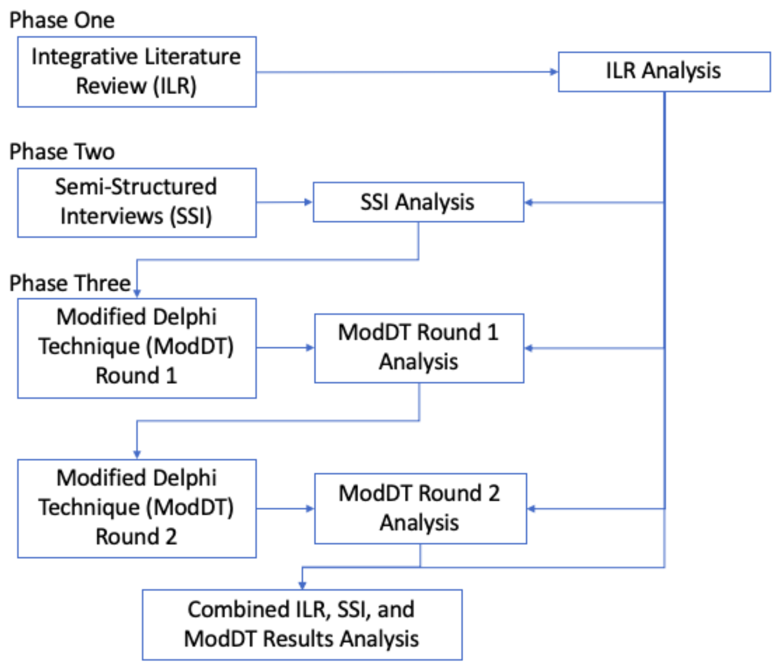
The aims of this PPD research reflected the complexity of both cancer rehabilitation and therapeutic relationships in that there was a need for both a deep and broad perspective on the topics. The philosophical and theoretical foundations described earlier in Section 3.3.2, were supportive of a mixed methods research approach. Using qualitative mixed methods would enable the flexibility to capture both the qualitative richness of individuals' experience and scope the extent to which there is common ground or diversity in opinion within the same study. This is what distinguishes it from a multi-methods study, which would seek to use multiple qualitative or quantitative methods in a single study, to answer the research questions (Schoonenboom & Johnson, 2017).

3.4.1 Mixed Methods Research

The use of mixed methods research is growing within health and social care research. This is largely in response to the desire to support the rich findings of qualitative narrative with the generalisability of quantitative numbers (Hesse-Biber, 2010). Research purists might argue that traditional research paradigms would be inherently incompatible with each other. However, pragmatic research allowed the choice of research methods to be determined by the research question. This recognised the practice-based nature of this PPD research. The potentially complementary nature of qualitative and quantitative data is key to applying a pragmatic approach, making it compatible with mixed methods design (Greene, Caracelli, & Graham, 1989).

Mixed methods research requires interaction between the qualitative and quantitative findings during analysis and interpretation. Building on the logic model (Appendix 6), briefly mentioned earlier in this chapter, Figure 7 illustrates the process through which the three phases of data collection in this research programme integrated both qualitative and quantitative data (Hesse-Biber, 2010). The results of each phase of data collection were analysed and used to inform the following phase. For example, the findings from the integrative literature review (ILR), were analysed alongside the subsequent research activities and were used to inform the semi-structured interviews (SSI). The findings of which were used to inform the first round of the Modified Delphi Technique (ModDT). The findings from the first round of the ModDT informed the subsequent round. Findings from all three phases were synthesised and are presented in Chapter Eight.

Figure 7. Overview of Research Phases



3.4.2 Semi-Structured Interviews

Semi-structured interviews (SSI) were selected as the first data collection method. Researchers are urged to carefully consider their purpose for selecting interviews, as other qualitative methods may be better suited to answering their research questions, especially if the aim is to gauge the beliefs or behaviours of a larger group (Kvale, 1996). For this patient population, it was felt that these would enable a small number of local cancer rehabilitation participants to describe their experiences of therapeutic relationships with local healthcare professionals in depth. This depth could then inform the breadth of experiences in subsequent data collection design.

As part of a mixed methods design, the SSI provided the most appropriate means to explore participant experiences of therapeutic relationships in detail. This first stage of data collection aimed to capture the unique experiences of individuals. As a result, a qualitative interview method, which offered people the opportunity to tell their story was chosen. Using an interview schedule meant that there was consistency in the questions asked of each participant, with flexibility to allow the participants to share thoughts and feelings which may not have been anticipated in the research planning stage. One of the pitfalls of SSI, is that the data obtained may be more subjective than that obtained from other methods and individuals' perceptions do not always reflect their behaviour (Kvale, 1996). These considerations will be taken into account during the analysis of the data and interpretation of the findings in later chapters.

Being practice-based research, it could be argued that a more observational approach to data collection may have suited this study better. This approach would have offered the opportunity to record observations relating to the behavioural aspects of therapeutic relationships in real time. However, it would likely have been more time and labour intensive and potentially more intrusive in terms of the technology required to record observations on film. Given many of the rehabilitation interventions were untaken in group setting, as described in Chapter 1.3.4, an observational approach may not have offered the same opportunity to explore as broad a range of individuals' reflections on their experiences to the same depth as SSI (Berg, 2004).

3.4.2.1 Semi-Structured Interview Procedure

The SSI were conducted as follows:

1. A participant briefing preceded each face-to-face SSI, during which informed consent for participation and audio-recording was confirmed.
2. Each SSI was to last no longer than 60 minutes and follow a pre-determined interview schedule (See Appendix 7) but offered the flexibility to follow participant conversation if deemed relevant to the topic.
3. Each SSI was to take place in a NHS, cancer charity or other location at participants' request. Locations were deemed suitable if they offered a quiet, comfortable and confidential environment, as agreed with the participant.
4. A de-briefing opportunity followed each SSI, to ensure that the research participant was aware of the purpose and proposed use of the interview content; and to provide emotional support and signposting to appropriate services if they found the interview upsetting.

3.4.2.2 Pilot Semi-Structured Interviews

Two pilot SSI were completed by a research colleague, following the procedure described above. No changes were made to the schedule or procedure following these interviews as the data obtained was felt to be satisfactory. The two pilot interviews were included in the final analysis. The findings from the SSI are presented in Chapter Five.

3.4.3 Traditional Delphi Technique

Traditional Delphi Technique is a structured group communication research method that is an effective way of enabling groups of experts to solve complex problems (Okoli & Pawlowski, 2004). It can also be used to ask experts to forecast or predict a future event or outcome. The technique can also be used as a prioritisation tool during goal setting processes (Brewer, 2006). The opportunity to generate both qualitative and quantitative data from the Delphi Technique (Hsu & Sandford, 2007), was appealing given the complexity of this PPD research topic.

Traditional Delphi Techniques have been found in healthcare research, particularly in relation to the development of clinical practice guidelines, or recommendations for practice, where there is little systematic review evidence available (Bloor & Wood, 2011). There appears to be growing support for the use of Delphi Technique within OT (Aguilar, Stupans, Scutter, & King, 2013; Holmqvist et al., 2013), especially in research projects which seek to explore less tangible elements of professional practice. The Delphi Technique was considered most suited to this research, for two key reasons. The first was the complex and intangible nature of therapeutic relationships in cancer rehabilitation. The second, highlighted by the ILR presented in Chapter Two, was the limited range of evidence available at the time this PPD research was design.

Keeney, Hasson, and McKenna (2006), suggest that very few researchers use a pure Traditional Delphi Technique, as it was defined in the mid-twentieth century. They present a summary of ways in which the Traditional Delphi Technique method has been seen to be modified. These modifications included the method of data collection used to inform the first round of the technique, the definition of ‘expert’ used for panel selection, and practicalities of conducting the technique through face-to-face or remote mechanisms. The following (Section 3.4.4), discussion explores how the Delphi Technique was modified for use in this PPD research.

3.4.4 Modified Delphi Technique

3.4.4.1 Informing Round One

The first round of a Traditional Delphi Technique might be informed by a synthesis of the available literature (Holmqvist et al., 2013; Keeney et al., 2006), or through data obtained via a first round of open ended questions posed to the expert panel (Hasson, Keeney, & McKenna, 2000). The Modified Delphi Technique (ModDT), employed in this PPD research used the findings from the SSI, described in Section 3.4.2, to inform the first round of ModDT questionnaires (Sandelowski, 2000).

3.4.4.2 Participants as the Expert Panel

A Traditional Delphi Technique poses questions to a panel of experts with the aim of identifying areas of common ground and difference of opinion in relation to a specific topic. This multi-stage process uses questionnaires, to understand the thoughts or experiences of individuals, considered experts on a topic. Traditional Delphi Techniques do not commonly invite healthcare participants to form the expert panel. The Delphi Technique requires that the expert panel consist of highly trained personnel who possess knowledge and expertise on the research topic (Brewer, 2006; Hsu & Sandford, 2007).

The panel recruited to the ModDT in this PPD research were not professionally trained in cancer rehabilitation and might not be considered to fulfil the criteria of ‘expert’. However, all eligible participants had been recruited based on criteria that valued their experience of having undergone cancer rehabilitation. Without direct experience of participation in rehabilitation, healthcare professionals were not in a position to know what it is to experience cancer rehabilitation, or to understand the impact of therapeutic relationships. This was perceived as the experts’ unique knowledge base. The definition of rehabilitation participants as experts might be considered one of the ways that the Traditional Delphi Technique was modified for application to this PPD research.

3.4.4.3 Practical Considerations of a Remote Group Communication Technique

There are similarities between ModDT and other group interview techniques, including Nominal Group Technique (NGT) (Brewer, 2006). Modified Delphi Technique might be considered a virtual version of an NGT as it adopts a similar prioritisation process. Other face-to-face group data collection techniques, such as focus groups, are favoured for the added richness in qualitative data generated from the interactions between participants, as they discuss and debate research topics (Leung & Savithiri, 2009). Both of these group techniques are limited in group size. Focus groups would not offer the potential to undertake quantitative exploration of the topic being researched. Whilst an NGT, may have been an acceptable method for this study, there were three significant benefits to selecting a virtual group technique.

First, remote participation eliminated the practical concerns that participants may have had relating to the resource implications of transport and travel, including both time and cost; and the logistics of negotiating research participation in relation to other work, family and social roles. The ModDT offered a flexibility in mode of delivery and therefore access to a broad range of participants. One of the challenges of traditional Delphi Technique is the risk of poor response rates (Hsu & Sandford, 2007). Poor response rates would potentially compromise any judgements that could be made from the available data. The ModDT was initially designed to be completed via hard copy, with return post using pre-paid envelopes. Following participant feedback, and to reduce the risk of poor response, the format was adapted to allow participants who preferred to use electronic communication, to participate via an electronic version of the questionnaire sent and returned via email.

Second, the ModDT was not restricted to the maximum group size of other face-to-face group data collection techniques. The purpose of the ModDT in this study was to explore the extent to which there was convergence and divergence in opinion, with respect to the themes emergent from the SSI, across as wide a population as possible. Understanding the level of importance of therapeutic relationships during cancer rehabilitation was likely to evolve as the result of the combined consensus and priority given to different aspects of rehabilitation by the group. Given the variation in characteristics across the participant cohort, it was important to engage with as many respondents as possible to gain a representative perspective on the research topic (Hsu & Sandford, 2007).

Most importantly, the ModDT offered a greater level of protection for less confident voices to express their opinion, affording the same opportunity for interaction as their more confident counterparts, without the risk of pressure to conform to more dominant opinions within the group. It was thought this approach may provide a more accurate reflection of the diversity of the cohort’s thoughts and feelings. The ModDT has been described as being facilitatory of creative thinking, offering the opportunity for participant reflection (Hsu & Sandford, 2007). This was an important feature for enabling people to change their opinion, without reprisal, in the face of new information in later rounds of the technique (Brewer, 2006; Hsu & Sandford, 2007).

Following the time-intensive nature of the SSI, the virtual practicality of the ModDT reduced the potential conflict in scheduling further face-to-face group techniques alongside clinical duties. As the ModDT responses were supplied in writing, there was also no resource requirement for transcription, as had been required for the SSI. The ModDT participants were afforded a quasi-anonymity. The iterative nature of the technique meant that their identity would be known only to the research team, but not to each other (Keeney et al., 2006). This also reduced the potential for peer group discussion of the research topic, and subsequent risk of identity disclosure for those people still undergoing rehabilitation. Further discussion relating to confidentiality and other ethical considerations is presented later in this chapter (Section 3.6).

3.4.4.4 Pilot Modified Delphi Technique

The tools used in this ModDT were not formally validated. However, pilot of the ModDT tools aimed to overcome the possibility of non-response, incomplete response, or data which was incompatible with the research questions, resulting from poor instrument content or design. The pilot tool was sent to those participants who had identified a preference for email communication, in the interest of expediency. In addition to completing the ModDT tool, the pilot cohort were asked to answer the six questions listed in Figure 8, to assist in determining if the tool would be suitable for use, and aid in refining the tool for the wider cohort.

Figure 8. Pilot Evaluation Questions

1. How easy was the survey to complete?

2. Did it makes sense to you?

3. Are the instructions easy to follow?

4. Is the survey too long?

5. Did the document work electronically?

6. Is there anything else you think I should know?

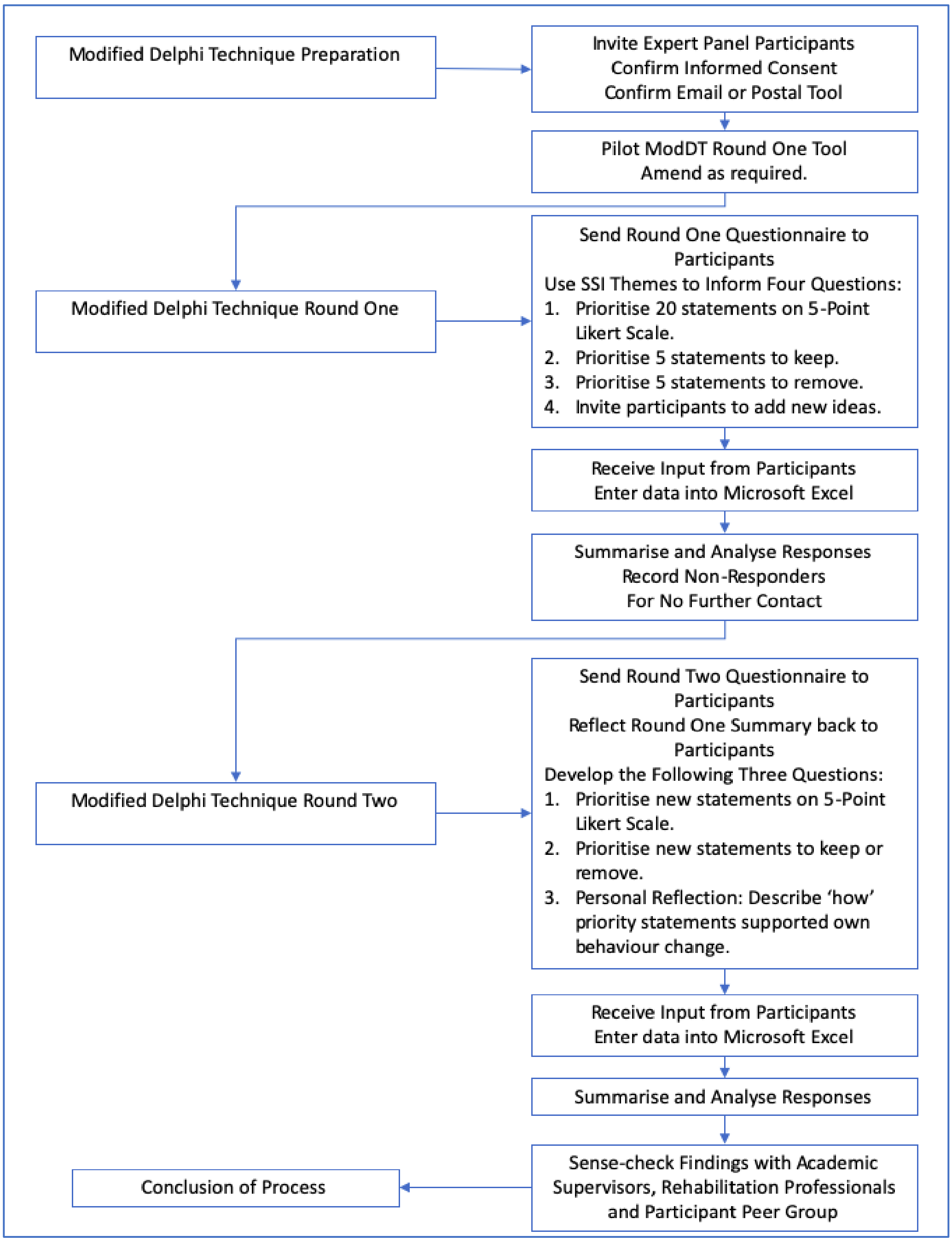
The pilot cohort recommended some minor grammatical corrections, and technical amendments to the electronic tool to make it easier for participants to complete. Beyond this there were no additional amendments required to the ModDT tool structure or content recommended by the pilot cohort. As a result, the pilot results were included alongside the wider cohort's responses for analysis. These results are presented in Chapter Six. Further discussion regarding the electronic adaptation of the ModDT is presented in Chapter 7.4.3.

3.4.4.5 Modified Delphi Technique Procedure

The ModDT was conducted using the process outlined in Figure 9. As described in Section 3.4.4.1 the SSI themes informed the first Round of the ModDT. On completion of Round One, the findings would be used to populate the tool used in Round Two.

Round One would include the opportunity for participants to make contributions which they perceived as being absent from the tool. Alongside the outputs from Round One questions, these contributions would be included for participants to prioritise in Round Two.

Figure 9. ModDT Process



3.5 Sampling and Recruitment

As this PPD research was undertaken in practice, potential research participants were identified from the local cancer rehabilitation service referrals database (See Chapter

1.3.4 for description of local service). Any person referred to the service and recorded on the database between 2011 and 2016 was eligible for invitation to participate in the research. This group varied in primary tumour site, stage of disease, time since diagnosis, and rehabilitation intent, i.e. preventative, restorative, supportive or palliative rehabilitation (Dietz, 1980). The following inclusion and exclusion criteria were therefore applied to the sample.

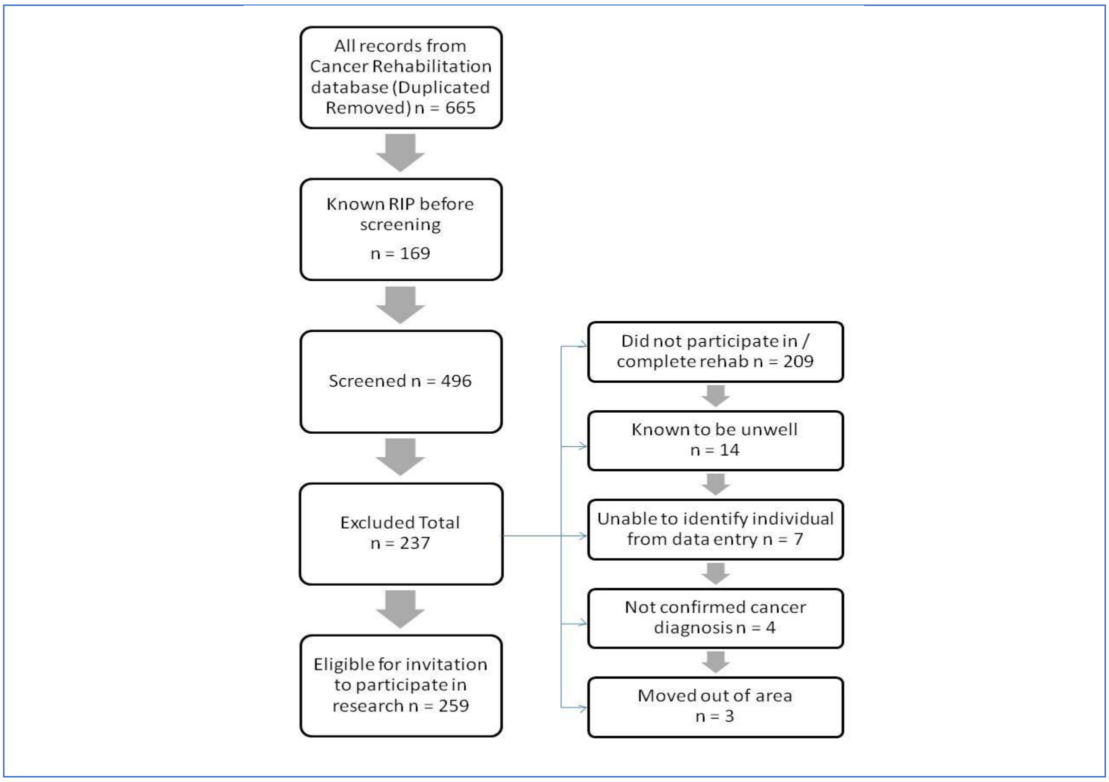
People were eligible to participate in this research if they:

- Were aged 18 years or older;
- Had been diagnosed with a cancer of any type and;
- Had presented with cancer at any disease stage;
- Had completed the local cancer rehabilitation programme or;
- Were in the process of participating in the local cancer rehabilitation programme at the time of recruitment.

3.5.1 Sampling

The research presented in this thesis was developed and undertaken within a local cancer rehabilitation context described in Chapter 1.3.4. There were no other equivalent cancer rehabilitation services in Wales at the time of the research, from which to recruit research participants. Given that the research aim was to explore a particular phenomenon, namely cancer rehabilitation, a purposive sampling approach was used to recruit individuals who were believed to be particularly knowledgeable or experienced in this phenomenon (Palinkas et al., 2015). Please see Figure 10. for an overview of the participant sampling procedure.

Figure 10. Participant Sampling Procedure



This PPD research followed a broad sampling plan which aimed to capture a range of experiences from participants with the characteristics described above (Section 3.5) (Moser & Korstjens, 2018). Please see Table 4. for an overview of the sampling matrix. Further detail regarding the characteristics of the responder and non-responder populations can be found in Table 5.

Table 4. Sampling Matrix

Characteristics	SSI	ModDT
Sample Size	n= 15 +/- 5	n=50
Sex (M:F) %	50:50	35:65

The sampling plan did not specifically seek to capture outlier cases or homogeneity in the sample. It did seek patterns of similarity and diversity of experience within the sample (Palinkas et al., 2015). A discussion relating to potential sampling bias is presented in Chapter 8.5.1. A comparison of the characteristics of the research participant population, the local cancer rehabilitation population and national Wales cancer incidence is presented in Chapter 4.2.6. This comparison was undertaken to explore the extent to which the findings from this PPD research might be generalised (Mays & Pope, 2000).

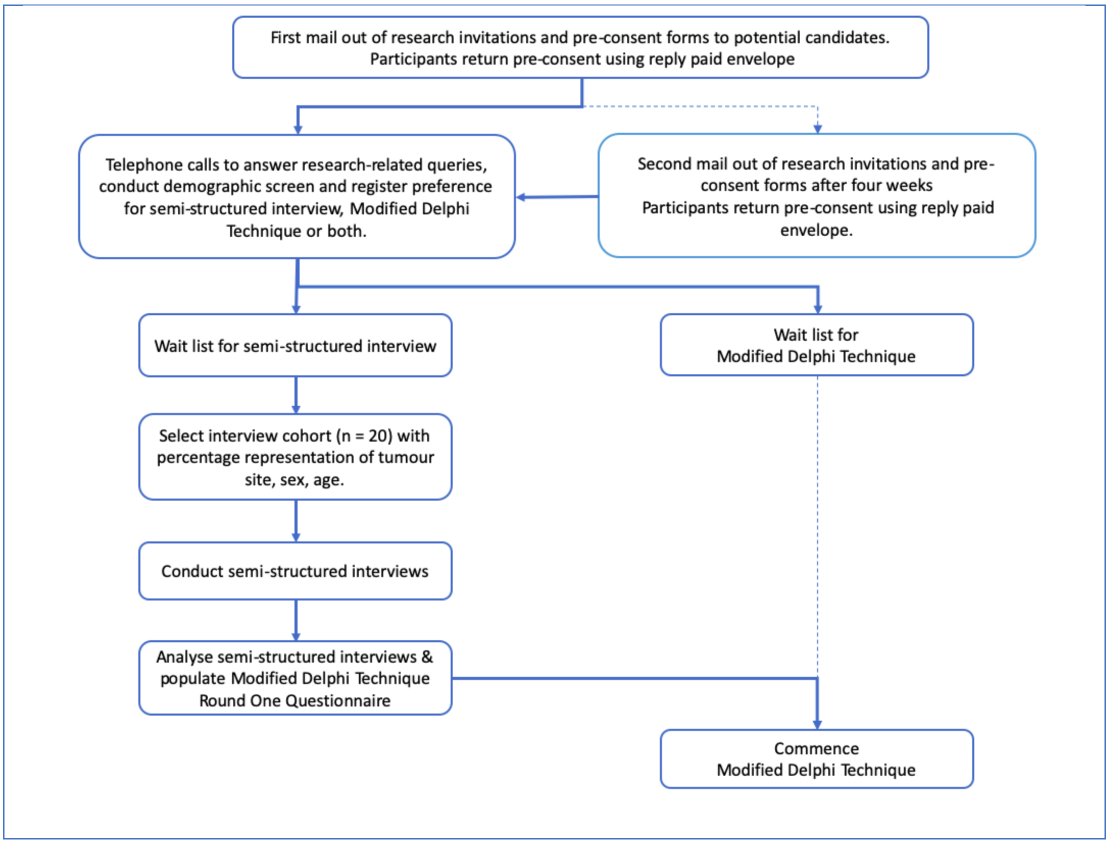
3.5.2 Recruitment Invitation Procedure and Informed Consent

The principal researcher posted an invitation to participate in the study to all eligible rehabilitation participants. The invitation pack contained a participant information sheet and a pre-consent form. Reply-paid envelopes were provided for candidates to return the pre-consent forms with preferred names and contact details.

This early consent was to invite first contact to discuss the study, undergo screening for eligibility for participation and registration of preference for data collection method. Using the national postal service to obtain pre-consent allowed time for candidates to consider if and how they would participate in the study. Each invitation was marked with a unique identifier to anonymise responses and aid response tracking. This identifier was sequentially allocated to each participant according to the first letter of their surname. Identification of individuals would not have been possible without the Microsoft Excel spreadsheet which contained full demographic details.

After a period of four weeks, a second postal invitation was sent to participants who had not yet responded. When no further response was received after another four weeks, it was assumed that consent for further contact was not forthcoming, and these individuals were not approached again. An overview of this process is described in Figure 11.

Figure 11. Study Recruitment Overview



On receipt of pre-consent forms, participants were contacted by telephone and asked to complete a demographic screening tool, modelled on the National Cancer Patient Experience Survey (Department of Health, 2014). This tool captured demographic data including age, sex, ethnicity, Welsh Deprivation Index, highest level of education, and main employment status at the time of starting rehabilitation. It also collected disease-related data including non-cancer LTCs, time since first cancer treatment, whether participants have been treated for one or more cancer diagnoses, and type of cancer treatment / disease responses status at the time of rehabilitation. A summary of this data is presented in Table 5.

Alongside responder demographics, available data from the non-responder cohort have been presented for comparison. This data suggests that there are no observable differences between the research cohort (responders) and the rehabilitation population (non-responders) with respect to year of rehabilitation, level of social deprivation and primary cancer site. This comparison provided a measure of confidence that the research participants were broadly representative of the local rehabilitation cohort.

Table 5. Summary Characteristics of Responder and Non-Responder Cohorts

Characteristics	**Total Responder Population** n = 126 (%)	**Sampling Frame Data (Non-Responder Population)** n = 133 (%)
Sex:		
Male	53 (42%)	46 (34.6%)
Female	73 (58%)	87 (65.4%)
Year of Rehabilitation:		
2011	5 (4%)	6 (4.5%)
2012	1 (0.8%)	2 (1.5%)
2013	24 (19%)	31 (23.3%)
2014	16 (12.7%)	26 (19.6%)
2015	79 (62.7%)	68 (51.1%)
2016	(0.8%)	-
Wales Deprivation Index: (<10% = Most Deprived / >50% = Least Deprived)		
<10% (21 – 142)	10 (8%)	16 (12%)
11-20 (216 – 358)	10 (8%)	12 (9%)
21-30 (409 – 570)	6 (5%)	6 (4.5%)
31-50 (584 – 939)	20 (16%)	26 (19.6%)
>50% (977 – 1908)	80 (63%)	73 (55.9%)
Primary Tumour Site:		
Breast:	44 (35%)	50 (37.6%)
CNS:	2 (1.5%)	3 (2.25%)
Colorectal:	10 (8%)	4 (3%)
Endocrine:	-	1 (0.75%)
Gynaecological:	6 (4.8%)	4 (3%)
Haematology:	9 (7%)	5 (3.75%)
Head & Neck:	10 (8%)	16 (12%)
Lung:	12 (9.6%)	27 (20.4%)
Male Genital:	2 (1.5%)	1 (0.75%)

Melanoma:	-	1 (0.75%)
Prostate:	21 (16.7%)	12 (9%)
Sarcoma:	4 (3.2%)	3 (2.25%)
Skin:	4 (3.2%)	1 (0.75%)
Upper GI:	-	1 (0.75%)
Urological:	2 (1.5%)	-
Other:	-	4 (3%)

All participant data was entered onto a password protected Microsoft Excel spreadsheet with access restricted. As principal researcher, I was the only person able to read or amend this file. This spreadsheet was essential for the practical purposes of maintaining a record of participants and non-participants. The spreadsheet offered a way of recording contact details for candidates who had requested supplemental information or additional explanations about the study to answer any practical questions.

It also enabled contact with candidates to undertake post invitation screening questions and register participant preference for research activity (i.e. either one semi-structured interview and/or up to three rounds of Modified Delphi Technique). Further details regarding participant preference for involvement in the research will be discussed in Chapter 4.3. The spreadsheet also recorded arrangements for face-to-face semi-structured interviews and the return rate for each round of the Modified Delphi Technique. Further detail regarding data management will follow later in this chapter (Section 3.9).

3.5.3 Sample Size

The framework outlined by Daniels (2012), was used to shape decision making about how many people to recruit to this research. According to the framework there are several factors to consider including, pragmatic considerations such as the nature of the population, the resources available, and the research design. For a small or rare population which is diverse in its characteristics, it is recommended to seek as large a sample as possible. Whilst this suited the Modified Delphi Technique, logistical factors including resource availability influenced the decision to aim for a modest, manageable sample for the semi-structured interviews.

3.5.3.1 Determining SSI Sample Size

A maximum SSI sample of n=20 participants was proposed following guidance from (Kvale, 1996), which suggested interview samples could be n=15 (±5) participants and was the target sample described in the ethics application. This number of interviews was perceived as feasible to accommodate alongside full-time clinical practice. However, the option to cease interviewing before this quota if the SSI data reached saturation, was included in the research proposal (Moser & Korstjens, 2018).

Guest, Bunce, and Johnson (2006), propose that data saturation may occur within as few as twelve interviews. Data saturation is a complex concept in qualitative research, with little clear guidance beyond some general principles to indicate when data saturation has been reached. These principles suggest that saturation has occurred when there are no new data or themes yielded from data collection method, no new coding opportunities within the transcripts, or when enough data has been captured to enable the study to be replicated (Fusch & Ness, 2015).

3.5.3.2 Determining ModDT Sample Size

There is no definitive recommendation or guidance regarding the size of the expert panel involved in a Delphi Technique (Hasson et al., 2000). Brewer (2006, p. 4), states that ModDT samples might range from “a few to hundreds of members”. Akins, Tolson, and Cole (2005), reported Delphi Technique expert panels in the literature ranged from 10 – 100 participants. Where Delphi-based methods have been applied in OT, Aguilar et al. (2013) reported a panel of n=68 members; and Holmqvist et al. (2013) reported a panel of n=14 members. Hsu and Sandford (2007) suggest there are pitfalls to having a panel which is either too large or too small. Too small a panel, and they may not represent a broad enough cross section of the population in order to draw conclusions. Too large a panel, and there may be a detrimental impact on response rates resulting from the delay resulting from time taken to process and analyse a large volume of response data.

Thangaratinam and Redman (2005), suggested the research question and the characteristics or qualities of the panel members should determine the panel selection, rather than focusing numbers alone. Following this advice, a pragmatic approach to determining the size of the expert panel for ModDT was adopted for this study and a target for recruitment for the ModDT was set at n=50. This was perceived as a large enough sample to obtain a diverse range of experiences and establish trends without generating an unmanageable volume of data.

3.6 Ethical Considerations and Research Permissions

There were three key themes relating to the ethical conduct of this PPD research. The first related to the competence of the principle researcher. The second considered the scientific, legal and ethical management of the research project. The third pertained to participant safety in terms of balancing benefit and risk associated with research participation and involvement in research design. These themes are reflected by the 15 best practice principles which underpins the ethics of all health and social care research (Health Research Authority, 2018). The following briefly outlines how these ethical considerations impacted on this PPD research and actions taken to produce quality research that was undertaken with integrity.

3.6.1 Researcher Competence

3.6.1.1 Outsider Interviewer(s)

In the initial ethics application, it was proposed that the semi-structured interviews would be conducted by two colleagues who were not directly connected with the cancer rehabilitation service. These colleagues were both trained in qualitative research methodology and had a cancer and/or nursing background. They had both completed Good Clinical Practice (GCP) research training (Health and Care Research Wales, 2019), which is one way to support the maintenance of research quality.

The rationale for including external interviewers in the research team was based on an assumption that some participants may be reluctant to disclose thoughts and feelings to someone with whom they already had a therapeutic relationship. Following briefing sessions with both colleagues, it was anticipated that we would proceed as a research team. To this end, two pilot interviews were completed by one colleague. However, due to workplace pressures, both colleagues withdrew from the research team. An amendment was submitted to LREC Committee enabling me to undertake the data collection. Further discussion relating to the impact of the dual role of practitioner-researcher is presented in Chapter 7.4.2.

3.6.1.2 Insider Interviewer

As principal researcher, in addition to GCP, I also undertook additional training in obtaining valid informed consent and managing essential research documents. As a novice researcher, academic supervision became the vehicle through which insight into research learning needs was developed. Access to a wider range of research skills development workshops, hosted by the university, supported the further development of research knowledge and skill.

The combination of this skills development and undertaking research activities helped to build a portfolio of research experience. However, as a novice researcher, having access to supportive challenge during reflective practice with the academic supervisory team, was integral to my learning. Much of this learning related to the management of a research project, including the navigation of scientific and legal research infrastructure.

3.6.2 Scientific, Legal and Ethical Conduct in Practice-Based Research

The governance of this research was monitored and maintained through formal monthly academic supervision sessions, periodic consultation with the Health Board Research and Development Team, publication, and reflexive journaling. These activities aimed to support the quality, integrity and transparency of the study. This combination of strategies supported this PPD research through the successful navigation of seeking ethical approvals, publishing an ‘a priori’ research protocol and preservation of participant privacy and confidentiality during this practice-based research.

3.6.2.1 Ethical Approval

Applications to Health Board Research and Development (R&D) and the Local Research Ethics Committee (LREC) were completed simultaneously on 26/05/2015 via the Integrated Research Application System (IRAS) Project identification: 183806. The ethics application was reviewed by the Wales Research Ethics Committee 6 and favourable ethical opinion was given (15/WA/0331) on 24/09/2015 (See Appendix 8). The research governance checks were undertaken by the local NHS Health Board R&D department and confirmation of permission was given on 06/11/2015 (See Appendix 9). The ethics approval was subject to minor amendments, as a result of unforeseen changes to the initial research protocol.

Details of these amendments and subsequent approvals can be found in Appendix 10.

3.6.2.2 Research Protocol

Early in the PPD research process, a protocol for the ILR was published on PROSPERO (Wilkinson et al., 2015). This was followed by a protocol for the PPD research as a whole, being accepted for publication by the BMJ Open (Wilkinson, Rance, & Fitzsimmons, 2017). By undergoing these processes of external peer review, the scientific value and potential clinical impact of this research was validated. As was the ethical approach used in the conduct of the study. One key practical, ethical challenge in this practice-based research was the protection of participant privacy and confidentiality. The following explores this in more detail.

3.6.2.3 Respect for Privacy and Confidentiality in Practice-Based Research

There was a significant risk of deductive disclosure, or participants being able to identify themselves, in this study’s research reports (Kaiser, 2009). This can be a consequence of qualitative studies with small samples, often characterised by rich descriptions of the participants. The consequence of deductive disclosure can include the potential destruction of researcher-participant relationships as a result of betrayed trust. This was a key consideration during the planning, data collection, data analysis and report writing stages of this research. The following safeguards were implemented to protect the identity of the research participants and maintain anonymity and confidentiality throughout this research.

During research planning, screening and data collection stages, participants were advised that they could expect to have their privacy protected though the use of anonymisation. However, complete anonymity cannot be guaranteed during the use of a ModDT, as the principal researcher knew the identity of all participants in order to be able track their responses. All participants were allocated a unique identifier in place of their name during the study. It might be more accurate to suggest that participants were afforded ‘quasi anonymity’ (Hasson et al., 2000; Keeney et al., 2006).

All data was collected and analysed prior to the Data Protection Act 2018. However, the SSI participant biographies, and direct quotes from both SSI and ModDT, presented in this thesis have been anonymised in compliance with the principles data protection requirements. This was achieved through the use of pseudonyms in place of unique identifiers, removing specific details relating to disease, and reporting age range instead of age at the time of participation.

All participants were asked to consider providing consent for their research contributions to be used verbatim, as part of research reporting, during the informed consent procedure. There is a risk that changing too many details in qualitative transcripts can corrupt the meaning of the data and render it potentially useless in answering the research questions (Kaiser, 2009). Therefore, although the quotes reported were anonymised, the content was reported verbatim. Whilst each participant may recognise their own contribution from the language used in data excerpts, the risk of them being able to identify other participants from the data excerpts used in the report is low.

Participant privacy and confidentiality was protected throughout all research data collection and management. All hard copies of documents which contained both identifiable and anonymised data were stored in a locked filing cabinet on NHS premises. Digital versions were stored in a password protected file on a secure drive on the Local Health Board network as per (Health Research Authority, 2018), legal and ethical standards of practice, NHS Local Health Board R&D procedures, data protection and security requirements. Access to these files was limited to the principal researcher for the purpose of data cleansing and analysis.

Preliminary research findings have been used to inform education sessions within the Health Board and with student cohorts in local universities. In addition to the privacy and confidentiality of participants, maintaining sensitivity to the privacy and confidentiality of the professionals involved in the team has also been a key concern during these sessions. Ahead of sharing results in any forum, organisation identifiable information was anonymised, as far as able, for the privacy and protection of both rehabilitation professionals and research participants. This included the removal of place names in any publications or conference presentations resulting from this research. For example, during the sharing of any aspects of this research outside the Health Board, results were discussed using a regional context ensuring that neither the service, professionals nor participants were identified.

There was significant feedback for professionals within the Health Board as a result of this research, which were directly and indirectly related to the research questions. It was not possible to avoid identifying the cancer rehabilitation team during feedback sessions conducted within the Health Board as there was only one cancer rehabilitation team in the region. However, care was taken to avoid identifying individual professionals or participants when sharing this information.

Participants were offered the opportunity to be involved throughout all phases of this PPD research. This raised concerns regarding the need to ensure their safety without compromising their autonomy. Consideration of the potential benefits to participants, appeared to outweigh the potential harms of involvement in this PPD research. The following describes this in more detail.

3.6.3 Participant Involvement, Choice, Information and Safety

The partnership between rehabilitation participants, research participants and myself as researcher was a key feature in the design of this research. Participant involvement was sought in relation to the choice of data collection and communication methods. In the earliest stages of research planning, informal conversations with rehabilitation participants, in practice, directly influenced the research questions which framed this study. Ongoing conversations throughout the research design and development, helped to refine and focus these questions.

3.6.3.1 Participant Involvement

This PPD research embraced the participant involvement ambitions described by Health and Care Research Wales (2017). These included increasing participant awareness of research and its impact on practice. This research aimed to create an environment where participants could not only participate in, but contribute to, research design. Through this PPD research, Wales would be identified as a centre of excellence for meaningful person-centred research.

Some research participants had prior experience of taking part in health research. Their previous research involvement was invaluable in understanding the type of experiences that the data collection methods within this PPD research might yield. Some of these participants were asked to proof-read research print materials ahead of circulation. Their contribution supplemented the use of plain language tools to ensure the content of the research participant literature was accessible. This input improved the structure and content of participant information sheets, consent forms, and data collection tools by streamlining the print materials without making them disrespectful by making them over-simplified. Examples can be found in Appendix 11.1 – 11.4.

Following the semi-structured interviews, some of the interview transcripts were shared with participants who had consented to communication via email. Their feedback not only validated that their interview had been recorded accurately, but also offered an opportunity for them to share any post-interview reflections. All of those who responded confirmed the accuracy of their transcripts. One interview candidate added a reflection which will be discussed in more detail, alongside the SSI results in Chapter 5.6.

Ongoing communication with research participants, regarding the research process was undertaken via written communication sent by post or social media. This was maintained throughout the duration of the study. Communications aimed to ensure that participants were aware of the pace and progress of the research. This was deemed necessary as there were occasional delays between research activities due to the challenges of balancing the parallel demands of research and practice.

This PPD research was structured so that the results of each phase of data collection could be reflected back to the research participants. This process allowed the participants to provide anonymous feedback. On conclusion of the study, the findings of the last round of data collection were shared with research participants at an annual social event held by the local cancer rehabilitation service. This final feedback which was used to help shape the analysis of the data.

In addition to participant involvement in the study design. Participants were invited to express a preference for how they might engage in the research. This is explored in more detail in Chapter 4.3. However, the ethical considerations of this decision are discussed below.

3.6.3.2 Participant Choice

Rehabilitation participants who were invited to participate in their research, were asked to provide written consent to further information about the research before consent procedures for data collection commenced. This was done because the initial sample was made up of rehabilitation participants from between 2011-2015, many of whom would not have been aware of the research. It was important to offer people the opportunity to withdraw from further communication at this earliest stage without reprisal. Several past rehabilitation participants wrote to explain their preferences for not taking part. Contact was made with all of these people to ensure that they understood that their withdrawal did not impact on their future access to the service, if needed. Written consent procedures were in place for each of the data collection methods, aiming to reduce the risk of coercion, and allow further opportunities for participants to withdraw at any time without censure.

An additional element of participant choice was built into the study design, reflecting rehabilitation participant preferences for how they engaged with the data collection methods. Two data collection methods were selected. The first offered face to face interaction. The second offered the possibility of remote participation. These choices catered for a small number who preferred direct contact with the researcher. And a more flexible approach, for a larger number of research participants, whose work or other commitments, travel restrictions, or communication styles, meant that remote participation was more convenient or comfortable. Participant preferences were recorded during screening, and every effort was made to accommodate these where practicable. Please see Figure 11 for an overview of how this influenced study recruitment and participation.

Offering this level of choice for was one mechanism which aimed to preserve the safety and wellbeing of potential participants. Further exploration of participant safety is explored in the following section.

3.6.3.3 Participant Safety

This research aimed to ensure a continuous commitment to safeguard the safety and wellbeing of the research participants. The SSI schedule was designed specifically to explore experiences relating to rehabilitation and therapeutic relationships with healthcare professionals. Questions around diagnosis and treatment were not included to reduce the risk of resulting in harm for those who experienced trauma at these early stages of their cancer pathway.

A wellbeing pack was developed, containing information to provide safe onward referral to appropriate emotional support for any participants who became upset during semi-structured interviews (Appendix 12). This was developed in anticipation of the potential need, as a result of asking participants to explore past experiences, which may include upsetting episodes in their care. Whilst the wellbeing packs were available to all SSI candidates, none were deemed necessary by either the research participant or the researcher.

It was more challenging to monitor the incidence of unintentional harm throughout the ModDT process. However, participants had greater freedom to withdraw from the ModDT, should they find the questions upsetting. The small attrition in response rate between first and second round ModDT might be taken to indicate that participants did not perceive the activity as harmful.

The ModDT also included opportunity for free-text responses from participants. These free-text contributions are included in the analysis presented in Chapter Six. None of the responses indicated that the activity had caused harm. This is not to say that all free-text were positive. Most of the free-text comments offered either critical appraisal of the rehabilitation programme, according to their experience, and many offered constructive suggestions for improvements. This might be interpreted as participants having experienced a benefit from participation in the research. Primarily through influencing the future direction of rehabilitation provision.

3.7 Data Management

There was a large volume of data captured throughout the three phases of this PPD research. Data management refers to the transfer of audio-recordings into type-written, verbatim transcripts in Microsoft Word and the transfer of coded data from transcripts to Microsoft Excel spreadsheets for analysis. As the ModDT data was provided in writing by participants, this data was also entered verbatim into Excel spreadsheets. As described in Section 3.5.2, in relation to the management of research data, Microsoft Excel was used to manage all of the participant screening data and monitor research participation activity. The following describes how this PPD research data was stored and organised to facilitate analysis and synthesis of findings.

3.7.1 Management of the SSI and ModDT Data

Following the decision to use a qualitative interview method for data collection, the principal investigator initially thought that a purpose-designed qualitative research data organisation and analysis software package would be required for data management and analysis. However, the benefits of manual techniques and tools, used by my supervisors in their own research were discussed during supervision, and offered a more intimate non-digital approach to data analysis. A hybrid approach to data management was developed for this PPD research.

The qualitative analysis framework offered by Taylor-Powell and Renner (2003), introduced the potential benefits of transferring transcribed qualitative data from Microsoft Word to Excel for data management. There were practical reasons for preferring a digital option for data recording and organisation. These included the convenience of access from different sites, including work, on campus and home. Having moved to a new house mid-research, electronic data storage and analysis would reduce the risk that manually coded hard copies of data could become damaged or lost.

Research skills training in the use of NVIVO software and an exploration of other qualitative research data organisation and analysis software available was completed. Despite the flexibility in coding, search functions and reporting capabilities of the software package (Basit, 2003). Once SSI audio-recordings were transcribed into Microsoft Word, it became clear that upload into NVIVO was not necessary. It was both possible and easier to manage the data coding between Microsoft Word and Excel software.

The use of word processing and spreadsheet software instead of qualitative research software may seem unconventional. However, using Microsoft Excel enabled the management of a large amount of data in one place, facilitating the qualitative analysis of the SSIs. This process made it possible to determine if patterns were present in the data. This was done by recording how often certain themes were discussed, by which participants. At this early stage of the research programme, it was important to present data that was an accurate reflection of the breadth of the group’s experiences, rather than presenting marginal views. The spreadsheet ‘tabs’ function enabled the data to be organised according to emerging themes. The search function within Excel meant that it was possible to navigate the data quickly.

On receipt of ModDT responses, the data was also entered into a Microsoft Excel spreadsheet. Binary responses were recorded for priority setting questions, object identification responses were entered by their numeric value and free-text responses were entered verbatim. It also enabled both qualitative and quantitative analysis of the ModDT data without switching between two software packages.

As described above, some researchers use manual methods for organizing data, often referred to as ‘desktop’ analysis. The hybrid approach to data management described earlier refers to hard copies of both the Excel spreadsheets and the full Word transcripts, which became invaluable reference materials throughout the analysis of this PPD research. Together, these hard copies facilitated accurate recollection of the data and ensured that data interpretation has been undertaken within the intended context in which it was created. These hard copies offered me more manual interaction with the digitally recorded data during analysis. As a person who finds it easier to process visual stimuli, they were particularly helpful in informing analytical discussions during academic supervision. The ability to generate tables of data with figures to illustrate decision-making, reasoning and analytical progress at supervision sessions was instrumental in shaping the PPD narrative.

3.7.2 Presentation of Direct Participant Quotes in this Thesis

All participants were assigned a unique identifier, as described earlier (Section 3.5.2). These identifiers were exchanged for pseudonyms for SSI participants, some of whom also contributed to the ModDT. For participants of the ModDT only, the unique numerical identifier is presented alongside their quotes throughout the thesis.

Some sections of the SSI data were difficult to transcribe for two reasons. For transcripts of SSI completed on hospital or third sector premises, the audio-recording was affected by occasional interference from unknown electrical sources or fire alarms. Irrespective of the location of the SSI, some participants’ speech became difficult to transcribe as a result of dysphasia following cancer or cancer treatments. These changes were largely evident when participants became animated or when their vocal volume dropped during responses. Ellipsis (…) have been used to indicate data that has been omitted, for either of these reasons. If participants identified a professional or organisation by name, these have been anonymised using terms such as “They”, “The Team”, or “The Health Board”.

3.7.3 Strong Language Warning

Research participants' contributions to this thesis include the use of direct quotes. These have been taken from the verbatim transcripts of SSIs and from handwritten ModDT responses. These contributions include strong language which some readers may find upsetting. No offence was intended by including this language in the thesis. A further discussion regarding rationale for including strong language is presented in Chapter 7.4.2.2.

3.8 Method of Analysis

3.8.1 Process of Semi-Structured Interview Analysis

Following transcription of audio-recordings a mechanism for cross checking that the SSI content was accurately recorded and represented the message that participants wanted to impart was introduced. This was achieved by sending the transcripts to several of the participants via email and asking for their feedback on the content. The transcription process had created a period of reflection after the interview. Participants were asked whether they felt the transcript was an accurate reflection of the SSI, from their perspective. They were offered this opportunity to amend any statements which were unclear, had been misinterpreted. Or add any additional detail to the transcript that they had forgotten to add during the SSI.

The SSI data were analysed by the principal researcher, using five stage qualitative analysis guidance suggested by Taylor-Powell and Renner (2003). The five stages included getting to know the data, focusing the analysis, categorising the information, identifying patterns and connection within and between the data categories, and finally using the data to explain the research findings. This approach offered the added benefit of describing a process for data management. As a novice researcher, this approach offered a practical solution to the combined management and analysis of the research data. Each of these stages are described below.

3.8.1.1 Getting to Know the Data

Before data analysis commenced, all audio-recordings of the SSIs were transcribed into Microsoft Word documents. Whilst support with the transcription of the interviews was received, the principal investigator completed the transcription of more than half of the SSI audio-recordings. These included transcripts for the interviews where the quality of the recording was less clear, or the SSI participant's speech was challenging to understand. All of the transcripts were double checked against the original recordings before accepting them as complete and accurate.

This initial step in the analysis aimed to create a level of familiarity with the data, especially for those transcripts that had been prepared by someone else. This first phase of analysis was to gain an understanding and assess the quality of the data. To achieve this familiarity, the digital recordings were played, and the transcripts read, several times each. Hard copies of each transcript were produced to enable easier reference to the original data throughout the analysis.

3.8.1.2 Focusing the Analysis

The twenty-two SSI transcripts resulted in between 180,000 – 200,000 words of data. Not all of the transcripts were going to be likely to provide good quality data that were relevant to the research presented in this thesis. One of three strategies that can focus the evaluation is selecting data which were directly relevant to answering the research questions posed at the outset of the SSI (Taylor-Powell & Renner, 2003). This approach was adopted to focus this analysis. This step was achieved by searching the transcripts to identify and code participant responses which were directly related to the research questions. During this step other responses, not directly related to the research questions, were noted. These were collated for analysis by individual or group during a later stage of analysis (Section 3.8.1.4).

3.8.1.3 Categorising the Information

Taylor-Powell and Renner (2003), propose that a combined approach to data analysis can be particularly effective, as this offers the flexibility to amend the categories as the data dictates. Often pre-set categories are used to initially establish the direction for the analysis, with emergent categories following from the data. This sequence was reversed in this study, seeking to delay the implementation of any pre-set categories until the emergent categories had been explored.

Once each SSI transcript had been read several times, meaningful data items including words, phrases, and sentences were identified. These were highlighted in the margin of the Microsoft Word document. The highlighted data items were transferred into a Microsoft Excel spreadsheet and grouped according to participant. Colours were used to highlight similar and divergent responses. This approach sought to allow the categories to emerge from the data.

It was not the initial intention to undertake a framework analysis of the SSI data. But as the emergent categories were identified, it was noted that there was common ground between the emergent categories and the SDT operational definitions described in Chapter 1.3.2.2. The extent to which the emergent themes were congruent with the SDT operational definitions offered the opportunity to use the SDT vocabulary to aid data analysis. This resulted in the decision to proceed with a combined approach to data categorisation which used both the SDT operational definitions and additional emergent themes. A framework analysis would be undertaken initially to determine the extent to which the data supported the rehabilitation assumption. This is presented in Chapter 5.2. The following analysis of SSI relating to the study questions used inductive analysis to explore emergent themes.

3.8.1.4 Identifying Patterns and Connections Within & Between Data Categories

Microsoft Excel was used to arrange the data according to the SDT operational definitions and emergent themes. For each category, similar data items were grouped together, forming sub-categories. It was then possible to identify which participants had contributed to each category. This process helped to explore whether some ideas or sentiments were widely held, or unique to individuals or small groups within the participant population. This data was presented in a table format, including up to three examples of participant responses to illustrate each category.

The analysis also sought to identify key connections, relationships and the possibility of relative importance between the categories. This was achieved by re-positioning sub-categories within the Excel spreadsheet, to allow the data to be compared with data from different categories. This process looked to identify convergent or divergent ideas, beliefs and experiences.

In order to cross-check data analysis to ensure data quality, consistency in approach and transparency of analytical decision making (Kvale, 1996). Twenty percent of the interview transcripts were analysed by a second reviewer. A third reviewer was involved, where needed, to undertake a further analysis or facilitate discussion if thematic discrepancies occur between the first and second reviewer. Ongoing data analysis cross-checking and monthly discussion during academic supervision provided an independent perspective to the analysis and helped to minimise practitioner bias (Stanley, 2015). Further discussion regarding mitigation of bias is presented in Chapter 8.5.2.

3.8.1.5 Using the Data to Explain the Research Findings

The greatest challenge of interpreting qualitative results is to avoid the pitfall of describing the findings, rather than synthesising the meaning and significance which results from the findings (Taylor-Powell & Renner, 2003). A description of the key themes from the SSI is presented in Chapter Five.

As SSI findings emerged, the principal investigator returned to the earlier ILR findings, and explored additional research literature to help with synthesis. These early findings from the SSI were used to inform the first round of the ModDT, the process through which this was achieved is described in Chapter 5.8. Researchers are urged to consider using data from different sources in this process as shared conclusions can improve confidence in the findings. An integrated analysis of the ILR, SSI and ModDT is presented in Chapter Eight. This integrated analysis identified the themes which were common throughout all stages of this PPD research and used the data to explain the impact of these on participants' perspectives of therapeutic relationships.

3.8.2 Modified Delphi Technique: Consensus, Diversity and Stability

There is variability in the literature with respect to the criteria that would indicate consensus agreement or disagreement. von der Gracht (2012), presents a summary of the key points of this discussion, highlighting that percentages for consensus published in the literature range between 51-95%. A review undertaken by Diamond et al. (2014), identified 75% as a minimum threshold for consensus as this was the median percentage reported by the papers included in their study. Several other authors comment that there appears to be little scientific rationale behind the decision to set the consensus threshold at 75% (Diamond et al., 2014; Hsu & Sandford, 2007; Keeney et al., 2006). They propose recommendations for improving the quality of Delphi Technique reporting.

One of these recommendations was that an 'a priori' statement of methodological criteria addressing the study objective, the participants and the process, precede all studies which use a Delphi Technique. This would enable consensus definitions to be adapted to meet the research question (Diamond et al., 2014). Hsu and Sandford

(2007), suggest that the stability of the responses is more important than percentage consensus. von der Gracht (2012) agrees that consensus without stability in responses between the Modified Delphi rounds leaves the results open to misinterpretation. The following aims to clarify the approach proposed in an ‘a priori’ protocol, for use in this ModDT to determine consensus, diversity and stability (Wilkinson et al., 2017).

There appears to be no concrete rule as to the number of rounds required for a Delphi Technique. A traditional Delphi Technique is described as requiring four rounds (Hasson et al., 2000; Hsu & Sandford, 2007), However, a minimum of two rounds would be considered the minimum required (Thangaratinam & Redman, 2005), and either two or three rounds most common (Hasson et al., 2000). These authors warn researchers of the potential for participant burden and attrition from non-essential additional rounds.

The purpose of the first round of the ModDT was to identify priority statements and reduce the starting list by half. To this end, a consensus percentage of 75% was used to achieve this (Brewer, 2006; Diamond et al., 2014). Hsu and Sandford (2007), suggest that in addition to this threshold, the responses should rate at least three, with a median score greater than 3.25 on a four-point Likert scale. The authors advised that the use of mode can also be a suitable option when reporting Delphi Technique results. These recommendations were adopted for use in this study.

In addition to the decision to use percentage consensus, mean scores and mode of item selection. Stability was considered to have been achieved if two conditions were met. The first was if there was consistency in response between the ModDT rounds, and the second, if there was a strong response to two out of three parameters per statement. Group response was considered superior to individual responses (Akins et al., 2005). The stability of the panel’s responses would be further enhanced by considering the qualitative responses alongside the quantitative data.

Although, not a common use of traditional Delphi Technique, the purpose of the second round of this ModDT was to gain insight into participants’ reasons for their choices and priorities (Hsu & Sandford, 2007; Okoli & Pawlowski, 2004). In this round, consensus was less important than the first round, as the questions were phrased to seek participant views on how the statements listed influenced their ability to self-manage.

In the research protocol and ethics application, it was proposed that the ModDT would be completed in up to a maximum number of three rounds. These documents were written to enable the ModDT to close after two rounds if there was sufficient data to answer the research questions. In consultation with the academic supervisory team, the decision was made to close the ModDT after two rounds. This was agreed as sufficient data had been generated to all the research questions to be answered, and it was felt that there was little value to be added from third round of ModDT.

3.9 Summary

This chapter started by providing an overview of the research aims and objectives. It then explored rehabilitation as a complex intervention and how this influenced the research approach, process and design. This was supported by the rationale, philosophical and theoretical foundations for this research. This chapter has also presented an overview of research methods, a description of participant sampling and recruitment procedures. Ethical considerations and the approach to data analysis were also explored.

The following Chapter Four will present the characteristics of the research participant cohort who engaged with this research. This has been presented as a separate chapter, primarily to reduce the risk of duplicated reporting, and to introduce the participant cohort as a whole, in light of the number who participated in both local data collection activities.

Chapter Four: Research Participants

As part of the recruitment process described in Chapter Three, all participants were asked to complete a post invitation screening tool. The tool was instrumental in understanding the characteristics of the research participants, to be able to explore trends in responder groups, during the analysis of the study data. The following section presents a summary of the characteristics of the participant cohort as captured by this tool.

4.1 Introduction to Chapter Four

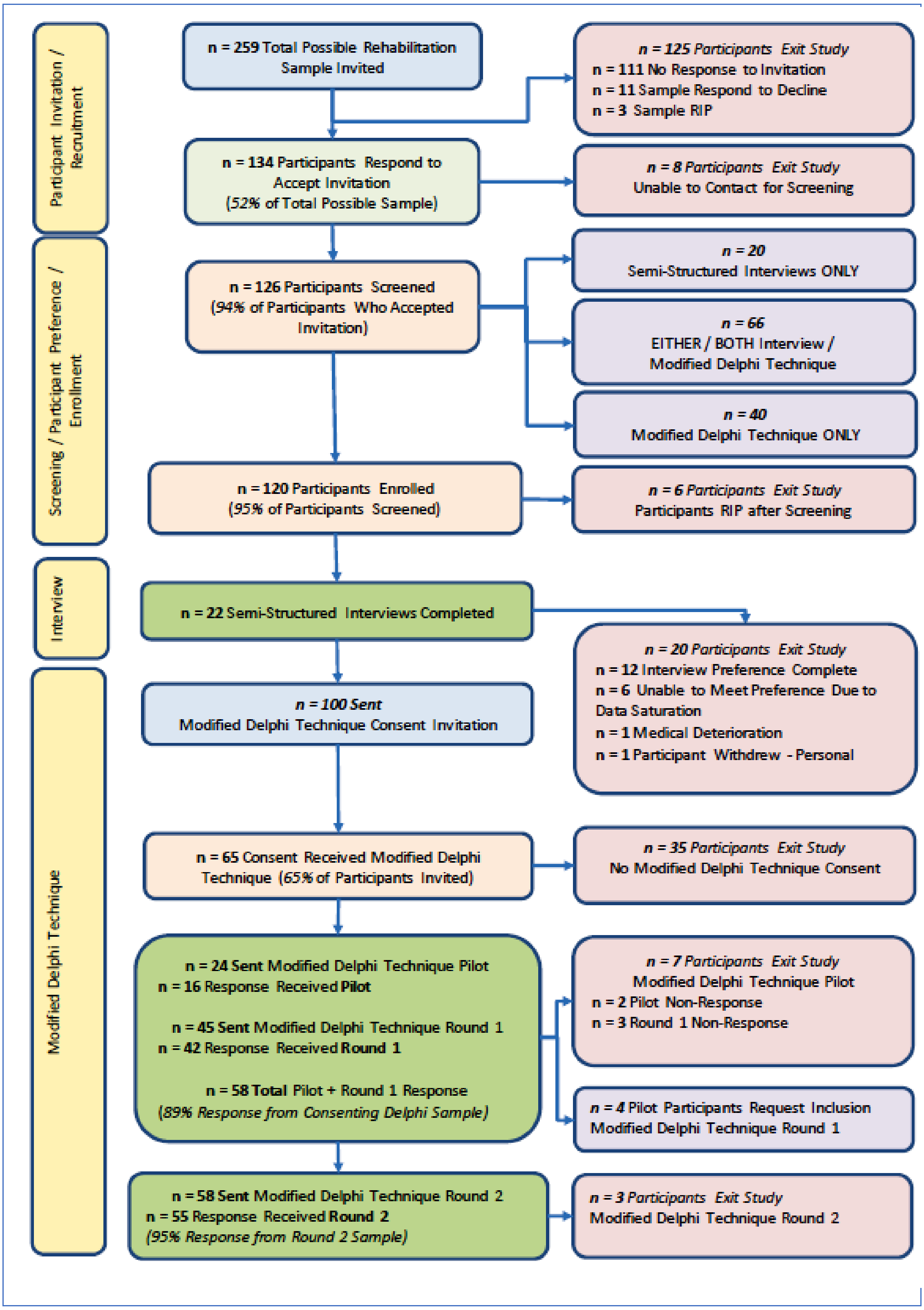
Research participants were invited to indicate a preference for their involvement in either SSI and/or ModDT during this research. Recruitment to both data collection methods was simultaneous, the process for which was described in Chapter Three. A small proportion of the research participants completed both data collection methods. For ease of data presentation and to reduce the risk of duplicate reporting, the total sample’s characteristics are presented together in this chapter.

The purpose of this chapter is to provide an overview of participant recruitment, introduce the research participants and explore the extent to which the characteristics of the research participant cohort can be compared with the local rehabilitation cohort and wider cancer populations. Participant choice has been a key theme throughout this PPD research. This chapter also explores how feasible meeting participant preference was during this study.

4.2 Study Participants

Of the n=259 people invited to take part in this research, n=134 responded to the invitation, n=126 people were screened for eligibility and a total of n=72 people took part in this study. Figure 12 presents the recruitment process and participant response rate.

Figure 12. Study Recruitment and Participation



4.2.1 Successful Participant Recruitment

The success of health research studies is dependent on being able to recruit people to take part (Newington & Metcalfe, 2014). Participant recruitment can be perceived by novice researchers as a challenging component of the research process (Archibald & Munce, 2015; Marks, Wilkes, Blythe, & Griffiths, 2017). The a-priori protocol and ethics application for the programme of research described in this thesis defined proposed recruitment targets (See Table 6). This study was successful in achieving these targets. Further discussion relating to this recruitment success will follow in Chapter Eight Discussion / Chapter Seven Reflection and Reflexivity.

Table 6. Achievement of Proposed Recruitment Targets

	Semi-Structured Interviews n = (%)	Modified Delphi Technique n = (%)
Proposed Recruitment Target	N = 15 +/- 5	N = 50
Recruitment Achieved	N = 22 (110%)	N = 58 (116%)

Eleven people either wrote or phoned to decline the research invitation out of a total of n=125 people who did not respond to the research invitation. There was a very supportive message which came through from this small group, whose decision not to participate was largely a result of their desire to 'leave cancer in the past' and 'get on with life'. An anonymised copy of one such letter can be found in Appendix 13.

4.2.2 Characteristics of Research Participants

Details of the demographic, social and diagnostic characteristics for the whole participant sample are described in Table 7. In this table the participants are described according to whether they took part in the SSI, the ModDT, or both. A summary for the combined research participant cohort is also included.

Table 7. Research Participant Characteristics

	Semi-Structured Interviews	**Modified Delphi Technique**	**Both SSI & ModDT**	**Total Sample**
Number of Participants (n)	**22**	**58**	**8**	**72**
Mean Age (SD) **Median Age** (Range in Years)	**65** (14) **67** (39 – 89)	**64** (12) **67** (39 – 90)	**60** (15) **63.5** (39 – 76)	**64** (12) **65** (39 – 90)
Sex (%)	Male n=10 (45.5%) Female n=12 (54.5%)	Male n=25 (43%) Female n=33 (57%)	Male n=3 (37.5%) Female n=5 (62.5%)	Male n=32 (44.5%) Female n=40 (55.5%)
Primary Tumour Site				
Breast	5 (22.75%)	21 (36.2%)	3 (37.5%)	23 (31.9%)
Colorectal	1 (4.55%)	3 (5.2%)	-	4 (5.5%)
Gynaecological	1 (4.55%)	4 (6.9%)	1 (12.5%)	4 (5.5%)
Haematological	1 (4.55%)	8 (13.8%)	1 (12.5%)	8 (11%)
Head and Neck	5 (22.75%)	3 (5.2%)	2 (25%)	6 (8.3%)
Lung	2 (9.1%)	5 (8.6%)	-	7 (9.7%)
Prostate	2 (9.1%)	10 (17.2%)	-	12 (16.7%)
Sarcoma / Skin	2 (9.1%)	2 (3.4%)	-	4 (5.5%)
Urological	1 (4.55%)	2 (3.4%)	1 (12.5%)	2 (2.8%)
Other Including: Brain & CNS Endocrine Upper Gastro-intestinal Male Genital Melanoma	2 (9.1%)	-	-	2 (2.8%)
First Cancer Diagnosis				
Yes	20 (90.9%)	50 (86.2%)	8 (100%)	62 (86%)
No – Same Tumour Site	2 (9.1%)	3 (5.2%)	-	5 (7%)
No – Different Tumour Site	-	5 (8.6%)	-	5 (7%)
Treatment Stage at Time of Rehabilitation				
Rehabilitation Before Cancer Treatment	3 (13.6%)	3 (5.2%)	-	6 (8.3%)
In Treatment – Unknown Response	5 (22.75%)	16 (27.6%)	4 (50%)	17 (23.6%)
In Treatment – No Signs of Cancer	1 (4.55%)	2 (3.4%)	-	4 (5.5%)
In Treatment – Living with Cancer	1 (4.55%)	2 (3.4%)	-	3 (4.2%)

Follow Up Treatment – Partial Cancer Response	2 (9.1%)	7 (12%)	-	9 (12.5%)
Completed Treatment – Unknown Response	2 (9.1%)	3 (5.2%)	1 (12.5%)	4 (5.5%)
Completed Treatment – No Signs of Cancer	7 (31.8%)	20 (34.5%)	3 (37.5%)	24 (33%)
Completed Treatment – Living with Cancer	1 (4.55%)	4 (6.9%)	-	5 (7%)
Time Since First Treatment for This Cancer				
< 1 Year	3 (13.6%)	6 (10.3%)	-	9 (12.5%)
1 - 5 Years	15 (68.2%)	36 (62.1%)	7 (87.5%)	44 (61.1%)
> 5 Years	4 (18.2%)	16 (27.6%)	1 (12.5%)	19 (26.4%)
Year of Rehabilitation				
2011	1 (4.55%)	5 (8.6%)	1 (12.5%)	5 (7%)
2012	-	-	-	-
2013	2 (9.1%)	11 (19%)	-	13 (18%)
2014	4 (18.2%)	8 (13.8%)	2 (25%)	10 (13.9%)
2015	14 (63.6%)	34 (58.6%)	5 (62.5%)	43 (59.7%)
2016	1 (4.55%)	-	-	1 (1.4%)
Non-Cancer Long Term Conditions				
No Long-Term Condition	8 (36.4%)	25 (43%)	4 (50%)	29 (40.3%)
>1 Long-Term Condition	7 (31.85%)	16 (27.6%)	1 (12.5%)	22 (30.5%)
Long-Term Physical Condition	3 (13.6%)	9 (15.5%)	1 (12.5%)	11 (15.3%)
Long-Term Medical Condition	3 (13.6%)	8 (13.8%)	2 (25%)	9 (12.5%)
Sensory Impairment	1 (4.55%)	-	-	1 (1.4%)
Highest Level of Education				
Higher Degree	5 (22.75%)	5 (8.6%)	2 (25%)	8 (11%)
First Degree	2 (9.1%)	14 (24%)	1 (12.5%)	15 (20.8%)
Nursing / Medical – Non-Degree	2 (9.1%)	1 (1.7%)	-	3 (4.2%)
Teaching – Not PGCE	1 (4.55%)	-	-	1 (1.4%)
Diploma	5 (22.75%)	21 (36.2%)	3 (37.5%)	23 (32%)
A Level	1 (4.55%)	6 (10.3%)	1 (12.5%)	6 (8.3%)
GCSE / O Level	4 (18.2%)	7 (12%)	1 (12.5%)	10 (13.9%)
CSE	2 (9.1%)	4 (6.9%)	-	6 (8.3%)
Employment Status at Time of Cancer Rehabilitation				
Full Time Employment	5 (22.75%)	13 (22.4%)	2 (25%)	16 (22.2%)

Part Time Employment	3 (13.6%)	11 (19%)	2 (25%)	12 (16.7%)
Retired	12 (54.6%)	29 (50%)	3 (37.5%)	38 (52.8%)
Other including: Unemployed – Seeking Work – Unable to Work (poor health or disability) Homemaker Voluntary Role	2 (9.1%)	5 (8.5%)	1 (12.5%)	6 (8.4%)
Ethnicity				
Black African	1 (4.55%)	1 (1.7%)	1 (12.5%)	1 (1.4%)
Mixed White & Caribbean	1 (4.55%)	-	-	1 (1.4%)
Other Mixed Background	-	1 (1.7%)	-	1 (1.4%)
White British	9 (40.9%)	35 (60.3%)	4 (50%)	40 (55.5%)
White Welsh	8 (36.4%)	21 (36.2%)	3 (37.5%)	26 (36%)
White English	2 (9.1%)	-	-	2 (2.8%)
White Other	1 (4.55%)	-	-	1 (1.4%)

4.2.3 SSI Participant Characteristics

Following two pilot semi-structured interviews, described in Chapter Three, a further twenty SSIs took place between April and June 2016. Each SSI lasted approximately 60 minutes each (range 30-90 minutes). Two thirds of the interviews took place in the OT department at one of the hospital locations within the Local NHS Health Board (59.1%). Almost a fifth (18.2%) took place in a cancer charity venue in Bridgend, 13.6% in a second cancer charity venue in Swansea, and 9.1% were completed in the participants' own homes.

Of the n=22 SSI conducted, there were n=10 men (45.5%) and n=12 women (54.5 %). The median age was 67 years (range 39-89). For almost all of the group (90.9%), this was their first cancer diagnosis, with 68.2% starting rehabilitation between one to five years following their first treatment. At the time that rehabilitation started, 31.8% had completed treatment with no residual signs of cancer, and a further 22.75% were in treatment with the response yet to be known. The SSI participants included primary diagnoses from eleven cancer sites; the most common being breast (22.75%), and head and neck (22.75%) cancers.

A large proportion of the cohort (73.6%) reported one or more non-cancer long term condition affecting their health, physical ability or sensory function. Over half, (54.5%) had retired from paid employment prior to their cancer diagnosis; 40.9% were in part- or full-time employment; or were actively seeking work at the time of their diagnosis. There was a relatively broad range of educational backgrounds, with 31.8% having completed tertiary level education; 31.8% completed secondary education up to and including ‘A’ Level; and 36.4% had completed a range of Diploma level qualifications relating to their employment.

4.2.4 Introducing Semi-Structured Interview Participants

Brief biographical details of the individuals who took part in the semi-structured interviews (SSI) are presented in Table 8. Each SSI participant has been given a pseudonym to protect their identity. In Chapter Five, the SSI results will include direct quotes from the interviews. These will be identified by quotation marks and highlighted in bold. The quotes will be attributed to the respective participants by using their pseudonym in brackets at the end of each quote.

Table 8. A Brief Introduction to SSI Participants
Nia (002), aged <40 years, was diagnosed with cancer in 2014. She was in the process of undergoing additional treatments when she commenced rehabilitation. She came to rehabilitation for support to balance her part-time work and her role as a parent.
Sioned (040), aged between 61-70 years, was diagnosed with cancer in 1989. She had completed all of her cancer treatments prior to commencing rehabilitation. She was retired and felt that she would benefit from increasing her level of activity but wanted advice as to how to go about this.
Heledd (042), aged between 51-60 years, was diagnosed with cancer in 2014. She was in the process of undergoing treatment when she commenced rehabilitation. She experienced pain after surgery and was looking for options to help manage this before she could consider returning to work.
Eirlys (050), aged >80 years, was diagnosed with cancer over 5 years ago. She had completed all of her cancer treatments when she commenced rehabilitation. She was looking for support to help her participate in her social activities following the impact of surgery.
Mair (053), aged between 51-60 years, was diagnosed with cancer in 2012. She was in the process of undergoing treatment when she commenced rehabilitation. She was looking for support to manage the fatigue which resulted from her treatment, to enable her to return to full-time work.
Carys (059), aged between 71-80 years, was diagnosed with cancer in 2010. She was in the process of undergoing preparatory treatment when she commenced

rehabilitation. She was eager to become as fit and active as possible to give herself the best chance of undergoing a treatment that was potentially curable.
Gwenllian (076), aged between 61-70 years, was diagnosed with cancer in 2013. She had completed all of her cancer treatments when she commenced rehabilitation. She experienced difficulty with walking due to peripheral neuropathy following treatment and was eager to try and find ways to overcome this challenge.
Ffion (081), aged between 51-60 years, was diagnosed with cancer in 2011. She was receiving additional treatment because her cancer hadn’t fully responded. She came to rehabilitation to find ways of managing the pain that resulted from her cancer surgeries.
Angharad (126), aged >80 years, was diagnosed with cancer in 2013. She had completed all of her cancer treatments when she commenced rehabilitation. She experienced difficulty with walking due to the impact of the surgery required to remove the cancer. She was eager to remain as independent as possible despite the challenges that cancer and ageing were both bringing to her daily life.
Elin (127), aged between 41-50 years, was diagnosed with cancer in 2013. She was in the process of undergoing treatment when she commenced rehabilitation. She wanted to return to her full-time work and make changes to her lifestyle to reduce the risk of a future cancer diagnosis.
Catrin (147), aged between 71-80 years, was diagnosed with cancer in 2013. She had completed all of her cancer treatments prior to commencing rehabilitation. Her family felt she needed to become more active after her cancer treatment. She felt she needed to get her ‘mojo’ back.
Bronwyn (150), aged between 61-70 years, was diagnosed with cancer in 2013. She was receiving additional treatment because her cancer hadn’t fully responded. Despite not having high expectations for what rehabilitation could offer, she was eager find ways to be able to carry out meaningful daily activities.
Osian (178), aged between 51-60 years, was diagnosed with a recurrence of cancer in 2015. He was in the process of undergoing treatment when he commenced rehabilitation. He had experienced rehabilitation for a non-cancer long-term condition in the past and was keen to regain the strength and endurance that he had lost due to his cancer treatments.
Tomos (198), aged between 71-80 years, was diagnosed with cancer in 2000. He had completed all of his cancer treatments prior to commencing rehabilitation. He came to rehabilitation to find ways of managing the pain that resulted from his cancer treatment. He felt he was starting to withdraw from daily activities, and this was causing his family concern.
Rhys (201), aged between 61-70 years, was diagnosed with cancer in 2013. He was receiving additional treatment because his cancer hadn’t fully responded. He was looking for support with both the emotional and physical impact of cancer on

his daily life and on his self-perception and enable him to return to full-time work.
Dai (217), aged between 51-60 years, was diagnosed with cancer around 2012. He had completed all of his cancer treatments prior to commencing rehabilitation. He came to rehabilitation to find ways of managing the pain that resulted from his cancer treatments. He was self-employed and was concerned that, if permanent, the impact of the cancer treatments may force him into premature retirement.
Ieuan (228), aged between 71-80 years, was diagnosed with cancer within the last 5 years. He had completed treatment for his cancer and was now living with residual disease. He was previously physically fit and active. He was looking for support to return being active as he saw this would give him the best chance of living well for longer.
Gethin (230), aged <40 years, was diagnosed with cancer in 2013. He had completed treatment for his cancer but was living with the uncertainty of not knowing how well the cancer had responded. He was previously fit and active. He commenced rehabilitation, seeking support to redefine a new normal in relation to his level of fitness, and confidence to return to full-time work.
Hywel (234), aged between 71-80 years, was diagnosed with cancer in 2008. He was in the process of undergoing treatment when he commenced rehabilitation. His cancer treatments had made it difficult to complete most of his daily activities. He had started to withdraw from his local community because he had lost confidence. He looked to rehabilitation to help him regain physical and emotional strength.
Gareth (235), aged between 51-60 years, was diagnosed with cancer in 2013. He had completed all of his cancer treatments prior to commencing rehabilitation. Having been previously fit and active, he was eager for rehabilitation to help him to overcome the impact of his cancer treatments and to help him to learn new ways to complete everyday activities.
Emyr (236), aged between 61-70 years, was diagnosed with cancer in 2015. He was referred to rehabilitation before his cancer treatment started. He completed his prehabilitation with another service and returned to the rehabilitation team after his surgery. He was retired and lived with his wife, for whom he provided care. He returned to rehabilitation seeking support to overcome the impact of the surgery on his general ability to engage with daily activities including gardening and walking to the village pub to meet friends.
Emrys (259), aged between 71-80 years, was diagnosed with a recurrence of cancer in 2015. He was known to the local cancer rehabilitation service as he had undergone prehabilitation / rehabilitation with them for his first cancer. He completed prehabilitation again, seeking to become fit and strong enough prior to surgery. He was in the process of undergoing rehabilitation to support recovery after surgery at the time of this research.

4.2.5 ModDT Participant Characteristics

The Modified Delphi Technique (ModDT), was completed between 01/12/2017 and 04/07/2018. Of the n=58 people who participated in the ModDT; n=25 were men (43%) and n=33 (57%) were women. The median age was 67 years (range = 39 - 90 years), which was representative of the local rehabilitation population. As described in Chapter Three, this study aimed to recruit as diverse a sample as possible. There was a strong trend in recruitment of people with breast and prostate cancer. However, nine of the most common tumour sites were represented in the sample.

4.2.6 Representativeness of the Sample

The following compares the population characteristics of the research sample with Health Board and national incidence data, with respect to age and sex, tumour site and social deprivation. It was not possible to make comparisons between the research sample, local rehabilitation cohort, Health Board or national cancer populations on the grounds of education level or employment status, or comorbidity as this data is not routinely collected and reported at a service, Health Board or national cancer population in Wales.

4.2.6.1 Age, Sex and Ethnicity

Depending on the availability of data, the following highlights observations from a comparison between the research sample (presented in Table 7), and the cancer population in the local cancer rehabilitation service, the local health board or the cancer population of Wales.

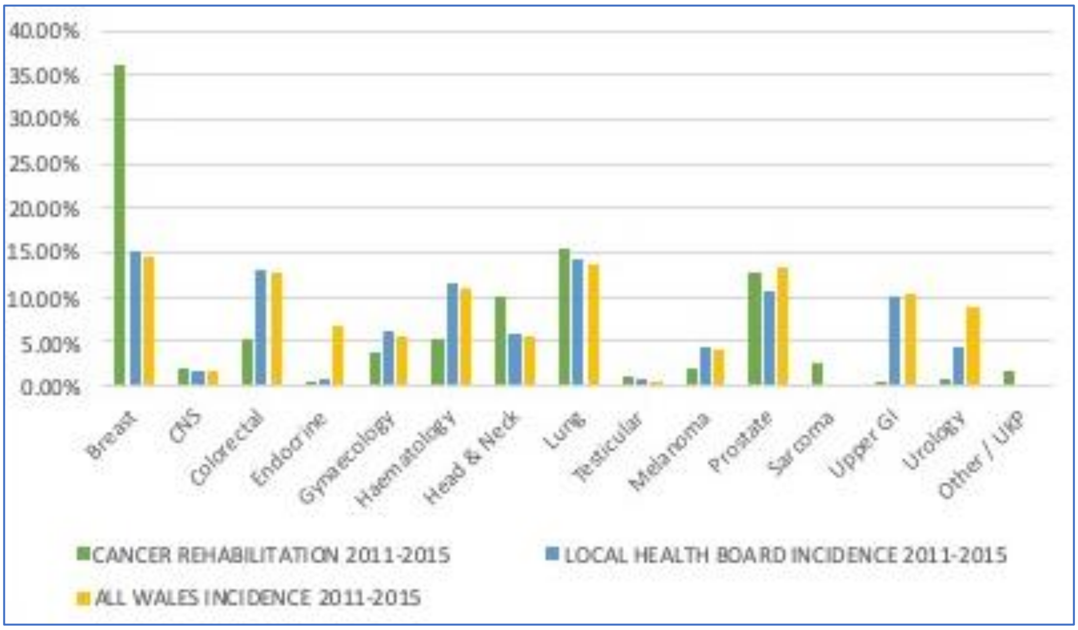
Between 2011 and 2015 there were 95,756 incidences of cancer across Wales recorded by Wales Cancer Intelligence and Surveillance Unit (WCISU). Of these 15,567 were recorded for residents of the local health board where this study was hosted (Welsh Cancer Intelligence & Surveillance Unit, 2016). Whilst the mean and median age of cancer diagnosis is not reported by WCISU, the number of new diagnoses of cancer reaches a peak between age 65-69 years. Which is consistent with the age profile of the research sample. The national incidence rates reflect that despite the rate reducing, more men (EASR 648.3/100,000 population), than women (EASR 554.1/100,000 population), are still diagnosed with cancer. This study saw slightly more women than men participating in this research.

In 2016, up to 8.1% of the local Health Board population was registered as being from a black and minority ethnic (BAME) background (Welsh Assembly Government, 2010). This data is not reported by WCISU. Of the SSI participants, 9.1% identified as being of BAME origin. This is consistent with the Health Board population. However, only 1.4% the total combined research sample identified as being of BAME origin. The observable majority (90.9%) originated from a White background (e.g. British, Welsh, English or Other). This was consistent with the profile of the local cancer rehabilitation population.

4.2.6.2 Tumour Site Profile

Figure 13 shows the breakdown of each primary tumour site group, according to rehabilitation population, the local Health Board population and national cancer incidence for the time period corresponding to the research sample. This data highlights differences between the three cohorts which includes greater representation of certain tumour sites within the cancer rehabilitation cohort compared with the other two groups. For example, there is more than twice the number of people affected by breast cancer, almost double the number of people affected by head and neck cancers, and a small percentage more of lung and prostate cancers than one would expect to see given the health board and national incidence.

Figure 13. Primary Tumour Site 2011-2015 Proportion by Rehabilitation, Health Board and All Wales

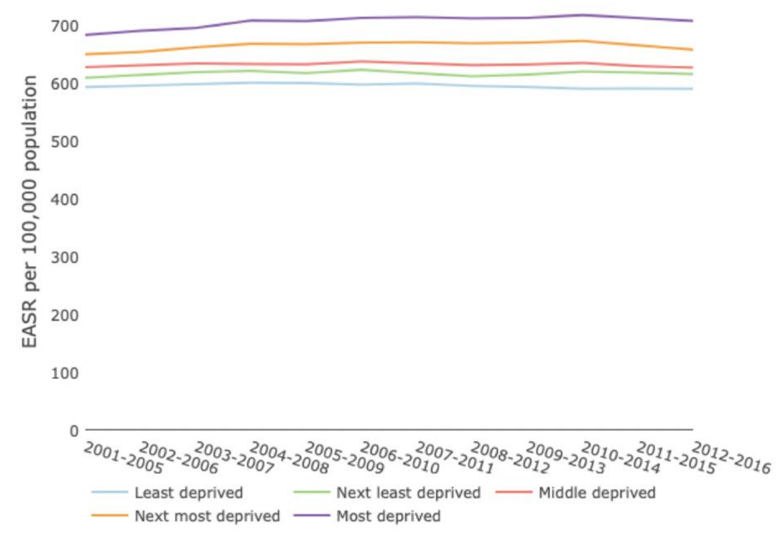


This variation may be a result of the close working relationships between the cancer rehabilitation team and other healthcare and third sector partners including shared initiatives for breast cancer with the local Lymphoedema Service; rehabilitation membership of the Lung Cancer Multi-Disciplinary Team (MDT); and partnership working with third sector partners in the provision of education and physical activity as part of survivorship courses for people diagnosed with prostate cancer.

4.2.6.3 Social Deprivation Profile

The data presented in Chapter Three illustrated that 63% of the research participant population lived within the least deprived communities across the local Health Board. This was not dissimilar to the profile of non-responders within the cancer rehabilitation cohort. However, this does not reflect the distribution of incidence by deprivation across Wales. Figure 14 presents the cancer incidence by deprivation across Wales. This describes a smaller variation between each of the levels of deprivation. Whilst the research population did not mirror the national picture, there was some representation from the more deprived communities within the research sample.

Figure 14. Cancer Incidence by Deprivation in Wales 2001 - 2016



Source: Welsh Cancer Intelligence and Surveillance Unit, Health Intelligence Division, Public Health Wales, January 2019

4.3 Participant Choice in Data Collection Method

Participants were offered the opportunity to nominate a preference for participation with either SSI and/or ModDT. Of the n=126 people screened, there were n=86 requests for participation in SSI and n=106 people indicated a preference to participate in the ModDT. These included SSI only (n=20), either SSI or ModDT (n=61), both SSI and ModDT (n=5), or ModDT only (n=40). All people who indicated an interest were invited to take part; 65 people (61.3%), returned a consent form.

Recruitment to the ModDT closed when the cohort reached n=58 participants. This exceeded recruitment expectations, as the sample in the research protocol and ethics application was n=50 participants.

It was possible to meet more than half of the participants' preferences for participation in either and/or both data collection methods. It was not feasible to accommodate every request for participation in the SSI, and following random allocation to data collection method, six potential participants were not able to have their preference for SSI accommodated. These candidates were removed from the sample as a result. In light of the small sample size required for SSI, achieving 60% of participant preference for this data collection method was considered as a positive outcome (Vandelanotte, Duncan, Plotnikoff, & Mummery, 2012).

Of the n=40 people who indicated a preference for ModDT only, n=13 (32.5%) participated in this data collection method, as n=21 (52.5%) of people in this cohort did not respond to post-screening communication. Details of participant preferences are described in Table 9.

Table 9. Participant Preference for Research Activity

	SSI Only	Either SSI OR ModDT	Both SSI AND ModDT	ModDT Only
Participant Preference Recorded	20	61	5	40
Participant Preference Achieved (%)	12 (60%)	36 (59%)	3 (60%)	13 (32.5%)
Investigator Unable to Offer Preference	6	0	0	0
Investigator Able to Offer Part Preference only	0	0	2	0
RIP	1	2	0	3
Participant Withdrew	1	2	0	0
Medical Deterioration	0	2	0	0
No Response to Modified Delphi Technique Consent	0	14 (23%)	0	21 (52.5%)
Consent Received / No Response to Study Activity	0	2	0	2
Consent Received / Partial Completion of Study Activity	0	2	0	1

4.4 Summary

Recruitment and study participation in this research exceeded expectations. The participant sample's demographic, social, and disease characteristics were comparable with the local cancer rehabilitation population. This suggests that the results of this research may be generalisable at a local level. There was some common ground between the research sample and the wider cancer population in Wales with respect to age at diagnosis and tumour site profile. However, due to the differences in deprivation profile, there could be regional, population-specific nuances which would affect the broader interpretation of the results of this research. Any attempts to generalise these findings beyond the Health Board in which they were generated would need to be undertaken conservatively.

The following Chapters Five and Six will outline the findings from the SSI and ModDT.

Chapter Five: Findings from Semi-Structured Interviews

5.1 Introduction to Chapter Five

As described in Chapter 3.4.1 (Figure 7), the ILR analysis was completed in parallel to undertaking the SSI and ModDT. The preliminary findings of the ILR were not used to directly shape the SSI interview schedule. However, they were helpful in sense-checking the early SSI findings and helped to inform the SSI analysis.

In Chapter Two, the findings from the integrative literature review (ILR), suggested that therapeutic relationships may act as the mechanism through which professionals support the development of SM behaviours. This chapter presents the findings from twenty-two semi-structured interviews (SSI), with local cancer rehabilitation participants. The findings explore their experiences of therapeutic relationships and aim to answer the research questions described in Chapter 3.2.

In this chapter, direct participants’ comments are represented in *italics*. Their pseudonym, sex and age are presented in parentheses at the end of each quotation.

5.2 The Rehabilitation Assumption

This research is based on the assumption that the local cancer rehabilitation service was effective in supporting self-management behaviours, which the SSI findings did confirm. Whilst there was a small number of respondents who reported that, to them, the therapeutic relationship was less important than autonomy or competence building aspects of rehabilitation. There were no responses which suggested that rehabilitation was ineffective in supporting their recovery and development of SM following a cancer diagnosis. This may reflect a responder bias, which will be discussed in Chapter 8.5. The following explores some of the participant responses to the question about whether rehabilitation helped to make changes to lifestyle or behaviour.

Fifteen (68%) of the SSI participants reported that cancer rehabilitation was effective in supporting them to make lifestyle changes. Six of these participants reported the need to adopt new daily routines to include physical activity, or changes to diet and nutrition, after cancer rehabilitation. These new routines were perceived as taking on a new importance.

“a platform, if you like, a springboard” (Osian; male, 51-60 years),

“reignited my interest … made it more interesting… opened new spheres, new ways of doing different exercises” (Ieuan; male, 71-80 years),

“my lifestyle has changed completely… I’ve eaten things that I would never eat before, like aubergine, what is that?” (Ffion; female, 51-60 years),

“I do it religiously, let’s put it that way” (Gwenllian; female, 61-70 years),

“I’m miserable if I can’t get out. I am not quite; I wouldn’t say addicted but … I guess for me, it’s around survival, I want to be here for a long time, I want to see my kids grow up” (Elin; female, 41-50 years),

Five of the fifteen participants reported that the changes they made after rehabilitation related more to their new sense of self-awareness, outlook or ownership of the future, rather than change of daily routine. This included ownership over priorities. Which resulted in a shift in motivation and perception of what had become possible.

“well I can’t do what I’m used to doin’… I know my limitations type of thing. … The most important thing to me at one time was that I could tie a bin bag… [now] I can actually carry some stuff” (Gareth; male, 51-60 years),

“I’ve reached a stage where I’m very, um, possessive, if you like, about my, my time. And what I do with my time… I’m sort of re-defining myself again” (Osian; male, 51-60 years),

“I am more willing to try things… this has given me a different outlook… I can carry on” (Sioned; female, 61-70 years),

Four of the fifteen participants valued rehabilitation for the perceived emotional benefits, rather than lifestyle changes. There was gratitude for a formalised relationship where it was safe to discuss emotions. This was not always perceived as having been available in the wider healthcare system.

“I felt that I don’t want to burden my relatives with it. My son won’t discuss health because he is frightened of hospitals, but I needed an independent point of view and people with experience” (Tomos; male, 71-80 years),

“let down by most of the NHS… I felt so frustrated up until you guys started listening to me. So, I think it helps to repair mentally as well. Knowing somebody listens” (Dai; male, 51-60 years),

Of the seven participants who did not report lifestyle change after cancer rehabilitation, two participants reported that rehabilitation was instrumental in helping them to prepare themselves for their first cancer treatment. They identified how unprepared people can be as they approach cancer treatments. They highlighted the risk that PABC may succumb to adopting a passive role during cancer treatments without timely prehabilitation.

> *"I was so much in the dark I didn't know what to expect… then you explained everything to me which made it a lot easier … to know what to expect [before] and what to expect after the operation as well" (Emrys; male, 71-80 years),*

> *"I've just got to go with the flow, you know what I mean, I am willing to fight it but I'm not fully in control of the situation… [before rehabilitation] I felt no I'm buggered, now I'll never be able to do this again… what you did to me, it gave me confidence, and I started getting better and better and better" (Emyr; male, 61-70 years),*

Three participants did not feel they needed to change their previous lifestyle. However, by describing their 'return' to usual activities or coping mechanisms, their language suggests that they experienced a deficit in their 'usual' lifestyle at the time of starting rehabilitation.

> *"not actually different lifestyles, I don't do much different… I go to bingo on Monday… I've started going back to the weekend club, a little club we go to on a Saturday and another one on a Sunday" (Eirlys; female, >80 years),*

> *"well, I don't know if change is the right word, but it has helped me to progress massively. Some of the things that inhibit me day to day aren't there when I'm running" (Gethin; male, <40 years),*

Two participants did not report specific changes to their lifestyle after cancer rehabilitation. They viewed cancer rehabilitation as having brought them closer to other people, and enabled them to form links with peers, helping to overcome social isolation. There was a strong message of camaraderie within the peer group, which was echoed in the responses of almost all of the participants. A dedicated conversation relating to this topic follows later in this chapter (Section 5.7).

> *"the point is that it got me out, it got me with other people, it got me to meet some nice people" (Carys; female, 71-80 years),*

> *"it doesn't matter how bad the situation is, there always a bonus. And the bonus is [in] the last two and a half years that I have met the most wonderful people" (Angharad; female, >80 years),*

Although almost one third of the SSI participants did not report a change in lifestyle, almost all reported a change in their behaviour, as a result of participation in cancer rehabilitation. All participants reported some impact of rehabilitation on making choices about or changes to their daily routines, regaining the skills or confidence to return to usual activities, or forming valued connections with peers. Any or all of these outcomes might be considered instrumental in supporting their physical and/or mental health long after their involvement with cancer rehabilitation had ended.

This preliminary analysis focused on clarifying whether the SSI data supported the rehabilitation assumption described above. This activity used a framework analysis using the core psychological needs described by SDT (Deci & Ryan, 2012). This completed by matching examples of participant responses to the SDT operational definitions of competence, autonomy and relatedness, as proposed by (Silva et al., 2014). Please see Table 10 for some of these examples. Further discussion relating to SDT is presented in Chapter 8.3.1.

Table 10. Evidence Supporting Cancer Rehabilitation Using SDT as Framework

Core Need	Component	Supporting Evidence from SSI Data
Autonomy	Relevance	"I might have my own objectives, or my own reasons for doing things in certain ways… they always asked me every week, how far you walked? And I said I'm not interested in how far I walked…if I'm walking its walking because I'm going somewhere to do something" (*Osian*).
	Respect	"I felt there was very much respect, I felt that there was very much, people were doing the right things for me, people were prepared to listen to what I wanted" (*Elin*).
	Choice	"the swimming, … I wasn't able to do, it didn't suit me with wet hair and all that rigmarole, I couldn't be bothered with swimming … it was just the effort of getting dressed and undressed. So, the tai chi was an easier option… it was the most appropriate for my state at the time" (*Carys*).
	Avoidance of control	"It was always at the person's speed, the person's ability, there was never ever a push, …, it was always down to what the individual was capable of, felt comfortable with. Maybe they could have done more, maybe they could have done that extra step, um but it was never expected" (*Osian*).

Competence	Clarity of expectations	“I was pretty drawn, skinny, you know. I have lost weight through treatment and the way my shoulder hung, I mean it was all, you know, crooked. But um, once I got into the sessions and you know um, there's no guarantees, right, and basically it was down to me. They made that pretty clear” (*Rhys*).
	Optimal challenge	“I knew that whatever I was being asked to do is not what the lady next to me is being told to do. Everything is tailored to me” (*Nia*).
	Feedback	“They never ever made me feel that I’d failed at anything. I might not have succeeded at the ultimate, but they always made me feel like getting halfway – that was a success” (*Hywel*).
	Skills training	“I been out the garden potterin’ about I can manage to carry things, not heavy, you know, I move things back and for’ and just, I know my limitations type of thing. The most important thing to me at one time was, that I could tie a bin bag” (*Gareth*).
Relatedness	Empathy	“I think it has to fit in with, someone’s personality and they will find their niche within that, but they can’t, especially to do with health and so on, you can’t, you can’t force yourself to be somebody that you are not, and fake empathy or sympathy” (*Carys*).
	Affection	“First thing they do is they welcome you in as if they've known you forever” (*Ffion*).
	Attunement	“Paying attention, and [they] noticed if somebody was struggling, [they] noticed if somebody was doing something better than they were last week. And [they] commented on it” (*Gwenllian*).
	Dedication of resources	“But [they've] always got time, some time with each person” (*Eirlys*).
	Dependability	“I knew you were all there, and I knew if I wanted any help, I could speak to one of you there. I know there's always somebody there” (*Eirlys*).

5.3 Themes from Inductive Analysis

Following this preliminary framework analysis exploring the rehabilitation assumption, an independent inductive thematic analysis was undertaken to answer the research questions in Chapter 1.1.1. These resulted in the following four key themes which were echoed, to some extent in the ILR papers:

- Professional attributes, knowledge, skills and behaviours have the greatest potential to either facilitate or inhibit the development of therapeutic relationships.
- There is a tension between professionals being adaptable to the needs of the individuals they're working, with whilst maintaining personal authenticity during healthcare interactions.
- Time for, and timing of, interactions between healthcare participants and professionals has the potential to impact on the development of therapeutic relationships and self-management.
- There is a tension around participant ownership of self-management in terms of interpreting what a successful outcome looks like and navigating the compliance dichotomy in practice.

In addition to these themes there were three sub-themes which were not described in the ILR findings. All three of these sub-themes specifically reflected the SDT component of relatedness. The first sub-theme described the impact of participants' previous relationship experiences on therapeutic relationships. These previous relationships experiences appear to have had the potential to either enable or inhibit therapeutic relationships.

The second sub-theme addressed the importance of the relationships that participant formed with peers during rehabilitation. These relationships offered the opportunity to provide and receive support from individuals who had a shared experience of cancer. Whilst those experiences may have been diverse, there was a perceived 'membership' of a cohort, that professionals without a personal cancer experience, could not claim to understand.

The third sub-theme reflected the perceived need for clear boundaries within which therapeutic relationships need to operate. This was described as being for the safety of both rehabilitation participants and professionals. This sub-theme appeared to articulate the participants' thoughts on the consequences of either party stepping beyond the expectations of a 'therapeutic' relationship and entering a 'personal' relationship.

There was congruence between the themes identified through the inductive analysis of the SSI data and the four themes synthesised by the ILR. The following sections will report the SSI findings in relation to the four ILR themes. The first and second of the three sub-themes will be discussed within the section relating to barriers and enablers of therapeutic relationships. As the third sub-theme relates to relationships with peers, this will be discussed towards the end of the chapter in relation to ownership of SM.

5.4 Therapeutic Relationships: Barriers and Enablers

The SSI participants resonated with the ILR findings (Appendix 5), whereby contributory factors might be perceived as either a barrier or a facilitator to the therapeutic relationship. The perspective depended on the expectations of the individuals involved and the context of the interaction.

Two major sub-themes emerged from the SSI data as influential in the development or maintenance of therapeutic relationships. The first echoed the ILR findings and considered how compatible healthcare professionals were for their role. This incorporated both personal characteristics and behaviours during healthcare interactions and their training, preparation or level of experience. Whilst more than half of the participants (12/22), reported professional characteristics were important in facilitating therapeutic relationships, almost all participants (18/22), identified professionals' training and experience as important.

The second sub-theme, not reported in the ILR findings, proposed that the translation of previous relationships, their associated beliefs and behaviours, into the therapeutic relationship, had the potential to enable or inhibit these. This included preconceived expectations about the individuals involved and perceived common ground between healthcare participants and professionals.

5.4.1 Healthcare Professionals' Attitudes and Behaviours: The 'Right' Person

Twelve of the twenty-two SSI participants commented that they thought it was important for the people who occupy healthcare professional roles to be the 'right kind of person'. There were varied opinions relating to professionals' attributes and behaviours. These ranged from idealistic expectations of the characteristics healthcare professionals should display and more pragmatic perceptions that allowed healthcare professionals the scope to be fallible.

> *"It's actually back to people being in the right job, isn't it?"* (Dai; male, 51-60 years),

> *"I personally think that if somebody doesn't have a caring attitude then they shouldn't be working in the NHS, they shouldn't be. Go and get a job doing something else, there are plenty of other jobs out there; why would anybody want to go into the NHS as a nurse or a doctor or anything if they are not a kind person?"* (Dai; male, 51-60 years),

> *"it doesn't bother me, to be honest with you, whoever is looking after me, as long as they're looking after me well"* (Gwenllian; female, 61-70 years),

> *"The attitude, the attitude, um from the word go, you know it wasn't this right you know, um, you're here for an hour, going to do this, going to do that, if we didn't want to do something you would say well try this, it is how you put it over. You know ... you can get someone to walk a mile because he knows he's got to do it. To get him walk a mile and a half, it's how you speak to him, how you treat him, the banter is going, before he knows it, he has done that extra half mile"* (Rhys; male, 61-70 years),

The synthesis from the ILR suggested that professionals' personal attributes, their knowledge and skills and their conduct or behaviour during healthcare interactions all have the potential to enable or inhibit therapeutic relationships. However, the ILR findings were not able to provide more detail as to the impact that professional attributes, skills or behaviours have on cancer rehabilitation participants.

To overcome this, the SSI participants were asked if they were able to identify some of the professional characteristics, body language or attitudes they had observed, or experienced. Once identified, they were asked to explain why they considered these important for facilitating therapeutic relationships. Their responses are arranged below, using the SDT operational definition headings for relatedness, to explore the extent to which they support, challenge or extend the SDT framework (Silva et al., 2014).

5.4.1.1 Empathy

The first of five operational definitions for relatedness, proposed by Silva et al. (2014), was empathy. The Merriam-Webster Dictionary (2015), defines empathy as "the action of understanding, being aware of, being sensitive to, and vicariously experiencing the feelings, thoughts, and experience of another of either the past or present without having the feelings, thoughts, and experience fully communicated in an objectively explicit manner".

Of the twenty-two interviews, only five participants used the word ‘empathy’ in describing attributes which assisted in, or posed a barrier to, the development of their therapeutic relationships.

> *“you, every one of you, … definitely had an empathy with us” (Gwenllian; female, 61-70 years),*

> *“they lack empathy and they lack understanding really, what you’ve been through” (Heledd; female, 51-60 years),*

There appeared to be different perceptions as to what empathy meant. For some, empathy was linked with healthcare professionals’ attributes, or personality characteristics. This perspective implied that, if empathy was a personality characteristic, it may not be a learnable skill. However, an additional fifteen participants commented on the importance of professionals who displayed the ability to understand the challenges faced by people after a cancer diagnosis.

> *“So I think it has to fit in with, someone’s personality and they will find their niche within that, but they can’t, especially to do with health and so on, you can’t, you can’t force yourself to be somebody that you are not, and fake empathy or sympathy, it’s got to be, you know, it’s got to be a suitable person to be doing this job” (Carys; female, 71-80 years),*

> *“there’s somebody there that you can speak to that will understand, because a lot of people wouldn’t understand, they don’t. It’s hard for other people to understand?” (Eirlys; female, >80 years),*

Twenty of the twenty-two participants identifying empathy as an important contributor to therapeutic relationships. It appeared easier for participants to identify the negative impact of a lack of professional empathy, than the positive impact of empathy on therapeutic relationships. There was a fine line between participants valuing professionals who attempted to see, or understand, the situation from their perspective and those professionals who made assumptions or value judgements about the participants’ experiences.

The impact of professionals who failed to be sensitive to this boundary was the potential development of hostile feelings and risk of disengaging from the healthcare partnership. The participants vehemently reinforced their need for professionals to respect the very personal and individual nature of each cancer experience. Participants highlighted that professional attitudes, knowledge and clinical experience were insufficient to enable them to understand the whole personal experience of cancer.

> *"it's very difficult for somebody who hasn't been in this situation that we have found ourselves in, um, I don't know, to provide the right attitude… you need somebody, not really sympathetic… who didn't belittle what you have gone through" (Sioned; female, 61-70 years),*

> *"Sometimes they say a load of shit, and I am thinking what the hell do you know, how do you know what I feel?" (Rhys; male, 61-70 years),*

> *"I dislike persons, extremely dislike persons, 'we know what you are going through', you haven't got a clue. You haven't been there, to know what it's all about, you haven't got a clue" (Osian; male, 51-60 years),*

> *"Don't imagine you know 100% what a patient needs. You have the academic and professional experience, but you are not walking in that patient's body" (Nia; female, <40 years),*

The local cancer rehabilitation professionals were observed to have conveyed empathy without overstepping any boundaries which might compromise participants' trust.

> *"You lot seemed to have mastered the art of pulling back without trying to say to us too much, 'look you know, um, I know what you are going through'. What you got over is that, 'I understand what you are going through'" (Rhys; male, 61-70 years),*

These responses suggest that the role of empathy in the development of therapeutic relationships is to engage participants, offering security and safety from professionals who have a greater level of understanding about the potential impact of cancer than social networks can offer.

5.4.1.2 Affection

The second operational heading for relatedness, was affection. The definition provided by Silva et al. (2014), describes affection as including behaviours which demonstrate or display genuine concern and appreciation of another person. Sixteen of the twenty-two SSI participants identified affection as being important to the development of therapeutic relationships. There were three behaviours through which the SSI participants perceived affection to be displayed by rehabilitation professionals. These included a shared liking of each other, the use of physical displays of affection, and the use of humour or banter.

Affection within the therapeutic relationships was challenging for participants to describe. However, the way in which the team greeted new rehabilitation participants facilitated this affection early in the relationship. Of the sixteen SSI participants who identified affection as being important, ten people described the impact of the affection between themselves and professionals meant that they felt cared for.

> *"People are very fond of you all, and I'm sure you've got certain amount of fondness for ..., you know other people as well. But nobody sort of thinks, ..., 'they're my best friends'. It not that, it's like a very fond, gentle, almost a slightly loving… relationship, without like, expecting to be bosom buddies" (Gwenllian; female, 61-70 years),*

> *"first thing they do is they welcome you in as if they've known you forever" (Ffion; female, 51-60 years),*

> *"[the team] were makin' us feel important type of thing. You know you're not there just as a number. ... We were individuals and [the team] showed the care that [they] feel for everybody type of thing" (Gareth; male, 51-60 years),*

Not all of the participants reported experiences where professional likability was present. Not all participants felt that professional likeability was as important as professional knowledge and skills as long as professionals were perceived to be doing their best for the participant. This allowed for the potential for an accord to develop over time.

> *"there are some people that you take to and there are some you don't…I just didn't gel with him at all" (Sioned; female, 61-70 years),*

> *"It doesn't bother me, 'cause to be honest with you, whoever is looking after me, as long as they're looking after me well…Even if like my GP got a slightly quirky personality. Um, I love him to death, you know because… he's a really good doctor and I've been with him a long time and I know his bedside manner needs work [laugh] actually I think he's been on a course, because he, he does, he's trying harder, but he is quite difficult, he finds it quite difficult" (Gwenllian; female, 61-70 years),*

The participants reported examples of physical displays of affection which they interpreted as indicating the extent to which affection was present or not within their therapeutic relationships. The use of physical contact between healthcare professionals and people receiving therapeutic manual techniques has been a long-standing topic of discussion in OT. Taylor (2008, pp. 189-190), summarizes the purposes for the "judicious use of touch", and provides guidelines to support the understanding of how and why touch can be beneficial or harmful to the development of therapeutic relationships. She describes the use of touch, for example a hug, as a mechanism for conveying caring, the use of which must be mindfully applied.

Being physically affectionate with healthcare professionals was not part of participants' wider healthcare experience. For one participant, their relationships with primary care professionals had been fragile and a source of tension. Being affectionate with rehabilitation professionals, appeared to have a direct impact on their level of engagement and commitment to rehabilitation.

> *"When I met you now, I gave you a hug, I couldn't do that with a GP, I'd never have that relationship" (Dai; male, 51-60 years),*

> *"I could probably give a hug to any of the other girls that has helped me get through that experience, it's not just a one on one thing it's anybody that you think 'wow these guys are helping me to live, they helped me to get stronger, they helped me to have a better life' and then anybody that you feel is contributing to that you feel as if you want to give something back" (Dai; male, 51-60 years),*

This account reinforces that both the affection, and the broader therapeutic relationship were reciprocal interactions between partners. Physical displays of affection did not always include touch. The use of body language was also perceived as conveying genuine concern.

> *"very open facially, the way which you expressed yourselves, always smiling, your eyes were always open wide, you can see a caring attitude" (Gwenllian; female, 61-70 years),*

One participant interpreted their observations of the relationships, and quality of interpersonal interactions that the rehabilitation professionals with each other, as a benchmark for how they might then interact with participants. Participants also observed professionals role modelling desired behaviour to less experienced professionals and students.

> *"well they have got an amazing rapport with each other and they've got an amazing rapport then with other people I think" (Angharad; female, >80 years),*

> *"It works down doesn't it? If the one at the top isn't ah, like yourself, you know grumpy, doesn't care, you know that way, it's gunna rub off on everybody else type of thing" (Gareth; male, 51-60 years),*

The impact of teams adopting undesirable body language and behaviour patterns might include the risk of participants' non-attendance, poor participation, or complete disengagement. There were two sides to this body language. The first was behaviour which conveyed inattention. The second, reinforced the importance for interest and affection to be authentic, not forced.

> *“It can be off putting if you go and there somebody who just turns away and goes to a computer screen” (Gwenllian; female, 61-70 years),*

> *“The tilting of the head. It is the worst thing ... they are not really caring for you, it’s just, they [are] going through the motion and you feel patronised basically” (Mair; female, 51-60 years),*

The quality of the interaction between professional and participant was clearly an important indicator of the therapeutic relationship. Care and affection were perceived to be displayed through a range of professionals’ behaviours, which included the use of humour and banter.

Whilst the SDT framework did not have a specific operational heading relating to humour, there were comments made by over half of the participants relating to the role that humour played in their rehabilitation. The introduction of humour into rehabilitation requires the ability to read behaviour and understand social boundaries at a time when people have the potential to be in a state of distress. The cancer world might be perceived as serious, where people adopt serene body language and hushed speaking voices. Participants may also have preconceived ideas about what good ‘professional conduct’ looks like. Professionalism was perceived as being displayed by professionals who were adaptable and approachable.

> *“When I first got in the pool you could have told me any joke, the funniest joke in the world, and I wouldn’t have smiled. I wouldn’t have laughed. I was dead serious because I had lost my humour” (Dai; male, 51-60 years),*

> *“Not professionally like regimented, there was flexibility in the approach” (Osian; male, 51-60 years),*

> *“I like the more informality” (Catrin; female, 71-80 years),*

> *“Less wooden… had less of this barrier in front of them” (*Dai; male, 51-60 years*),*

> *“My son told me that he never expected cancer patients to be laughing” (Ffion; female, 51-60 years),*

Humour had the potential to reduce tension and facilitate a sense of enjoyment during activity. The participants may have been unaware that there was a therapeutic intention behind the atmosphere that the humour created. Using humour to facilitate rehabilitation outcomes, whilst being able to have a laugh with people who shared a similar experience was seen as enjoyable. It was also perceived as part of the ‘normal’ human experience.

> *“Even though in between the sessions there were, there were jokes and it was made to feel relaxed, and that’s just it you know, you can get someone to walk a mile if you’ve got a bloody good conversation going”* (Rhys; male, 61-70 years),

> *“You mean makin’ light of everything, you can’t make everything serious, you know, serious is serious, but when I was in the pool with you. I’m not bein’ funny but the* atmosphere was lovely. *Everything was serious for what you were doin’, but it didn’t seem that way (Gareth; male, 51-60 years),*

> *“I suppose the lightening, taking the load off your mind and being able to relax and have a laugh and enjoying it. I think that was the biggest part that I enjoyed” (Emrys; male, 71-80 years),*

> *“For 1/2 hour or an hour you’re not the person that’s ill within your family, you’re just a normal person trying to do the best that you can. And, that for me made a big difference to me” (Ffion; female, 51-60 years),*

The use of humour was highly valued as it was seen as a reflection of the professionals’ consideration of participants as individuals. The role of humour in rehabilitation, was seen as a tool which facilitated relaxation and made the process of change easier to tolerate.

Banter was identified as one style of interaction that was valued, predominantly by small cohort of older male rehabilitation participants. The Merriam-Webster Dictionary (2015), defines banter as “good-natured and usually witty and animated joking”. This style of interaction was described by these participants as mirroring their experience of wider social interactions, reminiscent of previous life roles, or as a conduit to re-defining their personal identity. There was a perception that professionals expected that banter would occur during healthcare interactions.

> *“I am one of the biggest piss-takers going, but you knew, and made us remember that you are here to work, we’re here for a purpose not just fun and games, you know, but you made us feel relaxed - the whole team”* (Rhys; male, 61-70 years),

> *“The wind ups are there, you know, it’s all part of life. It reminded me of in the prison service”* (Ieuan; male, 71-80 years),

> *“A lot of humour, which is always nice to hang onto, you know, a … sort of little bit of um, aggravation, with each other, not in a sort of nasty way”* (Osian; male, 51-60 *years),*

> *“You know, it’s fun and games all the way through, and it’s not just the physical side your mentality as well is working, … because I don’t see myself as an old fogey, and*

> *a lot of them there were shocked to find out my age, you know. I said I know I've had a good life. [Laughter]. You know, no it is that banter from day one"* (Rhys; male, 61-70 years),

> *"Yes outside in life I think it helps you get along a lot easier if you can have a little banter and have a little laugh and joke, but it is knowing where to draw the line… I know exactly how far I can go and far I can't and even with the girls here I give them real hard stick, but I know exactly they can go, and I know exactly how far they will let me because they let me go so far you see. That is the game"* (Emrys; male, 71-80 years),

There is a complex skillset being described by participants, in terms of their expectations for how healthcare professionals convey their concern towards rehabilitation participants. In order to make decisions regarding the use of affection, body language and touch, humour or banter, a professional would need to have a clear understanding of participants' clinical needs and be in-tune with their communication needs. The following section explores this aspect of relatedness, described as attunement.

5.4.1.3 Attunement

Attunement was the third operational definition for SDT relatedness. In this context, it describes the extent to which professionals work in harmony with rehabilitation participants. Operational definitions of attunement reflect behaviours which include being attentive to people and gathering knowledge about them. Nineteen of the twenty-two SSI participants identified attunement as being an important contributor to therapeutic relationships. Of these, most of the comments (16/19), reflected the importance of professionals being attentive to the needs of participants, which may differ at different stages during their cancer treatment or rehabilitation experience.

5.4.1.3.1 Being Attentive

Participants were largely grateful for professionals' attention. Communication skills including listening during one-to-one interactions were the professional behaviours most commonly identified by participants. These behaviours conveyed that professionals were being attentive.

> *"I appreciate the fact that I have had a lot of attention really"* (Angharad; female, >80 years),

> *"it is because you listen to people"* (Mair; female, 51-60 years),

> *"this is my opportunity to be listened to"* (Nia; female, <40 years),

Participants' responses suggested that the impact of their perception of professional attunement, was to enable them to feel more at ease to share concerns. However, some participants were looking for proof that the attention conveyed through body language was authentic.

"you can tell them anything" (Ffion; female, 51-60 years),

"you spill everything to them don't you" (Heledd; female, 51-60 years),

"Having that ability, right, as I did that one day to know that I could talk to [them] without any fear of one - being ridiculed, … and knowing it was personal and private. That, if anything sticks in my mind, right, it was that one day when I really felt, [they] came in to give me exercises. But [they] must have seen how I was and, holding my hand, one here one there, and just letting me rabbit on, [they] hardly said anything, [they] sat and [they] listened. And I was able to get off my chest a lot of my regrets in life, my failures in life, … and that to me is, was a big turning point" (Hywel; male, 71-80 years),

*"you felt that you could talk to them more and more importantly you felt that when you were talking you were being listened to… and proving that you were listening by either taking notes or next time you see them they have just read your notes and it's 'right then this is where we are with you'" (*Dai; male, 51-60 years*),*

Attunement during groups was perceived as more than a safety feature built into the service. The attention paid by professionals was noted as being an essential component of change. Professionals were observed to have taken the time to recognise change from one session to the next. However, there was a value perceived by participants, when professionals expressed genuine emotion in response to the changes observed. This impact of professionals providing genuine emotional responses to change, and encouragement was described as influencing participants' resilience and endurance.

"there was normally always two maybe three, and you weren't sort of staying in one clique, you were walking around er, each and your eyes were all, eyes were all over the place and watching how people were in case someone was, not feeling ok" (Emyr; male, 61-70 years),

"paying attention, and you noticed if somebody was struggling, you noticed if somebody was doing something better than they were last week. And you commented on it" (Gwenllian; female, 61-70 years),

"and to see the improvement, you know, makes you feel good, and the expression that [they] give when, when we are getting more and more active and everything is good, well it's not good, its amazin'" (Gareth; male, 51-60 years),

"[they] do the coaching thing when it is required, but [they] are my personal cheerleaders too… it doesn't mean you are blinded to what hasn't been achieved but

> *helping them to celebrate the successes gives encouragement, it gives hope for the future… the team believes in me, so even if I am not doing as good as I think I am, they believe in me and I will carry on"* (Nia; female, <40 years),

Participants noted a change in the professional role in response to their needs. As the professionals came to understand participants better, their behaviours transitioned from being authoritative to celebratory. Professional behaviours transitioned further as participants progressed, enabling them to take ownership over their decision-making and behaviour change.

> *"When you are at the bottom of the pit and you really don't want to move, they bully you, they keep you going. Sometimes you need bullying"* (Bronwen, female, 61-70 years),

> *"It goes from the bullying, to sort of keying in; to a union almost if you like with them, a harmony if you like, so that you go along together. It's nice… and then having made that first move they are excited for you. They carry you along with enthusiasm… They find something that you enjoy doing. You know they key into the fact. I used to rush into hydro, all excited like a kid going to the pool"* (Bronwen, female, 61-70 years),

5.4.1.3.2 Gathering Information

Ten out of the twenty-two participants described the importance of gathering information about them as important in the development of therapeutic relationships.

> *"and then all the follow up questions. [They] always wanted to know more about me than other people did… it's like you're seeing someone not because of the tumour, but because of the stuff around it, your life as a whole, it's a different relationship yeah… you have the medical professionals who um understand all of the medical kind of things, and you have your friends and your family who understand you, and know how the chemo is going to affect you and your life. And then you guys seem to be right in the middle of that. You know enough about the medical side of things to be able to understand that and enough about the patients and their lives, to understand exactly how it was going to impact on them. So the conversations with you always um were a touch more meaningful and show that you have more of an understanding of the individual patients which is so complete that you bridge that gap between the medical advice that they were getting and the life that they had before"* (Gethin; male, <40 years),

Knowledge gathering appeared to convey the professionals' commitment to personalising the rehabilitation plan. This had a significant impact on navigating the transition between the recent 'health experience' and 'living their best life'. However, the information gathered relied on an assumption that the participants were openly sharing an honest view of their thoughts and feelings.

5.4.1.3.3 Honesty

A novice professional might assume that participants would not conceal information from professionals, not deliberately. It is worth exploring the degree to which professional behaviours and participant experiences of healthcare interactions affect whether participants feel able to be unrestricted in their self-disclosure. This section will explore some examples identified by the SSI participants, which reflect the role of honesty in therapeutic relationships. It will explore some reasons offered by participants for not being honest during healthcare interactions and participant expectations of how professionals could facilitate honest information disclosure.

There appears to be a link between open and honest communication, building trust through paying careful attention to participants, interpreting their non-verbal communication, and participant self-disclosure. A small number of the participants commented on how they had learnt to manipulate the content of their communication, in order to ensure their needs were met. This occurred when they felt that their concerns were not being taken seriously by referral triage processes.

> *"But she was again one of these gifted people. You could [take] a person, the most highly qualified person in the world, great knowledge, great everything, but if they haven't got that little bit extra, that ability to suss out the individual then it's very difficult, [to create] that one to one relationship of honesty"* (Hywel; male, 71-80 years),

> *"I will now lie through my teeth to get in to see a [healthcare professional] the next time… I now lie to the NHS to get noticed"* (Dai; male, 51-60 years),

> *"I will always be honest with you" (Carys; female, 71-80 years),*

Other examples saw participants withholding information regarding their compliance with treatment regimes in anticipation of a negative response from professionals. Participants reported that it was easier to start a treatment regime, with good intentions, but harder to maintain adherence.

> *"I could never say, even when I was going through chemo, I had a crap week last week, I couldn't, I'd lie and say I'd done it because I didn't feel the ease to say, 'I felt physically drained and I was just feeling at my worst ever', I couldn't do it, I never could, because you knew the response would be negative" (Heledd; female, 51-60 years),*

> *"She did tell me that if I didn't wear it, she was not going to have me as a patient anymore" (Catrin; female, 71-80 years),*

> *"I start off really well and I take it off one night and say, 'Oh bugger that' and then I don't wear it for 5 or 6 days, you know, or 5 or 6 weeks"* (Catrin; female, 71-80 years),

This small number of examples introduces an interesting concept around the ownership of SM, and how this is tailored to suit the needs and circumstances of individuals. This is a concept which will be explored in greater detail in Section 5.6. Professionals needed effective communication skills to be able to develop the level of understanding required to develop the therapeutic relationship. In addition to this, the ability to dedicate time and energy fostered an environment where participants felt safe to self-disclose. The following explores participants' perceptions of the importance of resource availability on developing therapeutic relationships.

5.4.1.4 Dedication of Resources

The fourth of the SDT operational definitions for relatedness, dedication of resources, included professionals' volunteering either their time and/or effort during the development of the therapeutic relationship. Almost all of the SSI participants (21/22), commented on professionals being either generous with their time or their energy. Seven participants identified both time and energy as being important in the development of therapeutic relationships. The concept of time or timing of therapeutic relationships was identified by the ILR, discussed previously in Chapter Two. The following section aims to explore the SSI data relating to professionals' dedication of time.

5.4.1.4.1 Volunteering Time

Of the twelve SSI participants who identified time as important in the development of therapeutic relationships, there appeared to be a sense that people felt they received the time they needed during both one-to-one and group sessions. This was in spite of a tension between the perception time was a limited resource, but that professionals had enough time for everybody.

> *"but you've always got time, some time with each person"* (Eirlys; female, >80 years),

> *"I got some individual attention, in the limitations of the group and the number of people, certainly"* (Carys; female, 71-80 years),

> *"I love the way they work together, and they have got time for everybody, that's what I find. And you know darn well that they haven't got the time because nobody has got the time in hospital"* (Angharad; female, >80 years),

Participants appeared to interpret this tension around the presence or absence of professional time in terms of whether this resulted in them feeling rushed during one-to-one interactions or groups. The impact of spending time was described as a contributory factor in relationship development. These relationships were perceived as also being valuable when they were used to understand the needs of the partners and family members who support PABC.

> *"you can listen, you just, you've got time, you might know you've got to see the next one in an hour, but I never know that. I'm never aware of, you know? You don't think 'oh god I've only got an hour now to spill all this out', I never ever feel like that" (Heledd; female, 51-60 years),*

> *"where you had a time limit in the pool. But you didn't have that rushed feeling" (Ffion; female, 51-60 years),*

> *"you get to know so many people better because you spend more time with them, I suppose and then you put your full trust into that" (Dai; male, 51-60 years),*

> *"it is not only what they did for me, but the fact is, when they came to my home, they had time to sit and talk to [my wife]" (Hywel; male, 71-80 years),*

There was a flexibility to the perception of time within a small number (6/22), of the participants' responses. This flexibility suggested that some participants were more tolerant of delayed appointments. Participants were respectful of the, perceived, greater or more pressing needs of peers. They were also sympathetic to professionals' need to travel between rehabilitation venues. This sympathy potentially reflected the professionals' efforts to ensure that planned group interventions were not compromised by travel delays, within the limits of venue availability. Within group interactions, the perception of 'enough time' may have signalled some participants' ownership over their rehabilitation programmes.

> *"When you are actually sitting in, in the day room. You know that somebody is in before you. And you are quite happy for them to stay for as long as they need. Because that's the atmosphere that's given, there isn't, there's no atmosphere that you have to be quick and get out" (Ffion; female, 51-60 years),*

> *"[they] may have been late, who cared, none of us cared. We all knew [they] would turn up and it wasn't as if [they] shortened the hour, [they] didn't, [they] took it over the hour, so I mean, the same time we were getting" (Sioned; female, 61-70 years),*

> *"you've got time in your head, and if you need something you only had to ask… You had a programme that you followed, that you gave us, and if you needed specific equipment to go with that programme, the girls would get up and go and get them for you" (Ffion; female, 51-60 years),*

Much of the SSI conversation, as described above, related to the availability of professional time. However, there were a small number of SSI participant responses, which wanted professionals' to respect or value participants' time. Seeing this as important in the development of therapeutic relationships. Professionals value of participants' time was not identified through the ILR synthesis. The following explores the importance of respect for participants' time in therapeutic relationships.

5.4.1.4.2 Impact of Time on Therapeutic Relationships

Participants' viewed time as a valuable resource. Some participants reported being acutely aware of the value of their time. Whether this related to longevity resulting from the potentially life-limiting nature of their diagnosis, or urgency as a result of noxious symptoms and side-effects of cancer treatment. When healthcare services were seen to waste or disregard the value of participants' time through inefficiencies and/or poorly organised service provision. It was perceived as disrespectful and became a subsequent barrier to therapeutic relationship development.

> *"I've reached a sort of stage where I'm very, um, possessive, if you like, about my, my time. And what I do with my time… I'm very intolerant about, if I have an appointment in the hospital or with someone and our appointment is like today at 10:30 appointment. I don't expect to turn up for the appointment and say, 'ah well we can't see you now until 12:00'. Well sorry I'm not staying I've got other things to do. Because if you tot all those things over nine years, I probably lost about a year of my life, sitting in waiting rooms, corridors, consulting rooms, and people don't realise that um, they say 'we have other patients to see'. Organise it better, get smarter"* (Osian; male, 51-60 years),

Services which aimed to provide the timeliness and efficiency called for by the previous participant, resulted in a rigidity which was seen as harmful to the therapeutic relationship. The rigidity of referral criteria, triage and appointment booking procedures across healthcare systems were punitive towards participants, when despite best efforts, they fell prey to practical barriers such as traffic or parking.

> *"I understand that everything got a system … but when you feel like shit and you think to yourself 'please see me, please, please, do something I've waited all week for this', um and you can't, that's a kick in the teeth, it really is"* (Heledd; female, 51-60 years),

For one participant, scheduled rehabilitation sessions were perceived as not being long enough to help them reach their personal goals. The need to schedule group interventions around other hospital users, was described negatively as a *"time restriction" (Ieuan; male, 71-80 years).* This perception became a catalyst to seeking additional opportunities to independently carry out rehabilitative activities. The new opportunities, being unrestricted in duration or frequency, were then viewed as part of their transition to SM.

"I started here as rehabilitation; I am now doing it to increase my fitness" (Ieuan; male, 71-80 years),

Beyond the discussion earlier in this section relating to the changes in professional-participant interactions over time, there was little data which explored participant perceptions of the timing of interactions. The participants did not comment as to whether they thought that their perception of there being 'enough time', to avoid feeling rushed, was deliberately 'managed' by professionals, or just a coincidence. However, the following describes the professionals' investment of energy during clinical interactions, which may go some way to adding to the participants' experiences of the quality of interactions with professionals.

5.4.1.4.3 Volunteering Energy

Twelve of the SSI participants identified professionals investing personal energy in their work as a contributory factor for therapeutic relationships. Participants perceived this investment as being evidenced by their enthusiasm for, or belief in the value of their job, co-participation in group activities, and making an effort to overcome obstacles in the rehabilitation experience.

Professionals' enthusiasm for their role, or the impact of professionals believing in the value of their work, was described as having a direct effect on how participants viewed their rehabilitation. For some, observations of professionals appearing to enjoy their work, may have been seen as rehabilitation being a shared experience.

"You, enjoying what you were doing, is infectious to us" (Gwenllian; female, 61-70 years),

"we felt that … if you believed in it, it was going to work, if you say it is going to work, it is going to work… it was working, because everybody was progressing you know" (Mair; female, 51-60 years),

"The fact that you do love your job and you do enjoy your job and you come out and do that takes you out of that…. That's what the therapy does for us as well to be honest" (Gwenllian; female, 61-70 years),

Active engagement in rehabilitation activities, appeared to have the potential to physically and/or emotionally effect the professional. Participants proposed that this shared experience, added a validity or authority to the activity, which reinforced its importance to their recovery. Participants were critical of professionals who conveyed an apathy towards their role.

"That is probably why we felt we were not going through the motions of just doing it for the sake of doing it. You could see the benefit of what was happening for yourself as well, you know. And that was important" (Mair; female, 51-60 years),

"Yes, it is their job but don't let everybody know it is just your job" (Sioned; female, 61-70 years),

The concept of genuineness of professionals during interactions was again described as important. Being able to observe professional body language was perceived as important to building trust. This pre-conceived perception of healthcare professionals, as not likely to invest energy in their work, was described as a reason for potential disengagement from rehabilitation.

*"You need to see somebody face to face; you need to believe that they will really listen to you, not looking at their watch thinking I have only got 10 minutes with this guy. And then not just turn to the computer … without even understanding what your problem is" (*Dai; male, 51-60 years*),*

"If you showed interest, I mean genuine interest as well, we're not fools, you can see when somebody is just saying something that they feel they've got to say" (Gwenllian; female, 61-70 years),

"when I came to see you all I was thinking… I would give you a shot of two, maybe three weeks max and that would be that. And I would just tell you sorry I have got other commitments and I am done with it. In my head I was already thinking if you guys don't help me, if push comes to shove, I would go to my GP and ask my GP to find me a physiotherapist or something like that you know… because I came in with that mindset that you guys were just pen-pushers" (Nia; female, <40 years),

A small group of participants (5/22), described feeling a sense of teamwork with professionals during rehabilitation. This view was expressed predominantly by male group participants, several of whom had previous life experience in sporting, military or emergency service roles. These participants praised professionals for their active engagement in group activities. This participatory style was described as contributing to participant confidence. It provided support and guidance without alienating people.

> *"Best way to describe it, we were a team. Ah, we were all members of the same team, different positions, but with the same goal"* (Hywel; male, 71-80 years),

> *"I think it is the fact that all the team were participating and not shirking in anyway… what we were doing they were doing"* (Ieuan; male, 71-80 years),

> *"You're not standing out in front of the class… saying do this, do that. When we do the circuit we are in a group, so I mean, you come in behind me or in front of me, but you are not in my face… so you've got the confidence of knowing that you are there, but you are not in my face… cause you know your job"* (Emyr; male, 61-70 years),

One participant compared his experience of cancer rehabilitation with a previous rehabilitation service and the impact that professional engagement had on his motivation. There was a respect for this investment of energy. Some participants described evidence of professional investment of energy in their role as the extent to which they would push boundaries of what was expected from them. For some participants this bordered on what they saw as professionals working above and beyond the call of duty.

> *"They were like, just doing their job, I'm there for the hour or you know, the time it's on and um, that was it… I just went there did what I needed to do… I had to push myself to go to... You know? You lot got involved with us… From the minute you walked in, or even before we walked in, the banter was going, you know, and it was going until you left, and you were looking forward to the next session"* (Rhys; male, 61-70 years),

> *"Sometimes I think, Jesus these poor buggers! They are doing the same thing as us, and you have been at it all day and we have only been doing for the last hour"* (Emyr; male, 61-70 years),

> *"They go above and beyond what they are supposed to do"* (Ffion; female, 51-60 years),

One participant described one professional's use of ankle weights to overcome buoyancy challenges during hydrotherapy. Whilst the technique may have been perceived as an accepted technique, or routine practice, by professionals. It was not only perceived as 'above and beyond', it was also a little amusing for the participant to experience. This added to the level of humour involved in the session and contributed to their enjoyment of a clinical intervention in which they had initially been reluctant to engage.

> *"Poor [person] had to put weights on her ankles, coz I been chuckin' her round the pool, and she said, 'what do you feel?' and I said, 'I feel amazing!'"* (Gareth; male, 51-60 years),

The impact of this investment in overcoming an obstacle to rehabilitation, not only facilitated improved rehabilitation outcomes, it may also have contributed to the general sense of enjoyment and camaraderie described earlier. Examples of this investment included participants being offered opportunities which were not strictly part of the rehabilitation timetable. Despite the experience of the extra-curricular activity not always being enjoying, which may not have benefited at the time, may have laid a foundation for future change.

> *"The classic example is … the walk on the Gower. It's like, that series of steps, the progression that maybe was suitable for me, but maybe not for everybody else, … [they] were able to go off and recommend me do it, it was based on [their] knowledge of what I was capable of doing before and exactly where I was in my recovery at that point"* (Gethin; male, <40 years),

> *"I think when I went on the mindfulness course. I don't think that was part of the normal thing that everybody gets. What I think is [they] thought I needed it, so I went on it… you actually think that they cared enough to do something about it"* (Dai; male, 51-60 years),

> *"You know when you did the study and we were meeting at 5 o'clock on a Wednesday night? I didn't enjoy any of that. I felt that it became, some people were just talking about themselves, and it was addressing like, how to do mindfulness… I thought Oh gosh! This is a waste of time! … You know, I am doing mindfulness at the moment… I mean it is brilliant!"* (Mair; female, 51-60 years),

There is overlap between professionals' investing time and energy and other behaviours which convey empathy, affection, attunement and humour. Many of these behaviours were perceived as facilitators or barriers to therapeutic relationships depending on participant expectations, and, perhaps, their needs at different times of their rehabilitation. The next section explores the last of the SDT operational definitions for relatedness, which may one of the most important for participants, but potentially the most challenging for healthcare professionals.

5.4.1.5 Dependability

The fifth and final operational definition of SDT relatedness, proposed by Silva et al. (2014), referred to dependability, which they characterize as professionals being perceived to be available in times of need. Dependability was identified by thirteen SSI participants as being important in the development or maintenance of therapeutic relationships.

The most common context in which dependability was described as being important, was in the event that participants' health status or personal circumstances changed after rehabilitation had ended. The ability to contact the team for advice or support was perceived as important. Being present, or easily contactable, was only half of this dependability picture for other participants. Trust was also a strong thread that emerged in relation to professional dependability.

> *"And you know, I'm not bein' funny, but knowin' that she is there, and [the cancer rehabilitation] team are there, coz if my arm is not thing and I'll come and see [them] and [they'll] probably say 'come on then, let's see if we can drown you this time'. You know it's important. Very, very, important"* (Gareth; male, 51-60 years),

> *"I knew you were all there, and I knew if I wanted any help, I could speak to one of you there. I know there's always somebody there"* (Eirlys; female, >80 years),

> *"It snowballs doesn't it? If you have a little respect to begin with, and take the advice, then the advice works, it flows from there… so it's possible for someone to not be able to gain that respect and trust"* (Gethin; male, <40 years),

Trust was not an automatic condition in therapeutic relationships for all rehabilitation participants. Trust between professionals and participants may be initially implied. But was subsequently built or damaged by participants' perceptions of the actions or behaviours of professionals.

In practice, not all rehabilitation participants presented with even an initial low-level of trust. Some participants experienced challenging relationships during their diagnostic or treatment pathways, which left them with a poor expectation of professional dependability. In the previous section, an example of one participant who perceived professionals as *"pen-pushers"* (Nia; female, <40 years), was one example of this. The following explores another example of this poor expectation and place of low trust.

> *"I didn't expect anything [from cancer rehabilitation] because I had been let down by most of the NHS until that time, so I had no expectations, other than hoping that somebody would listen to me and help me… in quite a short time I realised that it was helping… up until that time I had no support at all… once you realise that the pain was getting less after you had one of those sessions, you just put all your trust in it I suppose"* (Dai; male, 51-60 years),

There was another side to dependability, which considered how participants perceived the importance of rehabilitation professionals' own wellbeing. As role models for participants, professionals were seen as people who could be relied upon and trusted to be a constant throughout rehabilitation. Whilst this opinion was not described by more than a few participants, the following comment introduces a tension for professionals. What it means to be professional, what it means to be authentic in professional presentation, may not marry with participants' expectations of professionals as stable and solid points of reference during rehabilitation.

> *"I don't know how I would have reacted if I had seen [them] down…To me [they] were like a rock, you coming in and being 'aaargh', honestly, I think it would… it would have depressed me"* (Mair; female, 51-60 years),

This participant perceived professionals role modelling emotional strength as a desired outcome of rehabilitation. It was possible that professionals investing energy in group rehabilitation activities, could be taken as an example of professionals' role modelling the desired physical outcomes of rehabilitation. Different participants might want to see professionals' role modelling the different attributes they sought to develop in themselves. However, this potentially presents an unrealistic burden on healthcare professionals to always appear to be emotionally and/or physically robust.

Participants' perspective of dependability appeared to mean more than superficial actions such as knowing what telephone number to call when advice or support was required. Participants discussed the impact on trust and confidence of knowing that professionals were offering advice and support that was effective. Not only was it effective, but it was also provided by somebody who role modelled the emotional and physical attributes that were important to the participants. Throughout this discussion of the importance of professional behaviours and attributes, there were comments which reflected the importance of professional knowledge, skills and experience. The following section explores this in more detail.

5.4.2 Training, Preparation and Experience

Eighteen out of twenty-two participants identified some component of training, preparation, qualification or validation by association with Macmillan Cancer Support, as important to their cancer rehabilitation experience or development of therapeutic relationships. Trust and confidence were the predominant outcomes of this knowledge, training and experience. The SSI participants recognised that the team had access to knowledge, skills, and experience. All of which were relevant to their needs during cancer rehabilitation. Access to personnel with training, knowledge and experience was the prime reason for some participants to initially seek out contact with rehabilitation professionals.

> *"The knowledge and the experience is vital"* (Tomos; male, 71-80 years),

> *"I felt confident with [them], but [they] knew what they were talking about, and if [they] did not, [they] would look somewhere, you know? Trust, it was complete trust, basically"* (Mair; female, 51-60 years),

> *"They'd obviously um, been well trained and understood and were aware, that comes with experience doesn't it"* (Carys; female, 71-80 years),

> *"The job [they] were doing, [they] were equipped for"* (Eirlys; female, >80 years),

> *"An independent point of view and people with experience"* (Tomos; male, 71-80 years),

Participants perceived professionals being better prepared to support them than family and friends. Some participants turned to professionals for support, because sometimes family were seen as a barrier to recovery or achieving the outcomes of rehabilitation. Pathfinding and increasing participant awareness of the wider support network were described as part of this knowledge or skillset which were part of the guidance and support.

> *"I was very aware that I had to share all this with a true professional and not to burden, and not to burden my sister"* (Carys; female, 71-80 years),

> *"Family tend to be over-protective"* (Hywel; male, 71-80 years)

> *"[They] seem to find the right path of what [participants] need"* (Mair; female, 51-60 years),

Whilst pathfinding was agreed to be an important role of professionals, not all participants experienced well-coordinated signposting to support agencies. Professionals were perceived as continuing to work in silos, without understanding the importance of linking services. Joined up services and timely signposting were valued by participants as they learned to manage their conditions in the long-term.

> *"I found all of this for myself! Then I drew the lines and coordinated it and then [they] got put in the picture at some point, but it was late on, as I've said it took me some time to find [them]. So, you know the specialist is a wonderful specialist (whispers "little box"), ward are wonderful at what they do (whispers "little box"), GP little box, and there's a complete lack of, a complete lack of linkage"* (Carys; female, 71-80 years),

One final consideration relating to the preparation of professionals for supporting PABC was the association with Macmillan Cancer Support. Being a Macmillan professional provides access to a comprehensive learning and development offer. This training, if taken advantage of, can make a significant impact on the readiness of healthcare professionals to work with PABC. However, it is unlikely that the general public, or PABC, would be aware of this aspect of Macmillan's role. Therefore, the Macmillan association, from the participants' perspective, was largely informed and influenced by promotional and fundraising media, social expectations, and a sense of 'something' within the organisation's values.

> *"Macmillan has the title, the name alone. You are a caring concern, aren't you? You've always had this outlook and people do look at Macmillan as being that. They are there for support and not, nobody has surgery under Macmillan, nobody has injections under Macmillan, you there as [a] support network and the team to get you forward and not to look back"* (Heledd; female, 51-60 years),

> *"Safe, secure and trust and you must be, because you're Macmillan Therapists" (Gwenllian; female, 61-70 years),*

> *"It is this feeling that Macmillan, I don't know, whether it is a core value that you teach"* (Tomos; male, 71-80 years),

Not all associations with Macmillan were favourable. Some participants' expectations were negatively shaped by previous experiences with Macmillan professionals. These prior experiences had the potential to compromise therapeutic relationships with the local cancer rehabilitation team.

> *"I had experience of Macmillan nurses coming to my home some 25 years ago actually. My mother had terminal cancer and I looked after her at home… I didn't know quite what to expect. But I knew that it would be beneficial because it is the way they are trained and the way they look at things, isn't it?"* (Angharad; female, >80 years),

> *"I didn't realise that [she] worked with Macmillan when I first met her, because she had been fantastic"* (Bronwen, female, 61-70 years),

This chapter has presented findings from the SSIs. The data supports the SDT as a suitable framework for exploring participants perceptions of therapeutic relationships in a rehabilitation context. To this point, there have been additional contributions to the ILR findings relating to the role of humour and honesty in therapeutic relationships, understanding boundaries when navigating interpersonal interactions, the importance of time and timing on therapeutic relationships and the tension for professionals relating to their authenticity in role modelling health and wellbeing behaviours. The following explores this tension around authenticity and adaptability in more detail.

5.5 Balancing Adaptability with Authenticity in Professional Roles

Thus far in this chapter the operational definitions of relatedness, as developed from the SDT framework have been used to explore the SSI participants' experiences of professional attributes, knowledge, skills and behaviours as either facilitators or inhibitors of the development of therapeutic relationships. There were three further themes, from the ILR findings presented in Chapter Two, which would warrant exploration of the SSI data. The following section aims to understand the extent to which the local rehabilitation participants experiences reflected the tension between professional adaptability and authenticity.

5.5.1 Adaptability

Adaptability implies the capability to be easily modified to suit changes in conditions, needs, or uses (Merriam-Webster Dictionary, 2015). In the context of therapeutic relationships in healthcare, adaptability might refer to the professional's ability to recognise a need to change or modify their verbal or non-verbal communication in response to subtle changes in a participant's countenance, demeanour or behaviour. Adaptability in verbal and non-verbal communication includes the subsequent implementation of an alternative strategy, and the evaluation of the strategy's effectiveness in order to plan how to approach further interactions. This process reflects the importance of professionals using reflection-in-action (Finlay, 2004), as a tool for self-monitoring the impact of their verbal and non-verbal communication on the clinical interaction and ultimately the therapeutic relationship.

There is the potential for professional roles to transition, in response to the changes that participants make towards the development of SM. This transition may reflect the change in professional resource or skillset that would be most beneficial to support participants as their own knowledge, skills and confidence grow. Earlier in this chapter, one participant's description of this role transition ranged from bullying, through to a harmony, to almost a shared enjoyment (*Bronwen, female, 61-70 years*). The following echoes this change in roles. The wife of one of the participant's was present during the SSI. Although she had not intended to participate in the interview, she also observed professionals adapting to the needs of the group participants.

> *"You do the coaching thing when it is required but you are my personal cheerleaders too"* (Nia; female, <40 years),

> *"[They] have to be more or less a sort of chameleon, [they] have to suit [their] abilities to the person [they] are dealing with"* (Ieuan; male, 71-80 years – Wife),

5.5.2 Authenticity

Authenticity was defined as a person being "true to one's own personality, spirit, or character" (Merriam-Webster Dictionary, 2015). As described in a previous section, the idea of being the right person for the job was a starting point towards understanding professional authenticity. As one participant described, there was then a requirement for professionals to engage with rehabilitation participants in an authentic way.

> *"They've got to be the appropriate person, haven't they? It's not something you can fake, I mean, you can't pretend to be something or somebody you're not, it's got to be um, it's got to come natural to you, so you can deliver that which is necessary. It's, you can't do something that goes against the grain of your own personality"* (Carys; female, 71-80 years),

Authenticity was perceived through the way professionals approached their work, as their attitude and demeanour conveys their thoughts and feelings about the role, they are in. There seems to be an expectation that healthcare professionals are able to segment their own daily experiences, in order to fulfil their professional roles. But participants want assurance from professionals that their input is more than carrying out prescribed duties.

> *"I think it is hard when people are doing things day in, day out, day in, day out, you've really got to love your job for that to shine through"* (Gwenllian; female, 61-70 years),

> *"I don't think, in a cancer situation, people don't want to see you on an off day. I have never seen you or [another team member] on an off day and I don't know how I would have reacted if I had seen you two down, basically, you know? To me you were like a rock, you know? You had to be well for me to be well mentally you know? … But if I had seen you or [another team member] low or depressed, that would have depressed me"* (Mair; female, 51-60 years),

The tensions presented by these comments suggest that there is a mask that professionals need to wear, a role to play, during professional interactions, which separates their own life challenges from their work. However, they are expected to maintain an essence of authenticity of personality which assures participants that they are not faking their interest or empathy.

> *"Yes, well I was thinking well another bunch of NHS people measuring stuff and signing papers, that's all they know to do – paper pushers… I was expecting a mass-produced service. I was expecting oh everybody would go there together, and, in my head, I was already thinking I will try it once or twice if it is anything that insults my intelligence, they will not see me again for dust" (Nia; female, <40 years),*

> *"[I] had so much bad experience with the NHS of bad training…. I still get bad experiences with the NHS… Here is something of interest on rehab, sorry to butt in, that I found interesting, is the better you were with me the better, I wanted to get better quicker to prove that you were doing the right thing, does that make sense?" (Dai; male, 51-60),*

Maintaining professional authenticity as a human being whilst establishing safe working boundaries requires a complex skillset. This raises the importance of workforce wellbeing, in addition to appropriate recruitment and selection procedures. Protecting this positive regard for work is linked closely with reducing the risk of professional burnout. This will contribute further to the discussion regarding boundary setting which will be described in further detail in the following section.

5.5.3 Boundary Setting

The need for boundaries in therapeutic relationships was raised by several SSI participants. There were two perspectives on the need for boundaries. The first developed from the account described above and reflected the need for safeguarding both parties. The second, reflected the participants' recognition of the emotional toll, that caring takes on health care professionals.

The following account explores the thoughts of one particular participant who identified a significant similarity in the characteristics of a professional and a member of his family. This similarity appeared to have instigated a belief and behaviour set towards the professional, which shared similarities with the family member. However, he was the first to highlight the need for professionals to be aware of their personal boundaries as a result of this.

> *"She is so bubbly and so alive, and she just gets everybody going… but there has got to be a line drawn" (Emrys; male, 71-80 years),*

During the interview, there was an idea that professionals should maintain an element of 'separateness' from the rehabilitation participant which contradicted other SSI participants' analogy of being teammates. There were descriptions of feeling protective over certain professionals, due to the familial similarities. One participant warned that not all cancer rehabilitation participants may be vulnerable or share the same values and ideals as professionals. This would place the professionals at risk of being taken advantage of. This implies that the professional in question may not have appeared to understand the ‘rules of the game’ or were perceived to over-extend themselves. Since his first contact with the cancer rehabilitation team, five years earlier, he certainly was known for his happy-go-lucky, sometimes playful demeanour.

“You have got to have some barriers, you have got to have some lines where you can say this is where you can go, and this is where you can’t go because otherwise you could draw yourself into a lot of trouble” (Emrys; male, 71-80 years),

“Let’s put it this way I know exactly how far I can go and far I can’t and even with the girls here I give them real hard stick, but I know exactly how far I can go and I know exactly how far they will let me, because they let me go so far you see. That is the game” (Emrys; male, 71-80 years),

“I could come down there and do the therapy whenever and have a chin wag and a laugh and enjoy it” (Emrys; male, 71-80 years),

Whilst the professionals’ perspective on this phenomenon could not be included in this study, it would be of interest to explore the extent to which this perceived common ground affects professionals. This participant raised the importance of boundary setting in therapeutic relationships as a result of the impact of this association. This appeared to have changed the dynamic in the therapeutic relationship, to the extent that the participant expressed protective feelings towards the professional, which did not translate to wider team.

The age of the professionals he was working with also appeared to influence his perception of therapeutic relationships. As did the perceived level of education or training that more senior professionals may have. Age, experience and training seemed to have influenced how comfortable this person was in developing a connection with cancer rehabilitation professionals. The concern behind the need for clear boundaries between cancer rehabilitation participants and professionals was for both parties. This participant was one of a small group (4/22), who commented on this need for boundary setting.

“You have been around; you have earned it… She is so young she could be easily drawn into something… Senior staff got more education and they know exactly what’s what” (Emrys; male, 71-80 years),

> *“You have got to realize that you have got to safeguard her as well as me” (Emrys; male, 71-80 years),*

> *“It’s very easy, if you like, to become too involved; and the professionalism of the people running [the service]…, was very good in drawing a line in terms of saying right, ok, and you are there supportin’ them and that's the way it’s got to stay” (Osian; male, 51-60 years),*

There was potential for healthcare professional boundaries to be eroded, and risk undertaking roles which did not fit within their remit. Other participants viewed the need for boundary setting from the emotional impact on professionals. There was awareness of a tension between what participants gained from the therapeutic relationship and the emotional impact that therapeutic relationships could have on healthcare professionals.

> *“I firmly believe without [the team] there would be no future. … It’s that lack of self-control over your body that makes you think ‘I’m not being fair to people’. I hated those moments. I hated them. The embarrassment of that. Ah, but … at the end of the day, [the team] are not people … coming to help me, [they] belonged to us. I know it’s an unfair thing to say because everyone wants a bit of [them], we don’t want a bit of [them], but [they] always made us feel really important. And [they] always made us feel [they] cared, not because [they’re] doing a job, [they] cared because of us. That I think again, is important. I don’t know if you understand that” (Hywel; male, 71-80 years),*

> *“I can never understand people doing your work right; you build a relationship with people and they die; part of your job is seeing people die, isn’t it? I can understand the ‘them and us’, coz if it’s ‘us’, it hurts all the more, if its ‘them and us’, then it’s a bit easier to cope with it. I don’t know, think I could cope with that” (Hywel; male, 71-80 years),*

> *“I just look at you and think, how, with patients like me, how long is your day? You know, everybody got a story to tell and feelings to expel and you think oh god how many patients like me through the day, you know. But you do it” (Heledd; female, 51-60 years),*

These conversations captured the challenge that healthcare professionals face in balancing the provision of genuine care for others and essential care for self. There remains much to understand about how we define where professional boundaries lie, and how we articulate these. The next challenge will lie in how we teach less experienced healthcare professionals to achieve the balance between creating genuine therapeutic relationships, using personal attributes and connections for therapeutic purposes, and protecting themselves from becoming unnecessarily vulnerable in the process.

5.5.4 Common Ground

One of the reasons that SSI participants identified the need for boundary setting found its origin in a sense of sharing common ground with the rehabilitation professionals. In the previous section, one participant's account of a perceived similarity between a professional and a family member. It had been anticipated that more participants might have reported identifying with professionals on grounds of their shared characteristics with a friend or family member or social group. The following section explores participants' experiences of common ground with professionals which had an impact on the therapeutic relationships they formed, and possibly influenced their level of engagement in rehabilitation. This connection became helpful in supporting the individual to build social confidence. The therapeutic context became almost a mock social encounter which facilitated a safe place for learning, testing and adjusting social skills, which had become impaired as a result of significant cancer treatments.

"She's a bubbler… I have got granddaughters like her" (Emrys; male, 71-80 years),

"And then the personalities, um you start to meet people, like yourself and [another team member] in particular, you are like the type of people that, like I used to socialize with before… I knew that you were professionals so it's not like 'friends' but it was somewhere near being more friendly, it's just that, it's like that step, that intermediate step back to socializing" (Gethin; male, <40 years),

One participant and the principal researcher shared a connection relating to our common professional identity. As a person who had previously worked in a similar clinical role to mine, who would be familiar with the concept of therapeutic relationships, it was interesting to hear her perception of this connection.

"I think the fact that you were an OT and I was an OT; I couldn't let the side down. I used to wear that uniform. I think there is a camaraderie, I really do, you know, because, we, there is something special about being an OT and I am sure nurses would say there is something special that they've got. But it's something, it's like a kindred spirit within you, isn't it you know? You share the same ideals really, and you used to say to people 'this lady is an OT and was taught OT in the right way'" (Catrin; female, 71-80 years),

This person raised an essential point of tension relevant to the definition of SM during their interview, which will form the focus of the next section. In local practice, there had been a long-standing respect for rehabilitation participants to exercise independent decision-making. This decision-making included adoption and adaption of recommendations to suit their lifestyle and resources. This participant's SSI created the first opportunity to explore the concept of autonomous non-compliance as an expression of participant ownership over their SM. And, to a lesser extent, what supporting autonomous non-compliance would mean for professionals measuring and reporting SM outcomes.

5.6 Ownership of Self-Management: The Compliance Dichotomy

Building on the discussion relating to boundary setting, there is a stage in the therapeutic relationship at which point professionals need to handover ownership of SM to participants. Some rehabilitation participants may be eager to control their rehabilitation from initial contact, and others may need more guidance. There are some participants who may never feel that they could or would adapt their behaviour following rehabilitation. However, rehabilitation is not an infinite construct and at some point, decisions and actions taken by participants must be executed under their own motivation and volition.

Some of the SSI participants, had consented to receive anonymised versions of their interview transcripts via email. The purpose of this was to offer them the opportunity to confirm that their contribution reflected the message they had hoped to share and to add any thoughts which emerged on reflection of the transcripts. One of the participants used this opportunity to summarise the role that rehabilitation played in their recovery.

> *"A highly skilled and caring 'comfort blanket', preparing me for the outside world"*
> *(Gwenllian; female, 61-70 years – email 12/11/2016),*

This suggested that the therapeutic relationships during rehabilitation included a supportive component. In addition to an expectation that participants were preparing to return to the real world, outside of the healthcare setting, where they would resume ownership over their lives. Engaging in SM implies that participants undertake a process through which they learn new knowledge, or skills, or make lifestyle changes, which enable them to do something that they could not or did not do before. These changes may be described by guidelines and recommended by professionals. Respecting personal choice in the decision to adopt these recommendations, or not, is an interesting dichotomy in SM.

In practice, healthcare professionals might assume that therapeutic relationships can influence participants' engagement with lifestyle change. This was supported by most of the SSI participants (18/22), who reported having continued some or all of the recommended lifestyle or behaviour changes following rehabilitation.

5.6.1 Ongoing Self-Management

The primary aims of cancer rehabilitation were to facilitate recovery from cancer and cancer treatments, supporting the development of SM techniques for long-term health and wellbeing. Once cancer rehabilitation ends, there remain barriers to implementing some of the behaviour changes. These changes need participants to feel continued confidence if the barriers are to be overcome.

"Every time when I think I don't want to do this anymore and then I think about your programme … the team believes in me so even if I am not doing as good as I think I am, they believe in me and I will carry on" (Nia; female, <40 years),

"It encouraged me to take responsibility and made me feel that I could do this. I hadn't realised until then just how important it was in allowing me to realise that I could take steps to help myself, with the assistance of professionals. Now I look back on the whole experience, I understand what you all achieved with me – not just physical strengthening but mental strength too. You gave me the encouragement to take some control, which I have and continue to do so" (*Gwenllian; female, 61-70 years* – email 12/11/2016),

"Yes, it is a change in confidence. It is a change in attitude. I think, you know when you have got a family saying, 'oh you'll not do that, oh careful', you become too cautious. So, I made my own decisions. I wanted to do this, and go there, and I can do that. So yes, it gave me confidence" (Sioned; female, 61-70 years),

This sense of internal confidence or drive to recover, succeed, or change was echoed by participants who started to make conscious decisions about how their futures would look. Not all participants had a clear vision of their desired outcomes at the beginning of rehabilitation. Self-management was not seen as a clear state of being. It involved negotiating new challenges over time. Whilst that might mean that participants were not always compliant with recommendations, neither did it mean that they were not self-managing.

"I have developed an inner strength to survive. Ah, I've had the inner strength to say to myself, ah, accept what I can't do, I've had the inner strength to say to myself 'ok I can eat this now, which I couldn't eat before'… I am a bigger fighter now than I've ever been. I've always been a fighter" (Hywel; male, 71-80 years),

"I was a little bit, at first, I don't know um, sort of um 'what the fuck', you know? Um, got to a point where I was just happy to be alive, because the previous

> *Christmas they told my wife 'make this his best Christmas'... it weren't easy. Because I had doubts all the time, you know, 'is this effort for nothing?'... And here I am today you know, back in work"* (Rhys; male, 61-70 years),

> *"The first year, definitely, I was carrying on with the same changes, you know healthy eating and all that … since then it has gone pear shaped because I'm getting divorced now and that so, but it is still at the back of mind you know. The tai chi is still at the back of mind and it is not the Tai chi itself it is… I am doing mindfulness at the moment, I'm going to a mindfulness course and you know we keep talking about that feeling that you have got inside and when I think about [the team] it is wellbeing, you know it's like... (Exhales)"* (Mair; female, 51-60 years),

In order to explore the complexity of SM outcomes, there was one participant who described a range of examples which demonstrated how she adapted recommendations to suit her needs. She also took an active role in assisting her husband to make significant lifestyle changes, after an event which triggered a need for change.

> *"I had a DVT … and I had to have a dog walker… It was £10 per day … and I thought, I can't … keep this up. And I said I really don't want him to miss out on, she takes him with loads of other dogs, I don't want him to miss out on the company. And she said to me, 'why don't you come with me?' So, every morning I get a text at some point, … and every morning I do an hour or so with the dog… I enjoy it and it's great"* (Catrin; female, 71-80 years),

> *"I've just kick started my husband now; he's given up smoking for 12 weeks… I couldn't rouse him one morning and I thought he was … you know… he's really feeling the good effects of it, you know"* (Catrin; female, 71-80 years),

Measuring the success of SM after cancer rehabilitation programmes, may not be a straightforward matter of compliance with recommendations. There appears to be a tension between professional expectations that participants will adopt recommendations, and participant expectations that they will adapt recommendations to suit their needs, environment, beliefs and resources.

5.6.2 Autonomous Non-Compliance

The participant above, then reported that she did not wear her lymphoedema garment as she had been advised to despite being at a higher than healthy weight. Despite her awareness of the relationship between weight management and lymphoedema, the participant did not report plans to change her behaviours. She described the challenges she faced with healthy eating, despite her previous role in supporting others with weight management goals. During the interview, I took a risk and asked what she called a *"cheeky question"* (Catrin; female, 71-80 years), "what is so important about wearing your teeth and walking that isn't so important for your sleeve?" (WW).

> *"It is not a comfortable thing to wear, but then if I have worn it for long enough. It's like false teeth, when you have false teeth, at first they are not comfortable to wear, but you have got to get used to it, but you do get used to it" (Catrin; female, 71-80 years),*

> *"My healthy eating is not good...said Mrs Slimming World… It's not the making [that's difficult] it's the maintaining… I haven't quite got the balance right" (Catrin; female, 71-80 years),*

> *"This I suppose is personal choice, and I know in the back of my, I know in the front of my mind that it's the wrong choice; but I can shut it away and put it in the drawer, … I don't have to see it; I mean in my mind" (Catrin; female, 71-80 years),*

The importance of participant ownership and readiness for change reflected participants' deliberate choice not to modify their behaviour. For this individual, the choices were in relation to healthy eating and wearing a compression garment. She described waiting for an internal trigger, which may see her implement the knowledge and skills that she has and then make further behaviour change. As professionals, there is a risk of being too judgemental in terms of measuring 'compliance'. However, this example presents a perspective that time and timing are important to when, or if, people choose to adapt their behaviour.

> *"I probably think I know best, don't I?" (Catrin; female, 71-80 years),*

> *"all of a sudden one night I will think to myself, I will go on this diet; as I thought many, many times before and then all of a sudden it clicked" (Catrin; female, 71-80 years),*

There is one more aspect to this view of ownership over SM outcomes which needs to be considered. This is the prospect of autonomous non-compliance, which is not often incorporated into the accepted profile of successful outcomes for SM programmes in healthcare. However, Silva et al. (2014), advise that autonomous non-compliance should be accepted as a positive SM outcome. But only if a person has been adequately informed, has engaged in values-based reflection, and then makes the decision that they do not wish to adapt their behaviour.

There is the potential for person-centred practice to be biased by over-zealous healthcare professionals. This risks the therapeutic relationship if the person's and the professional's values are incongruent. This above excerpts reflects that the participant had not only adopted many of the recommended healthy lifestyle behaviours but had also supported others to adopt healthier lifestyle behaviours. Supporting others and developing a resilient peer group appeared to be important to the SSI participants. The following section explored this is more detail.

5.7 Peer Relationships

The experience of looking out for peers, and being looked out for by peers, featured in almost all (21/22) SSI transcripts. Forming relationships with rehabilitation peers was a significant feature of conversations and posed an essential dimension to therapeutic relationships. As healthcare professionals, we presume that the relationships which are most therapeutic are between professionals and rehabilitation participants.

However, relationships with peers played a significant role in supporting recovery but may also have played a role in sustaining outcomes after rehabilitation ended. Participants reported a reluctance to share worrying thoughts and feelings with people who are close to them in their daily lives. They saw the peer group as a safe place to share these thoughts and feelings. This shared experience of vulnerability was seen as resulting in a shared understanding that could lead to a shared confidence.

> *"I've joined this club at this moment, yea, it's like a club, not a club I freely joined but I'm a part of it and I'm in a survival phase of it and I'm in the recovery phase of it, I'm in a bloody elite club, that's the way I see it and I'm sure the others see it as well, you know" (Rhys; male, 61-70 years),*

> *"Sometimes you can't speak to your nearest person about worrying. You will speak to a stranger and in the pool, there is no inhibitions as you're in a bathing suit, you haven't got nothing to hide behind or nothing. So, you do tend to talk amongst yourselves about, you know… 'Oh, you know he's tired today and I'm feeling guilty'…" (Ffion; female, 51-60 years),*

> *"There was one very elderly gentleman, well probably younger than me but well a very elderly gentleman, and he was so pale. ... And I used to say hello to him every time I came. And then one day I was quite early... I don't know what his name was, and I used to say 'hello, how are you today?' And he looked at me one morning and said, 'have you got time to talk to me?' I said, 'Of course I have got time to talk to you' I said, 'we have got at least ¼ hour; we are both early today'. And he told me all about his illness. And he'd had cancer and he'd had oesophageal cancer. Well it's not easy is it? And I listened to it all. And then he smiled. I hadn't seen him smiling before" (Angharad; female, >80 years),*

The role of peer support was also seen as a shared responsibility between professionals and participants for creating an inclusive atmosphere during group interventions. For some of the rehabilitation participants, these peer relationships may have been a valuable way for supporting their transition back into their local communities.

> *"when banter's going, you need to remember to drag the others in, bring them into it, because there is always one who sits there like a little lamb afraid to go boo to, and he's being nudged and it's up to you guys and the group to nudge him too; don't forget about him, keep an eye on him, even though we're there as patients… There is nothing to stop us acting as coaches as well"* (Rhys; male, 61-70 years),

> *"I could only wish you could always keep in touch with those people, you know you stay as a group and you get, with them for so many weeks, um and you get chatting and often you say you now, Let's go for coffee"* (Heledd; female, 51-60 years),

Participants who shared their rehabilitation experience, may have been able to offer longer term support than healthcare professionals could offer. However, whilst they appeared to take a significant role in supporting long-term resilience and wellbeing throughout rehabilitation. There was too little data available from the SSI's to indicate whether participants would want an ongoing relationship with peers after rehabilitation. Or whether there would be a preference to return to usual social and community networks with no associations with cancer.

The following section explores how these findings from the SSI were used to inform the next phase of the study related to this thesis.

5.8 Semi-Structured Interview Data as a Foundation for Modified Delphi Technique

Despite a general sense from the SSI participants that therapeutic relationships were important. Participants appeared to experience some difficulty with describing the impact of these relationships on cancer rehabilitation or SM outcomes. Understanding the importance and impact of therapeutic relationships would be the focus for the second phase of data collection, a Modified Delphi Technique (ModDT).

Full details of how the ModDT was structured were described in Chapter 3.4.4. However, in this section more detail regarding how the findings from the SSI were key to populating the first round of the ModDT are described. To support the first round, SDT operational definitions (Silva et al., 2014), and key themes from the SSI, were converted into twenty first-person, active statements (described in Table 11).

Whilst this research focused on understanding the importance of therapeutic relationships, it was also deemed important to incorporate statements reflecting competence and autonomy in the starting list. This aimed to reduce the risk of leading participants by only offering the opportunity to prioritise relatedness statements.

The prioritisation activity, including competence and autonomy statements, allowed for the possibility that participants would perceive these as more important than therapeutic relationships in supporting their behaviour change outcomes. The starting list of statements also included one statement relating to peer relationships.

5.9 Summary

This chapter has presented evidence from the SSI data. A framework analysis using SDT operational definitions, supported the assumption that the local cancer rehabilitation service was effective in meeting participants' core needs for SM. The SSI data has started to describe the participants' experiences of therapeutic relationships locally. It identified barriers and enablers to the development and maintenance of these relationships. The SSI participants were often unable to articulate a clear description of what therapeutic relationships look like or how they influenced change in practice. However, their observations and perceptions were able to inform the ModDT, which aimed understanding this mechanism in more detail. The findings of this next stage of research can be found in Chapter Six.

Chapter Six: Findings from a Modified Delphi Technique

6.1 Introduction to Chapter Six

This chapter presents the findings of a Modified Delphi Technique (ModDT). The ModDT used the findings from twenty-two SSI, presented in the previous chapter, to inform the first round. Details regarding this process were described in Chapter 3.4.3. Of the aims described in Chapter 3.2, the following questions were used to focus the findings of the ModDT:

- the level of importance that rehabilitation participants attached to different aspects of cancer rehabilitation; and
- the impact that rehabilitation participants report therapeutic relationships with local providers had on their rehabilitation or self-management outcomes (if at all); and
- the extent to which the views from the SSI were shared by a wider cancer rehabilitation population.

The qualitative and quantitative data from both ModDT rounds will be presented together to describe participants' perceptions relating to these questions. There is no consistent, or agreed way of presenting Delphi findings (Hsu & Sandford, 2007). However, these authors recommend presenting participants' judgements alongside statistics to illustrate the range of opinions within the cohort. To this end, direct use of participants' comments are represented in *italics*, with their unique identifier, as described in Chapter 3.5.2, sex and age in parentheses at the end of the quotation.

An integrated discussion of the quantitative and qualitative findings of this ModDT will be undertaken in relation to the findings from the ILR and SSI in Chapter Eight Discussion and Conclusions.

6.2 Modified Delphi Technique: Recruitment and Response

As described in Chapter 3.4.4, the ModDT was completed in two rounds. There were n=58 responses to the First Round, and n=55 responses to the Second Round of ModDT. There was a high level of response completion within the First Round data collection tool, with 99.74% of possible responses to Question One completed (i.e. rate the importance of aspects of rehabilitation), and 93% of all possible responses to Question Two completed (i.e. identify up to five priorities to keep).

There was a higher level of incomplete responses to Question Three (i.e. identify up to five priorities to remove), with 74% of all possible responses being present. This may reflect the difficulty that a small number of participants reported in their free text comments. It may also reflect that the instructions asked participants to identify up to five statements to remove from the list. Participants, therefore, only identified those they perceived to be of lowest importance, not the five least important.

"I found it difficult to find 5 things to leave off the list most seem very relevant and important to me" (225; male, 51-60 years),

There continued to be a high level of response to the Second Round of the ModDT, with 98.9% response completion for Question One (i.e. rate the importance of participant contributions from Round One), and 99.3% response completion for Question Two (i.e. prioritise participant contributions from Round One). Whilst the overall response for Question Three (i.e. how aspects of rehabilitation influenced change), was high (92.9%), a small proportion (20%) of the responses to this question did not directly contribute to being able to answer the research questions. These responses included ticks, the names of supportive people, and single word comments such as *'yes'*, '*important*', *'agree'*, or *'always'*. Taking this into account, the response completion for Question Three was 72.9%.

6.2.1 Participant Feedback: Priority Setting Activity

Throughout the ModDT process there were free-text opportunities for the participants to share feedback relating to the research methods, or the research topic. This section presents some of this feedback, as it highlights the participants' experience of completing this type of research activity. Throughout the ModDT, participants were invited to add free text, providing thoughts, feelings or reasons for their responses, to supplement their quantitative responses. These participant comments will be presented alongside quantitative data throughout the chapter.

The participant cohort reported that they found the process of prioritising the statements challenging on the grounds that some of the questions were, *"Hard to answer" (120; female, 65 years)*. This was not necessarily a reflection on the tool structure. This feedback reflected that all of the statements were perceived to have some level of 'importance'.

Participants were asked to 'keep' or 'remove' statements from a prioritised list. This offered insight into those aspects of rehabilitation which they perceived as relevant to their own experience or needs. It was for this reason, that the 'relevance' of each statement became important in decision making, when interpreting the findings. Excluding items from the initial list appeared to be more challenging than including them. Some participants did not identify the maximum of five statements to be removed from the list.

"All of the questions have importance. It's just different people have different expectations. It was hard to choose least important. They all apply" (123; female 60 years),

"I feel that the questions are relevant and important to me and I had difficulty in choosing 'lesser' questions. Honestly, I would not wish to delete any of the questions" (239; male 68 years),

"To make these choices was very difficult because each has merit. I could have included all 20 in [Round One] Question 2. Question 3 was even harder for the same reasons" (Catrin; female, 71-80 years),

"I can think of no other topics, to those two shown above, that should not be included in the list" (255; male, 66 years),

The difficulty experienced by participants in prioritising aspects of rehabilitation, reinforces the complexity of this topic. Despite participants perceiving this as a challenging activity to undertake, the ModDT did yield enough data to answer the research questions. The remainder of this chapter presents the ModDT findings with this feedback in mind.

6.3 How Important are Different Aspects of Rehabilitation?

As described in Chapter Three, Round One asked participants to reduce a list of twenty statements relating to rehabilitation to a list of ten priorities. They were asked to make their decision based on how important they perceived these statements to be to themselves. As described in Chapter 3.7.2 there were four measures of importance built into the three questions of the ModDT Round One (See Appendix 14). A summary of the quantitative data for all four measures of the first twenty statements from Round One is presented in Table 11.

Table 11. Round One: How Important are Aspects of Rehabilitation?

Statement		Mean importance score (0-4)	% of Responses 3-4	Median	Mode	Sum +1 = Keep -1 = Remove
16	I need well trained professionals with the right knowledge and experience.	**3.114**	**80.70%**	3	3	15
9	I feel that I am talking with healthcare professionals who understand me.	2.94	**79.31%**	3	3	9
17	I need to laugh during rehabilitation, there's work to	**3.06**	74.14%	3	4	**19**

	do, but it can also be enjoyable.					
13	I need to know someone is there for me if I need support or advice in the future.	2.983	74.14%	3	3	15
18	My relationship with professionals needs to be open, honest and trusting.	2.991	74.14%	3	3	11
10	I feel the healthcare professionals care for me as a person.	2.905	72.41%	3	3	4
14	I need professionals to be the right type of person for the job that they're doing.	2.922	68.97%	3	3	6
8	I am learning the skills that I need to manage my future health and lifestyle.	2.784	63.79%	3	3	7
6	I need rehabilitation to be tailored for my needs, offering the right level of challenge.	2.698	62.07%	3	3	9
4	I am taking part in something that enables me to take some control back.	2.655	53.45%	3	2	12
19	I need to trust the quality of the service. I need to feel safe.	2.851	73.68%	3	3	-5
2	I feel I am respected and being treated as a whole person.	2.716	68.97%	3	3	2
11	I am noticed. The team notice if I struggle, or improve, and talk to me about this.	2.802	65.52%	3	3	0
3	It is my body, my life. I am offered choice and support to make decisions.	2.655	58.62%	3	3	-4
7	I need to hear if I am making progress, or not. A clear, gentle, independent opinion.	2.457	50.00%	2.5	3	2
12	I need the healthcare professionals to work with me, as a team, towards my goals.	2.526	50.00%	2.5	2	-3
1	I need to see the point in what I am doing during rehabilitation. It must be relevant to my needs.	2.422	48.28%	2	3	-8

5	I need clear information, so I know what to expect from rehabilitation.	2.518	50.88%	3	2	-11
15	I need to spend time with other people who have had similar experiences to me.	2.267	43.10%	2	2	-6
20	I need rehabilitation to be convenient and fit in with other commitments.	2.422	41.38%	2	2	**-20**

Participants were asked to identify any additional aspects of rehabilitation that they felt were important but not included in the initial list. This feedback generated five additional statements, listed in Table 12. At the beginning of Round Two, participants were asked to rate the importance and relevance for these items. For ease of presenting any findings relevant to the additional statements, they were numbered (21-25), to follow on from the initial list (1-20). These are presented below in Figure 15.

A summary of the descriptive data for all four measures of the five participant statements is presented in Table 12. To reduce response burden, the structure of the ModDT tool in Round Two was altered to accommodate the additional statements generated by the participants in Round One (See Appendix 15). Instead of asking participants to select a quota to 'keep' from only five statements, participants were asked to identify 'keep' or 'remove' for each statement.

Table 12. Round Two: How Important are Aspects of Rehabilitation?

Statement		Mean importance score (0-4)	% of responses 3-4	Median	Mode	Sum	Keep
21	I would like to stay in the classes, I would be happy to pay or volunteer to do this.	2.37	46.3%	2	2	26	74.10%
23	I would like contact from rehab professional after rehab has ended to assess needs and update info	2.39	37%	2	2	**37**	**83.60%**
24	I would like to go to a Macmillan building / suite, easy access, rehab & counselling areas, drop-in	2.35	44%	2	2	17	65.50%

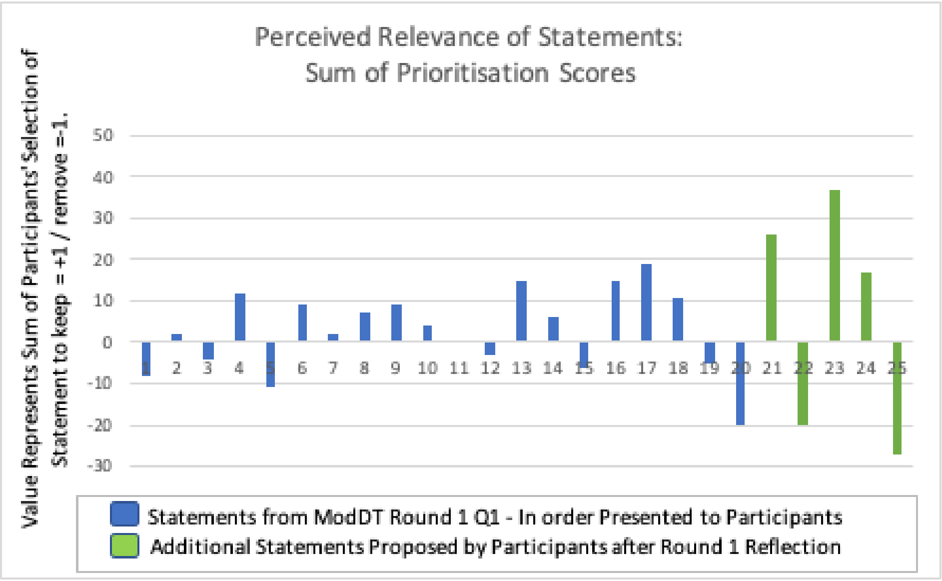
25	I would like some of the groups to be outdoors, having a positive effect on my wellbeing	1.42	22%	1	1	**-27**	25.40%
22	I would like to attend annual social events, keeping in touch with hcps and other PABC	1.48	17%	1	1	-20	31.50%

The following Figure 15 plots the cumulative scores given to each statement by the group. The cumulative score was calculated from the sum of the following:

- Each time a respondent selected the statement to 'keep' (+1) and
- Each time a respondent selected the statement to be 'removed' (-1)

This image represents the perceived relevance of each statement to the group. The original twenty statements are represented in blue, and the additional statements added by participants are represented in green. Some of the strongest reflections of relevance, or irrelevance, were for the participants' statements contributed. For simplicity, the prioritisation responses were collated and analysed together.

Figure 15. Perceived Relevance of Statements: Sum of Prioritisation Scores



A very brief summary of Round One findings were reflected back to participants at the beginning of Round Two and can be found in Appendix 15. The following discussion explores participant perceptions of the importance and relevance of twenty-five rehabilitation statements. The findings presented in the following sections are arranged according to four levels of importance (Most, Moderate, Less and Least Important / Relevant).

6.3.1.1 Most Important and Relevant

The criteria for inclusion in this section included the following:

- Participant consensus that the statement was 'very or most' important,
- Highest mean scores,
- Highest mode scores, and
- High frequency of participants choosing to 'keep' the statement.

Please see Table 11 for details.

Nine of the twenty-five statements presented in Tables 11 and 12 were considered 'most important'. When the statements were grouped according to perceived importance, the following four key themes were observed:

- Professionals being well-prepared for their roles,
- Humour and laughter during rehabilitation,
- The professional-participant connection,
- Long-term support, as rehabilitation and learning to self-manage are life-long pursuits.

6.3.1.1.1 Well-Prepared Professionals

Using the measures described above, there were only two out of the twenty statements in Round One which were perceived as 'highly important' by 75% or more of the group. Which suggests that a cohort consensus was achieved. These statements also scored some of the highest mean importance scores. They were deemed relevant to most of the cohort, by being frequently listed in the 'keep' section of the data collection tool.

These statements included:

- I need well trained professionals with the right knowledge and experience.
- I feel that I am talking with healthcare professionals who understand me.

These two statements describe participants' expectations for professionals to be well prepared for their roles. The first statement particularly highlights technical learning, through which professionals were seen as a key mechanism for change.

> *"When you are recovering, you don't want to waste your energy working with the wrong people, you need to move forward asap" (119; female, 51-60 years),*

> *"Training and expertise are very important but if in the hands of the wrong person they are less likely to be helpful" (068; female, 51-60 years),*

> *"The professionals could make or break the process"* (Nia; female, <40 years),

> *"One person (not Macmillan) was good at her particular activity but was very unfeeling and tactless. As much as I appreciated the help, she often made me feel angry at her attitude" (172; male, 61-70 years),*

Well-prepared professionals engendered a sense of trust and confidence in rehabilitation participants, which was seen as a core requirement for the therapeutic relationship.

> *"Trust and confidence in staff is vital" (188; female, 71-80 years),*

> *"Need to be able to put myself in their hands, confident in their skills"* (*Gwenllian; female, 61-70 years*),

> *"[It's] good to speak with a professional with a background knowledge of cancer... experience with cancer diagnosis and its treatment modalities essential"* (138; female, 51-60 years),

The second statement related more to professionals who aim to understand participants as people. The small amount of qualitative data which accompanied the selection of this statement was mixed. Not all participants felt this statement was a priority.

> *"Honest, caring knowledgeable professionals are imperative" (098; female, 41-50 years),*

> *"... professionals understand all that is told" (185; male, 61-70 years),*

> *"[it is] not necessary to be understood, just my condition" (172; male, 61-70 years),*

6.3.1.1.2 Humour and Laughter

The following statement, whilst not reaching 75% consensus criteria for overall importance. It scored the second highest mean importance score, and the highest mode score. It was the statement most frequently listed in the 'keep' section of Round One.

- I need to laugh during rehabilitation, there's work to do, but it can also be enjoyable.

Laughter and humour during rehabilitation appeared to have been valued by participants for a range of reasons. These included the anecdotal healing benefits of laughter, or as a diversionary tactic during rehabilitation. Laughter and humour were seen as a vehicle for change, a coping strategy. A tool to facilitate recovery.

"Laughter is the best medicine" (088; female, 61-70 years),

"Laughter is healing in itself" (116; female, 61-70 years),

"Laughter is important to wellbeing during, before and after treatment. Laughter reduces stress and promotes wellbeing" (098; female, 41-50 years),

"Helped to give a positive outlook" (226; male, 71-80 years),

"Cancer is grim. Laughter fights it" (199; male, 71-80 years),

"When you are laughing you are forgetting your worries" (119; female, 51-60 years),

"Humour lightens the sessions, takes focus away from pain" (*Nia; female, <40 years*),

"Laughter gets you through most situations" (135; female, 41-50 years),

"You need fun things [especially] if been ill" (123; female 51-60 years),

"Being able to 'have a laugh' has always got me through life. It has made the classes enjoyable & therefore encourages you to try harder & improve" (*Gwenllian; female, 61-70 years*),

"Makes you work to improve - laughter helps" (142; female, 71-80 years),

"I make better progress if enjoyable" (*Gwenllian; female, 61-70 years*),

Before rehabilitation, some participants' considered humour and cancer to be incompatible. However, as rehabilitation progressed, laughter and humour were seen as an outcome. It became one of the coping strategies that enabled resilience, or made the individuals feel more 'normal'.

"Friends and family, although they are supportive, they don't feel that they should laugh because 'cancer' is serious!" (*Heledd; female, 51-60 years*),

"… there is not much to laugh at when first diagnosed, but as you feel you're getting somewhere and start to feel stronger the humour returns with some help" (Dai; male, 51-60 years),

“Definitely! Laughter is what keeps me going in this whole thing 10 years on! It is hard sometimes to find a smile but during rehab we always managed to have a laugh and it lifted my spirits” (005; female, 41-50 years),

“For myself - laughter makes me feel normal” (120; female, 61-70 years),

“Having upbeat people and being treated ‘normally’ was so important” (027; female, 51-60 years),

“GSOH always helps – builds resilience and relationships” (130; female, 41-50 years),

“We learned to laugh at ourselves again. I honestly thought that I’d lost my sense of humour. I looked forward to the sessions – I never thought I would because of my history of failing in group exercise classes. Changing for hydrotherapy, no one was embarrassed by their altered body image because we all had something, and we all became aware that we had made that important step” (068; female, 51-60 years),

“Helped me not to take myself too seriously” (118; female, <40 years),

“After going through such difficult times during treatment, having fun during rehabilitation was paramount to me as it was a great release” (137; female, 41-50 years),

There was an underlying message within the participant comments, that humour and laughter were seen as tools that were to be used with care. That would accommodate the needs and nuances of each individual. Not all participants reported that this was a priority for them.

“Whilst it’s good to have a laugh it’s not the reason why I go” (068; female, 51-60 years),

“I do not need to laugh during rehabilitation” (255; male, 61-70 years),

6.3.1.1.3 Rehabilitation is a Life-Long Venture

Almost half of the participant cohort felt that two of the five participant statements, were ‘highly important’. Neither reached a threshold for consensus for overall importance. However, the following two statements scored the highest for relevance of all statements:

- I would like to stay in the classes I find beneficial indefinitely; I would be happy to pay, make a donation, or be a volunteer to do this.
- I would like contact from rehabilitation professionals at intervals after rehabilitation has ended, to assess my needs and provide updated information about other support programmes.

There were no qualitative comments relating to the prioritisation of these statements. However, there were free-text comments from other ModDT tasks which added context to these findings. These appeared to reflect a preference for continuing with the structured group rehabilitation activities. The following comments identify the strength of the connection created between participants and professionals during rehabilitation. They highlight the risk of participants becoming over-reliant on rehabilitation services. This undermined confidence to transition to supportive activities in the local community.

> *"I felt a little lost after finishing rehab and continuous access to rehab activities is needed. I would still love to access groups and activities 3 years on" (098; female, 41-50 years),*

> *"I didn't feel able to attend a proper tai chi class after my session finished as I didn't feel they could offer the same camaraderie" (125; female, 51-60 years),*

> *"The only aspect I regret was that the assistance cannot be permanent. I miss my group. I miss Macmillan" (239; male 61-70 years),*

> *"Support must include details of classes at this time of treatment, while recuperating & into the future. Better use of social media may assist this. Ask people to follow Macmillan / [Health Board] on Facebook / Twitter & post frequent info re: what is on offer locally. This is a cheap & effective way of communicating. The role can be undertaken by existing comms teams or designated member of Macmillan Team" (071; female, 51-60 years),*

The latter of these two participant statements closely resembled the following statement from Round One. Although it did not reach consensus or the threshold for mean importance. It was perceived as highly relevant by a large proportion of the participant cohort.

- I need to know someone is there for me if I need support or advice in the future.

This statement reflected the level of trust that participants had in professionals and implies reliability in the event of a crisis. Knowing there was a point of access, a safety net if needed, was described as reassuring and confidence-building. There was a sense of confidence from 'open door access' for participants whose needs may change or fluctuate due to future changes in their clinical condition. Especially within a healthcare system that was perceived as challenging to navigate. This extended to having access to changes in health and wellbeing information, guidance or advice. Or to use of the service for benchmarking, or as a mechanism to monitor their long-term progress.

> *"Cancer can be frightening and changes worrying. So, having someone other than family who understands is important, so advice is relevant e.g. what is normal or what to do to help (172; male, 61-70 years),*

> *"I wouldn't know where else to look when I needed it" (112; female, >80 years),*

> *"There is always the fear that because something went wrong (it did – I got ill and didn't get better quickly like I usually did) that even though you feel you can manage there is someone there if you needed help. I have never used it, but I feel very reassured and have persevered with an issue I had without seeking consultation with my GP or other health professional" (068; female, 51-60 years),*

> *"I have to stress that in my case, as I have an incurable cancer, the single most VITAL service I need is mental health support. My rehab will always be ongoing. I benefit from my contact with the Macmillan Team because as a result of good ongoing mental health support, I recognise this form of support (Macmillan) as being a part of rehab… a helpline with familiar professionals is most important because recovery is infinite" (Carys; female, 71-80 years),*

> *"Yes, but again, would like the offer of an MOT/ touch base, 3 months, 3 years, 10 years" (130; female, 41-50 years),*

A digital solution to share information with current rehabilitation participants, or to provide continued access to reliable information via social media, was proposed as a way to support participant confidence with long-term SM.

> *"Support must include details of classes at this time of treatment, while recuperating & into the future. Better use of social media may assist this. Ask people to follow Macmillan / [Health Board] on Facebook / Twitter & post frequent info re: what is on offer locally. This is a cheap & effective way of communicating. The role can be undertaken by existing comms teams or designated member of Macmillan Team" (071; female, 51-60 years),*

6.3.1.1.4 Professional – Participant Connection

There were a further three statements from the original list in Round One considered most important. These directly reflected the role of the professionals' characteristics and behaviour, highlighting their potential to influence the connection between professionals and participants.

Whilst these statements rated well in terms of importance, they did not reach 75% consensus as 'highly important'. They were just below the threshold mean score for importance. Despite this, the following statements were perceived as relevant to the participants:

- My relationship with professionals needs to be open, honest and trusting.
- I feel the healthcare professionals care for me as a person.
- I need professionals to be the right type of person for the job that they're doing.

These statements reflected the reciprocal nature of the therapeutic relationship.

"There has to be trust both ways" (165; male 71-80 years),

"You gain a close relationship with the professionals that help you and find yourself discussing personal information that you may not have told anyone else. It helps that you feel you can trust the person" (137; female, 41-50 years),

"I like to be told honestly about my progress or what I need to improve (005; female, 41-50 years),

They described a vulnerability of people who felt they are being viewed as vessels for disease. Highlighting the expectation that the 'right type' of healthcare professionals would provide the desired level of personalised care. Personalisation of rehabilitation was seen as important in achieving SM outcomes.

"Not just a number. One needs to be made to feel important" (211; male, 71-80 years),

"Important to talk about me, not just about cancer" (Heledd; female, 51-60 years),

"The most important. I need to be seen as a person, not an illness" (144; female, 71-80 years),

"Redundant - the right type of professional would care" (068; female, 51-60 years),

"This is important in my relationship with the team" (239; male 61-70 years),

"They shouldn't be there if [they're] not (044; female, 71-80 years),

The participants appeared to continue to face a challenge, in terms of defining who the 'right type of person' was, or what attributes they brought to the therapeutic relationship. There was a reiteration of the importance that professionals should be well-prepared for their roles. In light of the focus around therapeutic relationships in this section, the balance between who professionals are, and their knowledge and skills, highlighted the balance required for effective working partnerships.

"Approachable, knowledgeable re: cases like mine, to engage me" (172; male, 61-70 years),

"… must be dedicated to fully understand me" (165; male 71-80 years),

“It’s not about personality, it’s about training” (130; female, 41-50 years),

“This is very important as someone may be qualified but not have the interpersonal skills needed” (137; female, 41-50 years),

“Interpersonal skills are as important as training” (068; female, 51-60 years),

The statements perceived as most important or relevant by participants, predominately corresponded with the SDT concept of relatedness. Participants experienced rehabilitation as a life-long pursuit and therapeutic relationships as a conduit to achieving sustainable SM behaviour change outcomes.

The following section explores the statements which were perceived as moderately important and were therefore included in the prioritised ‘short list’.

6.3.1.2 Moderately Important

The final three, of the original twenty statements, to be included in the prioritised list were:

- I am learning the skills that I need to manage my future health and lifestyle.
- I need rehabilitation to be tailored for my needs, offering the right level of challenge.
- I am taking part in something that enables me to take some control back.

These three statements reflected the operational definitions of SDT needs for autonomy and competence (Silva et al., 2014). Whilst these items were perceived as only moderately important by the participants, they were viewed as relevant to their rehabilitation experience. There were three themes which emerged from these findings. These included participants being able to describe a ‘new normal’, having their rehabilitation tailor-made to help them achieve their vision of the future, and supporting participants to regain lost control after treatment.

6.3.1.2.1 A New Normal

The qualitative data related to skills development, seemed to consider that the development of new knowledge and skills would help to demystify uncertainty around the future. This clarity was perceived as occurring through the development of a sense of confidence which helped to facilitate adjustment to the ‘new normal’. This helped to prepare participants for what may come.

“Most important comment of all - the future seems so uncertain at times” (Gethin; male, <40 years),

“[It’s] about continuity - what happens next” (130; female, 41-50 years),

“This is what will hold me in good stead for the future” (165; male 71-80 years),

“It helps to know I am armed with info” (135; female, 41-50 years),

“To accept what I can and cannot do” (Hywel; male, 71-80 years),

“It helped me believe there is still life after cancer” (057; female, 51-60 years),

6.3.1.2.2 Tailored Rehabilitation

The qualitative data relating to tailored care, echoed the sentiments earlier in the chapter around the importance of being perceived as a person, as an individual, with unique needs.

“I feel strongly that rehab should be tailored to the individual as much as possible given the constraints of staffing and time etc. When I attended the course way back in 2011 (I think I may have been on one of the first courses you ran), I do remember the people on the course were at very different stages of their cancer journey. There were a few like myself who had adjuvant treatment and were aiming to get back to normal life but there were others who clearly had metastatic disease and their needs and goals were not the same as mine. We were all encouraged to take part in the activities, and no one was left out, but I think some were frustrated because they couldn't join in fully because of their illness. I wonder if this has changed since my experience and you now have groups for patients who are at the same stage in their cancer journey? I must say seeing patients who were clearly much sicker than myself did not affect me (considering I work in the oncology world anyway), but I do think mixing ‘well’ and ‘much sicker patients’ together on the same course is not ideal for patient's morale” (138; female, 51-60 years),

“Individualised programme tailored around my ‘normal life’- also adaptable, needs change” (130; female, 41-50 years),

“We all have individual needs which can vary” (116; female, 61-70 years),

“Sometimes I cannot perform certain things so I would need things to be achievable for what I could manage” (005; female, 41-50 years),

“I needed small achievable goals, to build confidence again” (057; female, 51-60 years),

Despite professionals’ efforts to embed PCC mechanisms into the local rehabilitation service infrastructure. Participants perceived that the practicalities of being able to deliver this level of personalisation, within the current healthcare environment, was not always achievable.

“… unrealistic to expect tailor made to each individual (022; female, 71-80 years),

6.3.1.2.3 Regaining Control

The qualitative data associated with regaining control, largely reflected the phenomenon of participants feeling that they handed over control to medical teams during cancer treatment. The desire to regain control was seen as a key trigger and an outcome of rehabilitation.

"We have to give control over to Drs during treatment, so need to take it back" (Gwenllian; female, 61-70 years),

"One of the biggest problems for me was the feeling of loss of control" (144; female, 71-80 years),

"Throughout my treatment I felt worthless and rehab made me feel mentally stronger" (233; male, 41-50 years),

"That is my objective for going to rehabilitation" (068; female, 51-60 years),

"... reclaim what cancer stole from me" (Nia; female, <40 years),

"I want to control my own destiny" (188; female, 71-80 years),

"That is the one defining thing about cancer…it takes away your control over your life, rehabilitation is all about getting it back!" (137; female, 41-50 years),

This section described the importance associated with aspects of rehabilitation which reflected the SDT needs for competence and autonomy. These were the last statements to be included in the final priority list at the end of Round One. The next section explores the ten statements from Round One, and the three remaining participant statements from Round Two, to which the cohort did not appear to attach any noteworthy level of importance or relevance.

6.3.1.3 Less Important

Of the ten statements which scored the lowest importance scores in Round One, the following five received moderate mean and mode scores for importance. They received quite ambivalent scores for relevance by the participant cohort.

- I feel I am respected and being treated as a whole person.
- I am noticed. The team notice if I struggle, or improve, and talk to me about this.
- It is my body, my life. I am offered choice and support to make decisions.
- I need to trust the quality of the service. I need to feel safe.

- I need to hear if I am making progress, or not. A clear, gentle, independent opinion.

There was less qualitative data available for the following statements than for those included in the previous sections. The data that did accompany the prioritisation of these statements are presented below.

6.3.1.3.1 I am Respected as an Individual

The qualitative comments which accompanied either the prioritisation, or not, of needing to feel respected by professionals, reflected a perception that respect for individuality was not always observed in healthcare. However, being respected and treated as an individual was seen as an expected feature of professional behaviour. It was described as a core duty, and a mechanism for change within the rehabilitation setting.

> *"So often patients are not allowed dignity and respect, particularly the elderly. At a time when you are so vulnerable it is good to have the support of professionals who are experienced and knowledgeable" (Catrin; female, 71-80 years),*

> *"After being ill you need to be treated as a person not as a someone with a disability" (123; female, 51-60 years),*

> *"Every patient should feel and be respected - duty of care of NHS" (Heledd; female, 51-60 years),*

> *"I would expect a professional member of staff to treat me with respect naturally and as a whole person" (226; male, 71-80 years),*

> *"Mutual respect essential to make progress in rehabilitation" (Gwenllian; female, 61-70 years),*

6.3.1.3.2 I am Noticed

The qualitative comments relating to the need to be noticed by professionals, or paid attention to during rehabilitation, ranged between being unimportant, or 'redundant'. Attentiveness by professionals was another characteristic that participants expected from professionals. This overlapped with being recognised as an individual. Other participants' reports were that being able to direct how much attention they received suited their needs better. There was a proposed that professional observations were a beneficial, external measure of change.

> *"Not a concern for me" (137; female, 41-50 years),*

“Sometimes I didn't want to be noticed, only part of the group” (057; female, 57 years),

“I do not need to be constantly noticed as long as I know there is support when I need it” (005; female, 41-50 years),

“Redundant - the right type of professional would do this” (068; female, 51-60 years),

“You are not just a number you are important” (098; female, 41-50 years),

“It's surprisingly difficult to know yourself” (Gethin; male, <40 years),

“Sometimes I would compare my lack of progress to someone else” (Heledd; female, 51-60 years),

“That the team acknowledge any difficult moments” (185; male, 61-70 years),

6.3.1.3.3 I am Offered Choice

The qualitative comments relating to being supported in decision making, again reflected a range of expectations, and was ambivalently scored. The comments ranged from participant preferences to trust professionals with some decision-making, to seeing decision-making as a component of regaining control.

“I'll put my trust in the professionals” (Gethin; male, <40 years),

“I would hate to make choices that would make my condition worse” (123; female, 51-60 years),

“To feel an individual and to be encouraged and corrected is so important” (Heledd; female, 51-60 years),

“Choices make you feel empowered” (110; female, 51-60 years),

“Included in taking back control” (Gwenllian; female, 61-70 years),

6.3.1.3.4 I Need to Feel Safe

The qualitative comments relating to participants trusting the quality of healthcare services, and feeling safe within these, reflected that safety and trust were expected from professionals. There was a link back to professionals being well-prepared for their role. This was seen as a measure for providing the confidence that services would be safe.

“Never no reason to not feel safe” (120; female, 61-70 years),

“With the right professionals, safety is a given” (Nia; female, <40 years),

“With a dedicated carer, I would have that trust” (165; male 71-80 years),

“It makes me feel secure in their knowledge” (135; female, 41-50 years),

“When in a bad place you have to have faith in the service” (211; male, 71-80 years),

“I think it is important that you have well trained professionals in whatever training you are undertaking” (123; female, 51-60 years),

“I need to have confidence in trainer to avoid injury” (233; male, 41-50 years),

6.3.1.3.5 I Need Feedback on Progress

The qualitative comments for this final statement, yielded similar trends as the previous statements. The comments appeared to suggest a transition in level of need. This might reflect participants’ growing confidence and/or ownership over their SM.

“Recovery is a journey, we need guidance. No progress would be a disaster” (088; female, 61-70 years),

“I would like to know I am doing things right/wrong” (125; female, 51-60 years),

“I felt in myself I was making good forward strides” (233; male, 41-50 years),

“I know my own body and would be able to check my own progress” (138; female, 51-60 years),

The range of qualitative responses for these five statements may reflect participants’ experiences at different stages of their rehabilitation and transition towards SM. These data may support a proposal that participants who report a greater level of independence from professional support, are further into their transition towards SM, than those who continue to seek professional support. This potential trend will be kept in mind during the integrated analysis in Chapter Eight. With so few responses for each statement, it is unlikely that there is sufficient evidence to draw this conclusion with any confidence.

6.3.1.4 Least Important and Relevant

Of the remaining three participant statements, the following two reached a consensus. Seventy-five percent or more of the cohort felt they were the ‘least important’ aspects of rehabilitation. They were also perceived as the least relevant to the participant cohort.

- I would like to attend annual social events, keeping in touch with Healthcare professionals (HCPs) and other people affected by cancer (PABC).

- I would like some of the groups to be outdoors, having a positive effect on my wellbeing.

The final statement from the participant contributions, failed to elicit a strong group consensus in terms of either perceived importance or relevance. More than half of the respondents indicated that access to purpose-built rehabilitation facilities would be valued, and perhaps, enjoyed by participants. However, the overall level of importance was low.

- I would like to go to a Macmillan building/suite, easy access, rehab & counselling areas, drop-in.

Of the remaining five statements from Round One, listed below, none elicited a particularly strong response in terms of either importance or relevance from the participant cohort.

- I need the healthcare professionals to work with me, as a team, towards my goals.
- I need to see the point in what I am doing during rehabilitation. It must be relevant to my needs.
- I need clear information, so I know what to expect from rehabilitation.
- I need to spend time with other people who have had similar experiences to me.
- I need rehabilitation to be convenient and fit in with other commitments.

Of these eight statements, there were three themes which warranted closer exploration within the qualitative data. These included the low level of importance associated with rehabilitation needing to be convenient, the identification of the peer group as not necessarily being defined by disease, and the role of the environment in facilitating therapeutic relationships or rehabilitation outcomes.

6.3.1.3.1 The Convenience of Rehabilitation

The first theme related to the low level of participants' priority given to the need for rehabilitation convenience. Despite this statement generating some of greatest volume of qualitative data, there was very little support for convenience of rehabilitation being perceived as important. Only two qualitative comments reported that the statement didn't apply to them due to being retired.

"… retired, so convenience not a problem" (110; female, 51-60 years),

"As I was not working at the time this was not an issue" (233; male, 41-50 years),

Although convenience was not highly rated, there was a perceived need for rehabilitation to be compatible with wider social circumstances including work and family life. Most of the qualitative comments supporting the importance of rehabilitation being convenient, were made predominantly by female participants of working age.

"May have busy lives and rehab should be flexible" (142; female, 71-80 years),

"Rehab has to fit in with my life, work and family" (071; female, 51-60 years),

"I would ensure I would attend (work permitting)" (135; female, 41-50 years),

"Tailored around my "normal" life" (130; female, 41-50 years),

"Not always possible" (120; female, 61-70 years),

"It's optional" (Nia; female, <40 years),

Of note, there was a greater volume of support from both male and female, retired and working age participants, for individuals to take personal responsibility and prioritise their rehabilitation needs over other commitments.

"Patients need to be as flexible as possible & fit in to the timetable" (Gwenllian; female, 61-70 years),

"This is something that I must be prepared to compromise on" (144; female, 71-80 years),

"Whilst this would be a little important, I am so keen to always get better that I would do whatever it took at any time given to achieve goals." (005; female, 41-50 years),

"Rehab and treatment is the most important" (188; female, 71-80 years),

"Rehabilitation becomes the most important thing; patients have to make an effort too" (Gethin; male, <40 years),

"Rehabilitation should be our importance" (098; female, 41-50 years),

"If it's in your own interest you would fit the times in" (165; male 71-80 years),

"I think I would have to make it convenient" (211; male, 71-80 years),

"This takes priority as long as it's not too early!" (172; male, 61-70 years),

"Needs to be a priority as life has to go on" (088; female, 61-70 years),

"Eventually, rehabilitation was more important than commitments" (057; female, 51-60 years),

These comments echo the SSI theme related to participant ownership over rehabilitation and SM. Prioritising participation in rehabilitation might be interpreted as an early indicator that people have started to take ownership over their rehabilitation.

6.3.1.3.2 Peer Group: Definition by Disease or Rehabilitation

The second theme perceived as least important, related to the need to spend time with other people who have had similar experiences. This was a complex theme which also generated a large volume of qualitative data. Within this theme there were three angles from which engagement with the peer group was perceived.

The first reflected the views of participants who felt that the connection with peers was helpful for both themselves and for others. This was especially participants perceived a risk of feeling isolated during treatment or rehabilitation.

"There is a common bond between people who have shared similar life experiences" (068; female, 51-60 years),

"It is important to understand other peoples' difficulties" (Hywel; male, 71-80 years),

"I found chatting to others who had been through similar experiences very helpful" (137; female, 41-50 years),

"Groups can be supportive environment for some cancer patients who feel isolated" (138; female, 51-60 years),

"A shared experience to feel you are not alone" (098; female, 41-50 years),

"Shared experiences, allowed me to feel less fearful" (057; female, 51-60 years),

"Important to see you're not alone" (110; female, 51-60 years),

"The people in the group don't always need to have similar experiences" (123; female, 51- 60 years),

"Don't necessarily have to share same experiences, just be open to rehabilitation" (Gwenllian; female, 61-70 years),

"Having the right support gives confidence" (116; female, 61-70 years),

"You must find a fellowship and friends who 'just know and understand'" (135; female, 41-50 years),

The second reflected that some participants experienced a potentially negative impact from spending time with people who had undergone similar experiences relating to disease, or treatment.

"Some people's experiences are not the same - monopolise discussions etc" (130; female, 41-50 years),

"I don't always want to talk about my cancer or listen to others doing the same" (Catrin; female, 71-80 years),

"Sometimes this can cause anxiety" (144; female, 71-80 years),

"It can be helpful but also upsetting" (211; male, 71-80 years),

"I felt fear, dread and scared listening to others" (Heledd; female, 51-60 years),

"Can sometimes drag you down rather than support you" (172; male, 61-70 years),

The third proposed that participants' needs for engagement with peers would be dependent on each participant's individual needs. This included their preferences for inter-personal interaction, and their existing level of support. These comments also introduced the peer group being re-defined on the grounds of their common 'rehabilitation' purpose which was more proactive and forward-facing than definition by 'disease' status.

"Not always necessary" (125; female, 51-60 years),

"Depends on individual to me - not important" (165; male, 71-80 years),

"Although helpful and enjoyable - personally not worried" (120; female, 61-70 years),

"I don't always need to talk to people experiencing the same. I do not mind being alone or working on my own" (005; female, 41-50 years),

"I get support from outside the NHS…" (188; female, 71-80 years),

"This reason will be important for some - not me. I use support mechanisms from home" (071; female, 51-60 years),

"The people in the group don't always need to have similar experiences" (123; female, 51-60 years),

"Don't necessarily have to share same experiences, just be open to rehabilitation" (Gwenllian; female, 61-70 years),

"Having the right support gives confidence" (116; female, 61-70 years),

"You must find a fellowship and friends who 'just know and understand'" (135; female, 41-50 years),

The large volume of qualitative data regarding the importance of the peer group could suggest that, whilst it was less important than other aspects of rehabilitation, it was still important to participants. The data would seem to suggest that engagement with the peer group is a variable aspect of rehabilitation. It would need to be tailored to each individual, accommodating their preferences for forming inter-personal connections. However, the concept that peer group may not always reflect disease status but may reflect a shared identity as people engaging in rehabilitative activities, was noteworthy.

6.3.1.3.3 Environmental Impact on Rehabilitation

The last theme within the least important statements related to the environment in which rehabilitation takes place. The environmental statement was generated from two of the participants' contributions at the end of Round One. The first reflected the value placed on spending time within the natural environment as part of their health and wellbeing. The second reflected the value placed on access to purpose-built rehabilitation facilities which housed a range of services to support the physical, emotional and social recovery from cancer.

There were no additional qualitative statements specifically in support of, or against, the role that the environment plays in facilitating rehabilitation and or SM behaviour change. There were a small number of participants' comments throughout the ModDT, relating to specific activities including hydrotherapy, which are dependent upon access to purpose-built facilities. Making them difficult to source outside of formal rehabilitation environments. The rehabilitation environment might become more important to participants if continued access to such facilities were at risk.

The large volume of qualitative responses for the first of these three least important statements may be more indicative of the range of participants' needs within the cohort. It may also reflect preference for, and availability of social support mechanisms. Rather than indicate that convenience and peer support were largely unimportant. The environmental context where this research took place, was able to provide access to the relevant facilities required by rehabilitation participants. This availability may have resulted in the statement been perceived as unimportant.

Eight of the ten most important and relevant statements, described earlier in this chapter, might be considered to directly influence, or be influenced by, the therapeutic relationship. The following section explores participant perceptions of how these aspects made a difference to their ability to adopt or develop SM behaviour change.

6.5 Modified Delphi Technique: Impact of Therapeutic Relationships

The second question posed to participants in the ModDT, asked them to describe how their ten most important and relevant statements, helped them to make changes to their lifestyle after cancer. This question aimed to identify the impact, if any, of the statements. Almost all of which either influenced the development of, or were influenced by the existence of, therapeutic relationships. A similar approach to the qualitative analysis of the SSI data was employed for the participants' ModDT responses. Coded data was organised to identify trends or themes specific to each of the ten statements, and those which were shared or common across statements.

This translated into two key themes which were represented by, or representative of, most of the statements. The first theme considered that some of the statements were seen to be of greater impact at certain 'times' or 'phases of rehabilitation'. This encompassed ideas relating to the 'process for change', which was interpreted as the observable aspects of rehabilitation.

The second theme suggested that some statements were perceived as delivering a 'result' for the participant. This reflected the participants' expectations relating to the 'outcomes of change' and were seen as including more subtle intrapersonal changes. There was a complex inter-relationship between the two themes, which are described below.

6.5.1 The Process for Change

There were four key timepoints throughout the rehabilitation process where the statements relating to therapeutic relationships seemed to have greatest impact by 'helping or hindering' rehabilitation participants. There were no clear boundaries for transition between timepoints identified by the respondents. There was no evidence within the data to suggest that participants perceived this as linear process. These timepoints are described below using participants' language to illustrate the change process that they perceived to have taken place.

6.5.1.1 Building Partnerships – 'I am a person, not a diagnosis'

Early in the rehabilitation process, the respondents identified the impact that healthcare professionals, their personal characteristics and their experience, had on engagement with rehabilitation participants. This process focused on creating a connection, a working partnership and negotiating a tailored plan to meet individuals' needs. The following comments highlight that the impact of effective relationship building at this early stage, engaged participants in the rehabilitative process at a time of vulnerability. The success of this engagement was often dependent on participant perceptions of professional characteristics. Participants suggested that for this partnership to be effective, the participant needed to believe that professionals had something to offer, something worth paying attention to.

> *"Building a relationship with healthcare professionals is essential to engender care and trust" (022; female, 71-80 years),*

> *"When you are recovering you don't want to waste your energy working with the wrong people you need to move forward asap" (119; female, 51-60 years),*

> *"If professionals are not 'the right type' they will lose their patient / client group. I am proof of this" (088; female, 61-70 years),*

These partnerships were perceived to be reciprocal. The impact of open and honest communication resonated with participants and resulted in greater investment in rehabilitation. Participants reported that they needed to believe that they were being treated and valued as an individual by healthcare professionals. This partnership building process might be considered to be the hook that enables a participant to overcome anxieties or noxious symptoms. This hook sees participants agree to take part in a first rehabilitation activity, come back for a next session, or begin to regain a sense of control.

> *"I respected the honesty of healthcare professionals from the very beginning. I was never given any expectation from them of what recovery I might make and what function may return, and as hard as that made it at times, it was better than them trying to tell me something they simply did not know; and I was honest with them in turn it allowed them to tailor my rehab to my needs. The relationship became very trusting as a result, so when new exercises or techniques were suggested, I was happy to try them (Gethin; male, <40 years),*

> *"Treated as a person" (172; male, 61-70 years),*

> *"Not just another statistic" (119; female, 51-60 years),*

> *“Being treated as an individual and not a ‘patient’ helps self-esteem” (116; female, 61-70 years),*

> *“Qualifications aren’t the whole story regarding one person’s impact upon another, nor is professionality: it’s the ability to connect with everyone there however they may feel about them. There was no ‘well you should be able to do this by now’ based on some idea of what was ‘normal’. The effect of cancer and its treatment on people varies so widely and this was clearly paramount in their minds. We all had our own stories of how some people outside did not seem to be able to appreciate this and had unrealistic expectations” (068; female, 51-60 years),*

> *“A cookie cutter approach will definitely not work” (Nia; female, <40 years),*

> *“I was unsure at first to attend. However, I am so happy that I went, as they helped re-build my physical and mental wellbeing” (057; female, 51-60 years).*

Nine out of the ten most important and relevant statements were connected to this process of partnership building. Of note, was the absence of needing to laugh during rehabilitation. Although the process was not perceived to be linear, there was a sense that this relationship building took place early in the therapeutic association. There was the potential that this process of relationship building might need to be re-engaged at different stages throughout rehabilitation. Examples included after a fracture in the therapeutic relationship or at times of increased demand on, or challenge for participants.

6.5.1.2 Learning to Change - 'My needs are unique'

Learning to change can be very difficult, as people try new strategies, fail, and continue to try until they discover tools and skills that are compatible with them. This process of increasing challenge and demand on skills development is often the most visible aspect of rehabilitation. Some people felt that the changes they needed to make were predominantly physical. Whereas others felt that the changes they made during rehabilitation were more cognitive and emotional. For others, learning to change during rehabilitation was a more complex process of self-discovery, which resulted in essential coping mechanisms, an increased sense of control and a vision for the future.

> *“This was vital in perfecting correct technique in obtaining the very most from the exercises, to help with improved recovery and condition” (233; male, 41-50 years),*

> *“They needed to change thought processes for me. Correct mental attitude coupled with physical effort was the right path to guide me forward to positivity” (239; male, 61-70 years),*

"It was sometimes hard to believe, and improvement was always in very small increments, but bit by bit I did get more control back. I had to find the life that was going to work for me within the confines of what I had lost during my treatment and that is what the rehab slowly began to allow me to do" (Gethin; male, <40 years),

"I remember it being suggested that I shouldn't become 'a victim'. This gave me much food for thought because I trusted the person who said it and in the years since has made me realize this is a default position I adopt when things go wrong. Now, at some years distant following having faced another life changing event I have sought psychological help with the intention of learning some strategies to try and reduce my tendency toward this way of thinking" (068; female, 51-60 years),

What the 'right help' looked like was different for every person. Believing that rehabilitation had been tailored to each participant made it more meaningful. The trust engendered by the partnerships described in the previous section, enabled open discussions.

"My needs, to identify what was or was not important and useful for me" (172; male, 61-70 years),

"Care for individuals with individual needs. We are all important" (098; female, 41-50 years),

"The right help at the right time" (Catrin; female, 71-80 years),

"A cookie cutter approach will definitely not work" (Nia; female, <40 years),

*"Once you step in that pool, that person's doing that, I can't do that, but that doesn't matter but they are not asking you to do that they are asking you to do this, oh that person is doing something different oh and that one over there is doing that and this guy is coming in being carried by his wheelchair and the thing and at least I have managed to walk although it hurt a lot. So, you very quickly realise that you have been treated as an individual" (*Dai; male, 51-60 years*),*

"I also like to be pushed out of my comfort zone from time to time" (005; female, 41-50 years),

"Yes, the challenge made me get out and go" (135; female, 41-50 years),

"If I couldn't do something it was ok - I could do something else" (female, 41-50 years),

"When I had rehabilitation there was no pressure and I could go at my own pace" (225; male, 51-60 years),

"Challenges will enhance recovery but must be at the right level to avoid daunting participation" (088; female, 61-70 years),

"I think everyone is different and everyone's expectation are different" (225; male, 51-60 years),

There were four statements which featured most within this theme. These included access to professionals with the right knowledge and skills. This was both during rehabilitation and into the future, if needed. As was being part of something that enabled participants to regain control and learn the skills required for future SM. This process of learning to change laid the foundation for increasing participant ownership over their long-term health and wellbeing.

6.5.1.3 Regaining Ownership - 'I am changing my frame of mind' / 'I am taking back control'

There was a small number of participants who reported that they did not feel that they had relinquished control as a result of their cancer diagnosis or did not feel that rehabilitation was instrumental in regaining a sense of control.

"I don't think I ever lost control" (199; male, 71-80 years),

"I did feel that I had some level of control over my treatment and rehab" (225; male, 51-60 years),

"Not really felt that my therapy did this" (142; female, 71-80 years),

However, almost all of the remaining comments reflected that participants felt an internal drive to maintain or regain control and ownership over their future, following their cancer diagnosis. The greatest impact of the partnerships with professionals, was as a mechanism for facilitating behaviour change. The partnership helped people to change their expectations and make the most of this internal drive to regain control.

"Taking control is important when so much else is out of your control" (110; female, 51-60 years),

"Very important. There is a huge feeling of loss of control when first diagnosed" (144; female, 71-80 years),

"I needed to move on" (Catrin; female, 71-80 years),

"I felt I could see 'light at the end of the tunnel'" (135; female, 41-50 years),

"It certainly helped to get me back on track" (226; male, 71-80 years),

"This again IS very important to me. This whole journey for me has been about maintaining some control" (005; female, 41-50 years),

"Essential - for me personally - I wanted to get some control back to move forward" (022; female, 71-80 years),

"Beating cancer is all about taking back control of your life. this is the start of the recovery process" (137; female, 41-50 years),

"After diagnosis, not even feeling human, you professionals had such a calming and reassuring manner you help to put things into perspective" (027; female, 51-60 years),

"This is very true - after the panic of knowing I had cancer, many, many, people assisted me to a place of hope for the future. Heading this group were the Macmillan […] therapists" (239; male, 61-70 years),

Participants felt they were encouraged to take ownership over their actions and emotional responses during rehabilitation. Participants were supported to develop a lifelong interest in maintaining their health and wellbeing. There was a delicate balance to be maintained at this stage of rehabilitation. Participants were undergoing a process of rebuilding their confidence but may not yet feel they had the skills or confidence to complete the process without professional support.

"If I couldn't do something it was ok - I could do something else" (135; female, 41-50 years),

"I have the choice of whether to join in or not" (065; female, 51-60 years),

"I learned the importance of keeping healthy" (110; female, 51-60 years),

"Learning to listen to my body and adapt my living routine to what I can do today was important" (172; male, 61-70 years),

"Taking back control of our lives is the main aim of recovery. After the devastation of cancer, we need all the professional backup possible" (088; female, 61-70 years),

"Self-help is important but support from professionals allow individuals to take control, which you lose during treatment" (098; female, 41-50 years),

Five statements contributed to this sense of regaining control and ownership over the future. These included professionals' skills, experiences, personal characteristics and behaviours. Which complemented participants developing the skills, which had been tailored to their needs. Participant ownership over SM might be seen as a prerequisite for the long-term sustainability of behaviour change.

6.5.1.4 Sustaining Change - 'I am doing things'

The data reflected a tension between participants who reported that they had sustained behaviour change after rehabilitation.

"Life was always going to be very different after treatment, and ultimately, I am the only one who can try to find a lifestyle that will work for me within the limitations

that I now live with. Both by getting to know me well and by giving me all of the advice, support exercise and training necessary, all health care professionals have helped me to get there" (Gethin; male, <40 years),

"I'll always have the tools to help me - 8 years on it's working!" (135; female, 41-50 years),

"I have increased exercise, walking daily was not something that I did before. I now love it - get a dog!" (Catrin; female, 71-80 years),

And those who reported that they continued to struggle with achieving or sustaining change.

"I felt a little lost after finishing rehab and continuous access to rehab activities is needed. I would still love to access groups and activities 3 years on" (098; female, 41-50 years),

"I feel less motivated outside the group. And advice would be good to progress" (233; male, 41-50 years),

"I enjoyed and benefitted from tai chi and hydrotherapy, even though both have now stopped, I would appreciate this 'adapted' exercise again" (172; male, 61-70 years),

For some participants, the process of managing the dissolution of the therapeutic relationship towards the end of rehabilitation, and the facilitation of transition out of rehabilitation may not always have been well managed. This would have the potential for a continued perceived need for professional support, rather than the assurance of self-reliance. For this cohort, there is the chance, that the desired outcomes from rehabilitation may not have been fully achieved. The next section explores the four outcomes that participants reported were influenced by aspects of rehabilitation which correspond with therapeutic relationships.

6.5.2 The Outcomes of Change

The following sections presents participants' perceptions of four outcomes, or internal changes, which they considered to have either been 'helped or hindered' by therapeutic relationships. These outcomes are described below using participants' comments to illustrate their experiences.

6.5.2.1 Building Trust – 'I want to change, but I don't know how'

Trust played a strong role in the building, and arguably maintaining, of partnerships with professionals. All ten statements generated comments which described how the trust engendered by the professional characteristics, knowledge and experience was important in creating a working connection, recognised as a partnership between rehabilitation participant and provider. Participants reported that whilst they may have been in a vulnerable place, trusting healthcare professionals was not always assumed or automatic.

"When you are first diagnosed, you want to fight, but don't know how" (Dai; male, *51-60 years),*

"I have had some bad experiences and lost trust. Having professionals that you trust is paramount" (110; female, 51-60 years),

Participant comments suggested that this connection was created by non-judgemental professionals. Building trust was key to creating the connection that resulted in people initiating or maintaining attendance at rehabilitation. At this early stage, some participants reported having a high expectation of professionals and a low threshold for tolerating being let down. Inter-personal compatibility was an essential ingredient in the development of therapeutic relationships.

"Show true interest in you" (165; male 71-80 years),

"…[have] the ability to connect with everyone there however they may feel about them" (068; female, 51-60 years),

"Made me feel special, whatever state I was in" (239; male 61-70 years),

"I didn't want platitudes, and was given good advice on what was possible, and on changing my perspective on what was my new 'normal'" (172; male, 61-70 years),

"It was possible to see different professional approaches from people with different personalities which makes it far easier for patients to open up and be honest with people. It was also possible to become more comfortable with some professionals than others which allowed me to direct certain questions and seek help from those I trusted the most" (Gethin; male, <40 years),

"You do get to know which person helps you most after a while" (142; female, 71-80 years),

Trust appeared not to be the only foundation outcome from the development of therapeutic relationships. It was also one of the most frequently identified conditions for therapeutic relationships. Trust appeared to be the key to unlocking participants' internal drive for change and the connection that maintained ongoing interaction and engagement in rehabilitation. Trust was the also the precursor to building confidence, by enabling participants to trust that professionals would not consciously place them at risk of harm.

6.5.2.2 Building Confidence – 'I worry less'

The participants' qualitative comments reflected a complex interplay between overcoming anxiety, developing physical strength and endurance, building confidence and regaining a sense of control.

> *"Tai chi classes gave me confidence, determination and stamina, I was in control again!" (Heledd; female, 51-60 years),*

> *"The trained staff helped me re-build my confidence to approach social outings" (057; female, 51-60 years),*

> *"I started to think about the importance of having support from professionals who really knew how it is hard living with cancer but also gave me confidence to get back out there" (005; female, 41-50 years),*

Professional characteristics, skills, knowledge and training appeared to be instrumental in the building of confidence. There was an almost osmotic transference of confidence implied by some of the qualitative comments. Success or failure in 'instilling confidence' in others, may have been a result of participant expectations of the professional role or the therapeutic relationship. There was insufficient detail in the qualitative comments to determine if the difference between positive or negative experiences reflected professionals' level of experience. Alternatively, involving the person in the development of the rehabilitation plan through coproduction, or the level of inter-personal compatibility between participant and professional, may have influenced understanding of needs.

> *"Speaking about my experiences to a trained professional gave me confidence in the advice given. I found my caseworker to be confident and this transcended to me" (137; female, 41-50 years),*

> *"Only personnel with the right attitude and practical experience are able to give confidence" (192; male, 71-80 years),*

> *"I felt they went above and beyond their role. Patient and re-assuring" (057; female, 51-60 years),*

> *"Knowing there is an experienced team gave me confidence to look forward" (116; female, 61-70 years),*

> *"I cannot have confidence in professionals who seem to know less than I do. Or those I am suggesting ways forward to" (125; female, 51-60 years),*

> *"I have tried to build relationships & support. I am not really confident about the future" (188; female, 71-80 years),*

All ten aspects of therapeutic relationships were perceived as having an impact on reducing anxiety and building confidence. This was the first stage at which humour appeared as a tool, used by professionals to aid the creation of a comfortable rehabilitation environment. Being comfortable within the rehabilitation setting, paired with the right level of challenge appeared to have been the catalyst for calculated risk taking. Successful risk taking in a safe environment, like rehabilitation, might be seen as a mechanism for building self-efficacy and self-esteem. This harnessed the internal drive for taking ownership over SM and lifestyle behaviour change.

6.5.2.3 Building Self-esteem – 'I feel more motivated'

The outcome around building self-esteem and unlocking internal motivation might appear to be subtle, if professionals are not vigilant. The impact of the therapeutic relationships on the development of self-esteem also appeared to be particularly individual. The outcome being dependent on participant personality characteristics, and their perceived level of vulnerability. Whilst some participants were looking for increased challenge, others sought to progress at a slower pace.

> *"It must be challenging to feel achievements" (116; female, 61-70 years),*

> *"As different people were able to do things at different levels and work on different areas of their body and we felt this was OK. There was no competitive element – the only person you were trying to compete against was yourself as the person you were immediately before rehab. I've never been very good in exercise groups and have often felt singled out by instructors because I always seem to do a bad copy of the way an exercise is supposed to be done, like I was trying to do some comic parody. This made me carry on doing the exercises on my own after rehab" (068; female, 51-60 years),*

> *"Macmillan helped me start to take back control of my health again & I'm still learning skills to help keep me healthy" (123; female, 51-60 years),*

> *"I'm healthier now than what I was before cancer" (120; female, 61-70 years),*

The professionals' approach to participants appeared to have a significant impact on this outcome through fostering individualism. This is a relatively new shift in healthcare culture for both participants and professionals and may not always be well managed.

> *"Being treated as an individual and not a patient helps self-esteem" (116; female, 61-70 years),*

> *"There were occasions where I felt I wasn't given full information but maybe I should have asked more questions" (225; male, 51-60 years),*

The stage at which participants start to regain control and ownership over their rehabilitation, the associated rise in self-esteem and unlocking of internal motivation, has the potential to be one of the more challenging shifts to get right. There is a friction point between support and SM that can be confronting to both professional and participant comfort zones. Laughter was seen largely as a facilitator at this stage. However, there was a chance that risk-averse cultures in healthcare could prevent the transition from support to SM. The consequence of this delay might then result in delayed transition to community integration, compromised rehabilitation outcomes and prolonged dependency on healthcare teams. Self-esteem, self-efficacy and internal motivation might be seen as the precursors for the resilience required for long-term, sustainable SM.

6.5.2.4 Building Resilience – 'I feel safe knowing I'm not alone'

The qualitative data suggested that the final stage of rehabilitation required a level of personal resilience. This would sustain the changes made during rehabilitation and adapt to any new changes which might be required in the future. This approach to SM and sustained change might be seen as part of the expected role of someone living with or after a diagnosis like cancer.

As described in earlier sections, there was a small number of participants who reported that continued formal support would be welcomed. For this cohort, a long-term outcome that included building sustainable links their local community might be considered a good outcome. This would be particularly relevant to those participants who will have to adjust to ongoing change as a result of incurable disease.

> *"Rehab is largely down to the way I approach things. I don't see a formal programme ahead" (188; female, 71-80 years),*

> *"I am post 5 years since treatment. I have always kept myself informed" (137; female, 41-50 years),*

> *"It's 5 years since I had my cancer treatment and I now lead a normal life. I still have a few problems & attend classes & currently am under the GP referral scheme. So, this is important (123; female, 51-60 years),*

There was a challenge to transition for some participants from the groups facilitated by rehabilitation professionals and either self-directed engagement in activity or participation in groups facilitated by community, third sector or leisure industry providers. The qualitative comments highlighted that easy access to advice and support from rehabilitation professionals, if required in future, was an important safety net. This ranged from the peace of mind knowing that the service was accessible via direct access. To some participants wanting periodic formal contact to update information or be invited to identify new or outstanding needs which would benefit from professional support.

"I didn't feel able to attend a proper tai chi class after my session finished as I didn't feel they could offer the same camaraderie" (125; female, 51-60 years),

"…the only aspect I regret was that the assistance cannot be permanent. I miss my group" (239; male, 61-70 years),

"This is important as I feel less motivated outside the group. And advice would be good to progress" (233; male, 41-50 years),

"I though once you had finished the course you were on your own. It is very important though to feel that help is there again if needed" (Dai; male, 51-60 years),

"There is always the fear that because something went wrong (it did – I got ill and didn't get better quickly like I usually did) that even though you feel you can manage there is someone there if you needed help. I have never used it, but I feel very reassured and have persevered with an issue I had without seeking consultation with my GP or other health professional" (068; female, 51-60 years),

"Ongoing support and advice is crucial so that I don't feel abandoned" (Nia; *female, <40 years),*

"A point of contact gives security in the event of a crisis" (Catrin; female, 71-80 *years),*

"[It is] so comforting to know that you can speak to someone if needed" (027; female, 51-60 years),

"Would like the offer of an MOT / touch base, after 3 months, 3 years, 10 years" (130; female, 41-50 years),

The qualitative comments reflected another area of tension around resilience. In practice, participants could initiate contact with the rehabilitation service in a timely manner, should their needs change after rehabilitation. This would be an appropriate mechanism for participants living with, or learning to adjust to, the long-term/late-onset consequences of their disease or treatment. However, the qualitative data reflected that a small number of participants would have preferred indefinite professional support. This may illustrate the impact of poorly management or dissolution of therapeutic relationships. It may reflect incomplete rehabilitation ownership, control and resilience outcomes. This may be due to participants not being ready for change and highlight the consequent long-term dependency on formal services. This tension will form part of the integrated discussion in Chapter Eight.

6.6 To What Extent Were the Views from the SSI Shared by ModDT Participants?

There were four key themes which emerged from the SSI. These included the importance of professional skills, training and behaviours; the tension around professionals adaptability and authenticity; the importance of time for, or timing of, rehabilitation interventions; and navigating the concept of compliance as participants take ownership of their SM behaviours.

The ModDT findings supported the first SSI theme relating to professionals including personal characteristics, experience, skills and training. The ModDT participants perceived well-prepared professionals to be one of the most important and relevant aspects of rehabilitation. This was one of the aspects of rehabilitation which reached a consensus of importance by at least 75% of the ModDT cohort.

The tension around professionals maintaining authenticity and adaptability was not explicitly explored through the ModDT findings. However, compatibility between professional and participant was rated within the highest scoring aspects of rehabilitation. The findings around this interaction suggested that participants sought honesty and openness from professionals. They actively sought to interact with rehabilitation professionals, with whom they felt a personal affinity.

The interaction between therapeutic relationships and time, or timing of, rehabilitation was a strong theme resonating throughout both the SSI and ModDT. Participants’ qualitative contributions throughout the ModDT described a complex link between the stage of rehabilitation, the role of the therapeutic relationship and the impact this had on the development of rehabilitation outcomes. These outcomes included trust, confidence, self-esteem and resilience.

The SSI participants focused on the building of therapeutic relationships early within rehabilitation. However, there was evidence within the ModDT data to support the cohort perceived regaining control and ownership as being of moderate importance. There was little data relating to the dissolution of therapeutic relationships as participants prepared for transition to SM. This dissolution of therapeutic relationships may link with the theme regarding participant ownership of SM and decision-making around integration of healthy behaviours into daily life. This may be a key consideration in understanding the potential impact of therapeutic relationships on SM outcomes.

6.7 Summary

The two rounds of ModDT ranked ten priority statements, describing aspects of rehabilitation, according to importance and relevance. The most important aspects of rehabilitation did appear to correspond with statements reflecting therapeutic relationships. Aspects of therapeutic relationships were seen as impacting on SM behaviour change after cancer rehabilitation. This was through the process of engaging in rehabilitation, and in effecting behaviour change outcomes.

There was a new area of tension identified from this data that will warrant further exploration in the context of previous the SSI and ILR findings. This concerns the dissolution of therapeutic relationships. Appropriately managed dissolution of therapeutic relationships enables participant ownership, confidence and resilience. It aims to prevent the perception of ‘abandonment’ or perpetuation of dependency on healthcare resources. This integrated critical discussion is presented in Chapter Eight Discussion and Conclusions.

Chapter Seven: Reflection and Reflexivity

7.1 Introduction to Chapter Seven

This chapter explores the reflective and reflexive aspects of the PPD research presented in this thesis. The following sections briefly introduce reflective and reflexive practice in the context of this PPD research. This chapter builds on a reflective case study which was submitted for publication (Wilkinson, 2020). The key topics in this discussion include reflections on:

- Developing an identity as practitioner-researcher within the physical and policy context of cancer rehabilitation.
- How my role as practitioner-researcher may have influenced different aspects of the research process.
- The experience of undertaking a PPD from a professional, personal and practical perspective.

7.2 Reflective Practice and Reflexive Research

Reflection is a core tenet of clinical practice in OT (World Federation of Occupational Therapists, 2016). Reflection is an active process of intellectual monitoring and evaluation during formal learning and professional practice activities. Reflection has been credited with being the mechanism through which new knowledge, self-awareness and understanding are developed (Kettler, 2017). It is not the purpose of this discussion to explore reflection in depth. However, it is helpful to note that reflection can take place during (reflection-in-action) or after (reflection-on-action) a learning opportunity. It can be undertaken by an individual on their own, or with others (Finlay, 2004; Schon, 1983). During clinical practice and prior academic study, I used both types of reflection to facilitate my learning. I did not experience any barriers to incorporating reflection into my role as a novice researcher.

Reflexivity is a more active and ongoing process of reflection during research, resembling Schon’s reflection-in-action, which takes place in real time (Finlay, 2004). Reflexivity might be perceived as more focused than reflection. As it involves the critical examination of how our own characteristics, beliefs, values, and feelings impact on actions and decisions in clinical practice. This correlates well with the view that the interaction between researcher and researched is the mechanism through which meaning can be created in qualitative research (Schon, 1983).

Throughout this PPD, reflective practice and reflexivity were facilitated by two tools. The first was the transcription of audio-recordings from monthly academic supervision. Although not transcribed verbatim, these records provided sufficient detail of how supervision had been used to test and challenge my decision making throughout the PPD. This tool reinforced my ownership over the PPD process.

The second tool was the maintenance of reflexive research journals (Stanley & Nayar, 2015). These journals articulated my experiences of the practitioner-researcher relationship with study participants. It is where the advantages and disadvantages of having had a prior therapeutic relationship with some of the research participants were explored. It was a safe place to explore how these prior relationships may have influenced the stimulation of accurate research data. It is where I explored my reasoning and decision-making during data collection and analysis. This combination of tools offered sustainable mechanisms for capturing my own reflections alongside the conduct of research activities. Both of these tools tend to reflect the reflection-on-action nature of reflection (Schon, 1983).

Holloway and Biley (2011), go as far as to say that it is not possible for researchers to exclude themselves from qualitative research. They describe the importance of maintaining a balance between interest and obsession in the research topic. They advise caution, as researchers write themselves into the research narrative, to avoid becoming self-absorbed. These authors highlight the reciprocal nature of the relationship between researcher and researched.

This relationship may share commonalities with the practitioner-participant relationship. However, they remind qualitative researchers that whilst the researcher is part of the research, the research is about the participants. Researchers should not presume that participants perceive the world as they do. This difference in perspective introduces a potential for confirmation bias, if the researcher is not self-aware during data analysis and interpretation. This is discussed in Chapter 8.5.2. The following presents some observations of which reflect the development of my identity as a practitioner-researcher.

7.3. Developing an Identity as Practitioner-Researcher

In 2008 I started a Macmillan developmental role in South Wales. I was asked to scope, design, develop, implement and evaluate rehabilitation services for local PABC. The physical context surrounding this role is where this PPD was conducted. The local service configuration was described in Chapter 1.2.4. An action research approach had underpinned the design and development of the local cancer rehabilitation service. This laid a sound foundation for my transition towards practitioner-researcher, as managers, colleagues and peers were already familiar with, and supportive of, engaging in collaborative partnerships with rehabilitation participants during service development activities.

7.3.1 Physical Context

In 2013, undertaking an Advanced Practice Portfolio through Swansea University, highlighted my development needs relating to research (National Leadership and Innovation Agency for Healthcare, 2010). Despite the growing evidence base for cancer rehabilitation, my practice-based questions were not being answered. In the same year, an opportunity to conduct practice-based research into cancer rehabilitation came up and I started a PPD at Swansea University. In doing so, I joined the small but growing number of OTs engaged in research (Sainty, 2013). Closing the proximity between research and practice created opportunities for me to explore the research question and study design with expert participants. The impact of this relationship is discussed in more detail in Chapter 7.4.1.

I started the PPD process as an Advanced Practitioner Occupational Therapist and conducted all of the study design and data collection during this role. My substantive job role changed twice. I moved towards more strategic positions as my PPD transitioned through the analysis and thesis writing phases. As my work situations changed, I participated in conversations with clinical and strategic leaders across Wales. These people were influential in shaping the PPD analysis. These conversations provided exposure to a wider health policy context would never have been available from within the clinical setting.

As my learning grew and the research findings started to take shape, there were opportunities to use the results of this research to inform conversations in wider clinical and workforce development contexts. The opportunity to work with the organisation responsible for workforce education and development arose as this thesis was almost completed and resulted in my second job change. How this role will take forward some of the recommendations around the developmental needs of the rehabilitation workforce, described in Chapter Eight Discussion, is yet to be understood.

7.3.2 Policy Context

During the lifetime of this PPD, policy in Wales was supportive of the PCC agenda in healthcare as described in Chapter 1.2.5. However, my concern was that NHS operational pressures and resource restrictions would place person-centred services at risk of being transformed into protocol-driven pathways. I wanted this PPD to raise awareness and understanding around the importance of the therapeutic relationship to counter this.

Some healthcare professionals believe that they know what participants' experience through diagnosis and treatment for cancer without needing to ask. As I was considered to be an expert in the provision of cancer rehabilitation, I considered cancer rehabilitation participants to be experts in their cancer rehabilitation experience. This was a key influence on this PPD research and the key role of rehabilitation participants as experts is described in the following section.

7.4 The Impact of the Practitioner-Researcher Role on the Research Process

This complex practice-based question lent itself to in-practice research. This PPD aimed to build understanding around the importance of therapeutic relationships, and in doing so, identify ways in which the local cancer rehabilitation service could be improved. My role as practitioner-researcher offered a unique opportunity for a relationship with participant experts whose involvement would provide invaluable influence in the planning and data collection stages of this PPD research. The following sections explore this relationship and its impact.

7.4.1 Research Planning and Recruitment

7.4.1.1 Rehabilitation Participants as Expert Partners

The single most significant impact of my role as a practitioner-researcher was the ability to involve the local cancer rehabilitation participants as expert partners in the design of this PPD research. The relationship between the research and this group went beyond the level of influence of an academic research Patient and Public Involvement (PPI) group. This was attributed to their level of intimacy with both their personal experiences, their observations of peers' engagement in cancer rehabilitation and their observations of the local service over time. This decision was potentially controversial, given the debate around role and definition of expert patients (Shaw & Baker, 2004). However, I knew that I could not achieve the same quality in the research, from my professional perspective alone, or with PPI advice from people without this level of familiarity with the local cancer rehabilitation service.

Asking participants of the local cancer rehabilitation to provide their insights lent a level of expertise that may not have been available from another PPI group. As several participants had taken part in other research projects, they were also able to provide the invaluable contributions that other PPI groups may have. This provided assurance that the research would be clinically relevant, could overcome challenges to implementation of findings into practice, and improve clinical outcomes (Vat, Ryan, & Etchegary, 2017). The expert participant contributions have added a unique perspective to this PPD research, especially given that cancer rehabilitation had previously been largely researched from a healthcare professional perspective (D. A. Scott et al., 2013).

There were two key benefits from this approach. The first was assurance that research outputs could be interpreted meaningfully having been informed by those with the closest experience of the service. Given the potential impact on rehabilitation outcomes, this was particularly relevant if change to clinical practice were to be recommended. The second was to inform attempts to reduce barriers to research participation. This included considering competing demands from family, work and community, and functional limitations (Fox et al., 2007).

The influence and impact of this partnership with expert participants was seen in the choice of a data collection methods and communication methods with research participants throughout the PPD research. As described in Chapter 4.2.1, the outcome of this partnership was to have been instrumental in overcoming some of the recruitment challenges often faced by novice researchers (Archibald & Munce, 2015). The following explores the impact of this relationship in more detail around sampling, recruitment and managing expert participants' expectations.

7.4.1.2 Sampling and Recruitment

For participation in this research, I felt it was essential to identify a specific cohort of individuals who had personal experience of cancer rehabilitation. Full details of the inclusion and exclusion criteria were provided in Chapter 3.5. Although recruitment to research can pose a challenge to novice researchers (Archibald & Munce, 2015; Patel, Doku, & Tennakoon, 2003), this was not an obstacle faced during this PPD research.

The recruitment rate exceeded the targets described in the research protocol and ethics application. This success was attributed to the early involvement of expert participants as partners in the design of the PPD research, through anticipating and overcoming practical barriers to engagement. This and the pre-existing therapeutic relationship between participants and practitioner-researcher may also have contributed to favourable recruitment and response rates. These positive therapeutic relationships offer familiarity with, and trust in, the practitioner-researcher and they imply that communication was effective. They may also represent a congruence in shared values and vision for the anticipated direction or outcomes of the research (Archibald & Munce, 2015).

There was fair representation of tumour sites included in the research participant population. Interprofessional relationships may have been responsible for greater participation from some groups, compared with Health Board and national incidence. These groups included people affected by breast, prostate, lung and haematological cancers. These relationships hadcreated clearly defined referral pathways, multi-disciplinary team cooperation, robust communication mechanisms and, for some, the physical proximity between the cancer rehabilitation service and the specialist care providers for people affected by these cancers. The favourable response to research recruitment brought an unforeseen challenge in terms of managing the expectations of participants who felt a sense of investment in or ownership over the PPD research.

7.4.1.3 Managing Expectations when Recruiting a Representative Sample

Sampling and recruitment to the PPD (described in Chapter 3.5), was relatively uncomplicated. However, a challenge arose once the sample had been recruited. This was managing participant expectations while trying to ensure the sample was representative of the disease and socio-demographic characteristics of the local rehabilitation cohort.

During screening, participants were offered the opportunity indicate a preference for how they participated in the study. Options included participation in the SSI only, ModDT only, either/both data collection methods. This decision aimed to increase research participation by reducing practical barriers such as access to transport, workplace and/or childcare responsibilities, or difficulties with communication.

More potential participants indicated a preference to participate in the SSI than were required. Some reported their preference was because of an aversion to ‘paperwork’. Any potential participants who were not selected for SSI, were asked if they would consider the opportunity to participate in the ModDT. Whilst many agreed, some potential participants exercised their right to withdraw from the study. This did not negatively affect overall recruitment to the study, which ultimately exceeded expectations. Some participants reported the need to juggle work and family commitments in order to accommodate a face-to-face appointment. They found they were more available to participate in a written research activity.

The impact of my role as practitioner-researcher did not cease once data collection started. The following sections explore my observations of the influence that my role had on the research, the impact that the research had on my role and some of the challenges faced in undertaking practice-based PPD research. These observations are presented according to the data collection methods, SSI (described in Chapter 3.5.1) and ModDT (described in Chapter 3.5.2).

7.4.2 Semi-Structured Interviews

My initial plan was for the SSIs to be facilitated by a colleague (a rehabilitation outsider). The decision to use an outsider-interviewer was made in consultation with the supervisory team and had two purposes. The first was to enable me to step back from my practitioner role and focus on the development of my role as novice researcher. The second was to reduce the potential bias resulting from pre-existing therapeutic relationships on the data. My particular concern was that participants might limit their contribution if they thought that potentially controversial beliefs would affect their ongoing relationship with an insider-interviewer and/or detrimentally impact on future care. Following the completion of two pilot interviews by my colleague, it became necessary to amend the research protocol so that I would complete the remaining SSIs. The following section describes my experience of the tension between practitioner and researcher roles during the SSIs. Further discussion regarding steps taken to mitigate practitioner bias is presented in Chapter 8.5.2.

7.4.2.1 Practitioner versus Researcher Interviews

The SSI procedure was designed to allow participants the flexibility to explore relevant topics or concepts, that they considered important, relating to the research question (Kvale, 1996). This approach closely echoed my practice-based interview style. However, in contrast to the approach in practice, all interviews were audio-recorded and transcribed verbatim for analysis.

Transcribing all of the audio-recordings was to be more time consuming than anticipated. Additional support with transcription was recruited. Despite the assistance this support offered, approximately 40% of the SSI recordings could not be transcribed by a transcription assistant. There were two reasons for this.

The first was electronic activity within NHS venues which resulted in significant interference in the audio-recording. Initially, the SSI protocol proposed that all interviews would take place in NHS and charity venues. This was a requirement for my outsider-interviewer colleague, whose clinical experience did not include community-based practice. I was able to accommodate participant requests for SSI to be conducted in their own homes, as these were neither unfamiliar nor challenging environments for me. Of note, preparing the transcripts for these interviews were the least problematic.

The second occurred when participants' speech was impaired by their disease or treatment, making the data difficult to interpret. As primary researcher I prioritised these more challenging recordings for transcription. It was during this transcription process that handwritten notes made during and immediately after the SSI, were used to complement the transcripts and finish them as accurately as possible. Typewritten transcripts were then shared with participants. They were asked to check them and confirm that they were accurate and conveyed their intended message (Holloway & Biley, 2011).

I anticipated that the interview process might be upsetting for some participants. Plans were included the ethics application to interrupt the SSI and provide required support, should participants become distressed. A support package of information, signposting to local agencies and services providing ongoing emotional support was also prepared ahead of time. As a qualified healthcare professional, skilled in supporting people experiencing emotional distress, I was confident in the ability to transfer my clinical skills and support participants if required. However, I was alert to the potential that our research relationship might transition into a therapeutic relationship.

It was simultaneously important to me to ensure both SSI participant safety and avoid compromising the validity of the research (Kvale, 1996). There were very few instances when this situation occurred. On the few occasions when a clinical concern was raised during the SSI, I asked for consent to address the concern outside of the research context and then redirected attention back to the research topic. It was not necessary to end the research activity and offer aftercare at any time.

7.4.2.2 Experience of an Insider-Interviewer

After making the decision to complete the SSIs, I compared the transcripts from the first two pilot interviews (completed by my outsider-interviewer colleague) and my first two interviews. Two observations from the comparison were that the pilot interviews were shorter, with less detail. My colleague had adhered closer to the interview schedule than I had. Despite briefing sessions and pre-interview preparation work the outsider-interviewer, I had a greater level of familiarity with the research topic and the local service. I had some level of pre-existing therapeutic relationship with many of the SSI participants, either from clinical practice or during the research recruitment and screening process. This enabled me to probe deeper into some of the participants' comments. I could recall actions or behaviours from practice that could be used to facilitate discussion. I was able to adopt a more challenging perspective to guide the participant through describing their thoughts, feelings or behaviours.

The academic supervisory team agreed that the pilot interviews completed by my colleague would be included in the analysis as they did yield valuable data relevant to the research questions. It would have been an exciting opportunity to compare and contrast the influence of insider- outsider-interviewers on the data. However, beyond the early observations outlined above, it was not possible to pursue this within the PPD. On reflection, it would seem that the decision for me to undertake the interviews was not only acceptable, but also preferable. These actions are examples of the interviewer qualification criteria for leading good interviews and yielding fruitful information (Kvale, 1996).

Initially, in my enthusiasm to pursue the research topic, I fell prey to the pitfalls of novice insider-interviewers by encroaching on participant silences (Holloway & Biley, 2011). My technique improved with practice, experience and reflection on the audio-playback. This was supplemented by the transcription process and reflection on feedback during academic supervision. This resulted in a heightened awareness of the potential influence, my own beliefs and values might play during the analysis of the SSI data. My concerns about participants being conservative in their contributions appeared to have been unfounded (Holloway & Biley, 2011).

At the beginning of each SSI, participants were read a verbatim introduction. At the end of the introduction was a request for participants to feel comfortable to *"tell me what you really think"* (See Appendix 7). Some of the participants' comments indicated that, as an extension of the clinical therapeutic relationship, a level of openness and honesty was assumed in the research relationship.

"Don't you worry about that, you ought to know me by now…[laugh]" (Ieuan; male, 71-80 years).

The SSI transcripts reflected an increase in the use of formal language, with less conversational dialogue between the outsider-interviewer and the participants in the two pilot SSI. This is congruent with what might be expected of two strangers meeting for the first time. Conversely, there was a high level of familiarity in language and behaviour between the SSI participants who had a prior therapeutic relationship with the insider-interviewer. This included introductory conversations exploring each other's welfare, enquiring after the welfare of significant others, or discussing non-clinical or research-related topics including sport. One of the SSI participants felt comfortable enough to 'make themselves at home', when midway through the interview they said,

"Excuse me, do you mind if I take my teeth out, I find them very uncomfortable" (Carys; female, 71-80 years).

This familiarity experienced as an insider-interviewer, leant me the confidence to probe the SSI participants in two ways that the outsider-interviewer did not during the pilot SSI. The first of these was to recall examples from clinical practice to prompt discussion. This often resulted in a greater depth of data than the initial question may have yielded. The second was by using the therapeutic relationship, to recognise when and how I could pose more challenging questions of SSI participants than an outsider-interviewer might.

Other signs of informality included participants’ use of strong language, including slang and swearing, during research interviews. A conversation regarding this during supervision (Supervision: 21/07/2017), reflected that strong language infrequently appears in research theses and publications. On the advice of the academic team, a note was included in Chapter 3.7.3 to inform readers that all language used by participants, including strong language, would be included throughout this thesis.

These contributions have not been edited or sanitised for two reasons. The first is to avoid changing the meaning of the quote through the use of different language (Holloway & Biley, 2011). The second was that this language was further evidence of the freedom with which the participants expressed themselves during the SSI. There were no other behavioural signs during the SSI, to indicate that they intended to cause offence, or convey menace or aggression towards the insider-interviewer through the use of such language. The strong language appeared to indicate a strength of emotion, or powerful belief behind the message being shared. I felt it important to represent the depth of feeling conveyed through this language as authentically as possible.

Each of the SSI transcripts contained a balance of praise and criticism for the local cancer rehabilitation service. This offered some assurance that the participants did not feel under undue pressure to present an overly positive account of their experiences with an insider-interviewer. The participants were also balanced in their praise and criticism of other professionals within cancer services and the wider NHS.

7.4.3 Modified Delphi Technique

When planning this PPD, I was eager to include a data collection method which offered the opportunity to generate discussion within a group setting. However, I was concerned that a face-to-face group discussion would not yield an accurate reflection of the diversity of opinions. I was also concerned about potential recruitment challenges, resulting from the use of research methods that were not sensitive to the needs of the research population.

Having discussed my concerns with local cancer rehabilitation participants, they agreed that less confident voices may be lost in a group setting. They also confirmed that the logistical challenges posed by family and work commitments may restrict peoples’ ability to commit to in-person data collection methods. The following explores some of the decisions taken during the design and management of the ModDT.

7.4.3.1 Modifying and Managing a Delphi Technique

We considered the use of digital technology to host a virtual focus group. The use of a virtual approach had its own challenges. These included the variability and reliability in participant access to digital infrastructure. The potential to use virtual options were also reduced by some participant’ communication impairments following sensory impairment or physical consequences of cancer treatments. Based on the advice of this participant expert group, I felt that using a ModDT, might go some way to addressing these challenges.

I opted to use a modified version of a Delphi Technique for this PPD because it offered the remote participation that could enable those people with less confidence or prior commitments the opportunity to participate in the research. There were aspects of a traditional Delphi Technique which remained unchanged. These included the selection of a panel of experts, conducting several ‘rounds’ of enquiry, and reflecting the early findings back to the expert panel in between rounds.

The research proposal and ethics application allowed for the ModDT to be completed in up to a maximum of three rounds. This made it possible to close the ModDT after the second round if sufficient data had been yielded to answer the research questions. In consultation with the academic supervisory team, the decision to close the ModDT after the second round was taken. The reasons for this included a concern about burden on the expert participants. The wealth of data obtained from the two rounds suggested that there would be little to gain from a third round of questionnaires. It was reassuring that this provision was built into the study protocol. I was keen to reduce the risk of post hoc decision making compromising the PPD findings.

During data collection, the ModDT was potentially less resource intensive than other group techniques. However, it was resource intensive during its planning and design.

The ModDT tool was designed and shared as a printed Microsoft Word document. Each round of ModDT was sent to participants using standard mail, via the hospital mail service. To encourage response return rate, reply-paid envelopes were included with each tool. This offered a greater number of participants the opportunity to contribute to the research than other face-to-face group discussion methods might. The tool was designed to preserve anonymity and reduce the risk that group coercion might influence responses.

In response to participant request, the ModDT was adapted for use electronically. The tools were emailed to the participants who registered their preference for email communication. There appeared to be little difficulty in completing the electronic tool for participants who used a Windows or iOS desktop computer or laptop. However, there were interface issues that hadn’t been anticipated for those participants who tried to complete the tool using handheld devices. Some participants may have been put off responding as a result.

Whilst Microsoft Word was adequate for the needs of this research, it was inflexible and suffered from formatting errors when transferred electronically. If repeating this ModDT, an alternative survey software package, and professional advice in tool design would be sought to overcome these challenges.

There were three aspects of a traditional Delphi Technique which were modified in the technique used in this PPD. These included the expert panel being made up of cancer rehabilitation participants, informing the first round of the ModDT with the results of the SSI, and trying to map where there was both consensus and diversity of expert opinion. Of these three modifications, defining consensus posed my greatest challenge.

7.4.3.2 Defining Consensus

Defining consensus or diversity was the greatest challenge in undertaking the ModDT. The literature around the criteria defining consensus agreement or disagreement in Delphi Techniques was itself, variable. Percentages indicating consensus ranged between 51-95% in Delphi Technique papers (von der Gracht, 2012). In response to the lack of clear scientific rationale underpinning a consensus threshold for Delphi Techniques, a systematic review by Diamond et al. (2014) identified 75% as a minimum threshold for consensus. Their reason was that this was the median percentage indicating consensus reported by those papers included in their study.

From the PPD results reported in Chapter Six, this threshold of 75% agreement or disagreement was observed for only two items rated for ‘importance’. However, the ModDT used in this PPD research aimed to create a greater level of understanding around the importance of therapeutic relationships. To this end, additional parameters were included. These included threshold mean and highest mode scores. These additional parameters aimed to understand more about the participant cohorts’ perceptions of the items than a focus on consensus alone would allow.

A final parameter included, introduced the concept of the ‘relevance’ of each item to an individual’s own circumstances. In addition to cohort consensus, mean and mode scores, relevance involved exploring the frequency of selection or deselection of items. This data made it possible to describe the ModDT findings with more meaning. By understanding what was important to rehabilitation participants, the findings would have a better chance of achieving the PPD’s intended aim of being able to influence local service provision.

7.5 The Professional Practice Doctorate Experience: Professional, Personal and Practical Perspectives.

Professional Practice Doctorates (PPD), were designed to close the gap between clinical practice and academic knowledge generation. PPDs enable practitioners to answer local questions in a ‘real world’ context through researching their own field of practice. Groundwater-Smith and Mockler (2007), propose that practice-based research should be collaborative and transformative, being able to justify itself to its community of practice. This PPD research considered clinical issues within the complexities of the local context. It was supported by a high level of collaboration with rehabilitation participants both as expert on, and participants in the research.

The ongoing participant engagement through research activities and informal communication allowed this continual sense-checking with the professional and rehabilitation participant community. This ensured that the topic remained relevant to practice (Wilkinson, 2020). While the PPD findings were relevant to the local context, suggesting less scope for generalizability, the study may still offer insights that rehabilitation providers in other specialities or settings could find useful.

Undertaking this research alongside full-time clinical practice, as an OT in cancer rehabilitation has simultaneously been one of the most challenging and rewarding experiences of my career. The remainder of this chapter explores my experiences from three perspectives. These included managing professional practitioner and researcher roles (Section 7.5.1), maintaining occupational balance during a PPD (Section 7.5.2) and considering the practicalities of undertaking a PPD (Section 7.5.3).

7.5.1 Managing Professional Roles

At the beginning of the PPD, I anticipated the potential for tension between my practitioner and researcher roles. I was particularly mindful of this possible role conflict during the SSIs. At times it was challenging to avoid straying into 'clinical consultation' mode. I discussed the strategies used for preventing this from negatively impacting on the research in Section 7.4.2.2. I had not anticipated that, as a result of reflecting on my research interview technique, I noted that the quality of my clinical interactions improved. By becoming more mindful of my interview style, I started to avoid interview pitfalls during practice-based conversations. Particular lessons that have remained with me include trying not to intrude on productive silences and making sure participants have finished before continuing the dialogue.

I was also particularly aware of the potential for pre-existing therapeutic relationships from practice to carry over into the research relationship. As my communication style in practice was relatively informal, this was how the research participants approached me in my researcher role. It was not possible to control for the transfer of this relationship into a research context. But I remained conscious of any impact that the relationship may have on the data analysis. There was the possibility that the pre-existing therapeutic relationship may have resulted in more disclosive responses from some participants. The freedom with which participants shared their thoughts during both SSI and ModDT gave me confidence that there could be synergy between my practitioner and researcher roles, as I began my initiation into the research community.

7.5.1.1 Initiation into the Research Community

An integrated, part-time approach to PPD research not only supports the development of research skills, but create links between academia and practice, and fosters the use of research enquiry in practice. I was reassured that I would not only maintain but enhance my practitioner identity. Practitioner-research offered the opportunity to view the workplace through a different lens.

This PPD was not just about producing a piece of research, or a change in service provision, but also facilitated the development of myself as an individual (Fulton, Kuit, Sanders, & Smith, 2012). Doctoral research has been likened to an intellectual apprenticeship into the research community (Kwan, 2009). I was not expected to be a research expert. I took comfort from the inference that my PPD was my novitiate, the gateway towards a research pathway or career.

During this PPD I found the resources provided by the Research Skills Development programme informative during the earliest phase of transition from practitioner to researcher. This programme reinforced my previous academic skills and abilities and introduced me to new academic skills and tools. These have been instrumental to the organisation and management of my research. This was one of the aspects I found most challenging.

7.5.1.2 Research Project Management

Having to negotiate the logistics of full-time clinical practice and part-time research, with its associated academic activities, was an unfamiliar challenge at the outset of this PPD. I found loosely following a project management formula helpful. I started to approach the PPD by first understanding my own internal needs and resources (e.g. time for self-directed research, planning and writing, energy levels, motivation levels and stress management strategies). Then I explored what external resources were available to me (e.g. time to undertake research activities, structured learning opportunities, and funding).

Once I had established clear role definitions for myself, I could then negotiate and manage the needs and expectations of my stakeholders, who came from two groups. The first were professional stakeholders and included clinical and academic colleagues. The second were personal stakeholders who included partner, family, and friends.

Finally, I tried to identify realistic goals and targets for the research 'deliverables'. One of the most challenging aspects of this project management approach, which is discussed in more detail in Section 7.5.3.3, was setting and adhering to project timelines.

7.5.2 Finding Occupational Balance Between Professional and Personal Roles

Supporting others to develop and maintain occupational balance was a mainstay of my practice-based role as an OT. I recognised the parallels between the strategies I recommended to others in practice and those I would need to manage a PPD. This prompted me to write an article for OT News, setting my intention to preserve occupational balance as practicable (Wilkinson, 2014b). These strategies included setting clear boundaries around time, activity prioritising, identifying assets within my supportive community, and making time for self-care. I needed to create a routine that was enabling and conducive to sustainable adherence.

One routine involved an evening 'homework' session for self-directed research and academic study that was familiar from my adolescence. This time was prioritised over other social activities, and meant I was able to prioritise weekend time for partner, family and friends. Another example was introducing early morning exercise for health and self-care. Despite not being a 'morning person', I found having an exercise buddy meant I was less likely to leave this essential component of my physical and mental health self-care out of my daily routine.

Some of these indicators are easier to measure than others. The use of tools including a fitness tracker, food and physical activity diary applications, my reflective journal and supervision have been invaluable. Looking back through the reflective journals, it is evident that this tool was not only effective in supporting the reflexive component of the research analysis. It contributed to maintaining my emotional wellbeing. It became a safe place to share thoughts. The following is an example of this at a time when thesis writing had fallen behind schedule, deadlines for conference presentations were due and my return to work and its associated pressures were imminent.

> *"I'm upset that I'm not holding everything together as well as I'd like to. I'm not doing very well with managing everybody's expectations – mostly mine" (Reflexive Journal: 20190610).*

On the whole I have been largely successful in managing the physical, emotional and social stressors throughout this PPD. My knowledge and skills as an OT provided a solid foundation from which to approach this challenge. I would encourage future PPD candidates to proactively invest in the development of their own health and wellbeing plan alongside their research plan.

7.5.3 Practical Considerations

There were four key practical considerations that had a significant impact on my experience during the PPD. The first was participant involvement, which has already been discussed in detail earlier in this chapter (Section 7.4.1). The following describes my experiences of managing the remaining three considerations which included language, funding and time.

7.5.3.1 Language Considerations

Compared with other parts of the country, there is less Welsh language spoken during clinical practice in the region of South Wales where this PPD research took place. None of the participants asked for the SSI or ModDT to be made available in Welsh. However, a small number of participants wanted to explore the semantics of certain key words related to the research during both SSI and ModDT. These discussions meant that it was important for me to negotiate a balance between academic terminology and language that the participants were comfortable using.

In a report by the National Literacy Trust (2019), low levels of adult literacy were highlighted across the United Kingdom. In response to their finding that one in eight or 12% of adults in Wales lack basic literacy skills, all research information and other print materials were checked using online readability software. This aimed to simplify the language used in print materials ahead of research invitation and recruitment to both the SSI and ModDT. The print materials were then proof-read by local rehabilitation participants to ensure that a balance had been reached between accessible, uncomplicated language, without the materials being perceived as patronising.

The following excerpts from my reflexive journal describe the insights and practical influence that this participant support had on designing the print media associated with the programme of research.

> *"I asked […], one of our ladies to read the consent / Pt Info Sheet. Her feedback was brilliant. Trying to marry academic content and readability (fatigue) has been the hardest thing for me. She has taken part in several trials already and I have halved the [number of] sheets in response to her feedback" (Reflexive Journal: 20150811).*

> *"…In talking with them I think the [research] title may be misleading or, rather, leading in nature and so I think I will have [something like] 'what is important for making life changes during cancer rehab?'" (Reflexive Journal: 20150813).*

The result of this compromise can be found in the print materials used throughout the programme of research (Appendix 11).

7.5.3.2 Research Funding

My PPD and research activities were funded using a portfolio approach. Funding sources included employer contributions, personal contributions, charitable funds, a teaching bursary and a UKOTRF research grant (Appendix 16). I did not choose this approach at the outset of the research. However, building a portfolio became necessary due to changing circumstances within my employing organisation and changes to my own employment status during the PPD. Having received a research grant meant this study became eligible for inclusion on the Health & Care Research Wales Portfolio and was allocated Study ID – 41653.

Finding the time and energy required for annual funding applications for tuition fees and the uncertainty around each years' funding were additional pressures during the PPD experience. In addition to this, assistance with practical research costs, including transcription and publication charges, which were not accounted for by tuition funding, demanded additional attention. The following excerpt describes the frustration that grew from the uncertainty as to whether the time required to complete a research grant application, would be worth the time not spent on research activities.

> *"This week I have continued to work on my UKOTRF research grant application… what a waste of time if I'm not successful!" (Reflexive Journal: 20180111).*

Working full-time alongside research did provide a secure income for the duration of my PPD candidature. Negotiating the balance between conducting research, undertaking teaching responsibilities and working in clinical practice, whilst not impossible, was demanding. The following excerpt from my reflexive journal describes how important having supportive colleagues was, in the situation not resulting in chaos.

> *"[… and …] have decided I do too much and I can't fight them as I'm too tired… they may have a point. I'm re-organising my work to make it easier, given all the leave and vacancies that are due to us in the next year" (Reflexive Journal: 20150715).*

Financial considerations are significant when undertaking a PPD. However, I felt the need to manage time was as important to the success of this project. The following explores my experience of the impact of time on a PPD.

7.5.3.3 Time

The PPD offered me one significant practical advantage over a full-time PhD route. This was time. I have consistently underestimated the time it takes to complete any and all research activities, from IRAS applications to data collection, analysis and writing this thesis. Using a thesis guide moved my innate 'scatter-gun' approach to everything from preparatory reading, research activities and thesis writing to a more systematic, structured approach (R. Murray, 2011). Helping to make the most of the time available and optimise productivity.

It was demanding, trying to balance PPD, work and life over seven years. However, I felt that this meant there was less pressure than a traditional PhD, when waiting for each research activity to be completed before starting the next. This was a topic discussed in supervision, where the academic supervisory team reinforced the importance of this 'luxury' of being able to take time over the research. My academic supervisory team encouraged me to avoid allowing the pressure of timelines to stifle creativity (Supervision: 15/12/2017). The trade-off for not having this pressure, was the need for dogged perseverance, as the self-talk from a reflexive journal entry describes.

> *"It doesn't matter how hard work is or how tired I am, I won't finish my PPD if I don't keep going!" (Reflexive Journal: 20180205).*

There is a natural ebb and flow of a PPD, much like any endurance event. There were times when the research or writing were my priority and times when work or home-life took precedence. The following excerpt from my reflexive journal describes a period of time when a change in job, moving to a new house or needing some self-care all demanded my attention.

> *"I will finish my novel tonight and then crack on with doing all of the things that I need to do for my PPD. It's taken a backseat to life and work so far this year, now I need to give it some time" (Reflexive Journal: 20160717).*

One of the ways that was particularly helpful in providing the time to focus on the thesis preparation was by taking a research sabbatical. This time away from work reduced the demands placed on time and energy and was the catalyst for shaping the research thesis. Uninterrupted time to interrogate the data and integrate the findings into a cohesive story was invaluable. The following describes this occurring as the thesis took shape.

> *"The results are starting to fall into place… now just to get them all written down in some coherent fashion" (Reflexive Journal: 20190610).*

7.6 Summary

Reflecting on the undertaking of this PPD research, I have seen that my practitioner and novice researcher roles have shared common skill sets. Making the most of these transferrable skills has improved my performance in both roles and made research design and data collection relatively uncomplicated to implement alongside clinical practice. I feel these will be invaluable as my research career evolves. The findings from this PPD have influenced my recent working roles, informing conversations which aim to shape the strategic direction of cancer rehabilitation in Wales.

Adopting a project management approach to undertaking the PPD has been helpful. There has been a need to consider how to manage the competing demands on both internal and external resources. Negotiation with personal and professional stakeholders was essential. This created a community which provided support throughout the duration of the PPD.

Throughout this PPD process I have been reassured that therapeutic relationships are not only influential in delivering outcomes following clinical intervention. They also have the potential to significantly influence practice-based research outcomes. Collaborating with rehabilitation participants as partners in this PPD provided the benefit of their unique perspective. It was also instrumental in many of the successes relating to recruitment and response rates. This level of collaboration is a feature that I will build into future research projects.

For other novice research-practitioners considering the prospect of applying for PPD candidature, I would offer my enthusiasm and encouragement. The richness from the proximity of research in practice has shaped my role as a practitioner-researcher, added depth to these findings, and to my learning, that may never have emerged from a PhD route. This chapter has explored the reflective and reflexive aspects of this PPD research. The next and final Chapter Eight, presents an integrated discussion of the ILR, SSI and ModDT findings. This discussion builds on the reflexive position presented above and culminates in the conclusions drawn from this PPD research.

Chapter Eight: Discussion and Conclusion

8.1 Introduction to Chapter Eight

The primary function of this thesis was to present the findings of PPD research, which explored the importance of therapeutic relationships in the development of SM behaviours after cancer rehabilitation. The three PPD research activities included an Integrative Literature Review (ILR), Semi-Structured Interviews (SSI) and a Modified Delphi Technique (ModDT). This final chapter weaves together the key findings from these three research activities. Implications of these findings for research, practice, and policy will be discussed, highlighting considerations for further research. The strengths and limitations of the study are presented, with a discussion of potential biases and actions taken to address these. The chapter closes with an overview of informal opportunities for the dissemination of findings and the key conclusions drawn from this PPD research.

8.2 Integrated Discussion of Main Findings

The ILR findings highlighted that, to date, there had been limited evidence describing the importance of therapeutic relationships on SM behaviour change in a cancer rehabilitation context. There was evidence relating to the importance of professional characteristics on the performance of healthcare professional roles, and the development of therapeutic relationships. However, this evidence had not yet incorporated a discussion around the impact of either professional characteristics or therapeutic relationships on SM outcomes after rehabilitation (Rowe, 2015).

The PPD research presented in this thesis has been successful in exploring the importance of therapeutic relationships from the rehabilitation participants' perspective. This is a perspective which was not represented in the ILR. It has described the factors which act as either barrier or enabler to therapeutic relationships. By exploring theoretical models, this PPD research has also started to describe potential mechanisms through which therapeutic relationships influence SM behaviour change.

There were three broad themes which emerged from the three PPD research activities. The first was the importance of professionals to be well prepared for their role. This included the potential impact of personal attributes and characteristics as barrier or enabler of therapeutic relationships. The second related to the complexity of creating, maintaining and dissolving successful working partnerships, as the vehicle for supporting participant ownership over their SM behaviours. The third reflected the tension around professionals needing to be simultaneously adaptable in their practice, whilst maintaining authenticity in their approach to therapeutic relationships. This third theme identified the need for clear boundary setting within each therapeutic relationship for the safety and wellbeing of both professionals and participants.

In addition to these key themes, this study was able to highlight some of the potential benefits of participant involvement in research design on recruitment and response. Whilst this PPD research was able to present qualitative data supporting the participants' perspective of the impact of therapeutic relationships on SM outcomes, this thesis was not able to capture or describe the quantitative impact of therapeutic relationships on SM outcomes. The study was also not able to describe the professionals', family or carers' perspectives.

Remarkably, the themes which emerged from the three phases of research reported in this thesis have reflected Gelso's (2014), tripartite model of therapeutic relationships. This model was developed within the clinical context of psychotherapy. Used in Chapter One to contribute to the concept definition of therapeutic relationships, it was not employed to directly shape the research infrastructure as Self-Determination Theory (SDT) was. However, together, they offer a complementary lens through which to explore the following discussion of each theme.

8.2.1 Well-Prepared Professionals

The first theme to emerge from this research identified the need for professionals to be well-prepared for their role as a healthcare or rehabilitation professional. This theme recognised the essential impact of professional attributes and characteristics on the development of therapeutic relationships and the subsequent compatibility of these with participants. Research participants highlighted the need for the 'right type of person' as a pre-requisite for professionals, perceiving many of the attributes or characteristics to be innate rather than learned. Professionals' knowledge and skills were seen as important over and above this baseline requirement for the right type of person. However, the fundamental need for professional attributes and characteristics to be conducive to supporting trust and confidence in therapeutic relationships was seen as essential for delivering outcomes.

8.2.1.1 Professionals Need to be the Right Type of Person

In the SDT framework, this need for relatedness is seen as the conduit for change. To form the level of connection and trust that could enable internal motivation to develop, rehabilitation participants need to feel respected, cared for and understood (Ryan et al., 2008). This foundation level of connection is described by Gelso (2014), as the 'real relationship'.

The personal qualities, attributes and behaviours of professionals which contribute to the connection described above, were represented in almost all of the papers included in the ILR. These characteristics included warmth, friendliness, empathy, honesty, sincerity, trustworthiness, portrayal of interest, effort and enthusiasm in their role. The importance of these attributes and characteristics were echoed by participants of both the SSIs and the ModDT.

The fundamental connection between professional and participant on a human level was identified as important, but there was an additional need for compatibility between professional and participant attributes. In a practical sense, there is no way of ensuring a complementary match between professional and participant at every contact. However, there may be an opportunity to inform recruitment procedures around the selection of healthcare personnel with the desired personal attributes. The potential to incorporate personality-testing in healthcare recruitment procedures has been identified as a potential solution to selecting ‘the right type of person’. This might go some way to support this research’s assertion that these form the foundation for well-prepared professionals (Health and Care Professions Council, 2014). However, this proposal was seen as needing significant work to ensure the validity and reliability of selection procedures and outcomes.

Additional characteristics or attributes, were not identified by the research described in this thesis, or the wider cohort of adult rehabilitation participants. These included professionals’ desire to seek continuous improvement within their practice, contribute to their development of their identity as a professional ‘being’, and metacognition and self-regulation which attends to and evaluates one’s own practice (Cutting & Saks, 2012; Kayes et al., 2015; Rowe, 2015). These aspects might be interpreted as the infrastructure for deep learning. Deep learning incorporates the ability to reflect in and on practice, and engage in complex reasoning processes. This involves the interplay between factual knowledge, social and ethical context, and understanding the needs and wishes of their participants (Meeks, Williams, Knotts, & James, 2013).

Without the ability to manage this complex reasoning process, there is a risk that professionals would default to providing technical knowledge and interventions ‘to’ participants. This is likely to influence the individuals’ identity as a professional being. Which may be passed on through educational processes including role modelling and practice-based education. This poses a challenge to healthcare employers, as a generational difference in aptitude for deep learning has been noted (Meeks et al., 2013), and may need to be considered within the recruitment and selection process.

8.2.1.2 Recruitment and Selection

Cancer rehabilitation is a multi-factorial, set of complex interventions, requiring the ability to simultaneously apply healthcare knowledge and skills, and develop meaningful therapeutic relationships with people who will need to learn SM strategies to support their long-term health and wellbeing. However, the question remains as to whether current selection processes for tertiary institution training places, based on academic achievement and healthcare recruitment procedures, based on similar achievement-based criteria, are designed to identify the most suitable candidates?

Whilst not directly discussed throughout this PPD research, but learning from the value of participant involvement in this research, there may be some benefit from involving healthcare participants in the recruitment process of healthcare undergraduates and professionals. Participants could inform recruitment decisions by contributing their view of professional characteristics in the context of the wider considerations of skills and other attributes. The positive impact of children and young people being involved in professional recruitment has resulted in guidance being developed to support for their inclusion in the NHS recruitment process (Ball, 2017; NHS Employers, 2015).

There was little evidence describing the benefits or risks of this approach in adult services was identified to inform this discussion. Guidance around supporting participant involvement in service design and improvement did not include the opportunity for participation in recruitment of professionals (Wales, Government, & Healthcare, 2010). It is essential to acknowledge that the involvement of healthcare participants in professional recruitment may not be a viable solution in healthcare organisations recruiting ‘the right people’. Before seeing this as the solution to ensuring that professionals are able to engage participants in meaningful therapeutic relationships and compatible working partnerships. There are a complex range of contributing factors including required skill mix, existing service demand, and pre-existing workforce barriers including rurality, that need to be taken into consideration.

8.2.1.3 Learning and Development

Preparing professionals for the relational aspects of healthcare at undergraduate and postgraduate levels is an essential aspect of the well-prepared professional (Hechinger et al., 2019). How professionals are currently supported to develop this relational aspect of their practice varies in both availability and quality. Mechanisms include formal education and training, workplace experience, or transference of previous relationships. Describing how professionals learn relational skills was outside the scope of this PPD. However, understanding this aspect of professional development would benefit from further post-doctoral exploration.

Over half of the papers included in the ILR described professional skills as influential in developing therapeutic relationships. Of all skills and tools, communication was one of the most influential described. The SSI themes included the importance of cancer-related knowledge and feeling ‘understood as a person’. There was complex interplay between the message and the method of communication, which was perceived as important to the development of therapeutic relationships.

This finding should not be interpreted as a recommendation for all professionals to undergo pedagogic training in communication skills. However, there is a need to support professionals to integrate self-awareness of their personal characteristics, behaviours, knowledge and experiences, with the skills for building, managing and dissolving therapeutic relationships. Participants in the ModDT concurred that the ability to undertake effective communication, required a balance between personal attributes, and the foundation knowledge enabling the translation of the medical context into meaningful terms.

The implications of this research may affect how we approach education and training for both pre- and post-registration professionals across the multi-disciplinary team. Providing a consistent approach to supporting this aspect of professional learning and development may be key to improving rehabilitation outcomes and would be considered a priority for future research, and training development.

8.2.1.4 Organisation and Systems

Over thirty years ago Kaplan et al. (1989), described the risk that healthcare system modernisation posed to preserving therapeutic relationships in practice. Given the recognition that the demand on the NHS has grown beyond expectation, there is continued momentum behind healthcare transformation (O’Dowd, 2017). Organisation and systems-related pressures continue to place professionals under increasing pressure to meet rising demand with little additional resource.

Dowling (2006), suggests that organisational factors may have resulted in behavioural boundaries which prohibit the development of therapeutic relationships in nursing. While the boundaries may have been organisational in origin, she proposes that they are reinforced by the professional peer group. Success in breaking down these obstacles to effective therapeutic relationships is likely to require a complex blend of training and education, professional self-awareness and practice experience.

The impact of this pressure on professional behaviours and attitudes may result in participants seeing professionals as unapproachable, not dedicating the time and energy to cultivating working alliances. It may also result in professionals defaulting to de-individualised protocol-driven care. The result of which may prevent participants seeking support, to avoid ‘being a burden’ on time-poor professionals. The impact of organisational or systems pressures was not reflected by either the findings of the ILR or the ModDT. However, some of the SSI comments suggested that professionals have been successful, whether intentionally or not, in educating participants to believe that they are under pressure and have ‘no time’.

This pressure is related to, but differs slightly from, the impact of time and timing on therapeutic relationships which will be discussed in the next section. As it reflects the professionals’ level of resilience to organisational and systems pressures, and the resulting impact on the preservation of a person-centred approach. Future research considerations could build on the findings in this thesis by understanding the barriers and facilitators to therapeutic relationships in practice from the professionals’ perspective. Any evidence generated could be pivotal to navigating tensions between the provision of PCC policy in a context of increasing organisational pressures.

Five of the top ten research priorities from the research reported in this thesis, describing professional attributes, behaviours, knowledge or skills, were also reflected by a wider cohort of adult rehabilitation participants across the UK (NHS England, 2015). This suggests that there may be some opportunity to consider the relevance of these findings, at least in part, across a broader UK rehabilitation context. The wider cohort also reported procedural aspects of rehabilitation as important. These procedural aspects included professionals’ communication with each other, inclusion of family members and informal care givers, goal setting and measurement, and streamlining of participant information about, or access to, rehabilitation services. Whilst these were discussed by participants in all three phases of this PPD research, they did not reach a consensus of importance with the local cancer rehabilitation cohort. Poorly coordinated systems and information were described by a small number of SSI participants as a source of frustration.

Despite the smll numbr of responses, the impact of inefficient and disjointed systems must not be interpreted as unimportant. For these are the mechanisms through which greater capacity to provide personalised rehabilitation may be created. This thesis was initiated with the aim of influencing improvements in clinical practice. These results have the potential to influence the shape of future models for clinical practice which celebrate the partnership between healthcare professionals and participants. Thereby protecting cancer rehabilitation from service rationalisation and de-personalised care.

Welsh health and social care policy (Welsh Government, 2018), continues to promote a significant shift towards more community-based service provision. This suggests that the interplay between professionals' skills and knowledge and their location in physical rehabilitation environments may become more prominent. The potential impact of this policy shift for future service models, workforce planning and provision will be key considerations that will influence my role within HEIW. There was insufficient data in this research to categorically suggest that participants did or did not feel the need for dedicated physical environments in which to undergo rehabilitation. The importance and impact of access to suitable rehabilitation environments would benefit from further investigation. As would the use of digital media and technology, as a source of increased capacity for more personalised care.

8.2.1.5 Digital Media, Technology and Telemedicine

The growing use of digital media, remote access technology and telemedicine within healthcare and rehabilitation, especially in rural or remote areas, is likely to affect the design and content of professional learning and development opportunities. There is growing evidence supporting home-based interventions which make the most of this technology for PABC (Cheng, Lim, Koh, & Tam, 2017). Mechanisms for enabling remote access include web-based and smart phone applications, artificial intelligence and virtual or augmented reality. The adoption of digital solutions to support the provision of rehabilitation was suggested by ModDT participants. This feedback may be useful in guiding the service improvement activities undertaken by the local service in future.

How therapeutic relationships differ during digital interventions or the use of remote access technology, compared with face-to-face rehabilitation provision, did not fall within the scope of the research programme reported within this thesis, as these technologies were not employed by the local cancer rehabilitation service. However, digital media and technology in health is gaining traction in Wales, as a possible solution to supporting a greater number of people without a significant increase in healthcare resource (Chartered Society of Physiotherapists, 2018).

Following the COVID-19 pandemic early in 2020, the increased use of virtual consultation in Wales was accelerated. The approach to supporting people ‘virtually’ may require a further adaptation of existing professional skills and characteristics. Digital engagement can make building relationships more challenging. Further exploration is required to determine what would ensure the formation and management of effective therapeutic relationships and compatible working partnerships in virtual contexts. The findings of this PPD research have been instrumental in shaping early conversations within HEIW, regarding the provision of pre- and post-registration training, to support this transition to new ways of working.

8.2.2 Compatible Working Partnerships

The second theme to emerge from this PPD research reflected the complexities of creating, maintaining and dissolving successful working partnerships. This included the development, maintenance and dissolution of therapeutic relationships, and their subsequent impact on rehabilitation outcomes. It also addressed the transition or handover of healthcare or SM ownership from professionals to participants. This included participants’ readiness to make behaviour and lifestyle change. And the potential for participants to self-select ‘compliance’ with aspects of SM advice that are meaningful and compatible with their social context.

The compatible working partnerships described by the participants of this research echo the working alliance of Gelso’s (2014), tripartite model of therapeutic relationships. This component of the relationship is seen as the catalyst for change. As participants progressed through rehabilitation, the impact of therapeutic relationships shifted from building trust between professional and participant, towards building participant confidence and self-esteem, thereby commencing a process of internalising motivation (Ryan et al., 2008).

The importance of this transition was reflected in the findings of the ILR where working partnerships were described in almost three quarters of the ILR papers. This is potentially the visible aspect of the therapeutic relationship. It is characterised by determining agreed roles, goal setting, action planning and active involvement in decision making which is acceptable to both parties.

In the results of the SSI and ModDT, the working partnership was not explicitly identified as a priority for the local rehabilitation cohort. However, throughout the findings, the participants proposed that a compatible working partnership was the consequence of professionals being well-prepared for their role. Participants appeared to describe a minimum level of expectation for how rehabilitation and other healthcare professionals would interact with them.

There were nuances described throughout the PPD research that suggested that the therapeutic relationship did, and must, change in response to the stage of rehabilitation. There were some attributes and behaviours which were welcomed at some points in the rehabilitation pathway, or stage of participant change than others. For a professional to read the needs of the participant wrong and act in a way that was incompatible with participant need, posed a risk that the working partnership might be torn. However, it has been proposed that the dynamic nature of tearing and repairing the working partnership is what makes it so effective in facilitating change (Gelso, 2014; Ryan et al., 2008).

8.2.2.1 Creating, Maintaining and Dissolving Working Partnerships

All three phases of PPD research, reported an emphasis on the development and maintenance of therapeutic relationships or working partnerships. The associated discussions may have addressed factors influencing either the presence or absence of therapeutic relationships or working partnerships. However, none of the papers in the ILR and none of the findings of the SSI or ModDT reflected an expectation that the working partnership should be consciously dissolved, alongside the facilitation of participant confidence, self-esteem, resilience and ownership of their SM outcomes. In a study conducted by Ashton (2016), investigating the dissolution of therapeutic relationships in nursing, very little research had been published on the topic since the 1960’s.

If the role of cancer rehabilitation is to foster a sense of SM and ownership over the future (Silver, Baima, Newman, Galantino, & Shockney, 2013), then it follows that the working partnership with professionals must come to an end. For some individuals this may take place automatically and with little emotional discomfort. For others, a potential consequence of not dissolving the working partnership well, is the perpetuation of dependency on professionals, or the creation of emotional discomfort which may negatively flavour working partnerships with healthcare professionals in the future (Ashton, 2016).

The ModDT participants described the impact of the working partnership as participants build trust, confidence and self-esteem during rehabilitation. It might be inferred from the discussion relating to preparedness of professionals, that the right preparation for managing the dissolution of working partnerships would follow a similar process as building partnerships. This means gradual negotiation of expectations in response to participant change. However, for some participants, their experiences of traumatic disengagement from rehabilitation, might suggest that professionals were not prepared to handover ownership of rehabilitation outcomes to participants (Murphy & Joseph, 2013), or participants were not ready for change (Prochaska, 2008).

8.2.2.2 Ownership and Compliance

At the outset of rehabilitation, therapeutic relationships have the potential to be fundamentally unequal. One partner has a need and the other has the means for supporting them in overcoming that need, thereby creating a power imbalance (Murphy & Joseph, 2013). However, the aim of rehabilitation includes the handover, or transition, of ownership or power from professionals to participants. This handover relies on participant confidence and resilience to continue with sustainable behaviour change outside of the rehabilitation setting.

This PPD research identified two potential barriers to achieving this handover of power and ownership. The first offers a narrow view of SM, as it relates to professional assumptions that participants should accept and adopt professional recommendations as they are prescribed (Dwarswaard et al., 2016). Three papers within the ILR reported findings which interpreted ‘patient non-compliance with professional recommendations’ in terms of ‘failure to self-manage’ (Dunne et al., 2018; Schulman-Green et al., 2012; Wood et al., 2013). These authors used language such as struggling to integrate SM behaviours into daily life (Dunne et al., 2018);

barriers to change (Wood et al., 2013), not achieving proficiency or being unsuccessful achievement of SM outcomes (Schulman-Green et al., 2012).

This perspective does not recognise healthcare participants as experts in their healthcare experience, family, work and life roles. This view of SM does not allow people to adapt health needs or accommodate recommendations for change into their life by assessing compatibility with the rest of their values and beliefs, the logistics of daily demands, and view of themselves within their life context. This assessment is essential if participants are to become responsible for the conscious decision-making which accepts the consequences of adjustments or adaptations to original professional message.

The second potential barrier to participant ownership and the transition or handover of power is related to this concept of compliance and is born from professional identity and the associated need to ‘look after’ others. Murphy and Joseph (2013), propose that professionals who actively seek to hold onto power within the therapeutic relationship, out of a well-intentioned drive to care for the participant, are compromising the therapeutic nature of the relationship and therefore compromising the outcomes of intervention.

In recognition of the long-term and late-onset needs that PABC will be increasingly experiencing, there is an additional value in dissolving the working partnership well. Dissolving the working partnership well can go some way to preserving the experience of the therapeutic relationship, thereby creating conditions which enable participants to seek advice and support, if required in future, without fear of being perceived as having failed in their SM. This is reflected by the participants’ feedback explaining the importance of being able to directly access services in future, if and when their condition changes.

Participants being able to directly access the services they need, when they need them, without having to navigate gatekeepers in either primary or secondary care, has the potential to unlock value from the rehabilitation pathway. There is a drive within healthcare policy in Wales to embed the voice and needs of healthcare participants in future services (NHS Confederation, 2018). The findings of this PPD research would seem to support the priorities embedded within Value Based Healthcare, which seek to re-dress the ownership of SM.

Tailored rehabilitation options and direct access to advice and support may go some way to instilling confidence for both healthcare professionals and participants. But both of these conditions require the sound management of the working partnership from initiation through to, and including, dissolution. This finding warrants further investigation within a Value Based Healthcare context. For it may help to inform future models of practice which enable both direct access and tailored rehabilitation.

8.2.2.3 Tailoring Rehabilitation: Participant Readiness for Change

Embedding a value-based approach in cancer rehabilitation would see the systematic use of behaviour change theory in practice. Transtheoretical Model (TTM), an integrative biopsychosocial model of intentional behaviour change (Prochaska, 2008), describes the stages of participant readiness for change. This model suggests that until people are in a state of preparation or activation, the focus of professional support should be informative and educational. The aim of which is to support the person to transition towards a state of readiness. When ready, a more involved therapeutic intervention would have the potential to have the greatest impact on SM.

The impact of therapeutic relationships during the pre-contemplative and contemplative stages still have the potential to influence change. For it is in how these stages are managed, without judgement or criticism, that may influence a person’s transition to preparation. The challenge of the TTM is that it only takes into account the individual’s readiness for change, it does not consider the wider social, cultural or contextual influences on behaviour change.

Self-Determination Theory offers a more harmonious approach to internalising motivation towards long-term sustainable behaviour change. It recognises that change must positively impact on the individual’s wellbeing. This is a unique perspective which accepts that an individual choosing not to change their behaviour, or autonomous non-compliance, may be a positive outcome (Silva et al., 2014). However, together TTM and SDT could offer the language to support individuals to make decisions regarding their health behaviour, in context, that does not then compromise their confidence in seeking professional support should it be required in future.

The Capability, Opportunity and Motivation Behaviour change model (COM-B) (Michie et al., 2011), is an emerging theory which offers the opportunity to tailor SM or behaviour change interventions during rehabilitation to the individual, contextual and motivational needs of the participants. Guidance supporting professionals to adopt this tailored approach was developed soon after this research commenced (National Institute for Health & Care Excellence, 2014). This model, whilst predominantly developed within a public health behaviour change context, offers professionals practical guidance to aid understanding the specific drivers for, or against, behaviour change in order to tailor intervention appropriately.

The impact of poorly tailored interventions includes the potential for the working alliance to be compromised by incompatibility between participants' state of internal motivation for change and the motivational requirements of the rehabilitation interventions prescribed (Prochaska, 2008). In practice, low participant motivation paired with an intervention that requires high internal motivation, may either alienate the participant and delay handover of rehabilitation ownership. This can result in a sense of participant abandonment on leaving an episode of rehabilitation and associated conflict during the dissolution of the therapeutic relationship.

Recognition of participant activation, readiness for change, and behaviour change theory can help professionals to tailor the level of rehabilitation intervention to the participants' preparedness to embark of a process of change. Frameworks such as TTM and COM-B, which seek to understand the resources and restrictions surrounding individuals who access rehabilitation services, may help to support professionals to articulate their reasoning for adopting interventions to educate or persuade individuals who are not yet ready for training, modelling or enablement interventions.

There are two benefits from adopting this approach. The first is the prudent use of limited rehabilitation services to support the achievement of optimal participant outcomes. The second is tailoring a suite of interventions for participants who are not yet ready to engage in a full rehabilitation programme. This would aim to meet their individual needs without the risk of them disengaging from support services or creating barriers to accessing services in the future, when their level of motivation reaches stage where rehabilitation would be a suitable intervention. This may account for some of the responses which emerged from the ModDT participants who expressed a preference for continued contact with professionals after their episode(s) of rehabilitation had ended.

Ideally, the ultimate impact of the working partnership would be to support the development of participant resilience. This resilience would enable the gains made during rehabilitation to be sustained beyond engagement with the formal programme. A systematic approach to assessing internal motivation, and access to an alternative suite of interventions, tailored for participants with lower internal motivation, may support professionals in their decision to not include participants in rehabilitation activities until they are ready. It also has the potential to increase professional confidence in handing over ownership of SM and rehabilitation outcomes as they grow to recognise the growth of internal motivation and resilience. Finally, this infrastructure would offer the opportunity to measure progress to enable inclusion in rehabilitation at the most suitable time, and a language with which to communicate this aspect of readiness with the wider multi-disciplinary team.

8.2.3 Balancing Professional Authenticity and Adaptability

The third theme to emerge from this research, reflected the transfer of previous relationship experiences onto the therapeutic relationship, by both professionals and participants. Professionals need to be consciously aware of this transference, its impact on the working partnership and subsequently on rehabilitation outcomes. There are two aspects to transference and countertransference that professionals need to consider. The first is recognising and negotiating potential tensions which might arise from professionals having to balance being both authentic and adaptable during clinical interactions. The second is navigating and managing the behavioural boundary between themselves and participants within the therapeutic relationship. Both of these are essential to preserve the safety and wellbeing of both parties during rehabilitation.

8.2.3.1 Professional Chameleon

The findings of the ILR highlighted conflicting messages between the importance of healthcare professionals’ being adaptable to participants’ needs and their ability to maintain authenticity during clinical interactions. Unfortunately, none of the papers included in the ILR, presented findings which could inform the discussion around this perceived tension. Both adaptability and authenticity were highlighted by research participants in both SSI and ModDT. They did not necessarily recognise the potential conflict for professionals in managing these two potentially polar behaviour sets. However, they did provide insight into the value they attributed to both professional adaptability and authenticity. By exploring their contribution alongside Taylor's (2008), Intentional Relationship Model, it is possible to reconcile adaptability and authenticity, so that they can be seen as complementary. Congruence between adaptability and authenticity can occur when professionals adopt a critical self-awareness as to how their personalities align with different therapeutic modes and how they integrate them into their clinical practice by matching different modes with the needs of their rehabilitation participants.

Throughout this PPD research participants have applauded the professionals' ability or criticised the inability, to adapt to each of their individual needs. In order to treat each person as an individual, it is essential for professionals to understand how participants prefer to engage and adapt their approach accordingly. Participants valued this adaptive approach, especially during group interventions, as some people preferred to be pushed, others preferred a gentler approach. Adjusting these approaches reflects the therapeutic modes described in Taylor's (2008), intentional relationship. These modes range from encouraging to collaborative through to instructing.

Superficially, it would seem incongruent that professionals could adapt their approach without appearing fake or insincere. During one of the SSI, a participant's partner described the professionals as adopting a 'chameleon' approach to negotiating these seemingly opposing traits.

Taylor (2008), highlights the role that the professional's personality will play in determining which mode or approach they default to. All modes are deemed to have the potential to facilitate therapeutic outcome, unless it becomes inflexible, is not congruent with the participant's progress, or is incompatible with the needs or personality of the participants. Interestingly, one of the SSI participants described how participants' take the initiative to select the professionals with whom they felt most able to connect and direct their questions according to the approach required.

Research participants largely described having enjoyed the vibrant approach that some of the rehabilitation professionals innately demonstrated. However, whilst humour and banter played a large role in this vibrant approach, there was also value placed on the professionals’ ability to moderate their behaviour when participant need required. Even for some of the most energetic and driven of rehabilitation participants, there is the potential for an unexpected action or situation to trigger a complete change in approach.

Some healthcare professionals appear to experience a dilemma relating to contrasting perceptions of what being authentic and being adaptable, or a ‘professional chameleon’, might mean in practice (Aranda & Street, 1999). These authors identified professionals’ discomfort with adaptability, describing it as a perceived loss of integrity or genuineness when altering interaction style which included adapting vocal tone, conversation topic. This discomfort also extended to being selective about which aspects of oneself are or are not shared with healthcare participants. This aspect relates closely to boundary setting and will be discussed in the next section.

This restrictive view implied that being a professional chameleon might mean that a professional adopts an alter-ego or artificial identity. Pretending or acting in a role, that is not consistent with the professional’s personality, values or beliefs may result in them inadvertently compromising their authenticity and integrity. This goes some way in explaining some of the participants’ experiences of professionals who were perceived as either uncaring or insincere.

Some possible reasons for professionals to default to an inflexible approach or artificial persona include professional burnout, frustration, negative past experiences, or lack of ability or understanding in managing the transition between therapeutic modes and approaches (Taylor, 2008). Whilst it is impossible for any professional to navigate the chameleon role faultlessly, striving to integrate therapeutic modes which are compatible with their personality is an essential starting point for all healthcare professionals.

Hechinger et al. (2019), propose that professional adaptability is informed by previous experiences of clinical interactions and social relationships, and rather than changing oneself, professionals are ‘multi-beings’ influenced by education, training, social and cultural background. Which offers all professionals the opportunity, through developing self-awareness and further training, to improve their ability to engage, manage and dissolve therapeutic relationships. Participants appear to hold more value in professionals behaving with authenticity and integrity, in a way that was in keeping with their personality, than some ideal or persona of a perfect healthcare professional.

Participants celebrated professionals who behaved with authenticity within their therapeutic relationships. The value of reinforcing their worth as more than a ‘cancer patient’, being open and honest during information sharing, and displaying genuine emotion were seen as the underlying traits of authenticity. This was seen as a dynamic and reciprocal aspect of the therapeutic relationship.

Some participants or professionals may seek to develop a greater level of intimacy within the therapeutic relationship than is conducive to effective therapeutic outcomes (Taylor, 2008). It is in this situation that a lack of clear behavioural boundaries can result in harm to either or both parties. In addition to learning how to navigate and transition between therapeutic modes, professionals also need to understand the practicalities of managing the associated boundaries that keep the therapeutic relationship safe and effective.

8.2.3.2 Navigating Therapeutic Boundaries

Within Taylor’s (2008), intentional relationship framework, professional boundaries is the term used to describe the protective mechanism which aims to ensure that neither professional nor participant seeks to use the therapeutic relationship to fulfil emotional or psychological needs that are beyond the scope of the therapeutic environment. These boundaries aim to provide reassurance that neither party will be subject to exploitation or manipulation. They prescribe the limits of the therapeutic relationship and help to set behavioural expectations for both professionals and participants, describing how the relationship will be conducted. For the purposes of representing the reciprocal nature of the benefits of these boundaries better, within this discussion, they will be referred to as therapeutic or behavioural boundaries.

Therapeutic boundaries were not discussed by any of the papers included in the ILR. However, their importance was highlighted by a small number of SSI participants. This may reflect that only a small number of participants felt that boundary setting was important, or it may reflect that there was an assumption that professionals within the team took an active role in monitoring and managing therapeutic boundaries in practice. One of the consequences of poorly managed therapeutic boundaries is the potential compromise of the therapeutic relationship and subsequently rehabilitation outcomes.

Interestingly, many of the other themes within the discussion have been supported by data contributed by women. This theme, particularly around boundary setting, saw a greater contribution from older men. For the duration of rehabilitation included in this research, the professionals who provided the local rehabilitation service were predominantly female, most of whom were under forty years old. It is possible that this finding reflects a protective instinct in the men. Of note, this protective attitude did not appear to extend to the older members of the team. Their comments suggested that experience plays a part in learning to navigate the therapeutic boundaries.

The ModDT data did not add any remarkable contributions to the discussion around therapeutic boundaries either. It may, therefore, seem a redundant discussion topic. However, professionals’ poor awareness or skill in navigating therapeutic boundaries may not only make balancing adaptability and authenticity more difficult, it can lead to professional stress and burnout (Lawton, Lawton, Stevens, Dietz, & Weis, 2019). For it raises the following questions. If therapeutic relationships are reciprocal in nature, then where does the boundary lie? How much of themselves should professionals share? And how do novice professionals learn to make the decision about what is shared and what is not? (Aranda & Street, 1999).

The Intentional Relationship Model (Taylor, 2008), goes some way to offer guidance for professionals in terms of understanding and managing therapeutic boundaries. This guidance describes a relationship, which was more formal than the style of therapeutic relationship cultivated within the local rehabilitation service. The reasons for this remain unclear and would require closer examination. This theme has raised more questions than it has answered.

As so little research has been undertaken within OT or rehabilitation settings around therapeutic boundary setting, it is important to explore a contemporary professional perspective on this (Ashton, 2016). There needs to be a better level of understanding into how these skills are developed by less experienced rehabilitation professionals and how they evolve for experienced professionals. There is the potential to develop more understanding into how existing mechanisms, such as supervision, can be used during training and on entry into practice to safeguard the wellbeing of novices. Supervision can offer a safe opportunity to explore their own personalities, develop a level of self-awareness, and make the decisions regarding where their boundaries lie (Ashton, 2016; Lawton et al., 2019).

8.2.4 Re-Defining Peer Group Identity

There was a fourth theme to emerge from this PPD research which relates to the local rehabilitation participants' view of who they saw as their 'peer' group and the importance of spending time with peers during rehabilitation. Although not reported by the ILR, some of the SSI participants described a reluctant sense of belonging to an exclusive fellowship following their cancer diagnosis. These connections were valued for enabling participants to discuss their thoughts and feelings with people who could empathise.

Surprisingly, the statement regarding the importance of spending time with peers polarised ModDT participants, with some valuing contact with peers as a means of overcoming feelings of loneliness and isolation. And others reporting that spending time with people who have had similar experiences can increase the emotional burden of a cancer diagnosis.

Qualitative research undertaken with similar cancer rehabilitation cohorts in South Wales have also highlighted the value that participants associate with peer relationships (Csontos, Roche, & Watts, 2019). However, there was insufficient consistency within the ModDT data to give a clear picture as to how to interpret the role or value of relationships with peers. Understanding how participants feel about who they share their rehabilitation time with is important as it has the potential to impact on the recovery process itself, as described above. It also offers potential alternatives to the current design of rehabilitation services, which might see benefits to healthcare providers and host organisations.

Some of the ModDT participants highlighted an interesting perspective which challenges historic approaches to 'disease pathway' service design. This was that rehabilitation could be perceived as a pathway of its own. The common ground for participants on this rehabilitation pathway would reflect their progressive momentum towards recovery, management or maintenance, SM and a re-defined future. In contrast to a regressive fixation on the disease, its symptoms, consequences and stigmas.

Service re-design which adopts this ‘rehabilitation pathway’ approach, irrespective of disease, fits with the transformation agenda promoted by health and social policy in Wales (Welsh Government, 2018). The impetus behind much of this policy development is the demand to meet the forecast increase in LTCs, including cancer, in a health system which may not receive significant additional future investment (Dieleman et al., 2017; Macmillan Cancer Support, 2015). Rehabilitation models for people diagnosed with multi-morbidity, or more than one LTC, are already showing promise in terms of clinical outcomes, cost-savings and participant acceptability (Barker et al., 2018; Cowie, McKay, & Keenan, 2018). Models such as these, have the potential to unlock capacity from within the local health system and provide more equitable access to rehabilitation for a wider population (Longley et al., 2017).

8.3 Meeting the Study Aims and Research Questions

The over-arching aim of the study was to understand the importance and impact of therapeutic relationships in supporting PABC to develop sustainable SM behaviours during cancer rehabilitation. This aim has largely been achieved. This discussion has integrated the findings from all three phases of PPD research, presenting evidence to suggest that participants do perceive therapeutic relationships to be valuable within rehabilitation and influential on SM outcomes. The following sections explore the contributions that this PPD research has made in terms of implications for knowledge, research, policy and practice.

8.3.1 Contribution to Current Knowledge Base

The findings from this PPD research would appear to support the premise that rehabilitation participants perceived therapeutic relationships to be an important contributor in their ability to develop SM behaviours after cancer. However, the data reflects the possibility that the effective management and dissolution of therapeutic relationships, whilst essential, was not always present in their experiences.

This PPD research was not able to explore the professionals’ perspective, or training and development aspects of this topic. Gaining a better understanding of how professionals are supported in the development of this aspect of their practice is something which I would like to explore further through HEIW. The development and coordination of pre- and post-registration training could have significant implications for all professions, across specialities, care settings and sectors. As could the opportunity to raise the profile of therapeutic relationships through HEIW's function as education commissioner for Wales.

The consequences of poor therapeutic relationship management may not only be participant disengagement from the current episode of rehabilitation, but the potential carryover of negative experiences into other episodes of rehabilitation or wider healthcare interactions. The implications of this could not be explored by this programme of research. In addition to poor individual outcomes, consequences may be anticipated to include damage to organisational reputation, and participants' reduced confidence and/or tolerance of human error in future (Andrews & Butler, 2014).

8.3.1.1 Theories of Motivation and Behaviour Change

The framework and operational definitions provided by SDT (Deci & Ryan, 2012; Silva et al., 2014), provided a solid foundation for exploring the importance of relatedness in a cancer rehabilitation setting; as participants adapt their lifestyle and behaviour in response to their changed health condition.

Theories of behaviour change, such as the COM-B, incorporate the participants' wider social context act as a bridge between SDT and OT theoretical models like the OPM-A (Ranka & Chapparo, 1997a, 1997b). The complex interplay between an individual's needs and internal resources, their physical, sensory, cultural and social environments and their daily living roles and routines are accommodated by the COM-B to a greater extent than other behaviour change models. Using the three models together can guide professionals as they approach the complex reasoning required to navigate the barriers and enablers to behaviour change within each participant's unique circumstances.

Ryan et al. (2008), highlighted the importance of relatedness in healthcare, identifying its potential role as a facilitatory mechanism for achieving health behaviour change. It was not within the scope of this research to concurrently investigate the motivation of the rehabilitation participants. However, there is the potential that rehabilitation and SM outcomes may not benefit from therapeutic relationships if the participant involved is not ready for change (Prochaska, 2008).

Whilst participants may have a positive experience of their therapeutic relationship, and even develop trust and confidence in professionals. This may not translate into taking ownership over their recovery or sustained behaviour change following the rehabilitation episode.

One of the aims of rehabilitation is to “instil hope, support ambition and balance risk to maximise outcome and independence” (NHS England, 2015, p. 10). The internalisation of motivation and aspiration are contributors to this outcome (Deci & Ryan, 2012). The results of this research would imply that the impact of effective therapeutic relationships may play a greater role in delivering sustainable rehabilitation outcomes than previously anticipated. The difficulty associated with defining and subsequently measuring relatedness, or therapeutic relationships, may be responsible for research into SM focusing on more tangible aspects of interventions which support participant autonomy and/or competence (de Silva, 2011).

The findings from this research propose that there may be additional aspects of relatedness, which are not currently included within the operational definitions posed by Silva et al. (2014). These additional aspects include relationship boundary setting and management, honesty within professional-participant relationships and the preparedness of professionals for their roles. Having said this, the SDT may not be at fault for these sub-themes not being reflected within the framework, for they may be better accommodated within more specific relationship models. Indeed, these three aspects are well accounted for within the Tripartite Model of Therapeutic Relationships (Gelso, 2014), and the Intentional Relationship Model (Taylor, 2008).

8.3.1.2 Models of Therapeutic Relationships

Participant experiences of therapeutic relationships in cancer rehabilitation, as described by the PPD research, echoed Gelso’s (2014, p. 117), tripartite model involving “a real relationship, a working alliance, and a transference-countertransference configuration”. When participant perceptions of factors which positively or negatively influence the formation and maintenance of therapeutic relationships were being explored, those relevant to the real relationship (a foundation interpersonal connection in all relationships based on perceived genuineness), and the working alliance (the catalyst or contract for influencing change), were the most frequently highlighted, across all three phases of the study.

Transference refers to the participant's experience of the therapist, as it is shaped by their own psychological structures and carryover of feelings, attitudes, and behaviours from previous relationships. Countertransference refers to the professionals' experience of the participant, as it is shaped by the same factors (Gelso, 2014). Transference had not been highlighted as a priority for investigation from within the ILR findings. Nor had it been triggered for inclusion in the ModDT by the SDT framework's operational definitions.

A small amount of data relevant to the transference-countertransference configuration was yielded from the SSIs and ModDT. This data discussed transference initially in terms of the importance of therapeutic boundary setting to safeguard participants' and professionals' wellbeing. The core aspect of transference from this data had largely demonstrated how participants identified, interpreted and responded to professionals' similarities with individuals from their family or social networks. In Chapter Five, SSIs participants described how their experiences of prior relationships with healthcare professionals flavoured their expectations for the quality of future therapeutic relationships and rehabilitation outcomes.

The importance of managing and dissolving working partnerships effectively, to limit residual emotional discomfort for participants, may be the most pertinent implication of transference within the context of this research. The challenge of participants presenting to rehabilitation with a poor expectation for relationship quality and rehabilitation outcome, places the therapeutic relationship under immediate pressure. These comments, while not representative of the whole research or local rehabilitation population, have flagged that this additional strain has the potential to compromise participant engagement and undermine treatment effectiveness. The evidence base relating to therapeutic relationships in a trauma context may offer some insight into the complexity of the development and management of therapeutic relationships, with participants who have experienced trauma within prior relationships (Murphy & Joseph, 2013).

Participants reported that relationships with professionals, as a whole, had the potential to impact on the development of SM behaviours at different stages of the rehabilitation pathway. It might be proposed that the real relationship was perceived as instrumental in influencing the development of participants' trust, confidence, self-esteem, and resilience. Whereas the process of building partnerships, learning to change, participants regaining ownership over their future and cementing sustainable behaviour change into daily routine, may reflect the influence of both the working alliance and transference (Hechinger et al., 2019), at different timepoints or stages of rehabilitation.

The theoretical evidence base for therapeutic relationships comes predominantly from psychotherapy. The Intentional Relationship Model (Taylor, 2008), is the only model of therapeutic relationships to have been developed within OT. This model offers a sound foundation for guiding novice professionals through the process of learning how to navigate this less-tangible aspect of practice. However, it also falls short of providing enough detail that could support novice practitioners through the dissolution of therapeutic relationships. Understanding more about how professionals disengage from participants without risking the compromise of future relationships is worthy of further research.

8.3.2 Implications for Policy and Practice

The initial purpose underpinning this programme of practice-based research, was for the findings of the ILR to complement and challenge local research data. It was anticipated that insights from this combined analysis could inform the future shape of cancer rehabilitation policy and practice in Wales. This study has been successful in identifying key theoretical frameworks which can guide the future direction of cancer rehabilitation. The next steps will be to influence policy change that can be used to support the required change in practice.

Recent reports would suggest that Wales has made less headway in improving equity in therapeutic relationships, than it has in the other prudent principles (Longley et al., 2017). This may reflect that therapeutic relationships and co-productive partnerships are more challenging to quantify than the other principles of prudent healthcare. It may also reflect that, despite therapeutic relationships' inclusion in the strategic vision for a Healthier Wales (Welsh Government, 2018), the necessary culture shift in healthcare professional attitudes, essential for therapeutic relationships to become core to clinical practice has not yet happened.

The findings reported in this thesis have the potential to influence the future development of rehabilitation services in Wales through two key avenues. The first is through the revision of the cancer rehabilitation standards (Welsh Assembly Government, 2010). This process will involve the aim of improving professionals' awareness of behaviour change theory. This opportunity will seek to update the rehabilitation assessment process to explicitly include consideration of participant activation, or readiness for change.

The second is through influencing the strategic direction of workforce development and innovative service transformation via HEIW. This reflects the need for professionals to have a greater understanding of how to dissolve the therapeutic relationship as participant ownership of recovery and or SM increases. There are UK wide workstreams that are exploring the curriculum content for pre-registration health professional education. Ensuring that therapeutic relationships has a place in this vision for educating the professionals of the future, has already been represented for medical professionals (Health Education England, 2020). It would be ideal for this to be replicated in the approach to curriculum review for nursing and AHPs.

8.3.3 Contribution to, and Recommendations for, Further Research

This research has explored the importance and impact of therapeutic relationships from the rehabilitation participants' perspective. The two other perspectives which would add to a more rounded view of the importance of therapeutic relationships, are those of the rehabilitation professionals and the family members and familial carers who make up participants' supportive communities. A third consideration is how therapeutic relationships can be measured and the extent to which they influence SM outcomes.

8.3.3.1 Professionals' Perspectives

The key considerations relating to the professionals' perspective have already been largely identified throughout the discussion earlier in this chapter. However, the shift away from paternalistic to true person-centred practice can be challenging to facilitate. Adopting a framework such as Care Aims Intentional Outcomes Framework, has been found to be beneficial in supporting a consistent person-centred, SM approach to practice. This framework provides professionals with a common language for articulating reasoning behind some of the challenges discussed earlier, including managing participants' low motivation or readiness for change, negotiating boundary setting and dissolution of therapeutic relationships (Waterworth, Willcocks, Selfe, & Roddam, 2015).

The Care Aims Intentional Outcomes Framework resonates with the principles within the Wellbeing of Future Generations Act (Welsh Government, 2015), which seeks to encourage healthcare professionals to adapt their practice. Shifting towards supporting the development of resilient communities, rather than reliance on statutory services. This shift invites participants' family members and informal caregivers to be a more active partner in supporting the sustainability of SM practice.

8.3.3.2 Family Members' and Familial Carers' Perspectives

Many of the definitions of self-management, and some behaviour change models, include participants' supportive communities, including family and friends as key players the sustainability of SM behaviours (Boger et al., 2015; de Silva, 2011; Lorig & Holman, 2003; Michie et al., 2011). It is imperative that participants' social contexts are considered, when exploring how to support sustainable SM behaviour change. From observations in clinical practice, family members and familial carers' anxiety had the potential to limit participant carryover of confidence and skills from the rehabilitation environment to their home or social environment. To reduce the risk of this compromising rehabilitation outcomes and support sustainable SM, family members were included in cancer rehabilitation treatment sessions, where practicable.

It was not possible to incorporate the perspectives of family members or familial carers within the scope of this research. However, this is a population whose contributions to the development of SM is pivotal. Further research into how professionals can enable members of their social networks to provide ongoing support for sustainable behaviour change would be beneficial. There is a potential role for professionals to dedicate more time working with supportive communities in preference to, or certainly alongside, the individuals undergoing rehabilitation. This offers a means of overcoming the challenge of dependent relationships with healthcare professionals. The challenge remains in protecting the time to dedicate to supporting resilience in social networks, through articulating the impact of therapeutic relationships. Measuring an aspect of practice that has the potential to be so different for each participant remains a challenge, not yet answered by the research reported in this thesis.

8.3.3.3 Measuring the Impact of Therapeutic Relationships on Rehabilitation Outcomes

The findings from this PPD research have laid the foundation for undertaking further research to understand the effect and impact of therapeutic relationships on SM outcomes. There is a growing evidence base interrogating the benefits of physical and psychosocial interventions used within cancer rehabilitation (Olsson Möller, Beck, Rydén, & Malmström, 2019; D. A. Scott et al., 2013). However, if there is potential for therapeutic relationships to influence the outcomes of cancer rehabilitation, including sustainable SM, then this aspect of practice needs to be explored in greater detail.

There is an emerging evidence base exploring therapeutic relationships outside of psychotherapeutic and other mental health settings. However, the direct translation of therapeutic relationships from these settings to rehabilitation may not be appropriate (Kayes et al., 2015). Much of the theory informing this research has been extrapolated from a psychotherapeutic perspective. There is a need to generate context-specific evidence to determine how the nuances of the therapeutic relationship vary according to the complexities of a cancer rehabilitation setting (Kayes, Cummins, Tagaloa, Grose, & Kersten, 2018). This line of research would complement other programmes of research seeking to gain a deeper understanding of how rehabilitation works (Csontos, Fitzsimmons, et al., 2019).

8.4 Strengths and Limitations

Three key considerations were integral to delivering this PPD research and support the application of the findings to a wider health context (Mays & Pope, 2000). These included coordinating data analysis from different data collection methods, integrating a data checking process with participants and aiming for the sample to be representative of the local cohort. Throughout this thesis, a transparent discussion of both research process and findings has been presented. The following presents a focused discussion relating to embedding rigour in research design, the impact of this research rigour on recruitment.

8.4.1 Research Participant Recruitment and Representation

Contrary to the experiences of some other doctoral candidates and novice researchers (Archibald & Munce, 2015; Patel et al., 2003), this study did not find participant recruitment to be a challenge. As described in Chapter Four, recruitment to the SSI cohort exceeded expectations, as did recruitment to, and response rates for, the ModDT. There was the potential for a larger SSI sample still, should the practicalities and the needs of the study have required.

Archibald and Munce (2015), propose four key challenges to research participant recruitment. These include recruiter characteristics, organisational gatekeeping, understanding the behaviours and nuances of the participant cohort, and transparency in decision making around sample size and composition.

Having undertaken this research in the practice setting, may have gone a long way to reducing the impact of the first two barriers. The close proximity of this research and practice meant that, for many of the research participants, there was a pre-existing therapeutic relationship with the researcher-recruiter. This could either positively or negatively affect recruitment, depending on the participants' experience of this pre-existing relationship. In this instance, favourable recruitment outcomes could be interpreted to reflect participants' positive perceptions of the pre-existing relationship as having been effective. Being a practitioner-researcher, also reduced the risk of a third-party organisation or professional acting as gatekeeper or being selective in their application of the recruitment strategy which aimed to target all previous cancer rehabilitation participants.

There was fair representation from participants who had engaged in rehabilitation from 2011 – 2016 with one exception. There was no representation from the 2012 rehabilitation cohort. On review of the clinical database, there were only twelve potential participants available from the 2012 sample. It is unclear why this cohort was under-represented, although the likelihood of inaccurate data recording has been assumed. Of the twelve possible participants, four people had died prior to the research invitation. Five people were not included in the research invitation cohort as they did not meet the study's eligibility criteria (i.e. did not complete rehabilitation programme or were unable to be identified by data available). Of the three people who were eligible for invitation to the research, one person withdrew following screening, one was unable to be contacted for screening, and one did not respond to the initial research invitation.

Involvement of rehabilitation participants, as described in Chapter Four, in the design of the research may have been crucial in preventing a third barrier to participant recruitment. By engaging members of the sample population ahead of recruitment, it was possible to gain an understanding of the potential challenges they might face in engaging in research. Co-production in the design of the study offered the opportunity to select data collection and communication methods which would be facilitatory of participation ahead of recruitment.

Presenting expectations for the sample size and characteristics in an ‘a priori’ protocol may have gone some way to overcoming the fourth and final barrier to recruitment. The aim for this study to provide transparency around the relationship between sample recruitment and data saturation was described in Chapter Three. The participants’ characteristics described in Chapter Four suggest that there was fair inclusion of both male and female participants, representation from a broad range of ages, different cancer sites, time since diagnosis, co-morbidities, and levels of education and socio-economic deprivation.

The research sample characteristics corresponded well with characteristics of a wider cancer rehabilitation population in Wales, suggesting that the findings could be interpreted and applied within the context of cancer services in Wales. This research focused on a cancer-specific rehabilitation cohort, but in light of the high level of comorbidity within the cohort, it is possible that these findings could be representative of a wider population seeking to live well after a significant health event or diagnosis. Further research to explore whether similar trends emerged from other LTCs rehabilitation populations would be required before assuming that these findings were directly translatable.

8.4.2 Rigour in Qualitative Mixed-Methods Research Design

This PPD research was undertaken using a pragmatic paradigm. This thesis has aimed to provide assurance of rigour. This was achieved by presenting not only the outcomes or findings of the mixed-methods research activities undertaken, but also by articulating the reasons behind the interpretation of the findings, and anticipating the potential impact these might have for knowledge, policy, practice and the research agenda (Morgan, 2014).

Adopting a pragmatic paradigm supported the interrogation and interpretation of the data yielded from three phases of data collection. This research was concerned with exploring the perceptions and experiences of a diverse population with complex rehabilitation presentations. The involvement of participants in research design was crucial in situating the research findings as close to clinical practice as possible, thereby making them as relevant to practice as possible (Glogowska, 2011).

Pragmatism is compatible with research topics which are underpinned by complex theoretical bases (Cryer, 2005). In this study, the theoretical foundation was made up of theories relevant to human motivation, behaviour change, OT and therapeutic relationships. This foundation made up of different layers and inter-dependencies, required a paradigm that would not force the data analysis and interpretation to conform to a dualist world view, but accepted that participants' experiences would need to be considered as both objective and/or subjective (Feilzer, 2010).

Embracing pragmatism enabled the research design to make the most of participant contributions to reflect the challenges of the 'real world' and allowed the analysis to be free from the constraints of polarity that either an objectivist or subjectivist stance would impose. It allowed the findings to be described in a more meaningful way, illustrating the different perspectives of both professionals and participants (Feilzer, 2010). Embedding reflexivity in the fabric of this programme of research, was a key facilitator for openness and transparency in decision-making. The following explores the potential biases in this PPD research and actions taken to mitigate the impact of these on the findings.

8.5 Potential Bias in this PPD Research

Common to all Delphi Techniques, the likelihood of reproducibility of results is directly influenced by the characteristics of the experts on the panel (Weir et al., 2018).

8.5.1 Sampling Selection and Responder Bias

There are fundamental limitations to the use of SSI and ModDT. These include the composition of the initial interview sample and the expert panel, and their selection via a non-randomised approach (Keeney et al., 2006). All participants were selected for their particular experiences of cancer rehabilitation, which could not be achieved through true randomisation.

Selection bias may occur when the characteristics of the cohort selected for participation differ from those who were not selected for participation (Daniels, 2012). There was a risk of this occurring with the sampling approach used in this research. However, recognising the range of tumour sites, ages and demographic variables within the cancer rehabilitation population, it was important to ensure that each potential participant met the required eligibility criteria for the study before selection.

This PPD study aimed to explore the perceptions of as broad a range of participants as feasible. To this end, the SSI participants were selected to broadly represent maximum diversity of rehabilitation population characteristics including tumour site, age, and geographical location. In addition to this, the ModDT expert panel was inclusive of all participants who expressed an interest, as this aimed to maximise the diversity within the cohort.

The data obtained from a screening procedure helped to demonstrate the congruent characteristics of the responder and non-responder groups. No weighting was applied to the selection procedure in terms of whether participants were likely to predecease the full data collection. It was anticipated that this would reinforce the findings by verifying that there was limited selection bias.

The number of participant experts who participated in this ModDT was relatively large. This aimed to provide a ‘safety in numbers’ approach to ensuring that the findings were less likely to represent minority opinions (Hasson et al., 2000). In addition to this, there was another bias relating to the sample. Despite the design of remote participation data collection method and efforts to maintain participant quasi-anonymity many participants were still actively engaged in the local rehabilitation service. This introduced the risk that participants may have known who else was participating in the PPD study, may have discussed the study and influenced each other’s responses.

A third bias was the potential that the participants who accepted the opportunity to take part in this PPD research would do so with an intention to contribute only favourable or positive perspectives. Whilst this bias could not be eliminated. The use of reflexivity, responder validation and exploration of negative or deviant case examples aimed to reduce the impact of this bias on these findings (Mays & Pope, 2000).

8.5.2 Practitioner Bias

Professional practice doctorates aim to close the gap between clinical practice and academic knowledge generation by enabling practitioners to examine real world practice problems. In addition to the potential risk of overly positive contributions from the responder bias (Section 8.5.1), the pre-existing therapeutic relationship between some participants and the principal investigator may have been an additional source of bias. An external interviewer may have reduced this bias. However, the principles of practitioner research supported the decision for the principal investigator to conduct the SSI. Academic supervision and reflexive journaling were used to scrutinise the process of data collection and analysis.

There were two sources of practitioner-bias throughout this PPD research. The first was in the development of the research tools. There was a risk that the language used and order that questions were presented, might inadvertently lead participants towards a pre-determined outcome. The principal researcher aimed to reduce this bias ensuring that the language used in all participant materials was accessible and had been sense-checked by rehabilitation participants prior to use (Section 3.6.3.1).

The second was the risk of confirmation bias during the analysis and interpretation of the research findings. Overcoming this bias required the principal researcher’s own values and biases to be made obvious. Reflexive journaling and academic supervision were helpful in facilitating this self-awareness. The presentation of any data which was negative or did not support the researcher’s hypothesis (e.g. Chapters 5.2 / 6.3), was evidence of efforts to overcome this bias. It was also important for the opportunity for stakeholders to question and challenge the early findings (Eastwood et al., 2017). Articulating the findings with different stakeholders (See Appendix 17), provided opportunities for sense-checking the data and helped to shape the interpretation of the PPD findings in a more balanced manner.

8.6 Dissemination of Findings

This research has been shared with professionals, participants and the public throughout the duration of the professional practice doctorate using a range of media. These include social media, scholarly and professional publications, conference presentations, academic teaching opportunities, and influence on policy and standards through my substantive working roles. Formal publications have been referenced throughout this thesis. Examples of other forms of dissemination can be found in Appendix 17.

Each form of dissemination offered an opportunity to share and sense-check early findings with different audiences. This greatly enhanced the analysis and interpretation of the findings presented in this thesis. Informal conversations with peers who have a range of professional backgrounds and experiences has validated the potential to broaden the scope of this work to include a LTC or multi-morbidity approach to future research activities.

Cancer’s identity as a LTC offers a significant opportunity to adopt a multi-morbidity approach to undertaking further research and applying the findings to a wider rehabilitation context. The findings of this study have relevance to a greater rehabilitation population and may offer insights into modernising LTCs rehabilitation whilst preserving PCC. The role of supporting participants’ social networks and prioritising the development of resilient communities may be key in securing the success of any future models of rehabilitation in Wales.

8.7 Conclusion

Supporting PABC to self-manage aspects of their disease, consequences of treatment and adapt, adopt or resume healthy lifestyle behaviours is a challenge facing healthcare professionals. This challenge is likely to increase as the incidence of cancer, subsequent survivorship, and presentation with concurrent comorbidity rises. The findings of the research presented in this thesis, provide evidence to support a person-centred approach to rehabilitation, through the protection of therapeutic relationships during cancer rehabilitation, as important in supporting PABC to engage in SM.

The single most important finding from this PPD research is that participants perceive variability in professionals’ capability and confidence with management and dissolution of therapeutic relationships. It is essential that professionals are prepared to not only build connections with healthcare participants, but also sensitively disengage from these relationships. Further exploration of how we prepare professionals would be a natural next step after this research.

A second significant finding relates to embedding more opportunities to tailor rehabilitation so that participants can be better supported in light of their readiness for change. This approach might go some way in supporting the management and dissolution of therapeutic relationships. There is an avenue through HEIW, to see the necessary changes in policy, directly influence the shape of health education provision and clinical practice. Further research into measuring the impact of therapeutic relationships may add weight to the findings of this research and inform future conversations with commissioning authorities.

9.0 References

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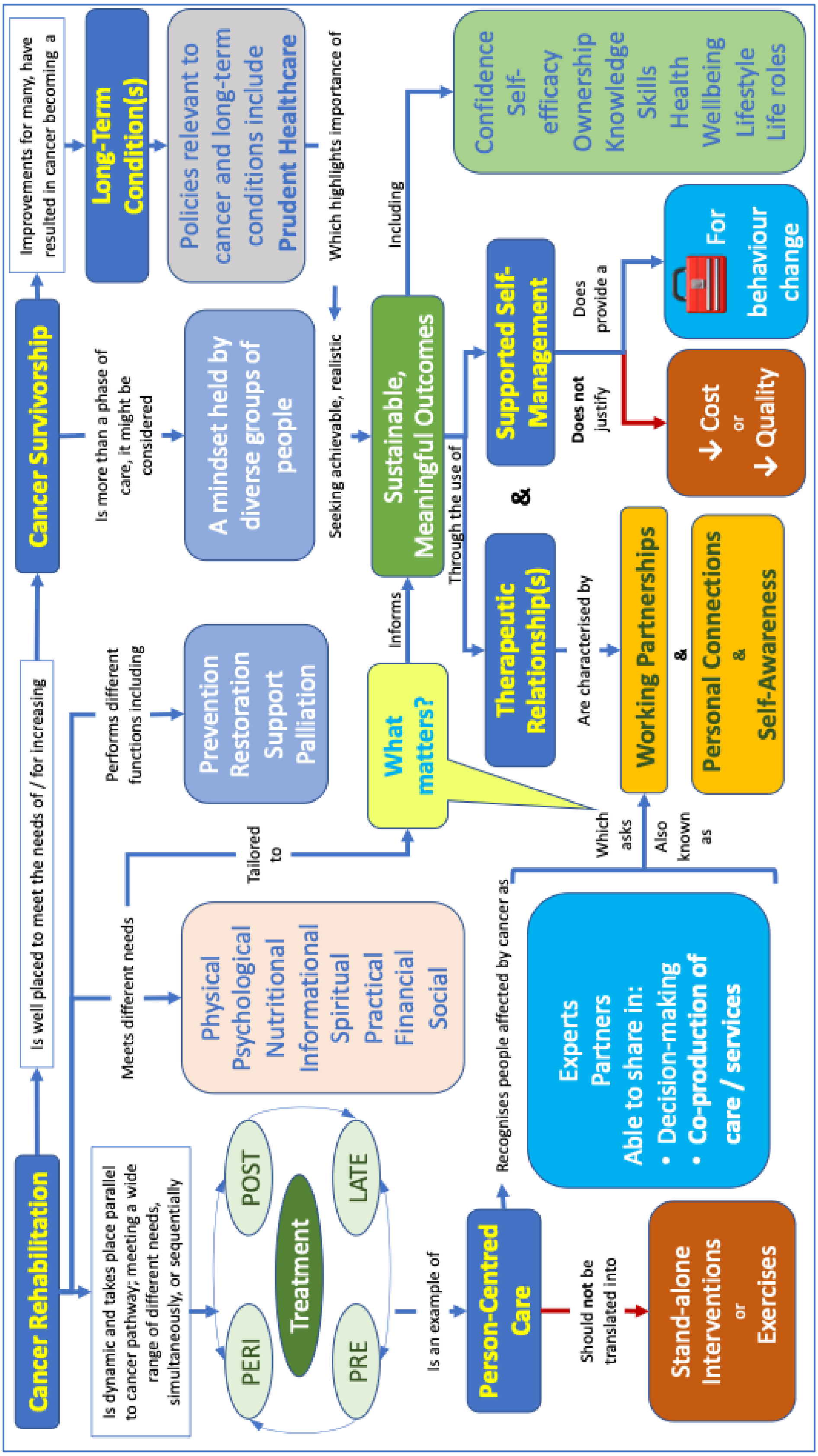
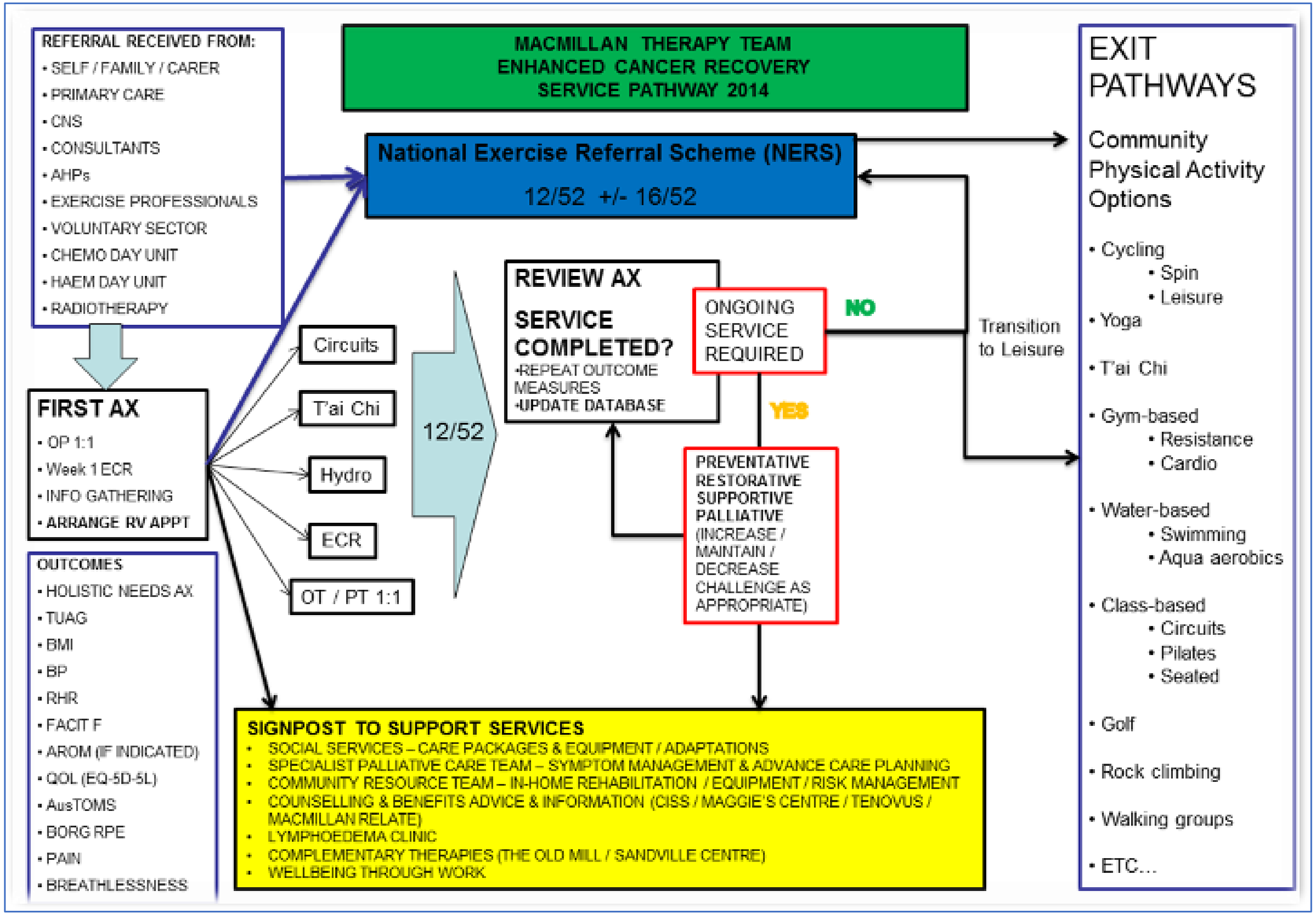
10.0 Appendices

Appendix 1. Concept Map



Appendix 2. Local Cancer Rehabilitation Service Model



Appendix 3a. ILR – Quality Assessment: AMSTAR

Reference, Location, Study Design	**AMSTAR SCORE (MAX=11)**	**AMSTAR Assessment Criteria (See below for details)**										
		1	2	3	4	5	6	7	8	9	10	11
Murray & McCrone. (2014). USA. Grounded theory.	11	1	1	1	1	1	1	1	1	1	1	1
Dwarswaard, Bakker, van Staa & Boeije. (2016). Netherlands. Grounded theory & meta-ethnography.	9	1	1	1	1	0	1	1	1	1	1	0
Schulman-Green, Jaser, Martin, Alonzo & Grey. (2012). USA. Qualitative Metasynthesis.	8	0	1	1	1	0	1	1	1	1	X	1
Schulman- Green, Jaser, Park & Whittemore. (2016). USA. Qualitative Metasynthesis.	8	0	1	1	1	1	1	1	1	1	0	0
Phillips-Salimi, Haase & Kooken. (2012). USA. Concept Analysis	4	0	0	1	1	0	0	0	0	1	0	1
Ackerman & Hilsenroth. (2003).USA. Descriptive.	3	0	0	0	1	0	0	1	0	1	X	0
Schnur & Montgomery. (2010). USA. Qualitative.	3	X	1	1	0	0	1	X	X	0	0	0
McCorkle, Ercolano, Lazenby, Schulman-Green, Schilling, Lorig & Wagner. (2011). USA. Quantitative Study.	2	0	X	X	X	0	1	0	0	X	X	1

AMSTAR Assessment Criteria:

1. Was an 'a priori' design provided?
2. Was there duplicate study selection and data extraction?
3. Was a comprehensive literature search performed?
4. Was the status of publication (i.e. grey literature) used as an inclusion criterion?
5. Was a list of studies (included and excluded) provided?
6. Were the characteristics of the included studies provided?
7. Was the scientific quality of the included studies assessed and documented?
8. Was the scientific quality of the included studies used appropriately in formulating conclusions?
9. Were the methods used to combine the findings of studies appropriate?
10. Was the likelihood of publication bias assessed?
11. Was the conflict of interest included?

AMSTAR Scoring Key:
1= YES
0= NO
X= N/A or can't answer

Appendix 3b. ILR – Quality Assessment: QATSDD

Reference, Location, Study Design	QATSDD SCORE %	QATSDD Assessment Criteria															
		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
Dunne, Coffey, Sharp, Desmond, Gooberman-Hill, O’Sullivan, Timmons, Keogh, Timon & Gallagher. (2018). Ireland & UK. Qualitative study.	90	3	3	3	3	3	3	3	2	*	*	3	3	3	3	0	3
Wood, Connors, Dogan & Peel. (2013). UK. Qualitative study.	90	3	3	3	1	1	3	3	3	*	*	3	3	3	3	3	3
Lee, Twinn, Moore, Jones, & Leung. (2008). Hong Kong. Grounded theory.	88	3	3	3	3	3	3	3	3	*	*	3	3	3	3	0	1
Thorne, Kuo, Armstrong, McPherson, Harris & Hislop. (2005). Canada. Qualitative study.	86	3	2	3	3	2	3	3	3	*	*	3	3	3	2	0	3
Kaplan, Greenfield, & Ware. (1989). USA. RCT.	83	3	3	2	3	3	2	3	1	3	3	#	3	3	#	0	3
Browall, Koinberg, Falk, & Wijk. (2013). Sweden. Qualitative study.	67	1	3	2	0	1	3	3	2	*	*	3	3	3	2	0	2
van de Bovenkamp & Dwarswaard. (2017). Netherlands. Qualitative Study.	64	1	3	1	0	1	2	3	1	*	*	3	3	3	3	3	0

QATSDD Assessment Criteria:

1. Explicit theoretical framework
2. Statement of aims/objectives in main body of report
3. Clear description of research setting
4. Evidence of sample size considered in terms of analysis
5. Representative sample of target group of a reasonable size
6. Description of procedure for data collection
7. Rationale for choice of data collection tool(s)
8. Detailed recruitment data
9. Statistical assessment of reliability and validity of measurement tool(s) (Quantitative only)
10. Fit between stated research question and method of data collection (Quantitative only)
11. Fit between stated research question and format and content of data collection tool e.g. interview schedule (Qualitative only)
12. Fit between research question and method of analysis (Quantitative only)
13. Good justification for analytic method selected
14. Assessment of reliability of analytic process (Qualitative only)
15. Evidence of user involvement in design
16. Strengths and limitations critically discussed

QATSDD Scoring Key:

0 = not at all
1 = very slightly
2 = moderately
3 = completely
* = no quantitative methods used
# = no qualitative methods used

Appendix 4. ILR – Summary of Papers

Study	**Methodology, Theoretical Framework & Analytical Approach**	**Sample Characteristics**	**Research Context**	**Therapeutic Relationships**	
				Intervention	**Outcome**
Ackerman and Hilsenroth (2003). USA	Descriptive Integrative Literature Review Analytical approach not explicit.	Total combined sample n=1601. No breakdown by sex or age. 1 x paper did not describe sample.	Outpatient services provided for psychology students; psychotherapy clients, and self-selecting people with diagnosed mental illness.	✓	
Browall et al. (2013). Sweden	Qualitative study. Content analysis of transcripts.	Total sample n=11. Mean age 54 years (range 32-72). 63.6% Female. Tumour sites: ovarian (n=5), retinoblastoma (n=2), breast (n=1), pulmonary (n=1), liposarcoma (n=1).	In/outpatient cancer settings, undergoing chemo +/- radiotherapy, before/during study.		✓
Dunne et al. (2018). Ireland & UK	Qualitative study. Inductive thematic analysis.	Total sample n= 27. Mean age unavailable (range 25-39 to 70+); 33.3% Female.	People with HNC from 4 x cancer centres in Ireland. 8-60 months post primary treatment.		✓
Dwarswaard et al. (2016) Netherlands	Systematic review in 2013 of qualitative studies. Grounded theory & meta-ethnography.	13/37 papers with cancer populations. 698/992 of the reported total combined sample with cancer. Mean ages reported in cancer studies 50–63.9 years; 2x studies reported >18 years, 3x studies did not report mean age. (Combined overall age range 20–86 years). Six studies did not report breakdown by sex; the remaining reported 36.5-100% Female.	Studies reported from USA (n=4), Europe (n=4), UK (n=3), Canada (n=1), and Australia (n=1).		✓
Kaplan et al. (1989). USA	3 x RCT chronic disease. 1 x non-equivalent trial with breast cancer. Analysis using Modified Bales' interaction analysis.	Chronic disease populations included: 1. Ulcer disease n=45. Mean age 55 years. 2% Female. 2. Hypertension (HTN) n=105. Mean age 54 years. 68% Female. 3. Diabetes (DM) n=59. Mean age 50 years. 49% Female. 4. Post-mastectomy breast cancer n=43. Mean age 47 years 100% Female (Age ranges not reported for samples).	Chronic conditions populations attended public and private outpatient settings in the USA. Cancer cohort recruited from private adjuvant chemotherapy / post-mastectomy clinics.	✓	
Lee et al. (2008). Hong Kong	Qualitative study. Grounded theory, inductive thematic analysis.	Total sample n=31. Treatment stage I n=4, stage II n=16, stage III or IV n=9. 46% RT only treatment. 19.5% recurrent disease - treated with surgery. Post RT time 6-151 month (mean 64.2 months). Mean age 50.4 years (range reported as <40 - >60). 58% < 50 years. 41.9% Female.	Regional teaching hospital in Hong Kong.		✓

McCorkle et al. (2011). USA	Literature Review of quantitative studies. Analysis using Chronic Conditions Model as framework.	Total combined sample included at least n=3143 (1 x study sample size not reported). Studies reported people affected by breast (n=7), solid tumours (n=2), oncology with symptoms including pain, mucositis, nausea and vomiting, infection or bone metastases (n=2), advanced cancer (n=2), cancer (n=1), lung (n=1), and gynaecological (n=1). n=1204 Female (uncertain due to unreported data).	Data from urban and rural cancer centres, community and outpatient clinics across the USA.	✓	
B. Murray and McCrone (2014). USA	Integrative literature review. Grounded theory.	Qualitative studies x12 total combined sample n=299. Quantitative studies x17 total combined sample n= 45,294. It was not possible to report specific characteristics of the combined samples due to differences in data presentation by the original authors. Populations included: rheumatic disease, lung cancer, HIV/AIDS, psychiatry, cardiology, diabetes; and healthcare professionals.	Empirical studies included from USA (19), Australia (2), Canada (2), Taiwan (2), Norway (1), Sweden (1), and UK (1). Clinical settings included primary care, internal medicine and surgery. Most studies were ethnically diverse, some low income / education, most metro / urban, nil rural populations.	✓	
Phillips-Salimi et al. (2012). USA	Integrative Literature Review. Hybrid concept analysis similar to that used by Haase et al 2009.	No specific data provided. Comment re: across lifespan early childhood to older adults. Review of reference list identified 3 x papers where samples included cancer.	Evidence from education, nursing, medicine, psychology and public health in USA.	✓	
Schnur and Montgomery (2010). USA	Systematic review. Excluded qualitative, survey, and feasibility studies; reviews meta-analyses.	Total combined sample of adults with cancer n=353/441. 4 x studies for breast cancer combined sample (n=257, mean reported from one study only 50.56 years); 1x study included adult outpatients with cancer (n=54, no other characteristics reported); 1 x study included adults with breast and prostate cancer (n=42, no other characteristics reported). 1 x study included relatives of people with cancer n= 52 (no other characteristics reported). 1 x study included children with acute lymphoblastic leukaemia (n=36, mean age 8.25 years).	2x studies included adults with cancer 1 x study included relatives of people with cancer 1 x study included children Country of origin for included studies not reported.	✓	
Schulman-Green et al. (2012). USA	Systematic literature review. A qualitative meta-synthesis was completed using iterative thematic analysis.	Populations included x49 different chronic conditions. The three largest included: • Type 1 & 2 Diabetes (n=34), • Cancer (all types n=16), and • Cardiovascular disease (n=13). Sample size range n=4-282 (median n=20), age range 18-93 years.	Studies reported from x19 countries, including men and women of diverse races and ethnicities (No other characteristic details reported).		✓

Schulman- Green et al. (2016). USA	Systematic literature review. Sandelowski & Barroso approach to qualitative meta-synthesis	Populations reported x16 chronic conditions, including Cancer (n=3). Sample size ranged from 3-387 (median n=24), Mean age 57 years (Range 18-94). Men and women of diverse races and ethnicities (No other characteristic details reported).	Studies reported from x20 countries,		✓
Thorne et al. (2005). Canada	Qualitative study. Interpretive description.	Targeted sampling of n=200. No mean age reported. Age range <30 (0.5%) - >70 (18%). 73.5% Female At least 6 tumour sites were represented: Breast - 50%; Prostate - 14%; Gastro-Intestinal - 10%; Haematology - 7%; Head & Neck - 5%; Gynaecological - 5%; Other - 6%	Urban and rural communities across Western Canada, with varied ethnicity, across treatment pathway.	✓	
van de Bovenkamp and Dwarswaard (2017). Netherlands	Qualitative semi-structured interviews. Inductive and deductive analysis.	Total sample n=20. Clinical conditions included: Rheumatic disease, diabetes, kidney failure, heart failure, tuberculosis, sensory disabilities, and immune disease. Sample included cancer (5%). 75% Female. No further detail was reported.	People diagnosed with chronic conditions from Dutch, Turkish, and African ethnicities. Receiving care in outpatient, home care or both settings.	✓	
Wood et al. (2013). UK	Qualitative study. Interpretive Phenomenological Analysis (IPA).	Total sample n=9. Mean age 70 years. (Range 56-80). 22% Female. 100% palliative cohort. Participants to have completed at least one session.	This study complemented a quantitative study of a non-pharmacological breathlessness management programme (NPBMP).		✓

Appendix 5. ILR – Analysis Matrix

THEMES	CODED DATA ITEMS	Ackerman, S J. & Hilsenroth, M J.	Browall, M Koinberg, I, Falk, H, Wijk, H	Dwarswaard, J., Bakker, E. J., van Staa, A., Boeije, H. R.	Kaplan SH, Greenfield, S Ware JE.	Lee, E. W. C., et al	Murray, B., & McCrone, S.	Phillips-Salimi, CR., Haase, JE. Kooken, WC	Schnur, J B., Montgomery, G H.	Thorne, S E et al	van de Bovenkamp, H M., Dwarswaard, J	Wood, H, Connors, S, Dogan, S, Peel, T	Dunne, S, et al	Schulman-Green, Det al (2012)	Schulman- Green, D, Jaser, S S. Park, C, Whittemore, R (2016)	McCorkle, R, et al
PERSONAL ATTRIBUTES & QUALITIES																
DEMEANOUR	Interest / Effort / Enthusiasm	✓	✓	✓			✓			✓						
	Respectful	✓				✓	✓	✓								
	Constant						✓									
	Open / Transparency	✓	✓								✓					
	Flexible / adaptable style	✓				✓		✓			✓					
COUNTENANCE	Trustworthy / Moral comportment	✓					✓	✓								
	Sincere		✓													
	Honest	✓						✓								
	Confident	✓														
	Warm / Empathy / Sympathy / Friendly / Care	✓	✓	✓	✓	✓	✓	✓	✓			✓				
KNOWLEDGE & SKILLS																
TOOLS & TECHNIQUES	Professional knowledge / competence	✓					✓					✓			✓	
	Active, bi-directional communication includes tone of voice	✓	✓	✓	✓	✓	✓					✓			✓	
	Listening		✓	✓		✓	✓									

INSTINCT & INTUITION	Sensitive to cues - thoughtful enquiry - Exploration, reflection, noting past therapy success, accurate cue interpretation	✓				✓				✓		✓			✓	
	Facilitating the expression of affect / adjustment / reciprocity	✓			✓		✓					✓				
	Attentive to the patient's experience	✓				✓	✓	✓							✓	
BEHAVIOURS																
PERSON-CENTERED	Paternalistic i.e. Prescriptive interventions vs tailor support to person / goal consensus / Focus on disease, treatment, medical records.	✓	✓	✓	✓	✓			✓		✓	✓				✓
	Restricting personal responsibility for health and wellbeing e.g. physical activity reduction on admission to hospital.		✓													
	Individual not 'patient' / unique / being known		✓			✓	✓			✓	✓	✓				
PARTNERSHIP	Shared effort / equal / active partner in decision making / power balance - agreed roles / partnering	✓	✓	✓	✓	✓	✓		✓		✓					
	Identify & repair ruptures in the alliance	✓			✓											
	Involving family members in conversations or considering their needs.		✓													✓
IMPACT ON PARTICIPANTS																
OWNERSHIP	Develop coping skills /emotional adjustment			✓		✓		✓				✓	✓			
	Confidence / Increased LOC / Empower	✓		✓	✓	✓		✓		✓		✓				
	Reduced perception of vulnerability															
	Sense of personhood / being known									✓	✓					

ABILITY	Adherence					✓										
	Helps with internalising knowledge information / guided discovery process			✓								✓	✓			
	Improved health and reduced risk taking							✓					✓			
OTHER																
TIME	Needs & outcomes will vary based on stage of disease / treatment pathway			✓		✓		✓								✓
	Duration / frequency of contact / time to talk		✓				✓									
MOTIVATION TO CONNECT	Need or desire to connect / self-manage							✓						✓		
	Shared experiences, beliefs with others							✓								
	A positive match / a 'sure instinct' / a decision to connect	✓	✓													

Appendix 6. Logic Model Describing Inter-Relationships Between Study Phases

Goal of Research	Inputs	Activities	Outputs	Outcomes
Develop an understanding of the research evidence base relating to therapeutic relationships and self-management in cancer rehabilitation	Time IT Reference software Library resources Critical analysis	Integrative Literature Review (ILR)	Define search strategy Implement search strategy Critically appraise papers Synthesize findings Recommendations for subsequent research activities	Identify scope of existing knowledge Confirm conceptual definitions Clarify conceptual inter-relationships Identify gaps in knowledge Identify questions for next phase of research
Develop an understanding of participant experience of therapeutic relationships and self-management during contact with local cancer rehabilitation service	Time IT Venues Informed consent procedures Theoretical framework (i.e. SDT) ILR outcomes Transcription support Critical analysis	Semi-Structured Interviews (SSI)	Design interview schedule Undertake interviews with local cancer rehabilitation participants Transcribe audio-recorded interviews Code data and organize into themes Critically appraise themes in relation to ILR findings	Identify trends (if any) in experiences of therapeutic relationships Identify facilitators (if any) for therapeutic relationships Identify barriers (if any) for therapeutic relationships Identify participant perception of cancer rehabilitation, self-management, therapeutic relationships Scope participant perception of importance of cancer rehabilitation, self-management, therapeutic relationships Identify questions for next phase of research
Develop an understanding of the impact of therapeutic relationships on the change process towards self-management during cancer rehabilitation	Time IT Informed consent procedures Theoretical framework (i.e. SDT) SSI outcomes ModDT tool Critical analysis	Modified Delphi Technique (ModDT)	Design Modified Delphi Technique tool Conduct up to three rounds of ModDT with local cancer rehabilitation participants Collate ModDT data in Microsoft Word Excel spreadsheet Conduct descriptive statistics for quantitative data Critically analyse quantitative data and present findings Code qualitative data and organize into themes Critically appraise qualitative data and present findings Critically appraise findings in relation to ILR and SSI findings	Identify convergence / divergence of opinion between SSI and ModDT participants with respect to above outcomes. Draw conclusions from combined analysis and present these in response to initial research aims, objectives and questions

Appendix 7. Semi-Structured Interview – Schedule

<table>
<tr><th colspan="2">Introduction</th></tr>
<tr><td colspan="2">Interviewer & interviewee introductions. **(Read Verbatim to Interviewee)**
“This interview will help us to learn more about how rehabilitation works for people affected by cancer. I will ask you questions to help you describe in your own words your thoughts, feelings and beliefs about if / how cancer rehabilitation has helped you to make life changes after cancer. We know that everybody’s experience of cancer is different. I want you to feel comfortable enough to say what you really think”.</td></tr>
<tr><th>Self Determination Theory Domains</th><th>Interview Prompts</th></tr>
<tr><td>Autonomy</td><td>1. Can you tell me how you first came in contact with the cancer rehabilitation service? (e.g. Keyworker / doctor / nurse / self-referral)
2. Can you tell me why you came in contact with the cancer rehabilitation service?
(e.g. symptoms of cancer / treatment or return to life role)</td></tr>
<tr><td>Understanding and Expectations of Cancer Rehabilitation</td><td>1. What did you expect from cancer rehabilitation before you had your first assessment? (e.g. Get back to normal? / Didn’t know what else to do?)
2. Did these expectations change after starting cancer rehabilitation? If so, what made you change? If not, was there a reason?
3. What was the best part about being involved in cancer rehabilitation? (If any)
4. What was the worst part about being involved in cancer rehabilitation? (If any)</td></tr>
<tr><td>Competence</td><td>1. Has taking part in cancer rehabilitation helped to make changes to your lifestyle or behaviour? (If so, what types of changes have been made? If not, was there a reason?)
2. Can you tell me how important to you it has been to make changes to your lifestyle or behaviour?
3. Can you tell me how confident you feel in maintaining any changes into the future?</td></tr>
<tr><td>Participant Perspective of Relatedness</td><td>1. Can you tell me what you think the rehabilitation team does the best?
2. Can you tell me what the rehabilitation team could do better?
3. Is there anything that the rehabilitation team did or said that stands out in your memory? (e.g. special / significant / specific moments that were good or bad)</td></tr>
<tr><td>Importance of Relatedness</td><td>1. How important has the relationship between you and the rehabilitation team been in making lifestyle or behaviour changes?
2. Many people think of rehabilitation being provided by NHS therapists. Sometimes other practitioners have an important role in your recovery from cancer. Is there anyone else who you feel you have had a significant therapeutic relationship with?
3. Can you describe what it is about this relationship that has helped you / held you back?</td></tr>
</table>

Appendix 8. LREC Approval Letter

Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

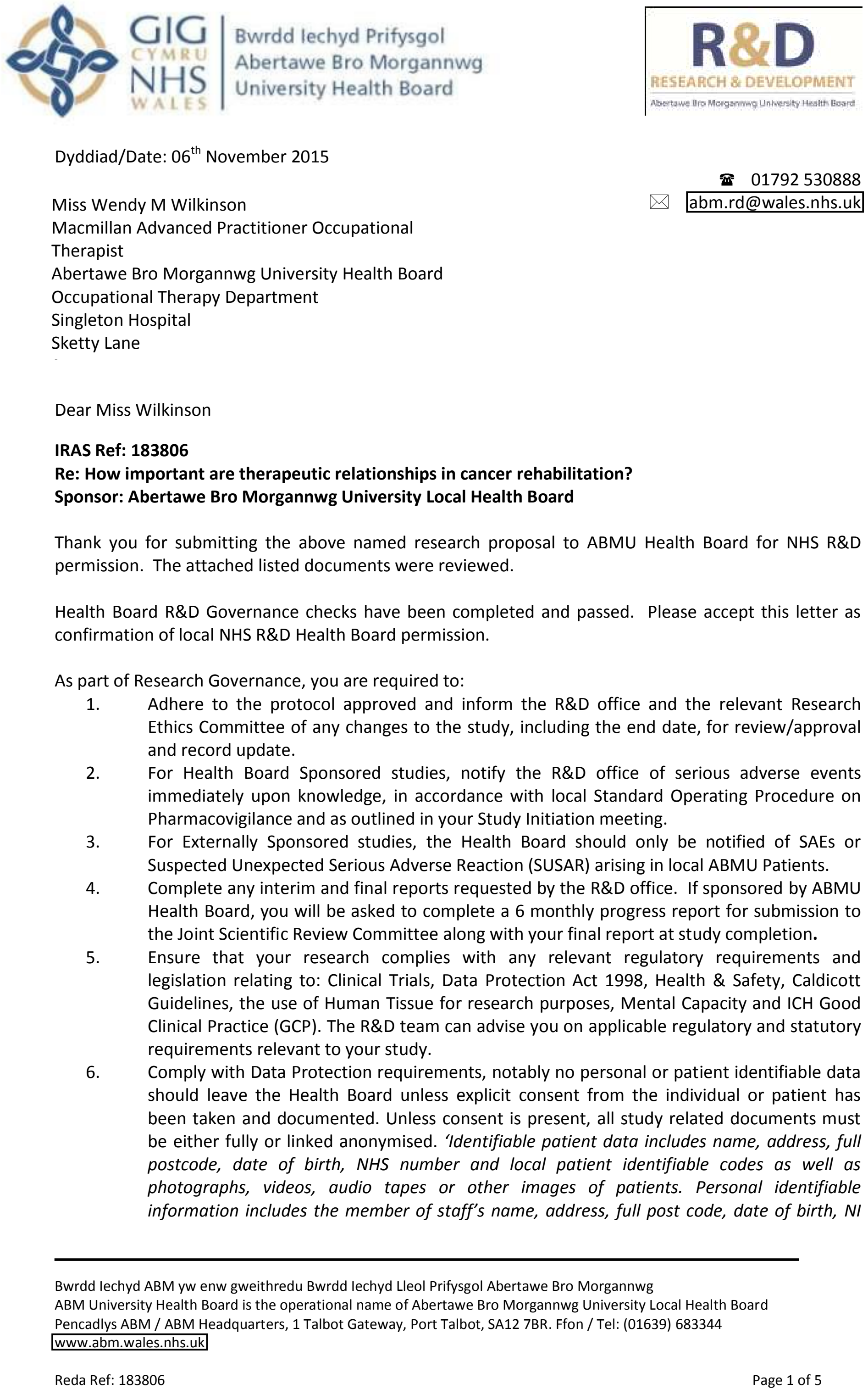
Gwasanaeth Moeseg Ymchwil
Research Ethics Service

Ariennir gan
Lywodraeth Cymru
Funded by
Welsh Government

Thank you for your letter of , responding to the Committee’

Where a NHS organisation’s role in the study is limited to identifying and referring potential

Appendix 9. R&D Approval Letter



GIG CYMRU NHS WALES | Bwrdd Iechyd Prifysgol Abertawe Bro Morgannwg University Health Board

R&D RESEARCH & DEVELOPMENT Abertawe Bro Morgannwg University Health Board

☎ 01792 530888
✉ abm.rd@wales.nhs.uk

Dyddiad/Date: 06th November 2015

Miss Wendy M Wilkinson
Macmillan Advanced Practitioner Occupational Therapist
Abertawe Bro Morgannwg University Health Board
Occupational Therapy Department
Singleton Hospital
Sketty Lane

Dear Miss Wilkinson

IRAS Ref: 183806
Re: How important are therapeutic relationships in cancer rehabilitation?
Sponsor: Abertawe Bro Morgannwg University Local Health Board

Thank you for submitting the above named research proposal to ABMU Health Board for NHS R&D permission. The attached listed documents were reviewed.

Health Board R&D Governance checks have been completed and passed. Please accept this letter as confirmation of local NHS R&D Health Board permission.

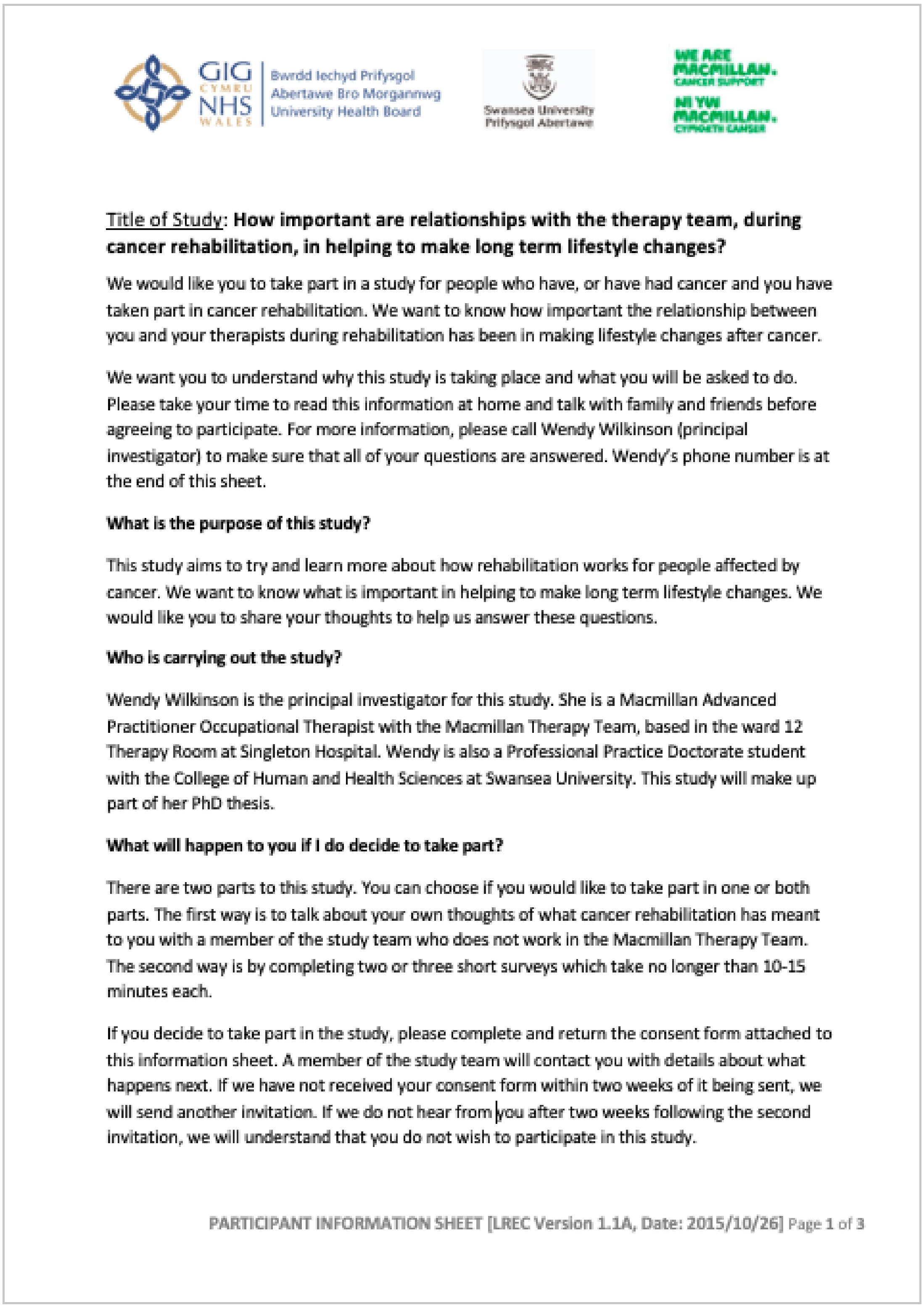
As part of Research Governance, you are required to:

1. Adhere to the protocol approved and inform the R&D office and the relevant Research Ethics Committee of any changes to the study, including the end date, for review/approval and record update.
2. For Health Board Sponsored studies, notify the R&D office of serious adverse events immediately upon knowledge, in accordance with local Standard Operating Procedure on Pharmacovigilance and as outlined in your Study Initiation meeting.
3. For Externally Sponsored studies, the Health Board should only be notified of SAEs or Suspected Unexpected Serious Adverse Reaction (SUSAR) arising in local ABMU Patients.
4. Complete any interim and final reports requested by the R&D office. If sponsored by ABMU Health Board, you will be asked to complete a 6 monthly progress report for submission to the Joint Scientific Review Committee along with your final report at study completion.
5. Ensure that your research complies with any relevant regulatory requirements and legislation relating to: Clinical Trials, Data Protection Act 1998, Health & Safety, Caldicott Guidelines, the use of Human Tissue for research purposes, Mental Capacity and ICH Good Clinical Practice (GCP). The R&D team can advise you on applicable regulatory and statutory requirements relevant to your study.
6. Comply with Data Protection requirements, notably no personal or patient identifiable data should leave the Health Board unless explicit consent from the individual or patient has been taken and documented. Unless consent is present, all study related documents must be either fully or linked anonymised. *'Identifiable patient data includes name, address, full postcode, date of birth, NHS number and local patient identifiable codes as well as photographs, videos, audio tapes or other images of patients. Personal identifiable information includes the member of staff's name, address, full post code, date of birth, NI*

Appendix 10. Summary of LREC Amendments and Approvals

Amendment Date	Amendment Type	Amendment Details
27/10/2015	Minor	Post LREC version control to PIS and consent forms for all three phases and to reflect change in research team members.
05/07/2017	Minor	Extension of timelines

Appendix 11.1. Research Invitation Letter and Pre-Consent Form



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Bwrdd Iechyd Prifysgol
Abertawe Bro Morgannwg
University Health Board

Swansea University
Prifysgol Abertawe

WE ARE MACMILLAN.
CANCER SUPPORT
NI YW MACMILLAN.
CYMORTH CANSER

Title of Study: **How important are relationships with the therapy team, during cancer rehabilitation, in helping to make long term lifestyle changes?**

We would like you to take part in a study for people who have, or have had cancer and you have taken part in cancer rehabilitation. We want to know how important the relationship between you and your therapists during rehabilitation has been in making lifestyle changes after cancer.

We want you to understand why this study is taking place and what you will be asked to do. Please take your time to read this information at home and talk with family and friends before agreeing to participate. For more information, please call Wendy Wilkinson (principal investigator) to make sure that all of your questions are answered. Wendy's phone number is at the end of this sheet.

What is the purpose of this study?

This study aims to try and learn more about how rehabilitation works for people affected by cancer. We want to know what is important in helping to make long term lifestyle changes. We would like you to share your thoughts to help us answer these questions.

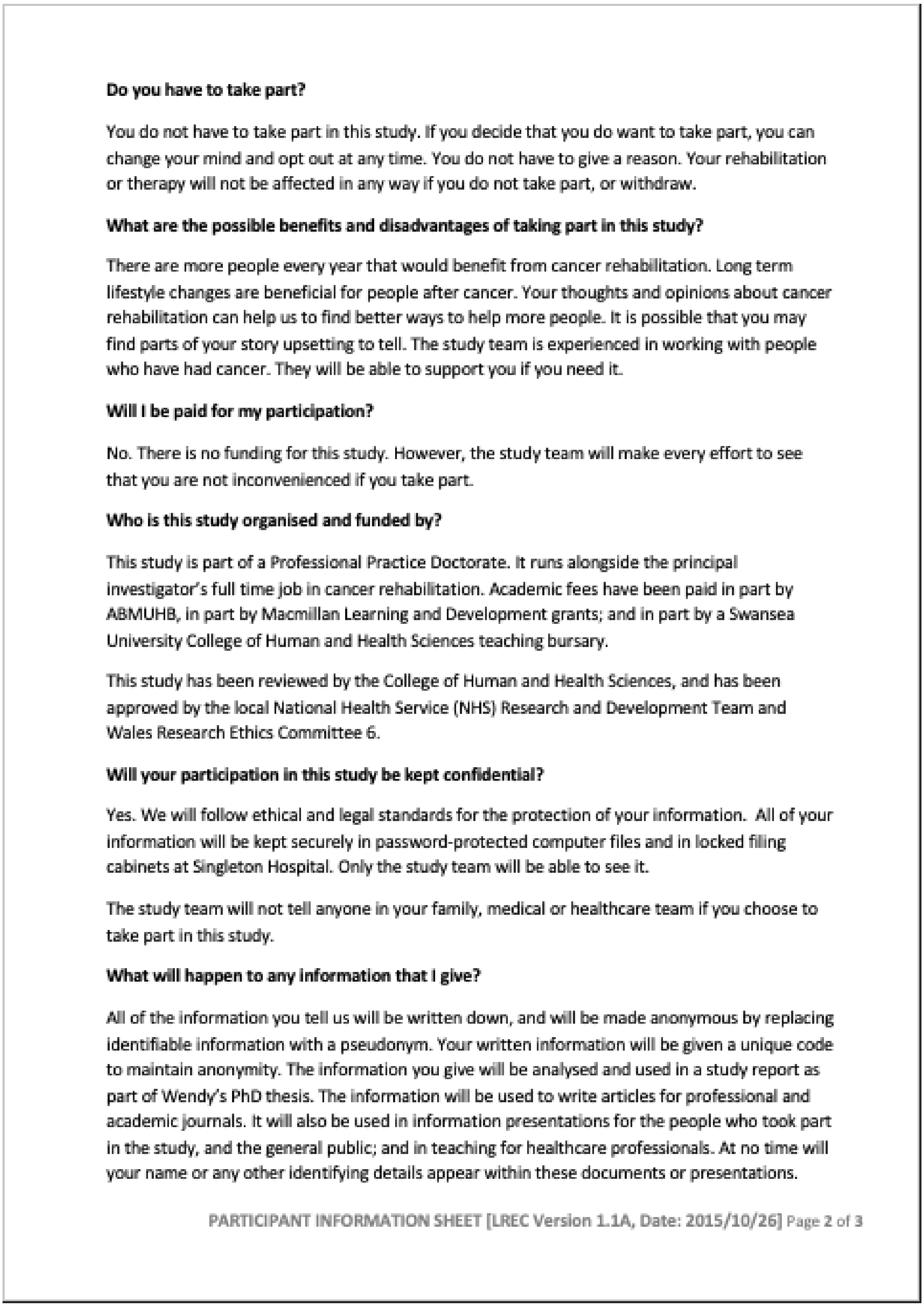
Who is carrying out the study?

Wendy Wilkinson is the principal investigator for this study. She is a Macmillan Advanced Practitioner Occupational Therapist with the Macmillan Therapy Team, based in the ward 12 Therapy Room at Singleton Hospital. Wendy is also a Professional Practice Doctorate student with the College of Human and Health Sciences at Swansea University. This study will make up part of her PhD thesis.

What will happen to you if I do decide to take part?

There are two parts to this study. You can choose if you would like to take part in one or both parts. The first way is to talk about your own thoughts of what cancer rehabilitation has meant to you with a member of the study team who does not work in the Macmillan Therapy Team. The second way is by completing two or three short surveys which take no longer than 10-15 minutes each.

If you decide to take part in the study, please complete and return the consent form attached to this information sheet. A member of the study team will contact you with details about what happens next. If we have not received your consent form within two weeks of it being sent, we will send another invitation. If we do not hear from you after two weeks following the second invitation, we will understand that you do not wish to participate in this study.



Do you have to take part?

You do not have to take part in this study. If you decide that you do want to take part, you can change your mind and opt out at any time. You do not have to give a reason. Your rehabilitation or therapy will not be affected in any way if you do not take part, or withdraw.

What are the possible benefits and disadvantages of taking part in this study?

There are more people every year that would benefit from cancer rehabilitation. Long term lifestyle changes are beneficial for people after cancer. Your thoughts and opinions about cancer rehabilitation can help us to find better ways to help more people. It is possible that you may find parts of your story upsetting to tell. The study team is experienced in working with people who have had cancer. They will be able to support you if you need it.

Will I be paid for my participation?

No. There is no funding for this study. However, the study team will make every effort to see that you are not inconvenienced if you take part.

Who is this study organised and funded by?

This study is part of a Professional Practice Doctorate. It runs alongside the principal investigator's full time job in cancer rehabilitation. Academic fees have been paid in part by ABMUHB, in part by Macmillan Learning and Development grants; and in part by a Swansea University College of Human and Health Sciences teaching bursary.

This study has been reviewed by the College of Human and Health Sciences, and has been approved by the local National Health Service (NHS) Research and Development Team and Wales Research Ethics Committee 6.

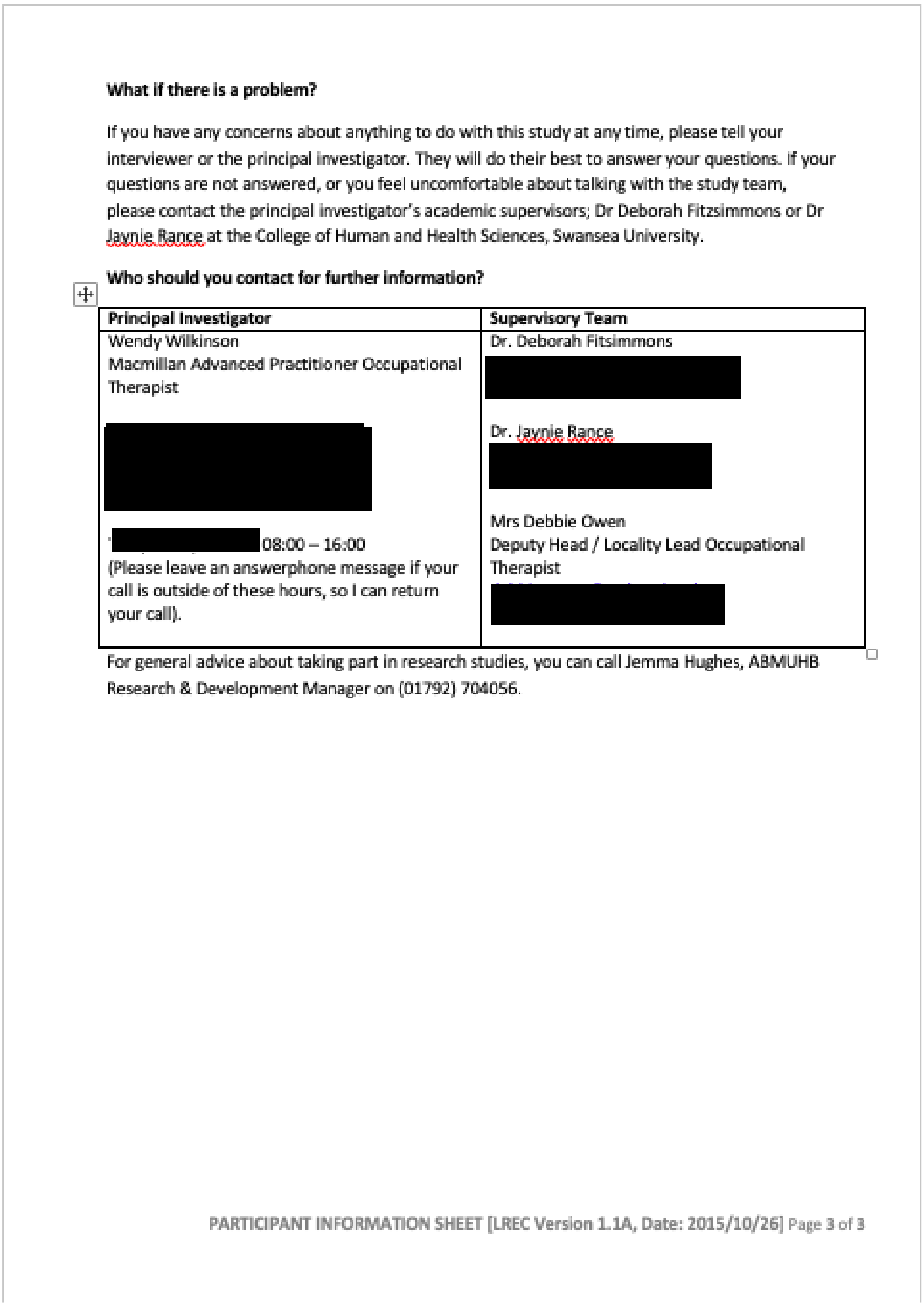
Will your participation in this study be kept confidential?

Yes. We will follow ethical and legal standards for the protection of your information. All of your information will be kept securely in password-protected computer files and in locked filing cabinets at Singleton Hospital. Only the study team will be able to see it.

The study team will not tell anyone in your family, medical or healthcare team if you choose to take part in this study.

What will happen to any information that I give?

All of the information you tell us will be written down, and will be made anonymous by replacing identifiable information with a pseudonym. Your written information will be given a unique code to maintain anonymity. The information you give will be analysed and used in a study report as part of Wendy's PhD thesis. The information will be used to write articles for professional and academic journals. It will also be used in information presentations for the people who took part in the study, and the general public; and in teaching for healthcare professionals. At no time will your name or any other identifying details appear within these documents or presentations.



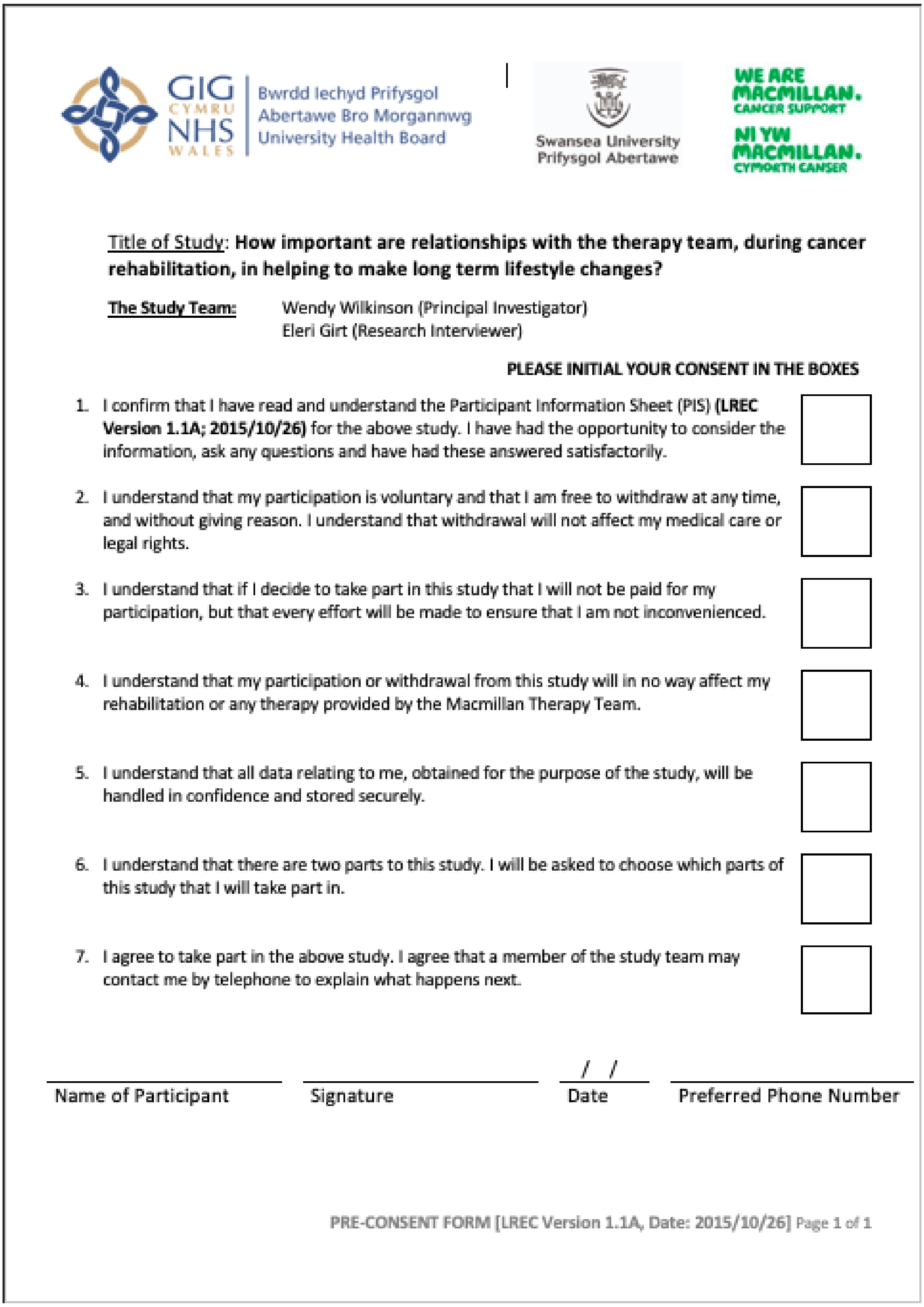
What if there is a problem?

If you have any concerns about anything to do with this study at any time, please tell your interviewer or the principal investigator. They will do their best to answer your questions. If your questions are not answered, or you feel uncomfortable about talking with the study team, please contact the principal investigator's academic supervisors; Dr Deborah Fitzsimmons or Dr Jaynie Rance at the College of Human and Health Sciences, Swansea University.

Who should you contact for further information?

Principal Investigator	**Supervisory Team**
Wendy Wilkinson Macmillan Advanced Practitioner Occupational Therapist [redacted] [redacted] 08:00 – 16:00 (Please leave an answerphone message if your call is outside of these hours, so I can return your call).	Dr. Deborah Fitsimmons [redacted] Dr. Jaynie Rance [redacted] Mrs Debbie Owen Deputy Head / Locality Lead Occupational Therapist [redacted]

For general advice about taking part in research studies, you can call Jemma Hughes, ABMUHB Research & Development Manager on (01792) 704056.



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Swansea University
Prifysgol Abertawe

WE ARE MACMILLAN. CANCER SUPPORT
NI YW MACMILLAN. CYMORTH CANSER

Title of Study: **How important are relationships with the therapy team, during cancer rehabilitation, in helping to make long term lifestyle changes?**

The Study Team: Wendy Wilkinson (Principal Investigator)
Eleri Girt (Research Interviewer)

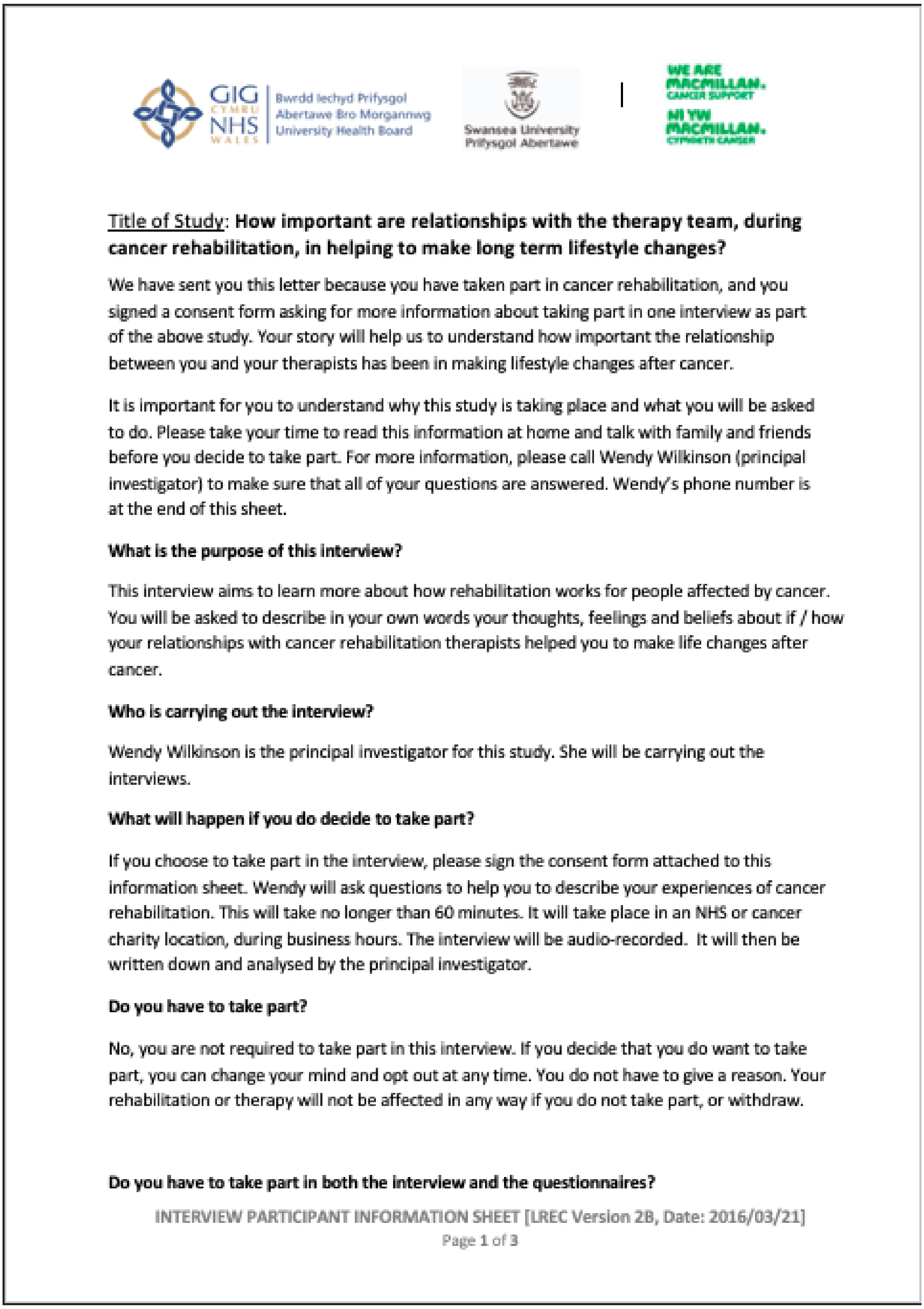
PLEASE INITIAL YOUR CONSENT IN THE BOXES

1. I confirm that I have read and understand the Participant Information Sheet (PIS) **(LREC Version 1.1A; 2015/10/26)** for the above study. I have had the opportunity to consider the information, ask any questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, and without giving reason. I understand that withdrawal will not affect my medical care or legal rights. ☐
3. I understand that if I decide to take part in this study that I will not be paid for my participation, but that every effort will be made to ensure that I am not inconvenienced. ☐
4. I understand that my participation or withdrawal from this study will in no way affect my rehabilitation or any therapy provided by the Macmillan Therapy Team. ☐
5. I understand that all data relating to me, obtained for the purpose of the study, will be handled in confidence and stored securely. ☐
6. I understand that there are two parts to this study. I will be asked to choose which parts of this study that I will take part in. ☐
7. I agree to take part in the above study. I agree that a member of the study team may contact me by telephone to explain what happens next. ☐

____________________	____________________	/ /	____________________
Name of Participant	Signature	Date	Preferred Phone Number

PRE-CONSENT FORM [LREC Version 1.1A, Date: 2015/10/26] Page 1 of 1

Appendix 11.2. Semi-Structured Interview Participant Information and Consent Form



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Swansea University Prifysgol Abertawe

WE ARE MACMILLAN. CANCER SUPPORT
MI YW MACMILLAN. CYMORTH CANSER

Title of Study: **How important are relationships with the therapy team, during cancer rehabilitation, in helping to make long term lifestyle changes?**

We have sent you this letter because you have taken part in cancer rehabilitation, and you signed a consent form asking for more information about taking part in one interview as part of the above study. Your story will help us to understand how important the relationship between you and your therapists has been in making lifestyle changes after cancer.

It is important for you to understand why this study is taking place and what you will be asked to do. Please take your time to read this information at home and talk with family and friends before you decide to take part. For more information, please call Wendy Wilkinson (principal investigator) to make sure that all of your questions are answered. Wendy's phone number is at the end of this sheet.

What is the purpose of this interview?

This interview aims to learn more about how rehabilitation works for people affected by cancer. You will be asked to describe in your own words your thoughts, feelings and beliefs about if / how your relationships with cancer rehabilitation therapists helped you to make life changes after cancer.

Who is carrying out the interview?

Wendy Wilkinson is the principal investigator for this study. She will be carrying out the interviews.

What will happen if you do decide to take part?

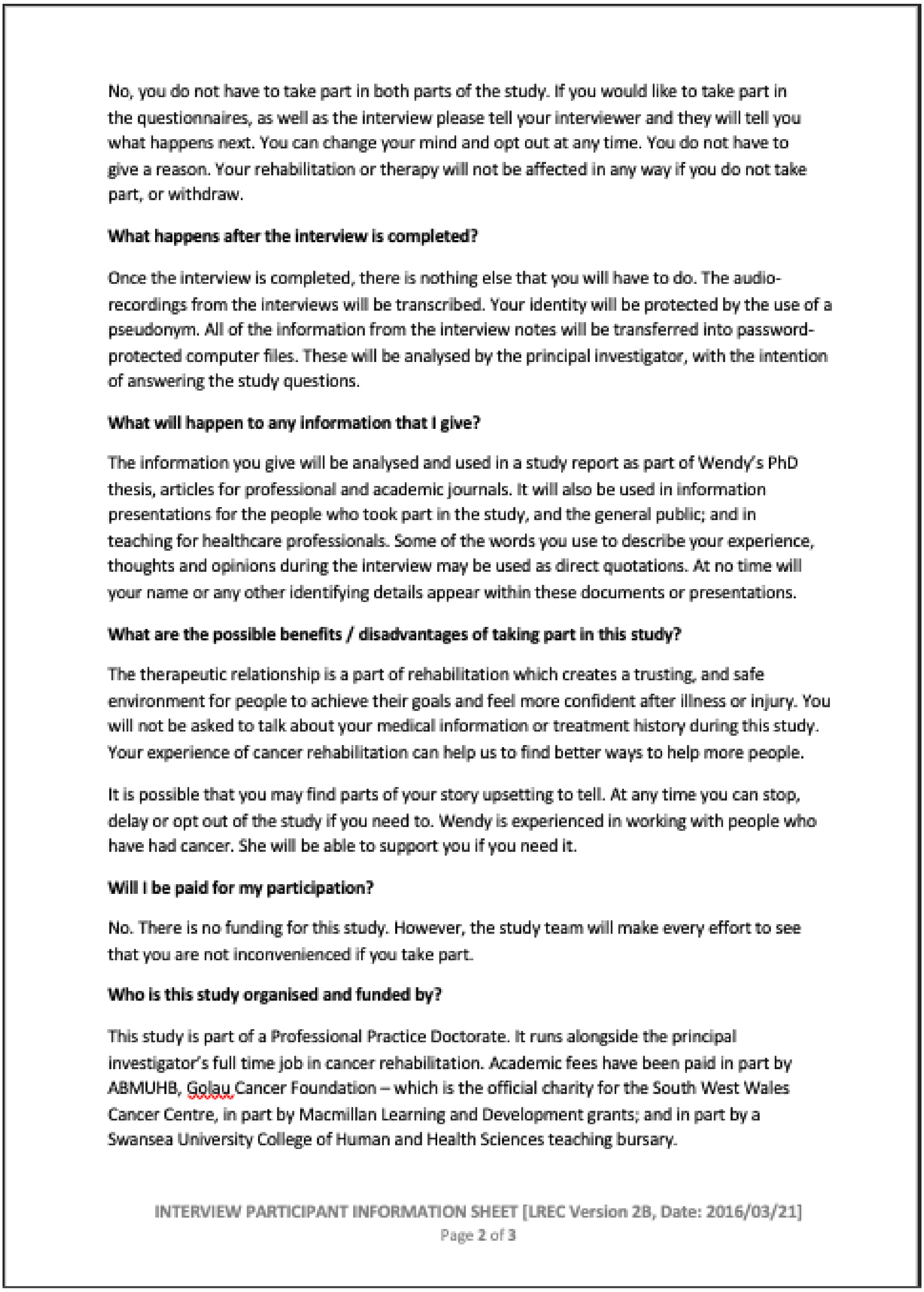
If you choose to take part in the interview, please sign the consent form attached to this information sheet. Wendy will ask questions to help you to describe your experiences of cancer rehabilitation. This will take no longer than 60 minutes. It will take place in an NHS or cancer charity location, during business hours. The interview will be audio-recorded. It will then be written down and analysed by the principal investigator.

Do you have to take part?

No, you are not required to take part in this interview. If you decide that you do want to take part, you can change your mind and opt out at any time. You do not have to give a reason. Your rehabilitation or therapy will not be affected in any way if you do not take part, or withdraw.

Do you have to take part in both the interview and the questionnaires?

INTERVIEW PARTICIPANT INFORMATION SHEET [LREC Version 2B, Date: 2016/03/21]
Page 1 of 3



No, you do not have to take part in both parts of the study. If you would like to take part in the questionnaires, as well as the interview please tell your interviewer and they will tell you what happens next. You can change your mind and opt out at any time. You do not have to give a reason. Your rehabilitation or therapy will not be affected in any way if you do not take part, or withdraw.

What happens after the interview is completed?

Once the interview is completed, there is nothing else that you will have to do. The audio-recordings from the interviews will be transcribed. Your identity will be protected by the use of a pseudonym. All of the information from the interview notes will be transferred into password-protected computer files. These will be analysed by the principal investigator, with the intention of answering the study questions.

What will happen to any information that I give?

The information you give will be analysed and used in a study report as part of Wendy's PhD thesis, articles for professional and academic journals. It will also be used in information presentations for the people who took part in the study, and the general public; and in teaching for healthcare professionals. Some of the words you use to describe your experience, thoughts and opinions during the interview may be used as direct quotations. At no time will your name or any other identifying details appear within these documents or presentations.

What are the possible benefits / disadvantages of taking part in this study?

The therapeutic relationship is a part of rehabilitation which creates a trusting, and safe environment for people to achieve their goals and feel more confident after illness or injury. You will not be asked to talk about your medical information or treatment history during this study. Your experience of cancer rehabilitation can help us to find better ways to help more people.

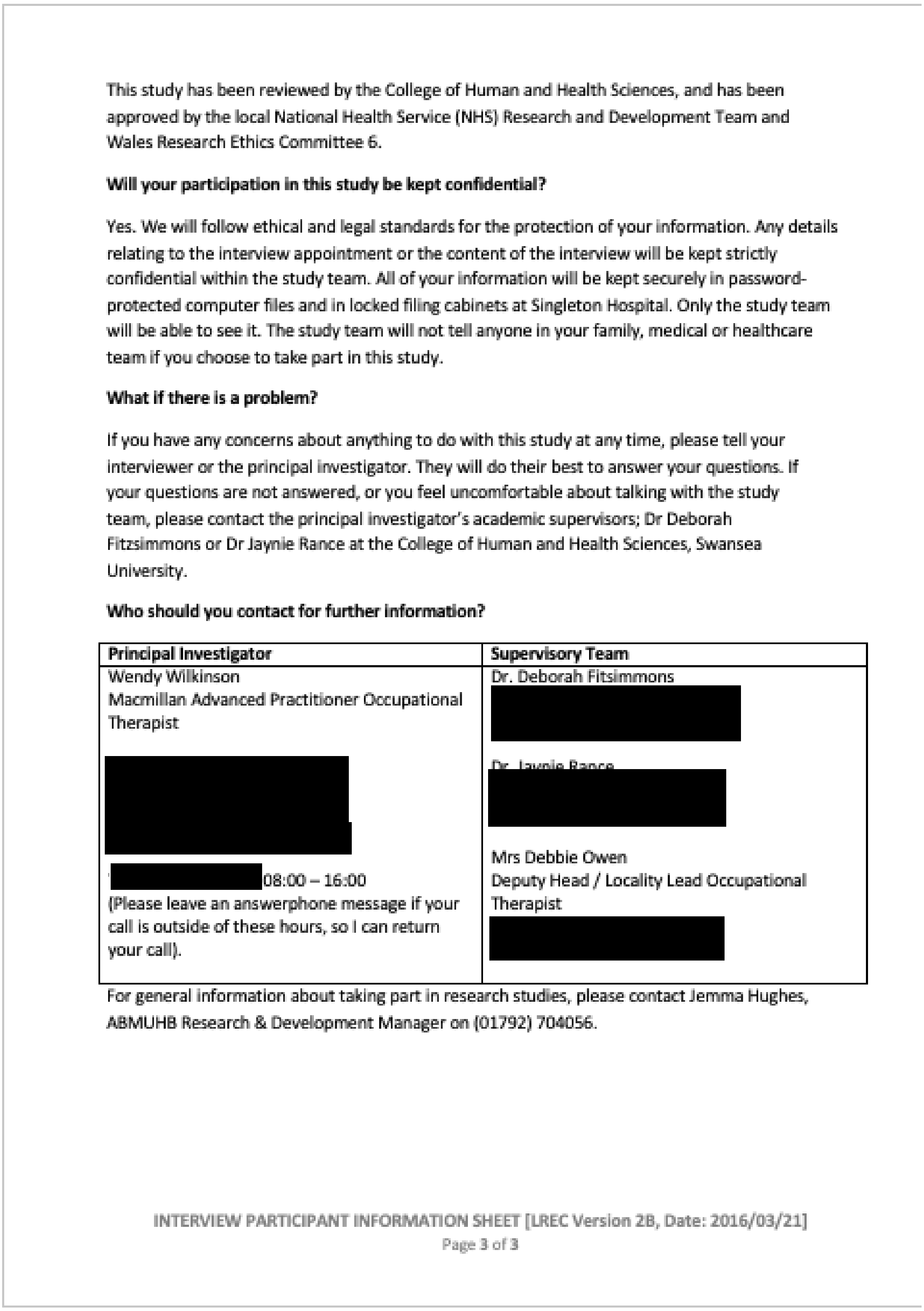
It is possible that you may find parts of your story upsetting to tell. At any time you can stop, delay or opt out of the study if you need to. Wendy is experienced in working with people who have had cancer. She will be able to support you if you need it.

Will I be paid for my participation?

No. There is no funding for this study. However, the study team will make every effort to see that you are not inconvenienced if you take part.

Who is this study organised and funded by?

This study is part of a Professional Practice Doctorate. It runs alongside the principal investigator's full time job in cancer rehabilitation. Academic fees have been paid in part by ABMUHB, Golau Cancer Foundation – which is the official charity for the South West Wales Cancer Centre, in part by Macmillan Learning and Development grants; and in part by a Swansea University College of Human and Health Sciences teaching bursary.



This study has been reviewed by the College of Human and Health Sciences, and has been approved by the local National Health Service (NHS) Research and Development Team and Wales Research Ethics Committee 6.

Will your participation in this study be kept confidential?

Yes. We will follow ethical and legal standards for the protection of your information. Any details relating to the interview appointment or the content of the interview will be kept strictly confidential within the study team. All of your information will be kept securely in password-protected computer files and in locked filing cabinets at Singleton Hospital. Only the study team will be able to see it. The study team will not tell anyone in your family, medical or healthcare team if you choose to take part in this study.

What if there is a problem?

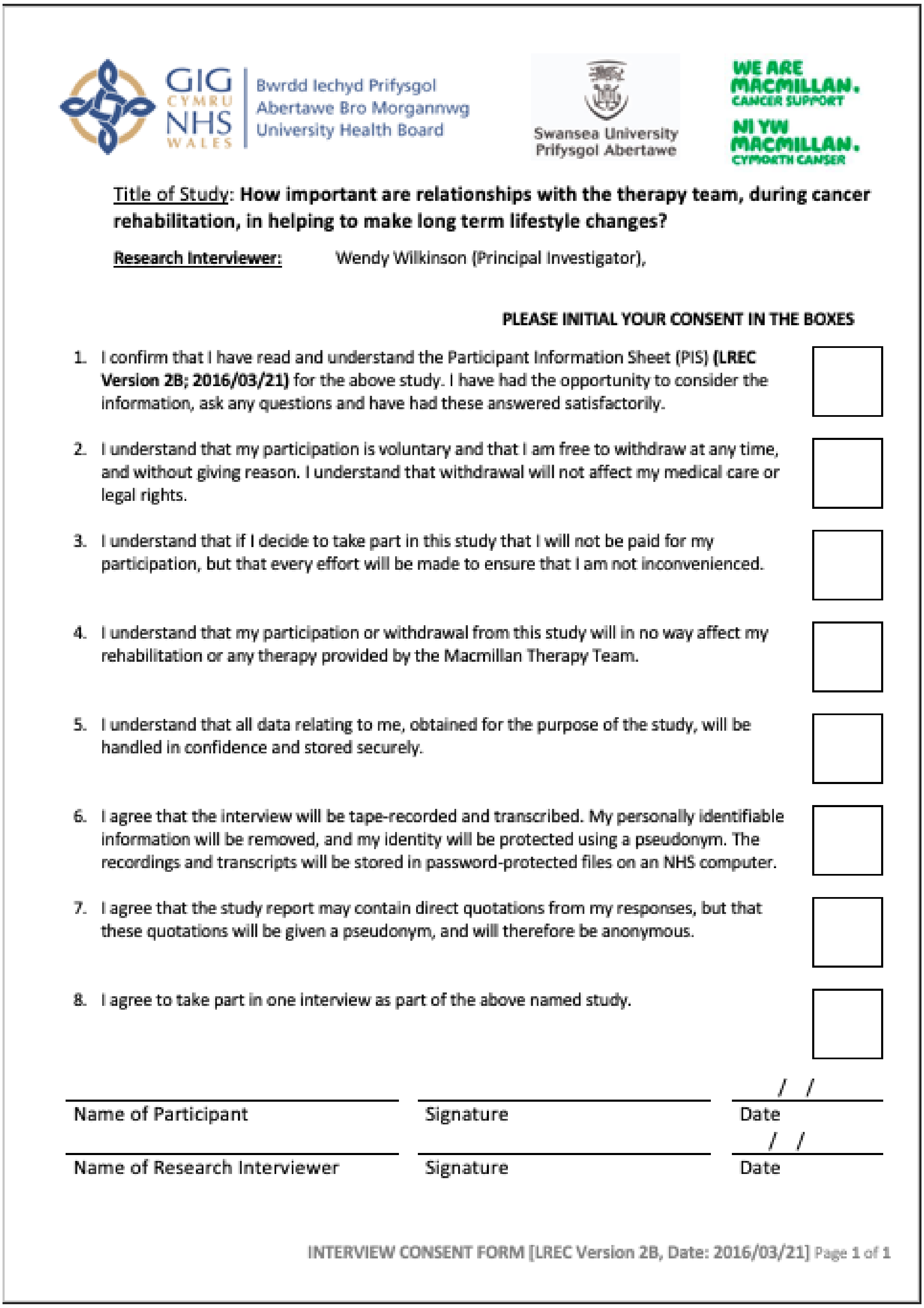
If you have any concerns about anything to do with this study at any time, please tell your interviewer or the principal investigator. They will do their best to answer your questions. If your questions are not answered, or you feel uncomfortable about talking with the study team, please contact the principal investigator's academic supervisors; Dr Deborah Fitzsimmons or Dr Jaynie Rance at the College of Human and Health Sciences, Swansea University.

Who should you contact for further information?

Principal Investigator	**Supervisory Team**
Wendy Wilkinson Macmillan Advanced Practitioner Occupational Therapist [redacted] [redacted] 08:00 – 16:00 (Please leave an answerphone message if your call is outside of these hours, so I can return your call).	Dr. Deborah Fitsimmons [redacted] [redacted] Mrs Debbie Owen Deputy Head / Locality Lead Occupational Therapist [redacted]

For general information about taking part in research studies, please contact Jemma Hughes, ABMUHB Research & Development Manager on (01792) 704056.

INTERVIEW PARTICIPANT INFORMATION SHEET [LREC Version 2B, Date: 2016/03/21]
Page 3 of 3



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Abertawe Bro Morgannwg
University Health Board

Swansea University
Prifysgol Abertawe

WE ARE MACMILLAN. CANCER SUPPORT

NI YW MACMILLAN. CYMORTH CANSER

Title of Study: **How important are relationships with the therapy team, during cancer rehabilitation, in helping to make long term lifestyle changes?**

Research Interviewer: Wendy Wilkinson (Principal Investigator),

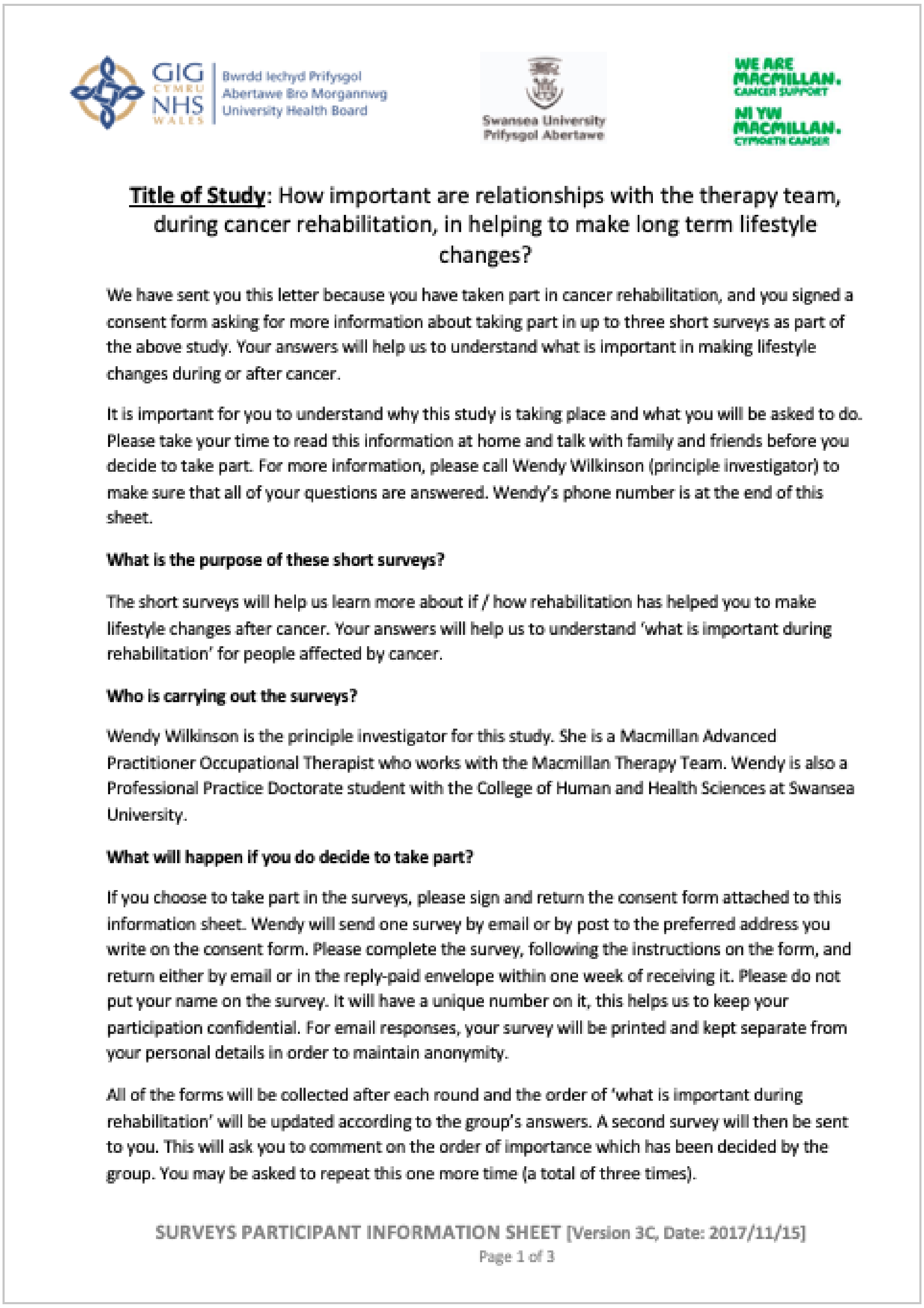
PLEASE INITIAL YOUR CONSENT IN THE BOXES

1. I confirm that I have read and understand the Participant Information Sheet (PIS) **(LREC Version 2B; 2016/03/21)** for the above study. I have had the opportunity to consider the information, ask any questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, and without giving reason. I understand that withdrawal will not affect my medical care or legal rights. ☐
3. I understand that if I decide to take part in this study that I will not be paid for my participation, but that every effort will be made to ensure that I am not inconvenienced. ☐
4. I understand that my participation or withdrawal from this study will in no way affect my rehabilitation or any therapy provided by the Macmillan Therapy Team. ☐
5. I understand that all data relating to me, obtained for the purpose of the study, will be handled in confidence and stored securely. ☐
6. I agree that the interview will be tape-recorded and transcribed. My personally identifiable information will be removed, and my identity will be protected using a pseudonym. The recordings and transcripts will be stored in password-protected files on an NHS computer. ☐
7. I agree that the study report may contain direct quotations from my responses, but that these quotations will be given a pseudonym, and will therefore be anonymous. ☐
8. I agree to take part in one interview as part of the above named study. ☐

		/ /
Name of Participant	Signature	Date
		/ /
Name of Research Interviewer	Signature	Date

INTERVIEW CONSENT FORM [LREC Version 2B, Date: 2016/03/21] Page 1 of 1

Appendix 11.3. Modified Delphi Technique Participant Information and Consent Form



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University Health Board

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WE ARE MACMILLAN. CANCER SUPPORT
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Title of Study: How important are relationships with the therapy team, during cancer rehabilitation, in helping to make long term lifestyle changes?

We have sent you this letter because you have taken part in cancer rehabilitation, and you signed a consent form asking for more information about taking part in up to three short surveys as part of the above study. Your answers will help us to understand what is important in making lifestyle changes during or after cancer.

It is important for you to understand why this study is taking place and what you will be asked to do. Please take your time to read this information at home and talk with family and friends before you decide to take part. For more information, please call Wendy Wilkinson (principle investigator) to make sure that all of your questions are answered. Wendy's phone number is at the end of this sheet.

What is the purpose of these short surveys?

The short surveys will help us learn more about if / how rehabilitation has helped you to make lifestyle changes after cancer. Your answers will help us to understand 'what is important during rehabilitation' for people affected by cancer.

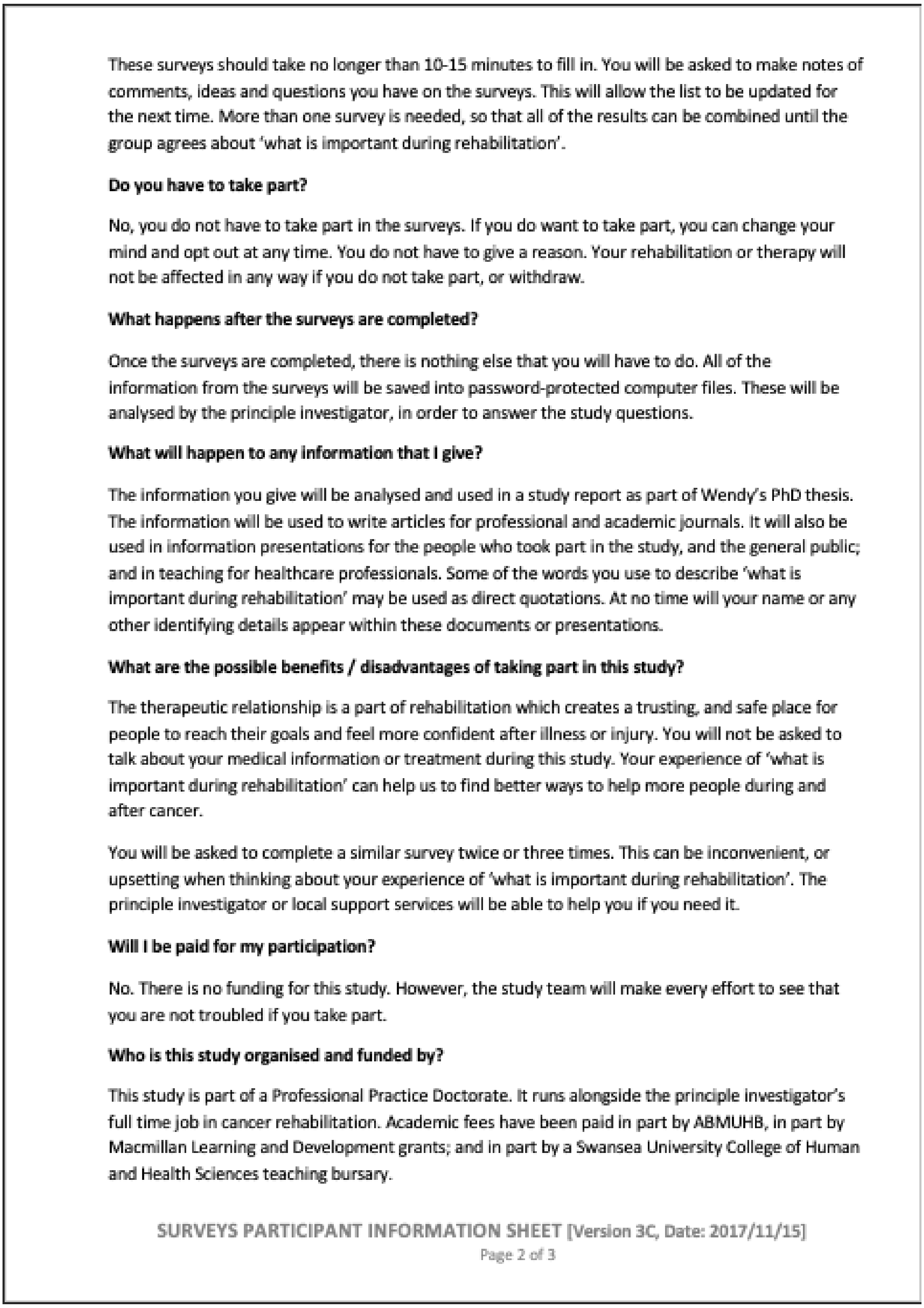
Who is carrying out the surveys?

Wendy Wilkinson is the principle investigator for this study. She is a Macmillan Advanced Practitioner Occupational Therapist who works with the Macmillan Therapy Team. Wendy is also a Professional Practice Doctorate student with the College of Human and Health Sciences at Swansea University.

What will happen if you do decide to take part?

If you choose to take part in the surveys, please sign and return the consent form attached to this information sheet. Wendy will send one survey by email or by post to the preferred address you write on the consent form. Please complete the survey, following the instructions on the form, and return either by email or in the reply-paid envelope within one week of receiving it. Please do not put your name on the survey. It will have a unique number on it, this helps us to keep your participation confidential. For email responses, your survey will be printed and kept separate from your personal details in order to maintain anonymity.

All of the forms will be collected after each round and the order of 'what is important during rehabilitation' will be updated according to the group's answers. A second survey will then be sent to you. This will ask you to comment on the order of importance which has been decided by the group. You may be asked to repeat this one more time (a total of three times).



These surveys should take no longer than 10-15 minutes to fill in. You will be asked to make notes of comments, ideas and questions you have on the surveys. This will allow the list to be updated for the next time. More than one survey is needed, so that all of the results can be combined until the group agrees about 'what is important during rehabilitation'.

Do you have to take part?

No, you do not have to take part in the surveys. If you do want to take part, you can change your mind and opt out at any time. You do not have to give a reason. Your rehabilitation or therapy will not be affected in any way if you do not take part, or withdraw.

What happens after the surveys are completed?

Once the surveys are completed, there is nothing else that you will have to do. All of the information from the surveys will be saved into password-protected computer files. These will be analysed by the principle investigator, in order to answer the study questions.

What will happen to any information that I give?

The information you give will be analysed and used in a study report as part of Wendy's PhD thesis. The information will be used to write articles for professional and academic journals. It will also be used in information presentations for the people who took part in the study, and the general public; and in teaching for healthcare professionals. Some of the words you use to describe 'what is important during rehabilitation' may be used as direct quotations. At no time will your name or any other identifying details appear within these documents or presentations.

What are the possible benefits / disadvantages of taking part in this study?

The therapeutic relationship is a part of rehabilitation which creates a trusting, and safe place for people to reach their goals and feel more confident after illness or injury. You will not be asked to talk about your medical information or treatment during this study. Your experience of 'what is important during rehabilitation' can help us to find better ways to help more people during and after cancer.

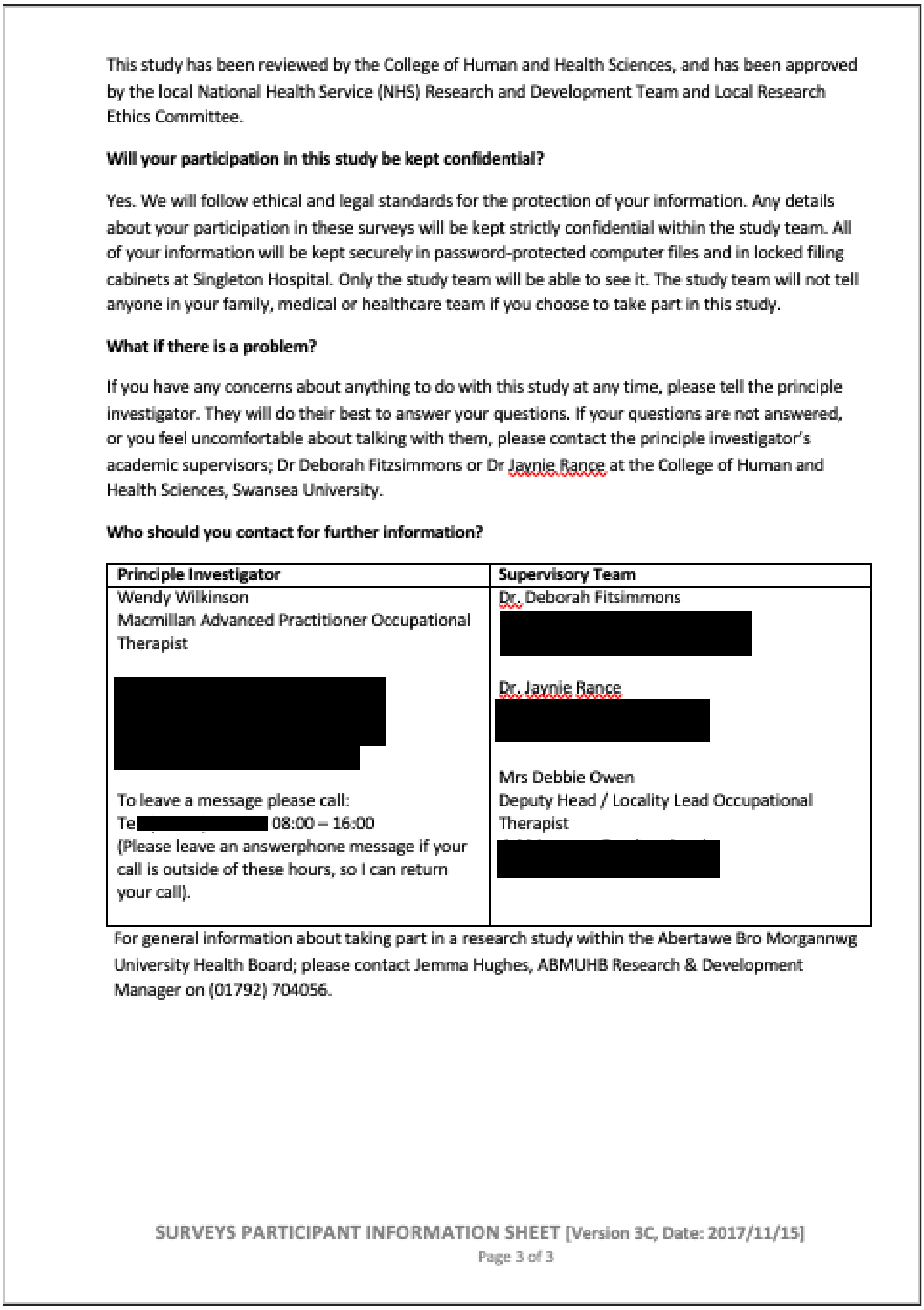
You will be asked to complete a similar survey twice or three times. This can be inconvenient, or upsetting when thinking about your experience of 'what is important during rehabilitation'. The principle investigator or local support services will be able to help you if you need it.

Will I be paid for my participation?

No. There is no funding for this study. However, the study team will make every effort to see that you are not troubled if you take part.

Who is this study organised and funded by?

This study is part of a Professional Practice Doctorate. It runs alongside the principle investigator's full time job in cancer rehabilitation. Academic fees have been paid in part by ABMUHB, in part by Macmillan Learning and Development grants; and in part by a Swansea University College of Human and Health Sciences teaching bursary.



This study has been reviewed by the College of Human and Health Sciences, and has been approved by the local National Health Service (NHS) Research and Development Team and Local Research Ethics Committee.

Will your participation in this study be kept confidential?

Yes. We will follow ethical and legal standards for the protection of your information. Any details about your participation in these surveys will be kept strictly confidential within the study team. All of your information will be kept securely in password-protected computer files and in locked filing cabinets at Singleton Hospital. Only the study team will be able to see it. The study team will not tell anyone in your family, medical or healthcare team if you choose to take part in this study.

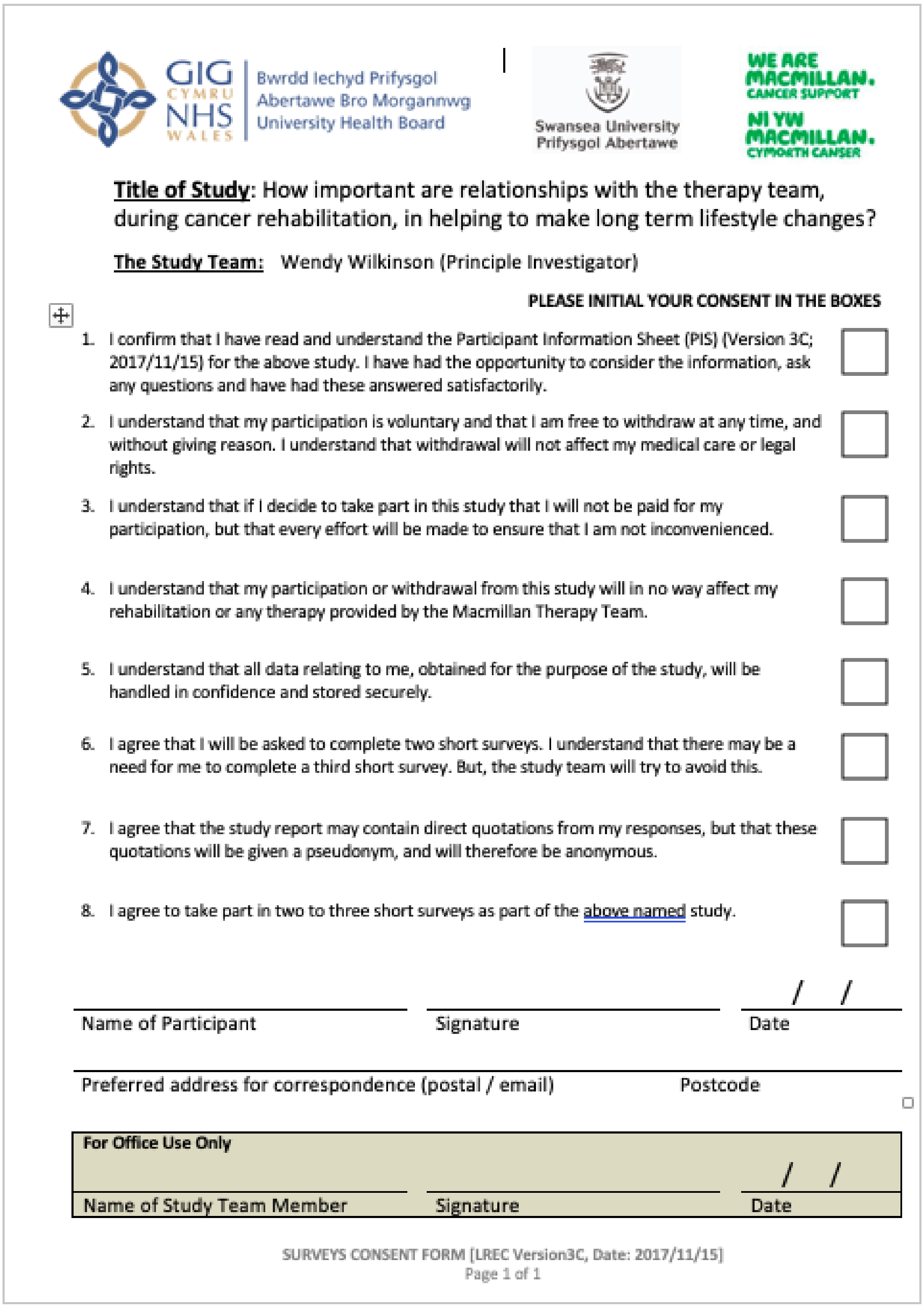
What if there is a problem?

If you have any concerns about anything to do with this study at any time, please tell the principle investigator. They will do their best to answer your questions. If your questions are not answered, or you feel uncomfortable about talking with them, please contact the principle investigator's academic supervisors; Dr Deborah Fitzsimmons or Dr Jaynie Rance at the College of Human and Health Sciences, Swansea University.

Who should you contact for further information?

Principle Investigator	**Supervisory Team**
Wendy Wilkinson Macmillan Advanced Practitioner Occupational Therapist [redacted] To leave a message please call: Te[redacted] 08:00 – 16:00 (Please leave an answerphone message if your call is outside of these hours, so I can return your call).	Dr. Deborah Fitsimmons [redacted] Dr. Jaynie Rance [redacted] Mrs Debbie Owen Deputy Head / Locality Lead Occupational Therapist [redacted]

For general information about taking part in a research study within the Abertawe Bro Morgannwg University Health Board; please contact Jemma Hughes, ABMUHB Research & Development Manager on (01792) 704056.



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Swansea University Prifysgol Abertawe

WE ARE MACMILLAN. CANCER SUPPORT
NI YW MACMILLAN. CYMORTH CANSER

Title of Study: How important are relationships with the therapy team, during cancer rehabilitation, in helping to make long term lifestyle changes?

The Study Team: Wendy Wilkinson (Principle Investigator)

PLEASE INITIAL YOUR CONSENT IN THE BOXES

1. I confirm that I have read and understand the Participant Information Sheet (PIS) (Version 3C; 2017/11/15) for the above study. I have had the opportunity to consider the information, ask any questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, and without giving reason. I understand that withdrawal will not affect my medical care or legal rights. ☐
3. I understand that if I decide to take part in this study that I will not be paid for my participation, but that every effort will be made to ensure that I am not inconvenienced. ☐
4. I understand that my participation or withdrawal from this study will in no way affect my rehabilitation or any therapy provided by the Macmillan Therapy Team. ☐
5. I understand that all data relating to me, obtained for the purpose of the study, will be handled in confidence and stored securely. ☐
6. I agree that I will be asked to complete two short surveys. I understand that there may be a need for me to complete a third short survey. But, the study team will try to avoid this. ☐
7. I agree that the study report may contain direct quotations from my responses, but that these quotations will be given a pseudonym, and will therefore be anonymous. ☐
8. I agree to take part in two to three short surveys as part of the above named study. ☐

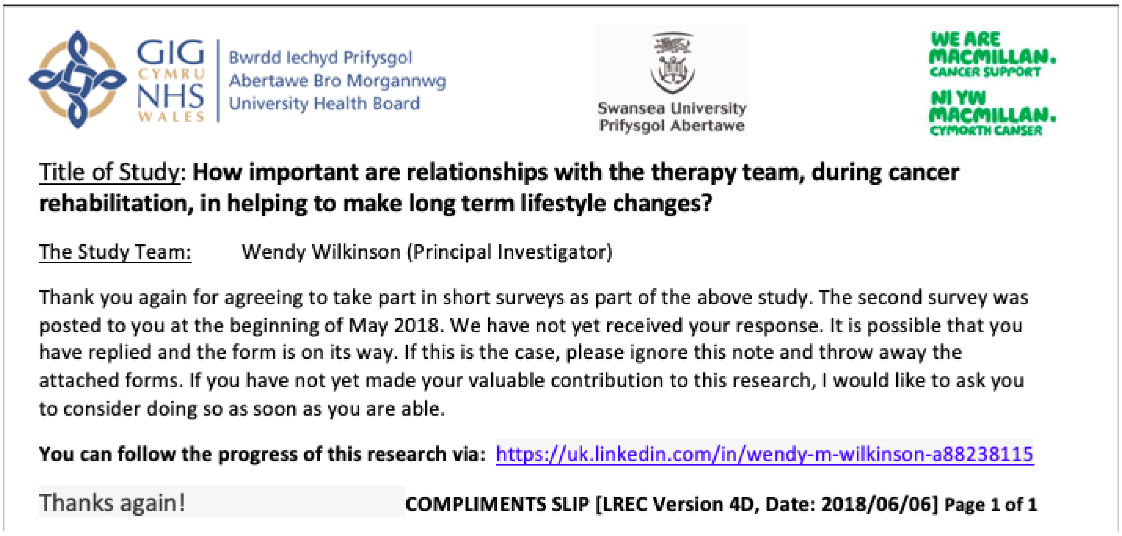
		/ /
Name of Participant	Signature	Date
Preferred address for correspondence (postal / email)		Postcode

For Office Use Only

		/ /
Name of Study Team Member	Signature	Date

SURVEYS CONSENT FORM [LREC Version3C, Date: 2017/11/15]
Page 1 of 1

Appendix 11.4. Compliment Slips



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Title of Study: **How important are relationships with the therapy team, during cancer rehabilitation, in helping to make long term lifestyle changes?**

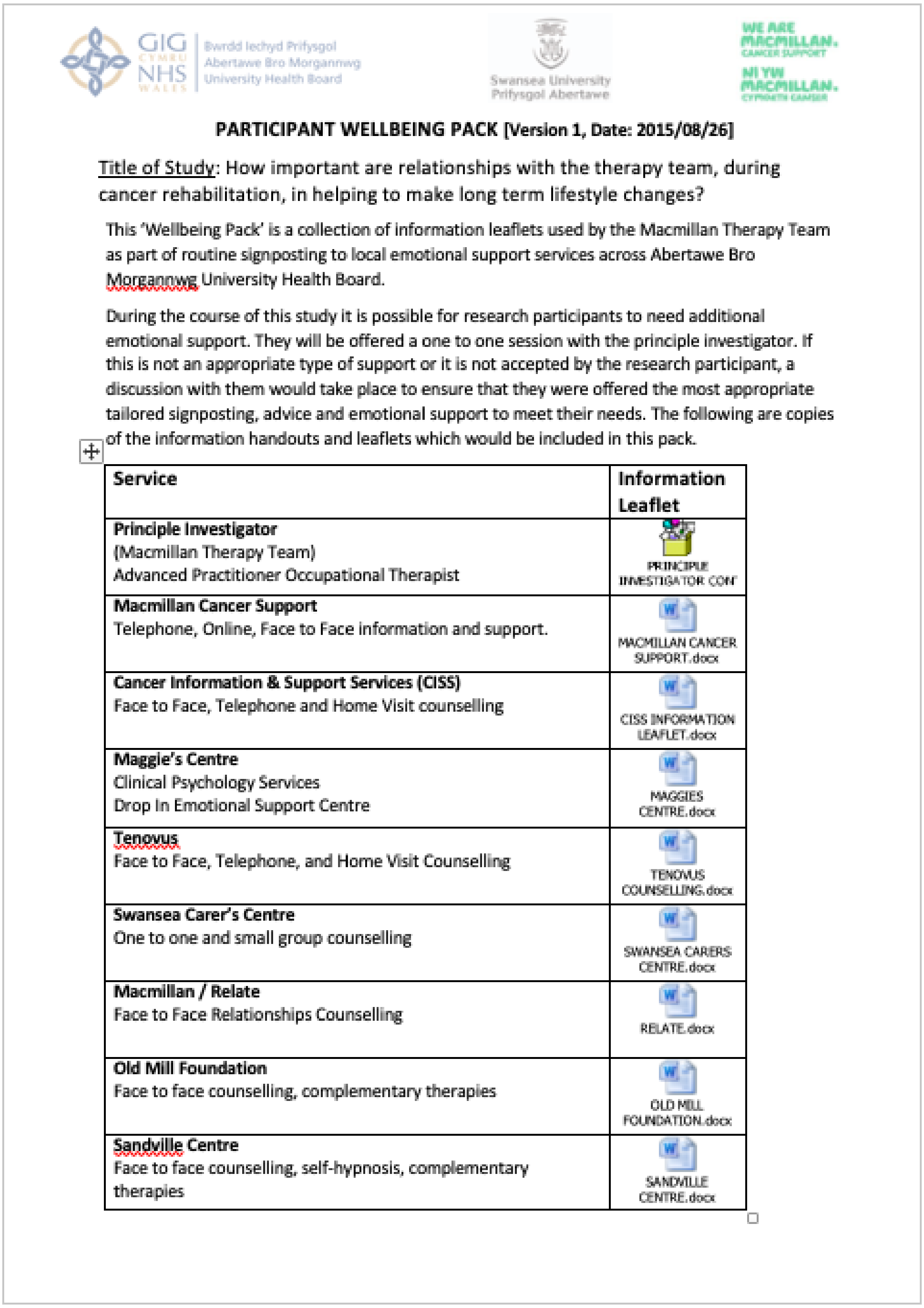
The Study Team: Wendy Wilkinson (Principal Investigator)

Thank you again for agreeing to take part in short surveys as part of the above study. The second survey was posted to you at the beginning of May 2018. We have not yet received your response. It is possible that you have replied and the form is on its way. If this is the case, please ignore this note and throw away the attached forms. If you have not yet made your valuable contribution to this research, I would like to ask you to consider doing so as soon as you are able.

You can follow the progress of this research via: https://uk.linkedin.com/in/wendy-m-wilkinson-a88238115

Thanks again! **COMPLIMENTS SLIP [LREC Version 4D, Date: 2018/06/06] Page 1 of 1**

Appendix 12. Wellbeing Pack for Interview Participants



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PARTICIPANT WELLBEING PACK [Version 1, Date: 2015/08/26]

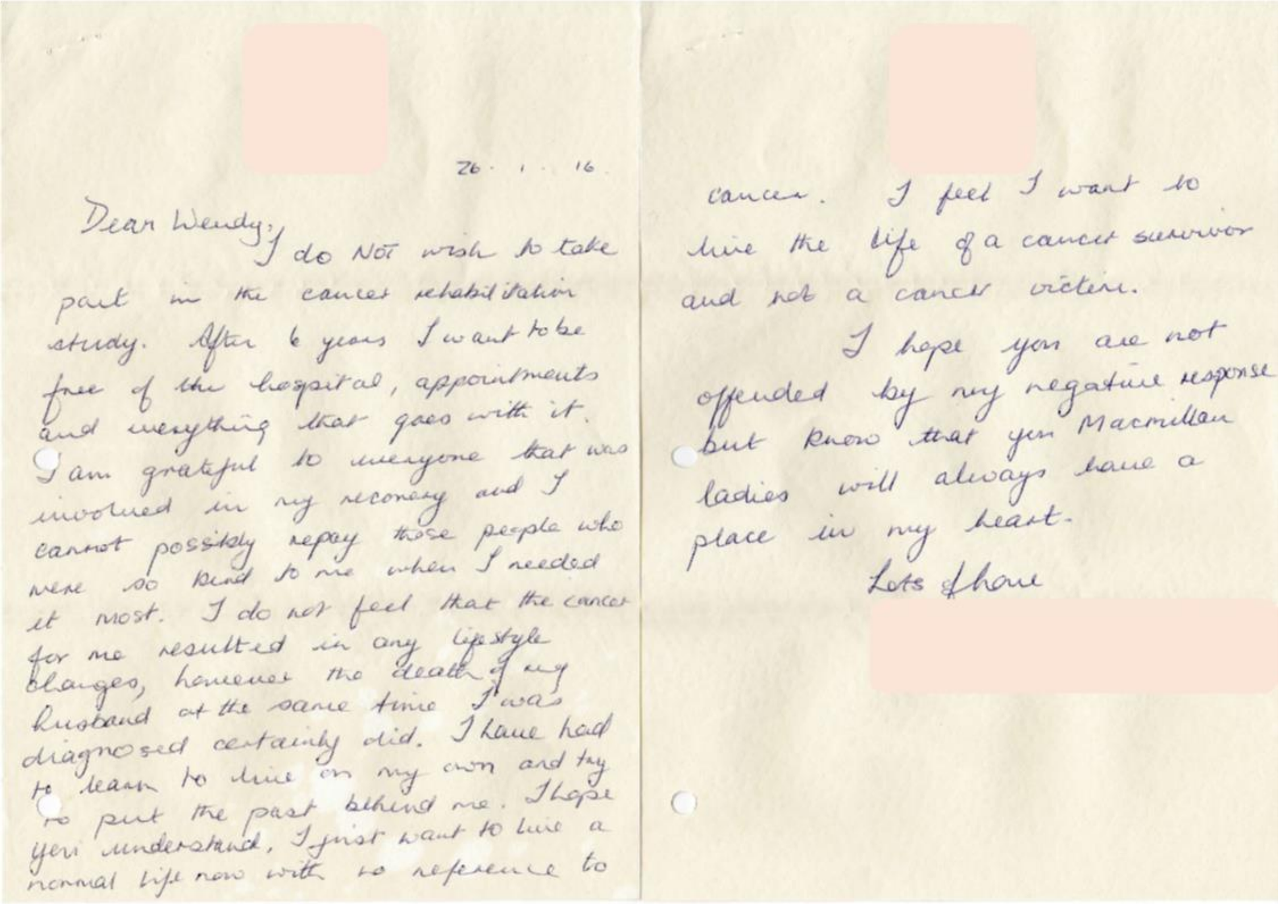
Title of Study: How important are relationships with the therapy team, during cancer rehabilitation, in helping to make long term lifestyle changes?

This 'Wellbeing Pack' is a collection of information leaflets used by the Macmillan Therapy Team as part of routine signposting to local emotional support services across Abertawe Bro Morgannwg University Health Board.

During the course of this study it is possible for research participants to need additional emotional support. They will be offered a one to one session with the principle investigator. If this is not an appropriate type of support or it is not accepted by the research participant, a discussion with them would take place to ensure that they were offered the most appropriate tailored signposting, advice and emotional support to meet their needs. The following are copies of the information handouts and leaflets which would be included in this pack.

Service	**Information Leaflet**
Principle Investigator (Macmillan Therapy Team) Advanced Practitioner Occupational Therapist	PRINCIPLE INVESTIGATOR CON
Macmillan Cancer Support Telephone, Online, Face to Face information and support.	MACMILLAN CANCER SUPPORT.docx
Cancer Information & Support Services (CISS) Face to Face, Telephone and Home Visit counselling	CISS INFORMATION LEAFLET.docx
Maggie's Centre Clinical Psychology Services Drop In Emotional Support Centre	MAGGIES CENTRE.docx
Tenovus Face to Face, Telephone, and Home Visit Counselling	TENOVUS COUNSELLING.docx
Swansea Carer's Centre One to one and small group counselling	SWANSEA CARERS CENTRE.docx
Macmillan / Relate Face to Face Relationships Counselling	RELATE.docx
Old Mill Foundation Face to face counselling, complementary therapies	OLD MILL FOUNDATION.docx
Sandville Centre Face to face counselling, self-hypnosis, complementary therapies	SANDVILLE CENTRE.docx

Appendix 13. Scan of Letter Declining Participation



[redacted]

26. 1. 16

Dear Wendy,

I do NOT wish to take part in the cancer rehabilitation study. After 6 years I want to be free of the hospital, appointments and everything that goes with it. I am grateful to everyone that was involved in my recovery and I cannot possibly repay those people who were so kind to me when I needed it most. I do not feel that the cancer for me resulted in any lifestyle changes, however the death of my husband at the same time I was diagnosed certainly did. I have had to learn to live on my own and try to put the past behind me. I hope you understand, I just want to live a normal life now with no reference to

[redacted]

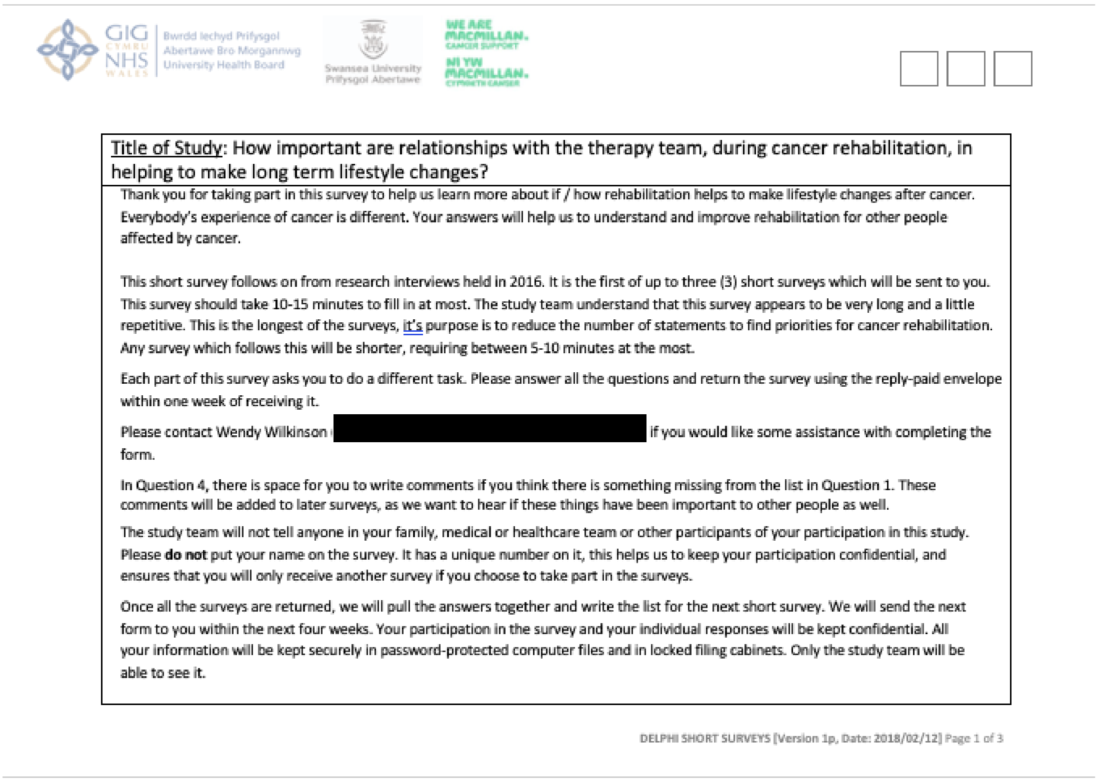
cancer. I feel I want to live the life of a cancer survivor and not a cancer victim.

I hope you are not offended by my negative response but know that you Macmillan ladies will always have a place in my heart.

Lots of love

[redacted]

Appendix 14. ModDT – Round One Data Collection Tool



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☐☐☐

Title of Study: How important are relationships with the therapy team, during cancer rehabilitation, in helping to make long term lifestyle changes?

Thank you for taking part in this survey to help us learn more about if / how rehabilitation helps to make lifestyle changes after cancer. Everybody's experience of cancer is different. Your answers will help us to understand and improve rehabilitation for other people affected by cancer.

This short survey follows on from research interviews held in 2016. It is the first of up to three (3) short surveys which will be sent to you. This survey should take 10-15 minutes to fill in at most. The study team understand that this survey appears to be very long and a little repetitive. This is the longest of the surveys, it's purpose is to reduce the number of statements to find priorities for cancer rehabilitation. Any survey which follows this will be shorter, requiring between 5-10 minutes at the most.

Each part of this survey asks you to do a different task. Please answer all the questions and return the survey using the reply-paid envelope within one week of receiving it.

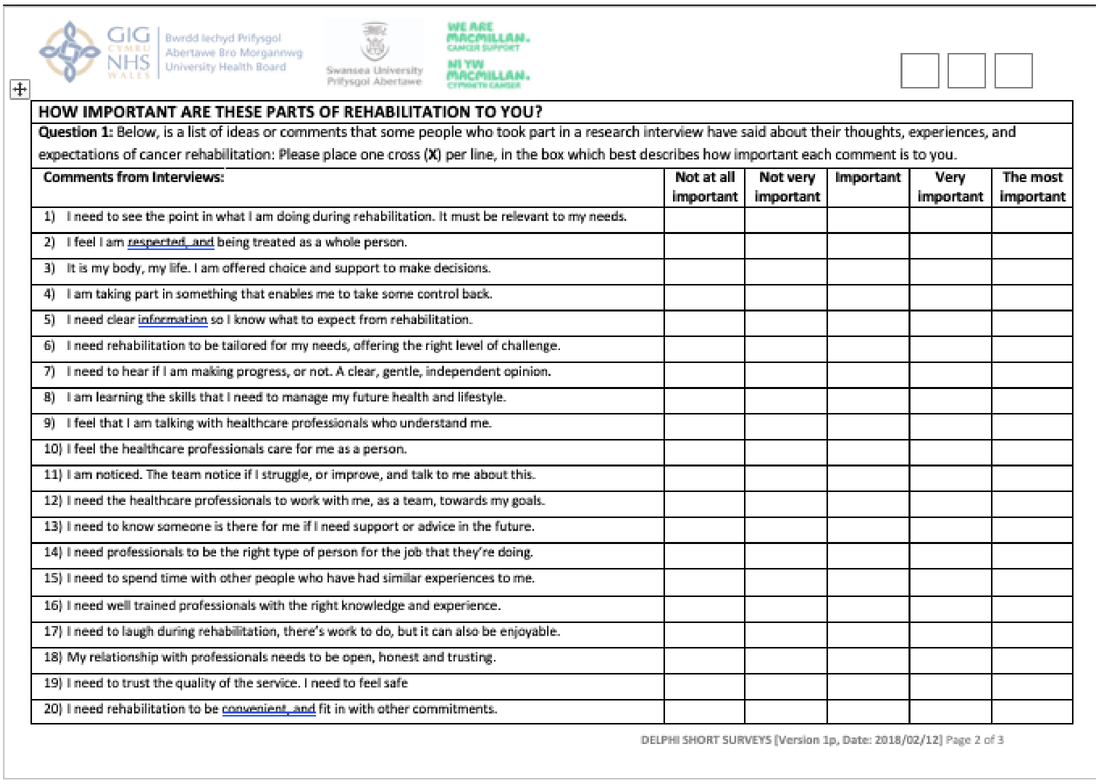
Please contact Wendy Wilkinson [redacted] if you would like some assistance with completing the form.

In Question 4, there is space for you to write comments if you think there is something missing from the list in Question 1. These comments will be added to later surveys, as we want to hear if these things have been important to other people as well.

The study team will not tell anyone in your family, medical or healthcare team or other participants of your participation in this study. Please **do not** put your name on the survey. It has a unique number on it, this helps us to keep your participation confidential, and ensures that you will only receive another survey if you choose to take part in the surveys.

Once all the surveys are returned, we will pull the answers together and write the list for the next short survey. We will send the next form to you within the next four weeks. Your participation in the survey and your individual responses will be kept confidential. All your information will be kept securely in password-protected computer files and in locked filing cabinets. Only the study team will be able to see it.

DELPHI SHORT SURVEYS [Version 1p, Date: 2018/02/12] Page 1 of 3



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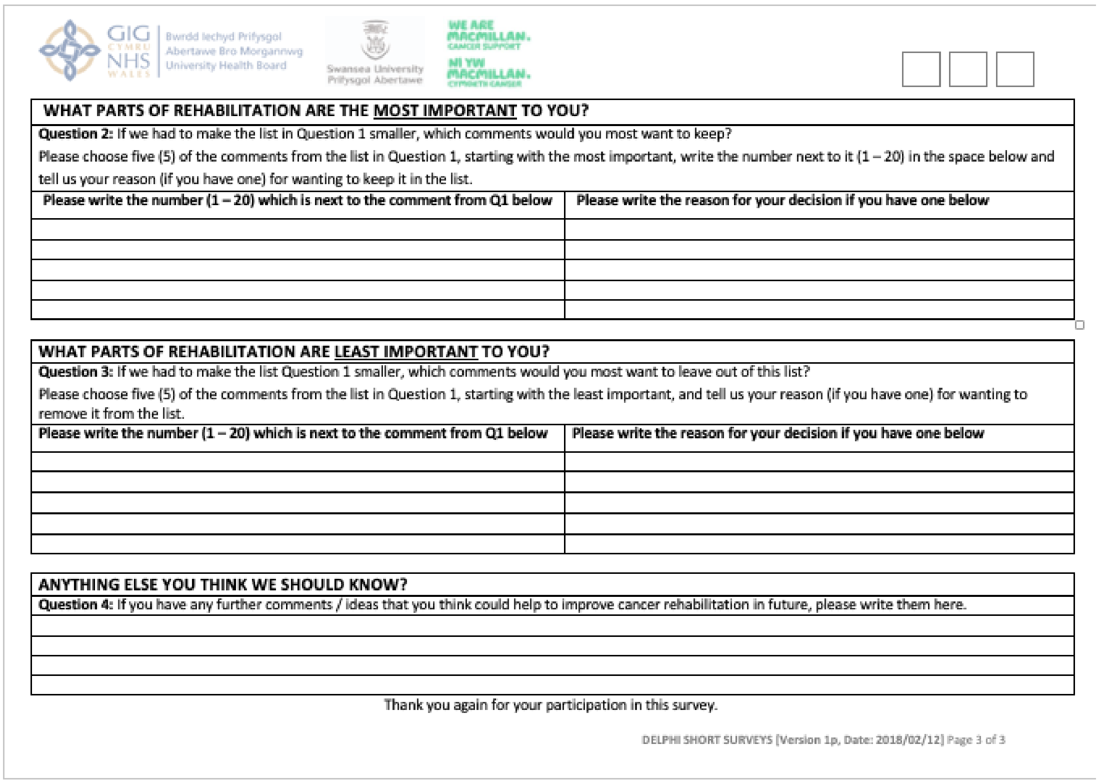
☐☐☐

HOW IMPORTANT ARE THESE PARTS OF REHABILITATION TO YOU?

Question 1: Below, is a list of ideas or comments that some people who took part in a research interview have said about their thoughts, experiences, and expectations of cancer rehabilitation: Please place one cross (**X**) per line, in the box which best describes how important each comment is to you.

Comments from Interviews:	**Not at all important**	**Not very important**	**Important**	**Very important**	**The most important**
1) I need to see the point in what I am doing during rehabilitation. It must be relevant to my needs.					
2) I feel I am respected, and being treated as a whole person.					
3) It is my body, my life. I am offered choice and support to make decisions.					
4) I am taking part in something that enables me to take some control back.					
5) I need clear information so I know what to expect from rehabilitation.					
6) I need rehabilitation to be tailored for my needs, offering the right level of challenge.					
7) I need to hear if I am making progress, or not. A clear, gentle, independent opinion.					
8) I am learning the skills that I need to manage my future health and lifestyle.					
9) I feel that I am talking with healthcare professionals who understand me.					
10) I feel the healthcare professionals care for me as a person.					
11) I am noticed. The team notice if I struggle, or improve, and talk to me about this.					
12) I need the healthcare professionals to work with me, as a team, towards my goals.					
13) I need to know someone is there for me if I need support or advice in the future.					
14) I need professionals to be the right type of person for the job that they're doing.					
15) I need to spend time with other people who have had similar experiences to me.					
16) I need well trained professionals with the right knowledge and experience.					
17) I need to laugh during rehabilitation, there's work to do, but it can also be enjoyable.					
18) My relationship with professionals needs to be open, honest and trusting.					
19) I need to trust the quality of the service. I need to feel safe					
20) I need rehabilitation to be convenient, and fit in with other commitments.					

DELPHI SHORT SURVEYS [Version 1p, Date: 2018/02/12] Page 2 of 3



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WHAT PARTS OF REHABILITATION ARE THE MOST IMPORTANT TO YOU?

Question 2: If we had to make the list in Question 1 smaller, which comments would you most want to keep?

Please choose five (5) of the comments from the list in Question 1, starting with the most important, write the number next to it (1 – 20) in the space below and tell us your reason (if you have one) for wanting to keep it in the list.

Please write the number (1 – 20) which is next to the comment from Q1 below	**Please write the reason for your decision if you have one below**

WHAT PARTS OF REHABILITATION ARE LEAST IMPORTANT TO YOU?

Question 3: If we had to make the list Question 1 smaller, which comments would you most want to leave out of this list?

Please choose five (5) of the comments from the list in Question 1, starting with the least important, and tell us your reason (if you have one) for wanting to remove it from the list.

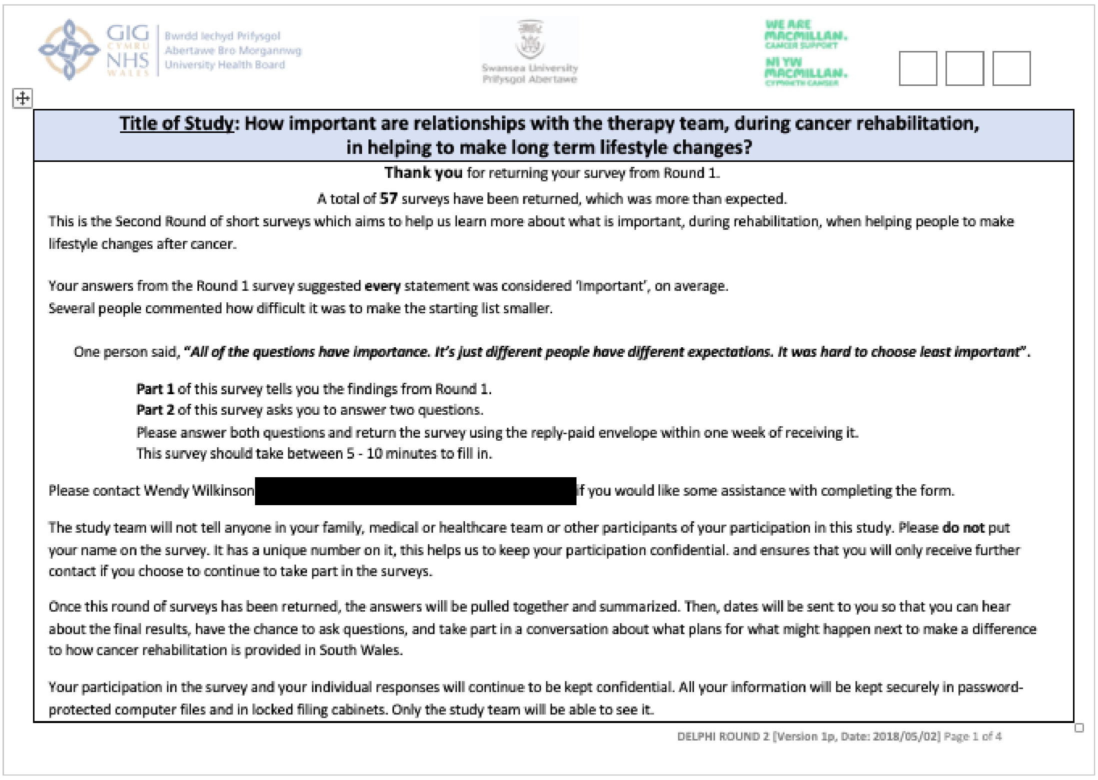
Please write the number (1 – 20) which is next to the comment from Q1 below	**Please write the reason for your decision if you have one below**

ANYTHING ELSE YOU THINK WE SHOULD KNOW?

Question 4: If you have any further comments / ideas that you think could help to improve cancer rehabilitation in future, please write them here.

Thank you again for your participation in this survey.

Appendix 15. ModDT – Round Two Data Collection Tool



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Title of Study: How important are relationships with the therapy team, during cancer rehabilitation, in helping to make long term lifestyle changes?

Thank you for returning your survey from Round 1.

A total of **57** surveys have been returned, which was more than expected.

This is the Second Round of short surveys which aims to help us learn more about what is important, during rehabilitation, when helping people to make lifestyle changes after cancer.

Your answers from the Round 1 survey suggested **every** statement was considered 'Important', on average.
Several people commented how difficult it was to make the starting list smaller.

One person said, ***"All of the questions have importance. It's just different people have different expectations. It was hard to choose least important"***.

Part 1 of this survey tells you the findings from Round 1.
Part 2 of this survey asks you to answer two questions.
Please answer both questions and return the survey using the reply-paid envelope within one week of receiving it.
This survey should take between 5 - 10 minutes to fill in.

Please contact Wendy Wilkinson [redacted] if you would like some assistance with completing the form.

The study team will not tell anyone in your family, medical or healthcare team or other participants of your participation in this study. Please **do not** put your name on the survey. It has a unique number on it, this helps us to keep your participation confidential. and ensures that you will only receive further contact if you choose to continue to take part in the surveys.

Once this round of surveys has been returned, the answers will be pulled together and summarized. Then, dates will be sent to you so that you can hear about the final results, have the chance to ask questions, and take part in a conversation about what plans for what might happen next to make a difference to how cancer rehabilitation is provided in South Wales.

Your participation in the survey and your individual responses will continue to be kept confidential. All your information will be kept securely in password-protected computer files and in locked filing cabinets. Only the study team will be able to see it.

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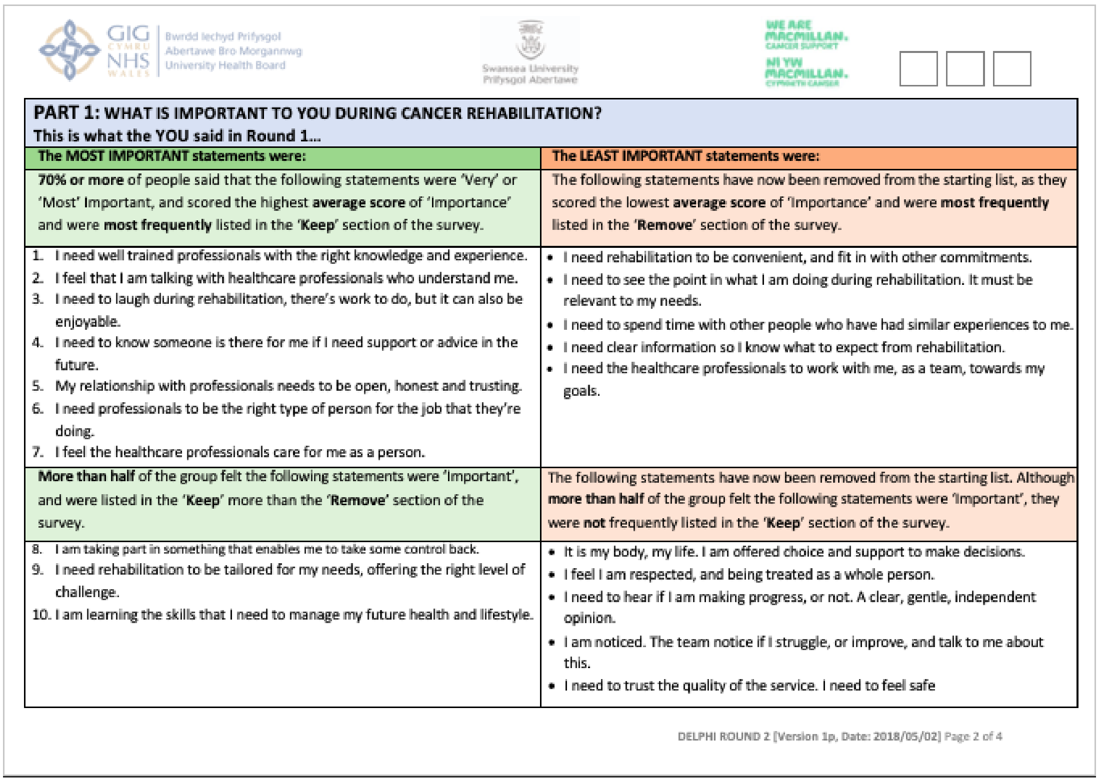

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PART 1: WHAT IS IMPORTANT TO YOU DURING CANCER REHABILITATION?
This is what the YOU said in Round 1…

The MOST IMPORTANT statements were:	**The LEAST IMPORTANT statements were:**
70% or more of people said that the following statements were 'Very' or 'Most' Important, and scored the highest **average score** of 'Importance' and were **most frequently** listed in the '**Keep**' section of the survey.	The following statements have now been removed from the starting list, as they scored the lowest **average score** of 'Importance' and were **most frequently** listed in the '**Remove**' section of the survey.
1. I need well trained professionals with the right knowledge and experience. 2. I feel that I am talking with healthcare professionals who understand me. 3. I need to laugh during rehabilitation, there's work to do, but it can also be enjoyable. 4. I need to know someone is there for me if I need support or advice in the future. 5. My relationship with professionals needs to be open, honest and trusting. 6. I need professionals to be the right type of person for the job that they're doing. 7. I feel the healthcare professionals care for me as a person.	• I need rehabilitation to be convenient, and fit in with other commitments. • I need to see the point in what I am doing during rehabilitation. It must be relevant to my needs. • I need to spend time with other people who have had similar experiences to me. • I need clear information so I know what to expect from rehabilitation. • I need the healthcare professionals to work with me, as a team, towards my goals.
More than half of the group felt the following statements were 'Important', and were listed in the '**Keep**' more than the '**Remove**' section of the survey.	The following statements have now been removed from the starting list. Although **more than half** of the group felt the following statements were 'Important', they were **not** frequently listed in the '**Keep**' section of the survey.
8. I am taking part in something that enables me to take some control back. 9. I need rehabilitation to be tailored for my needs, offering the right level of challenge. 10. I am learning the skills that I need to manage my future health and lifestyle.	• It is my body, my life. I am offered choice and support to make decisions. • I feel I am respected, and being treated as a whole person. • I need to hear if I am making progress, or not. A clear, gentle, independent opinion. • I am noticed. The team notice if I struggle, or improve, and talk to me about this. • I need to trust the quality of the service. I need to feel safe

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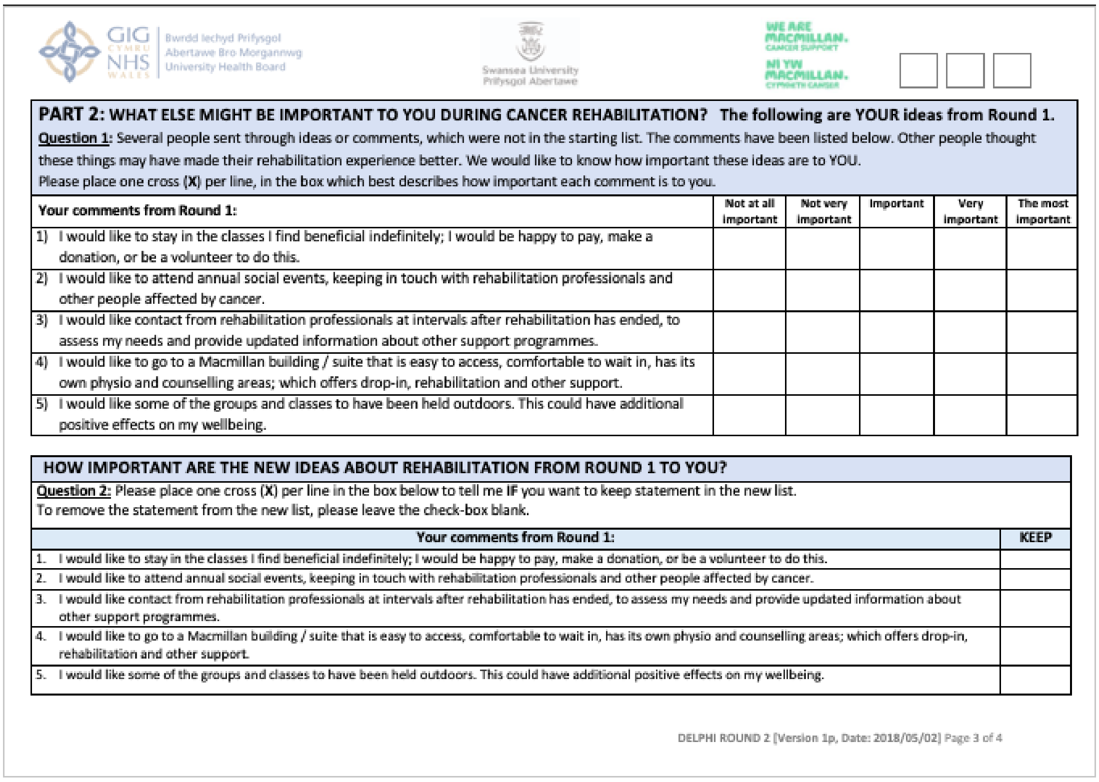

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PART 2: WHAT ELSE MIGHT BE IMPORTANT TO YOU DURING CANCER REHABILITATION? The following are YOUR ideas from Round 1.

Question 1: Several people sent through ideas or comments, which were not in the starting list. The comments have been listed below. Other people thought these things may have made their rehabilitation experience better. We would like to know how important these ideas are to YOU.
Please place one cross (**X**) per line, in the box which best describes how important each comment is to you.

Your comments from Round 1:	**Not at all important**	**Not very important**	**Important**	**Very important**	**The most important**
1) I would like to stay in the classes I find beneficial indefinitely; I would be happy to pay, make a donation, or be a volunteer to do this.					
2) I would like to attend annual social events, keeping in touch with rehabilitation professionals and other people affected by cancer.					
3) I would like contact from rehabilitation professionals at intervals after rehabilitation has ended, to assess my needs and provide updated information about other support programmes.					
4) I would like to go to a Macmillan building / suite that is easy to access, comfortable to wait in, has its own physio and counselling areas; which offers drop-in, rehabilitation and other support.					
5) I would like some of the groups and classes to have been held outdoors. This could have additional positive effects on my wellbeing.					

HOW IMPORTANT ARE THE NEW IDEAS ABOUT REHABILITATION FROM ROUND 1 TO YOU?

Question 2: Please place one cross (X) per line in the box below to tell me **IF** you want to keep statement in the new list.
To remove the statement from the new list, please leave the check-box blank.

Your comments from Round 1:	**KEEP**
1. I would like to stay in the classes I find beneficial indefinitely; I would be happy to pay, make a donation, or be a volunteer to do this.	
2. I would like to attend annual social events, keeping in touch with rehabilitation professionals and other people affected by cancer.	
3. I would like contact from rehabilitation professionals at intervals after rehabilitation has ended, to assess my needs and provide updated information about other support programmes.	
4. I would like to go to a Macmillan building / suite that is easy to access, comfortable to wait in, has its own physio and counselling areas; which offers drop-in, rehabilitation and other support.	
5. I would like some of the groups and classes to have been held outdoors. This could have additional positive effects on my wellbeing.	

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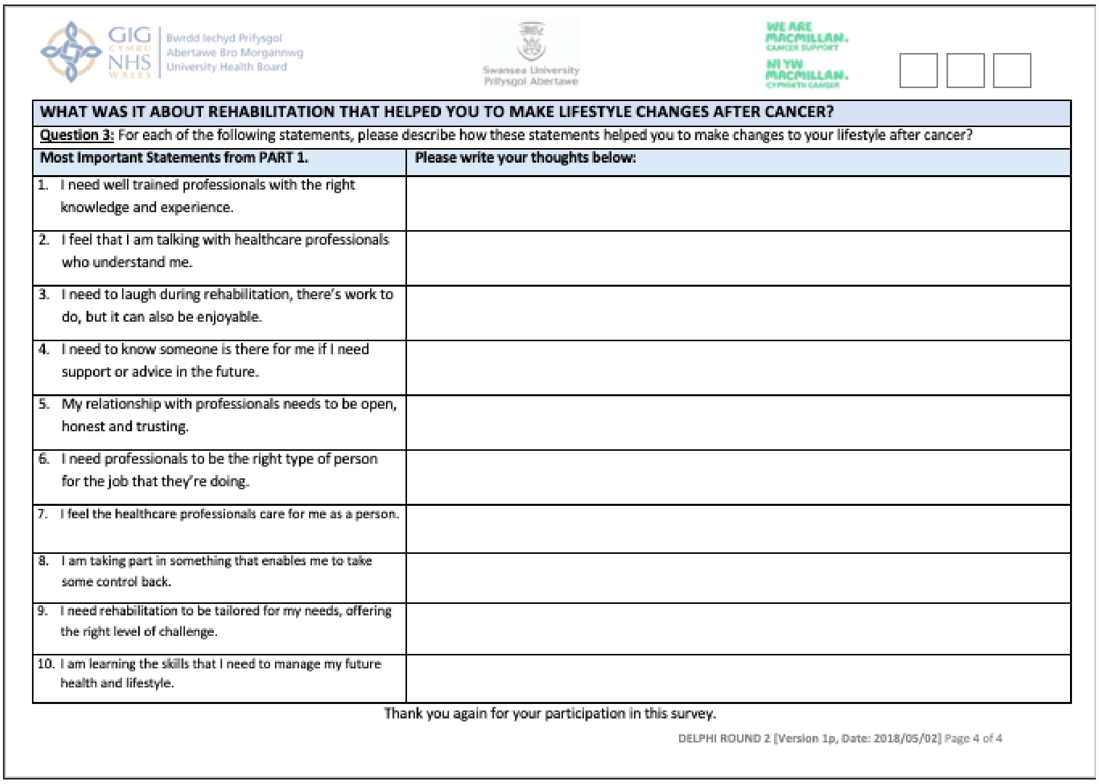

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WHAT WAS IT ABOUT REHABILITATION THAT HELPED YOU TO MAKE LIFESTYLE CHANGES AFTER CANCER?

Question 3: For each of the following statements, please describe how these statements helped you to make changes to your lifestyle after cancer?

Most Important Statements from PART 1.	**Please write your thoughts below:**
1. I need well trained professionals with the right knowledge and experience.	
2. I feel that I am talking with healthcare professionals who understand me.	
3. I need to laugh during rehabilitation, there's work to do, but it can also be enjoyable.	
4. I need to know someone is there for me if I need support or advice in the future.	
5. My relationship with professionals needs to be open, honest and trusting.	
6. I need professionals to be the right type of person for the job that they're doing.	
7. I feel the healthcare professionals care for me as a person.	
8. I am taking part in something that enables me to take some control back.	
9. I need rehabilitation to be tailored for my needs, offering the right level of challenge.	
10. I am learning the skills that I need to manage my future health and lifestyle.	

Thank you again for your participation in this survey.

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Appendix 16. Royal College of Occupational Therapists – Research Career Development Grant Letter

Patron
Her Royal Highness The Princess Royal
President
Professor Sheila the Baroness Hollins
Chief Executive
Julia Scott

Royal College of
Occupational
Therapists

106–114 Borough High Street, London SE1 1LB
T: 020 7357 6480 www.RCOT.co.uk

Via email only
Miss Wendy Wilkinson
Macmillan Allied Health Professional Lead
Wales Cancer Network
[redacted]

24 May 2018

Dear Wendy

Research Career Development Grant proposal 2018
The impact of therapeutic relationships on self-management outcomes after cancer rehabilitation: understanding participant perceptions using a Modified Delphi Technique

Thank you very much for submitting an application for the 2018 round of funding opportunities from the UK Occupational Therapy Research Foundation (UKOTRF) in respect of the above project. I am delighted to formally confirm that your project has been recommended for support.

Both the Advisory Group and reviewers felt this was a well-presented application. The Advisory Group appreciated how the application clearly identified the discreet elements to be funded by the UKOTRF within your larger research and the solid theoretical underpinnings to your proposed method. Furthermore, they applauded your intention to invite participants to a conference to disseminate the results. They commended you for having your protocol published and your strong academic trajectory with an understanding of practice and research. If there is an area that might have benefitted from a little further polishing, it would be to clarify how much time (e.g. hours or days) will be released by the funding and how this will be utilised (e.g. as a day at a time or in blocks). With that in mind, it may be helpful to note that the Advisory Group suggested it may be beneficial to consider utilising the UKOTRF-funded time in one block rather than piecemeal.

The next stage in the process is for the College to prepare a draft grant contract, and my colleague Angie Thompson (R&D Officer – Projects) will be in touch with you about this shortly.

For your awareness, it is anticipated that details of the outcome of the 2018 UKOTRF funding round will be published in either August or September OTnews. This year's grant winners will also be invited to attend a special celebratory Awards event in central London on Wednesday 19th September and you may like to note this date in your diary pending further information. The College will meet reasonable travel costs for you and a guest to attend the event in line with the organisation's expenses policy.

Very many congratulations on your success and all best wishes for your project activity.

[redacted]

Dr Jo Watson
Assistant Director - Education and Research

Royal College of Occupational Therapists (or 'RCOT') is a registered charity in England and Wales (No. 275119) and in Scotland (No. SCO39573) and a limited company registered in England (No. 1347374).
Registered office: 106–114 Borough High Street, London SE1 1LB. VAT Reg. No. 242 7829 47.

Appendix 17. Unpublished Dissemination of Preliminary Findings

Dissemination Activity Type	**Description**
2011 – 2018: Swansea University Medical Students Workshop	Opportunity to share and discuss research process / findings with PG medical students.
2013 – 2019: Cardiff University Practitioner Workshop.	Opportunity to share and discuss research process / findings with PGD OT students.
2017 – 2018: Wales Cancer Patient Experience Conference	Preliminary findings presented to healthcare participant audience.
October 2018: Cancer Allied Health Professional Forum	Preliminary findings presented to cancer AHP audience.
December 2018: Rehabilitation Participant Christmas Event	Informal presentation of preliminary findings to rehabilitation participants including, but not exclusively research participants.
2017 – 2019: Annual teaching opportunities with Cardiff University	MSc Module Understanding Cancer: Patient & Professional Perspectives.
March 2019: Local Health Board Impact Conference	Research findings shared via delegate handout.
March 2019: All Wales Breast Cancer Site Group Annual Workshop	Preliminary presented to multi-professional specialist breast cancer audience.
April 2019: Wales Cancer Network AHP & Nursing Conferences	Preliminary findings presented to cancer nursing and AHP professional audience.
June 2019: RCOT Annual Conference	ILR findings poster / Preliminary SSI & ModDT findings oral presentation
2019: Person-centred care sub-group of the Cancer Implementation Group.	Preliminary findings presented to multi-professional cancer audience.