

Physiotherapy palliative cancer care: A case study approach

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Abstract

There is evidence to suggest that the role of the allied health professional continues to evolve in the delivery of palliative cancer care services. Whilst it appears that there is an increasing need for physiotherapists, there is a lack of understanding about the nature of their role, their educational needs and their place within the rehabilitation team.

The aim of my work was to explore a local palliative cancer care physiotherapy service provision in the light of best practice recommendations, using both my own practice development and a research study. For my research a qualitative approach using a single case study design was chosen as it provided a framework to facilitate the inclusion of multiple perspectives in a complex context within an area of healthcare where little research has been undertaken. Multiple methods of data collection were used from numerous perspectives, which included four data sets: interviews (healthcare professionals [10]); interviews (service users [10]); observations (physiotherapists [2] treating service users [5]); and policy document collection (NICE guidelines; white papers [12]). Detailed data analysis was then carried out using a thematic approach within a framework, comparing and contrasting patterns within and across the four data sets. Emergent themes highlighted a number of important aspects relating to physiotherapists including: new ways of working, shift in mindset and treatment planning, emotional adjustment and integration of professional boundaries.

My primary research and practice development project combined to evidence the metamorphosis of both the physiotherapist profession and service provision where competencies around mentorship, entrepreneurship, leadership, policy championship, integrated teamwork, humanisation and self-reflection embodied within the psycho-social-cultural-spiritual model of healthcare enabled them to meet key policy recommendations of service quality and innovation. A debate is necessary around the need for profession specific or service specific outcomes in this area, and how physiotherapists 'prove their worth' now that they are an integral part of palliative cancer care provision.

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Author's Declaration

No portion of the work referred to in this thesis has been submitted in support of an application for another degree or qualification of this or any other university or other institute of learning.

CHAPTER 1: Introduction

1.1 Introduction

In this chapter I have started off with my reflexive narrative (part of the requirements of this professional doctorate) introducing the reader to me, as the research tool, explaining why I wanted to explore physiotherapy palliative cancer care service provision. All reflections throughout my thesis have been presented in italics to differentiate them from the main text. This has been followed by a general overview of the doctor of professional practice (DProf) and then palliative cancer care, the prevalence and epidemiology of cancer as well as the background to palliative cancer care service provision. I have then discussed palliative cancer care rehabilitation services and the multi-disciplinary team, focusing on the role of the physiotherapist. This includes an overview of palliative cancer care physiotherapy service provision and the modalities and interventions used. Following this I have established the need for my study and the rationale for my research. At the end of the chapter I have reflected upon how my research and practice development project evolved together overtime and how my DProf group and individual supervision linked into this process. I have concluded with the aims and objectives of my research.

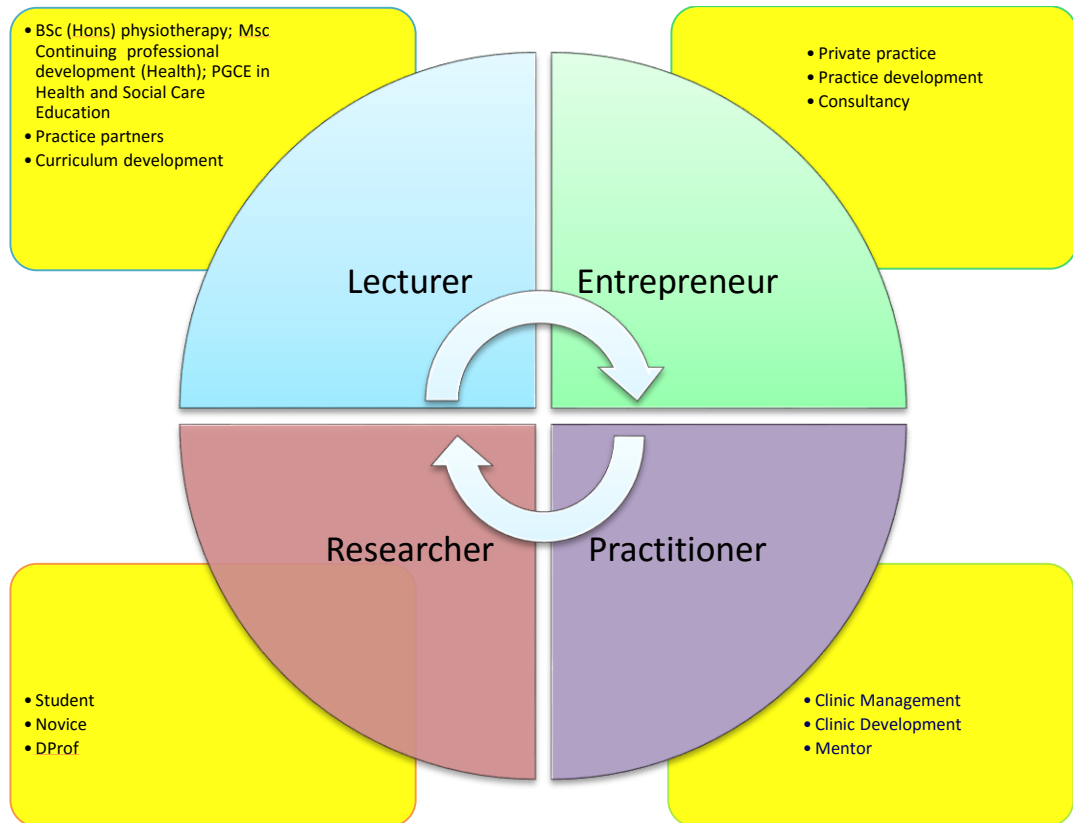
1.2 Reflexive Narrative

I have begun my reflexive narrative with introducing you as the reader, to me as the research tool and finished with a critical review of myself at the start of my doctoral journey, examining how I as a researcher influenced the development of my research. Using a research diary, I recorded methodologically and analytically the twists and turns in my professional and doctoral journey as they intertwined with each other. Coffey and Atkinson (1996) state that it is imperative that the exploratory process is both documented and retrievable providing a confessional tale (Van Maanen 1990) and a transparent account (Finlay and Gough 2003). Therefore, for the reader I have threaded my reflexive narrative throughout my thesis. My journey of discovery uncovered key crossroads that have led to reflection upon my own personal, professional and research development, as well as questioning my profession and the path it has taken.

Research Tool

I have multiple roles and commitments (Figure 1); I undertook my DProf part-time over a six-year period, which has been presented as sequential phases in my thesis. I have started by explaining how my multiple roles came about.

Figure 1: Diagrammatic representation of my roles



My professional journey commenced at the University of Brighton, where I qualified as a physiotherapist in July 1993, graduating with a BSc (Hons) degree and becoming a registered physiotherapist. I completed my two-year rotational post at two different National Health Service (NHS) hospitals, working in a diverse range of specialities: respiratory, paediatrics, neurology, medical, and surgical, eventually specialising in respiratory. My first encounter with people living with cancer occurred when I moved into the private sector after five years in the NHS. I used my core physiotherapy knowledge and skills to treat them, but there were times that I felt unable to meet their needs and would use continuing professional development to try to address this issue. My interest in this specialist area grew from this, leading to my post at a local hospice, where a breathlessness clinic pilot study was being carried out and the

physiotherapist running the clinic was retiring. This was an exciting phase of my career, as I was required to draw on a variety of skills including my respiratory and new oncology knowledge, whilst also learning about palliative cancer care, a new and growing speciality for allied health professionals.

From the hospice setting I moved back into the NHS onto acute oncology wards to lead and develop the physiotherapy service and bring specialist expertise to the area. Here I developed my knowledge of chemotherapy and radiotherapy and the treatment of people with cancer in a totally different environment to the hospice. It took time for me to adjust to the pace and expectations of the hospital and in particular the target driven environment that had developed under the Labour government.

Running parallel to my clinical work was my involvement over a three-year period with the National Institute for Health and Care Excellence (NICE) for lung cancer and the local Cancer Network. I sat on the NICE guideline development group for lung cancer and was invited to attend the launch of the guidelines (NICE 2005) in February 2005. This and the work in the breathlessness clinic led me to being recognised as a lung cancer respiratory specialist by the local Cancer Network. In addition, I was offered an honorary fellowship at the Royal Society of Medicine for a year. During this period, I was also involved as membership secretary for ACPOPC and provided regular updates in their journal.

It was at this point that my journey into higher education commenced. I was asked to write and deliver lectures to students studying on the essence of palliative care unit of the BSc (Hons) Health Studies (Palliative care pathway) at Bournemouth University. This inspired me to become self-employed with a local agent and obtained the part-time post of specialist training consultant for occupational therapists and physiotherapists working in oncology and palliative care. For two years I wrote and delivered study days on the non-pharmacological approach to breathlessness and rehabilitation in the context of oncology and palliative care in the south of England, whilst continuing with my work at the local NHS hospital. Within this post I developed my own teaching and IT skills but did not have any mentorship or support. Therefore, when I saw

an advert for a part-time physiotherapy lecturer post at Bournemouth University I decided to apply. I was successful in obtaining a three year fixed term contract with two conditions attached; to complete a postgraduate certificate in Health and Social Care Education (PGCE) and to start my doctoral studies.

Transition from the clinical to the academic environment was a huge learning curve. It was an exciting time helping to write and deliver a new BSc (Hons) physiotherapy programme. Although I felt like a novice again I brought with me my knowledge in oncology and palliative care and was keen to introduce this to the undergraduate students, with the hope that it would inspire students to want to work in this specialist area. In addition, I felt that it was important that they understood the role of the physiotherapist in oncology and palliative care, as well as being aware of cancer symptoms so that new cases might be brought to medical attention sooner.

After successfully obtaining my Post Graduate Certificate in Health and Social Care Education I was keen to get back into clinical practice and obtained an honorary contract with a local hospice. It was at this point that I started to reflect on the oncology palliative care services and from my experiences within both the hospital and hospice environment, stimulating me to explore this area further. Therefore, through my preliminary literature review I was able to see where gaps in this specialist area lay, leading to my application submission to the Bournemouth University doctoral track, which was approved in March 2008.

In the next section I have described how my research interest came about.

Research Interest

My research interest commenced in the year 2000 when I moved into the specialist field of palliative cancer care. This new environment (hospice) and experience (working with people who were living with cancer and coming to the end of their lives) caused me to reflect and question my role as an allied health professional including the knowledge and skills that I used, as well as my professional practice and identity. A significant episode whilst in post at the hospice was the discovery of my Christian faith, which played an important role

in shaping my career and development. Interestingly Delamont et al (2000) compared doctoral study in the context of faith with the aptitude to sustain optimism, endure and manage a variety of challenges throughout the research process, which I can identify with in my doctoral journey.

As well as developing spiritually during this phase of my career my intellect was being stimulated by commencing a Master of Science (MSc), which enabled me to immerse myself in practice and reflect upon it. Lee (2009), states that a study journey should inspire intellectual, personal and professional development by forming knowledge and expertise, which then enhances and underpins professional practice. This was demonstrated when a 'light bulb moment' occurred during the ACPOPC autumn conference in 1999 and the research idea for my MSc dissertation was born. It was at this time that the National Health Service (NHS) cancer plan (DH 2000a) document was launched and ignited my research interest. Completing my MSc dissertation on rehabilitation in the context of palliative care in 2002 (Belchamber and Gousy 2004) was the spring board from which my doctoral research has evolved.

Within the hospice environment I was able to advance my knowledge, skills and research interest through involvement in data collection for the breathlessness clinic pilot study (Hately et al. 2001) and then in the dissemination of the findings at the ACPOPC spring conference in 2002. This led me to develop a three-day reflective course with the lead nurse on the management of breathlessness for healthcare professionals at the hospice. It was at this point in time that the Chartered Society of Physiotherapy (CSP) introduced continuing professional development (CPD) to their members. This linked with my MSc in continuing professional development (Health) and I found it an invaluable tool, which helped me navigate my way through my career pathway.

My research interest was re-kindled when I moved back into the NHS environment to gain further knowledge in oncology in an acute setting. Here I realised my specialist role was not fully understood by my physiotherapy colleagues or other health care professionals, thus leading to my research. This specialist area was also understaffed and service user's needs were not being met. Some service users asked if I provided private physiotherapy and

this put the notion into my head to look into this area of practice and led to my first draft of a business plan and consequently my practice development project.

Having described the journey that brought me to start my doctorate I will now discuss the background to my work.

1.3 Doctor of Professional Practice

In this section I have introduced the reader to the Doctor of Professional Practice (DProf) role providing an overview of the key components of the DProf and finishing with an outline of my thesis structure. A DProf has been described as connecting doctoral education with challenges and questions related to practice (Tennant 2004), central to which is the demonstration of the learning taken place and the knowledge and research skills acquired, further advancing professional practice (Lee 2009). Therefore, in order to describe my journey of becoming a researching professional within practice, I have presented a reflexive narrative throughout my thesis, which aims to place me in the context of my research. Lee (2009) states that acknowledgement of this fundamental association between professional practice, the study focus and the practitioner / researcher role is fundamental to the context of the DProf, which comprises four integral components:

1. Systematic review of the literature
2. Research
3. Practice development
4. Reflexive narrative

I have provided an overview of each of these components within my thesis chapters to give the reader a better understanding of how they link with my study.

Chapter One – Introduction

In this chapter I have documented why I decided to explore physiotherapy in palliative cancer care service provision; providing a very preliminary literature

review with an overview of palliative cancer care, the palliative cancer care rehabilitation team and the role of the physiotherapists within the team, an overview of the DProf and an initial reflection of my role in the process. The purpose of the preliminary literature review was to set the contextual scene and no attempt has been made to critique the underpinning research, which has been reserved for the literature review chapter. The chapter concludes with the aim and objectives of my research.

Chapter Two – Literature Review

Within this chapter I have described the three phases of my literature search and review within a qualitative framework approach. Phase One was carried out to set the scene and place the current palliative cancer care services, including physiotherapy and significant policies into context. Phase Two was carried out to enable an in-depth exploration of palliative cancer care services, with a central focus on physiotherapy within palliative cancer care. Phase Three was carried out to explore national palliative cancer care standards and best practice recommendations. The purpose of my preliminary literature search (Phase One) will be documented in this chapter, along with the systematic approach to my academic literature search (Phase Two), while the systematic approach to my policy document literature search (Phase Three) will be presented in my methodology chapter, as part of my data collection. Within this chapter a critical review of the existing literature and research has been presented, identifying where there are gaps, paving the way for the study. A reflexive narrative journey of the literature review that I undertook has been documented at the end of this chapter.

Chapter Three – Methodology

In this chapter I have set out my methodological approach, methods of data collection and method of analysis. I carried out a qualitative single case study research design into physiotherapy palliative cancer care, to address the aim and objectives of my research. Following this I have discussed the theoretical and philosophical foundation of my qualitative case study approach underpinning its application in practice. As part of my methods of data

collection, Phase Three of my literature search has been documented in detail in this chapter. A reflexive narrative of my methodological journey has also been woven through this chapter to provide transparency to the reader.

Chapter Four – Findings

This chapter presents my overarching research theme, followed by my initial findings. I have then documented my key themes and sub-themes identified from my case study findings and presented them in depth. This has been accompanied by a reflexive narrative discussing bias, exploring my assumptions values and beliefs associated with my cultural heritage and how they may have influenced the interpretation of my findings.

Chapter Five – Practice Development

Within this chapter I have explored the health care system in the United Kingdom with an overview of physiotherapy private practice. This has been followed by my practice development idea, the rationale for my practice development project and the frameworks that I used. A reflexive narrative has again been provided at the end of the chapter reflecting on my practice development journey.

Chapter Six – Discussion

In this chapter I have discussed my research findings and my practice development project outcomes in relation to the current literature and present recommendations for practice. The strengths and limitations of my work will then be discussed including how I will disseminate my findings, skills, knowledge and research. This chapter will finish with a reflexive narrative of my doctoral journey and final concluding points.

In the next section I have included reflections on my funding journey, as well as the work that I carried out prior to developing my DProf study in order to identify gaps in the literature. This activity occurred between 2008 and 2009.

Funding Journey

At the outset of my doctorate I applied to four funding bodies: ACPOPC; CSP Charitable Trust; CSP, PRF scheme B; and Dimbleby Cancer Care Research Fund, two of which offered funding. I feel that I became successful with practice, collaborating with peers and understanding what the funding bodies were looking for. I made sure that I was meticulous in reviewing my application form and gaining feedback from supervisors and the DProf group. Obtaining funding from the CSP Charitable Trust and ACPOPC provided me with confidence to take my research forward, as it had been deemed a worthwhile piece of work by my professional body and special interest group. In addition to this the local Cancer Network supported me in my research, with the service development officer providing a letter in support of my funding application (Appendix 1).

I will now discuss palliative cancer care in general during the period of 2008 and 2009, followed by a description of my case study physiotherapy cancer care service provision during this timeframe.

1.4 Palliative Cancer Care

Palliative cancer care in general has been defined as the total care of the service user, whose condition is no longer responsive to curative treatment. Therefore, the aim of palliative cancer care is to enhance quality of life for service users with advanced disease and their families by reducing debilitating psychological and physical symptoms, using specialist knowledge and skills. These include communication and management of symptoms (psychological, spiritual and physical) by co-ordinated multi-disciplinary teams (NCHSPCS 2002). Since the publication of the Calman Hine report (DH 1995), palliative cancer care service provision has progressed rapidly. The Campbell report (1996) followed with the aim of evaluating the palliative cancer care services in accordance with the Calman Hine report (DH 1995). Both white papers highlighted the significance of the primary care team and the requirement of a multi-disciplinary approach in the future management of people living with cancer (DH 1995; Campbell 1996). With cancer reforms being high on the Government's agenda the NHS cancer plan (DH 2000a) was developed

outlining the first ever inclusive national cancer program for England, aiming to bring the NHS in line with the twenty first century. Two aims were highlighted in this report; to streamline cancer services around people with cancer's requirements and to 'save lives' ensuring people with cancer are provided with the best practice, as well as adequate health care professional support (DH 2000a). Central to the latter is the document, a First Class Service: Quality in the New NHS (DH 1998a). This document refers to the concept of clinical governance and evidence-based practice.

The inclusion of allied health professionals in palliative cancer care is an area that is developing rapidly and with the publication of the National Institute of Health and Care Excellence (NICE) guidelines on supportive and palliative care (NICE 2004a) will continue to grow. These guidelines recognise that rehabilitation services are an essential and fundamental part of enhancing the lives of people living with cancer (NICE 2004a).

Palliative cancer care is a comparatively new clinical discipline, which has progressed in an informal way producing a wide variety of service provision within this specialist area (Robbins 1998). Over the last twenty six years there has been a noticeable development in palliative cancer care service provision (Cooper and Hewison 2002) with major changes taking place, including the appearance of specialist multi-disciplinary teams (MDTs). In addition, new configurations of service delivery have also evolved leading to integrated services (Jack et al. 2009) with an important shift in palliative cancer care service delivery from hospital and hospice environments into the community (Kealey and McIntyre 2005). Health care professionals are also being challenged to enable the transfer of palliative cancer care expertise from the hospice settings and specialist teams to the wider communities (Carr et al. 2008), but this is being hampered by lack of education and resources in this area. In addition the modernisation agenda (DH 2001) is putting a strain on local service providers, where cost cutting is reducing the workforce and resources required to achieve this. This will become even more challenging in the future, as the population of people living with cancer is growing.

1.5 Local Palliative Cancer Care Service Provision

In 2008-09 the physiotherapy palliative cancer care service provision (my case study) consisted of two part-time physiotherapists, providing a total of 24 hours per week cover for service users within the specialist palliative cancer care unit. The bulk of the service provision occurred on the wards, with minimal input into day care, out-patients and domiciliary visits. Referrals to physiotherapy were made by the ward medical staff or nurse in charge and in the other areas by day centre staff and community or hospital palliative cancer care sisters. The physiotherapists were based in the ward rehabilitation office, so their presence within this area was the norm. In-patient service users therefore had priority over the other areas mentioned. Assessment targets were set within two working days from referral for in-patients and within five working days for the other areas. The role of the physiotherapists was to promote rehabilitation within a multi-disciplinary team to help minimise the impact of the service users' condition on their psychological, spiritual and physical functioning.

During this timeframe the physiotherapists were starting to explore ways of developing their practice and were keen to explore my knowledge base as an honorary physiotherapist. Spending one day a week at the specialist palliative cancer care unit over a one-year period, allowed me to become part of the team and gain an insight into the service provision prior to becoming an honorary researcher. Understanding this need for developing the physiotherapist practice is discussed in the next sections.

1.6 Prevalence and Epidemiology of Cancer

In the United Kingdom around two million people are living with cancer with 300,000 new diagnoses made in 2008 (Macmillan Cancer Support 2008). People with cancer are living longer and the incidence of cancer increasing (DH 2000a). In the Western World the number of people living with cancer has risen progressively due to increased incident rates; improved treatments and prolonged life expectancy (Fossa et al. 2008). Therefore, with improved treatments cancer is becoming a more chronic condition (Cheville et al. 2007)

leading to the growing demand on allied health professionals services in palliative cancer care (Findlay et al. 2004).

1.7 Palliative Cancer Care Service Provision

Evidence confirms that cancer is becoming a chronic illness with a greater need for rehabilitation services (Aston 2009). This has led to the emergence of services within palliative cancer care as a driving force for change (DH 2007). The United Kingdom health care system consequently is going through a major upheaval, with policy changes increasing the number of people with palliative cancer care needs being cared for at home (Payne et al. 1999). The latter has placed a huge stress on the palliative cancer care services in the community with the main providers being primary care teams (Addington-Hall and McCarthy 1995). Doyle (1997) states that palliative cancer care should be established as a key constituent to all 'good clinical practice', no matter what phase of the cancer journey or where the person is being cared for. Community care is also seen as 'ideal' and people living with cancer and their carers frequently articulate a preference to die at home (Addington-Hall et al. 1991), mirroring government policy (DH 2008a). The challenge to palliative cancer care services therefore is the facilitation of dying within a community setting (Thorpe 1993). This will impact upon family carers, who may interpret the diagnosis of cancer of a loved one as impending death, requiring only a short burst of their involvement in concentrated care, whereas in reality modern treatments and therapies are enabling people living with cancer to survive longer, potentially placing further burden upon carers (Payne et al. 1999).

There are however numerous compensations for the person dying at home (Field and James 1993), including improved psychological well-being nurtured by a familiar environment and resulting in increased quality of life (Hinton 1994). Palliative cancer care services are therefore diverse in nature and the transition from the voluntary / charity setting into the National Health Service setting and then into the community have occurred informally. The latter may explain why there are barriers to effective service delivery, which includes: inadequate and variable service provision; poor recognition of rehabilitation; poor detection of the needs of the service user; poor understanding of allied health professional's

roles; limited evidence of allied health professional involvement; poor communication and co-ordination between services and a lack of broad and inclusive assessment (NICE 2004a; NCAT 2008; Roe 2009).

1.8 Rehabilitation Services

Rehabilitation in palliative cancer care is a fairly recent concept (Santiago-Palma and Payne 2001; Montagnini et al. 2003; Belchamber and Gousy 2004). The concept of cancer rehabilitation was originally described by Dietz (1969) following disease stages: preventative, restorative, supportive and palliative. Supportive rehabilitation endeavours to maximise the palliative cancer care service user's function following permanent disabilities arising from the cancer and / or its treatment. Mainstream rehabilitation services were established upon function, referring to the person's capability to complete activities of daily living, whereas palliative rehabilitation is the process of supporting the palliative cancer care service user to achieve their best, not only from a physical aspect but also from a psychological, spiritual, social, educational, cultural and vocational aspect. Ideally this occurs in harmony with the palliative cancer care service user's deteriorating condition, environmental limitations, wishes and life plans (Santiago-Palma and Payne 2001; Montagnini et al. 2003; Belchamber and Gousy 2004). Consequently, the traditional concept of rehabilitation, improving function following intervention is not always achievable in palliative cancer care. In addition, the rehabilitation of service users towards the end of life has received little attention, with a scarcity of data to support its efficacy (Santiago-Palma and Payne 2001).

Rehabilitation is often a priority for palliative cancer care service users as they try to maintain or regain physical function (Schleinich et al. 2008). However, there may be common perceptions by health care professionals and the public that little if any physical improvements can be achieved for people receiving palliative rehabilitation, even though maintenance of independence and autonomy are often extremely important to palliative cancer care service users (Yoshioka 1994; Twycross 2002a; Chevill 2005; Guo and Shin 2005; Olson and Cristian 2005; Coyle 2006; Spichiger 2006). Evidence nevertheless suggests that during palliative cancer care the service user's condition can fluctuate, with

rehabilitation being an appropriate option at different points along their care pathway (Sliwa and Marciniak 1999; Morasso et al. 1999; Scialla et al. 2000; Porock et al. 2000; Chevill 2001; Taylor and Currow 2003; Kristjanson 2005; Winton and Thomas 2005; APTA 2005). Even so, the distribution of resources for palliative rehabilitation has been ignored (Hopkins and Tookman 2000; Frost 2001; Taylor and Currow 2003; Findlay et al. 2004) resulting in palliative rehabilitation services being marginalised (Cheville 2005).

Supportive and palliative rehabilitation services have historically been delivered within the hospice environment, but are now starting to be delivered in other settings (NICE 2004a). Recent rehabilitation services have developed around regional cancer networks in order to provide quality, equitable and seamless services in response to the cancer-tumour-specific groups such as breast, lung, gynaecological (NICE 2000; NICE 2003; NICE 2004b) in a variety of care settings. The combination of changes in palliative cancer care along with a predicted increase in cancer survivors due to new and improved treatment regimens will impact significantly on future rehabilitation services (Rankin et al. 2008). Rosen et al (2006) predict that because of this the demand for cancer rehabilitation will inevitably rise in all care settings, but particularly in settings such as the community, where cancer care has not traditionally been provided. This will consequently have an impact upon generalist physiotherapists who may only come into contact with cancer care service users on an occasional basis (Schleinich et al. 2008). This will challenge the managers and commissioners to ensure their staff are adequately skilled to provide an appropriate service for this growing patient group (Rankin et al. 2008).

1.9 Role of the Palliative Cancer Care Rehabilitation Team

The role of the specialist palliative cancer care rehabilitation team (to be referred to as team) is to provide an overall detailed assessment, review and management of the service user and their family, where the service user and their family is the unit of care, as defined by Dame Cicely Saunders (Saunders 1972; Saunders and Sykes 1993).

Teams take a problem / goal-orientated approach to care, assessing the key problems for the service user and their family (Higginson and McCarthy 1993; Higginson 1997; Twycross 2002b; Higginson and Bruera 2002). The main aim of the team is to reduce the burden of care, enhancing quality of life for palliative cancer care service user's families and / or carers (Yoshioka 1994; Cheville 2001; Santiago-Palma and Payne 2001; Belchamber and Gousy 2004). This includes reducing physical symptoms, such as pain and psychological symptoms such as anxiety, as well as increasing functional status (Sabers et al. 1999; Marciniak et al. 1996; Cole et al. 2000; Scialla et al. 2000; Chevill 2005; Olson et al. 2005; Jordhoy et al. 2007). The team need to work together applying professional expertise in a co-ordinated manner to enhance service users' quality of life until the end of life (Schleinich et al. 2008). This includes sharing of expertise and problem solving to deliver high-quality expertise (NICN 2006).

As changes occur within the palliative cancer care services the role of the teams are slowly transforming in response to the cancer-tumour-specific groups (as described in the next section) in order to increase expertise and overall outcomes (Rankin et al. 2008). This has seen the development of clinical nurse specialists dedicated to tumour specific teams. However, physiotherapists also have specialist knowledge and they could be encouraged to specialise and integrate further to become dedicated team members delivering a more comprehensive level of care (Rankin et al. 2008). This level of care has been documented as level 4 in the National Institute for Health and Care Excellence guidelines (NICE 2004a). Generalist physiotherapists are not exclusively concerned with specialist palliative cancer care, as their role involves looking after a variety of service user groups therefore they cannot be fully up to date in complex palliative cancer care treatments (NIHR 2007). In contrast to the latter, specialist palliative cancer care physiotherapists are specifically trained in palliative and hospice care, including emotional, spiritual, social support, as well as complex communication and symptom management (Rankin et al. 2008).

1.10 Role of the Physiotherapist in the Palliative Cancer Care Team

Physiotherapy entails communication between physiotherapists and service users (patients, families, care givers) through a procedure of assessments. This includes the assessment of movement potential to ascertain agreed goals and objectives by employing knowledge and skills unique to physiotherapists (WCPT 2010). Therefore, physiotherapists perform an intrinsic role in the team through improvement of function and quality of life, when people living with cancer require physical and functional dimensions of care (Egan and Abbott 2002; CSP 2002). The latter includes: symptom control and management of physical aspects such as: mobility; strength; flexibility; endurance; deformity; co-ordination; balance; gait; breathing; exercise tolerance; energy expenditure (Mackey and Sparling 2000; APTA 2001); pain; weakness; cough and breathlessness (Kumar and Rajagopal 1996). Within palliative cancer care the physiotherapist's role is three fold: 1) delivering direct care to the person living with cancer; 2) education of the person and their family, as well as health care professionals and 3) performing as a member of the team (Toot 1984; Fulton 1994; Robinson 2000; Luciano and Gonzalez 2004).

When the service user's condition is advancing and functional limitations become unavoidable the specialist palliative cancer care physiotherapist is able to support both the service user and their carer in coping with these changes, whilst maximising their potential to achieve agreed goals, consequently optimising quality of life (Doyle et al. 2005). A key issue here is maintaining a balance between optimal function and comfort, providing a reasonable degree of independence and quality of life where a pre-morbid level of function is unlikely to be restored (Santiago-Palma and Payne 2001).

1.11 Physiotherapy Modalities and Interventions in Palliative Cancer Care

Originally, traditional physiotherapy modalities and interventions were adapted and tailored to treat palliative cancer care service users, including: education, exercise; respiratory programs; mobilisation and transfer training; lymphoedema treatments; pain relief and psychological support (Gray 1989; Rashleigh 1996; Robinson 2000; Joliffe and Bury 2002; CSP 2002; CSP 2003a; Doyle et al.

2005). Physiotherapists are now however, part of the team and therefore involved in palliative rehabilitation (Scialla et al. 2000; Tang et al. 2007; Ruff et al. 2007; Tang et al. 2008; Kendig et al. 2008), applying treatment modalities and interventions such as: Transcutaneous Electrical Nerve Stimulation (TENS) to relieve pain; heat and cold therapies; strengthening and positioning exercises in relation to activities of daily living (ADL); provision of adaptive and assistive equipment (Ebel and Langer 1993) and the support of functional range of movement (Rankin and Gracey 2008). Education of service users and carers (Drouin et al. 2009) is seen as one of the core interventions of palliative cancer care physiotherapy, with palliative cancer care service users identifying psychological support as a key benefit of physiotherapy (Martlew 1996; Belchamber and Gousy 2004; Dahlin and Heiwe 2009).

Although physiotherapy has been available to palliative cancer care service users within the hospice and palliative cancer care units for the last two decades, there remains a dearth of international research on this topic and very little informs practice. However, evidence supporting physiotherapy in palliative cancer care is starting to emerge with studies documenting that exercise can improve strength, endurance and function or slow down the rate of decline in palliative cancer care service users with advanced cancer (Lowe et al. 2009; Beaton et al. 2009; Jones et al. 2009; Temel et al. 2009). Therefore, with approximately 30% of all cancer deaths associated with poor exercise and nutrition (Pate et al. 1995; Bryan et al. 2007), comprehending the positive properties of exercise and physical activity, as well as the role of the physiotherapists in palliative cancer care is growing and the need for evidence increasing. In addition, physiotherapy is now mentioned as part of the team and included in standards for service provision in the United Kingdom (NICE 2004a; NACPC 2001; NCPC 2000).

1.12 Palliative Cancer Care Physiotherapy Services

In the United Kingdom hospices have increasingly become the centre for the evolution of palliative cancer care with more and more physiotherapists becoming involved in this process (Gillham 1992; Rankin and Gracey 2008). The boundaries of palliative cancer care are continuously changing and

developing and physiotherapists working in this specialist area are constantly challenged to improve their knowledge base, as well as enhancing their skills and expertise (Robinson 2000).

In 2008-09 the demand for palliative cancer care physiotherapy services greatly exceeded resources and generalist staff often with large and varied caseloads carried out most of the palliative cancer care (Thomson et al. 2006). Cooper and Hewison (2002) believe that the growth of palliative cancer care service provision has not been reflected in the quantity of research that has been carried out to date. Thomson et al (2006) also state that there is a lack of research and evidence based practice within palliative care for physiotherapists generally. There is therefore a need for physiotherapy representation at network and corporate levels, to influence both service development and policy. However, with this swift advancement physiotherapy is struggling to identify itself (Chadda 2008). This has led to physiotherapists being warned that they will need to establish their 'worth' to 'those who hold the public purse,' otherwise the profession may become isolated and ignored (Kell and Owen, 2008). Kell and Owen (2008) feel that this dynamic changing nature of the profession has had an impact upon the profession, physiotherapists, professional bodies, the state and the wider society as a whole.

Physiotherapists are concerned with the rehabilitation of people living with cancer from the point of diagnosis to the end of life (Donnelly et al. 2010), however there exists four main barriers to the integration of physiotherapy into palliative cancer care: professional knowledge and skills in palliative cancer care among therapists and other team members; professional and public attitudes about the goals of physiotherapy; financial and structural attributes of the health care industry (Meier et al. 1997) and an apparent lack of awareness of the role of physiotherapy for people living with cancer (CSP 2003a).

1.13 Establishing the Need for the Study

Immersing myself in the culture of palliative cancer care and exploring research ideas highlighted the evolving role of the allied health professionals and in particular the increasing need for physiotherapists. In my local area, allied

health professional palliative cancer care audits (e.g. service evaluation) carried out in hospitals have demonstrated that there is a distinct lack of physiotherapists in this specialist field, but with little acknowledgement from stakeholders (clinical governance, primary care teams). In addition, within my case study area the palliative cancer care physiotherapy service maybe withdrawn temporarily if there are physiotherapy staff shortages in other areas of the hospital, placing palliative cancer care service users as a low priority. These issues leave palliative cancer care physiotherapists feeling unsupported and demoralised with a lack of identity. This draws attention to the gaps in education both within the team and in the wider remit. Consequently, there is a need to explore the palliative cancer care service, against government policies and procedures to discover if it fits the physiotherapists' needs and ultimately the service users' needs, which is a necessary prerequisite to improve service provision.

1.14 Summary

I have highlighted in this chapter that physiotherapists can enhance their clinical decision-making skills by integrating evidence based-practice and evidence-informed practice into current practice. In addition, qualitative research can add substance to evidence-informed practice. The palliative cancer care literature suggests that evidence based practice recommendations and guidelines are not being met, so this needs to be explored. The literature also highlights that people living with cancer have unmet needs, such as the management of a variety of distressing cancer symptoms. There is also a major shift in the delivery of cancer care out into the community, producing huge challenges for health care professionals, as well as the people living with cancer and their families. Currently there is a revolution in cancer service delivery in the United Kingdom to address inequalities, provide best treatments and invest in the cancer workforce prompting the aim of my study.

Aim: To explore the context and provision of a local palliative cancer care physiotherapy service provision in light of best practice recommendations, in order to find out if best practice recommendations and guidelines are being met. Evidence suggests that a physiotherapist's competence to provide satisfactory

palliative cancer care may not be enough to meet existing guidelines and best practice prompting the first objective for this research:

Objective 1: To identify issues highlighted within palliative cancer care in relation to best practice recommendations (policy document collection), with the intention of uncovering key areas that need to be addressed by physiotherapists to meet best practice recommendations and guidelines.

Evidence also indicates that there is a lack of knowledge relating to the role of the physiotherapist from both health care professionals, as well as people living with cancer and their families, thus prompting the second objective of this research:

Objective 2: To explore the beliefs, assumptions and perceptions of the role of physiotherapists in palliative cancer care from health care professionals (HCP) and service users (SU) perspectives (semi-structured interviews) in order to explore what HCP and SU understanding is of the physiotherapist's role in palliative cancer care.

Further evidence indicates that there is a gap in current health care professionals' knowledge base within palliative cancer care and that education is lacking especially with regard to physiotherapists working in this specialist area, so prompting the third objective for this research:

Objective 3: To examine physiotherapists performance and behaviour in the palliative cancer care environment (observations) in order to examine the physiotherapists' knowledge base and education in palliative cancer care.

I will now reflect upon my doctoral journey before discussing the literature review chapter.

Doctoral Journey

As a specialist palliative cancer care physiotherapist I am familiar with the language and culture of palliative cancer care and feel comfortable in this setting. However, I reasoned that this familiarity could blind me to specific

aspects of the setting that perhaps I took for granted. I realised therefore, that I needed to balance being immersed in the detail of my research, whilst taking time to step back and see the meaning emerging from the dialogue of my participants. Charmaz (2004) states that to construct meanings from participants it is necessary to not only 'be' reflexive about our own meanings but to try to 'flow' with the studied world. In doing so the tacit and implicit knowledge that is not easily shared may become visible.

As an experienced palliative cancer care physiotherapist I had a network of existing contacts, which permitted me to gain access to the specialist palliative cancer care unit for my research. It also enabled me to obtain a contract between my private practice (practice development) and local hospice, initiating the improvement element (breathlessness clinic) of my practice development project. Even so, I still remained concerned whether I would gain access, which has been documented as a 'real sense of trepidation' in commencing doctoral study (Back 2002). Health care professionals working in palliative cancer care are understandably protective towards their service users, especially those coming towards the end of their lives. Therefore, I felt that it was only natural to feel concern about requesting access to carry out my research in this area, acknowledging that gatekeepers have the ability to agree or decline my request. Fortunately, having been granted an honorary contract with the specialist palliative cancer care unit a year before my request I felt that the gatekeepers would be keen to support my research and perhaps forge closer links with the university where I worked.

I sensed that once I had obtained access to the specialist palliative cancer care unit, it would be important for me to establish whether my host community saw me as an expert – someone to be welcomed, or a critique - someone who would be unwelcomed. At this point in my doctoral journey I felt that I was being positioned towards expert status rather than critique as I had built up a good relationship in the previous year with my honorary contract. This was also true in my practice development setting, where I had previously worked in the breathlessness clinic. However, I did feel unease at being positioned as a so called expert. Firstly, this may put undue pressure on me as there may have been expectations from the health care professionals and / or service users that

I would not be able to fulfil in my researcher / facilitator role, such as providing treatments or in-service training. Secondly, the health care professionals may have seen me as being excessively inquisitive and / or attempting to evaluate their work, making them uncomfortable or unapproachable. Therefore, I worked at appearing relaxed and agreeable with the aim to put the health care professionals at ease so that they felt able to approach me, in turn helping me to obtain my participants and accomplish my data collection. This also helped with the facilitation of change within my practice development project at the breathlessness clinic (Chapter 5, 5.5).

When explaining my research to the health care professionals at the specialist palliative cancer care unit, I emphasised that I was a part-time research student, while working as a physiotherapy lecturer and working towards my doctorate. At the local hospice where I was carrying out the improvement element of my practice development project I presented myself as a senior physiotherapist, to be non-threatening to the staff and encourage inclusiveness. Interestingly, in both contexts my role as a mother helped to reduce any feelings of social distance. However, presenting me was dynamic in nature, as I found I was constantly working to monitor myself and others that I was working with, not only in the palliative cancer care unit and the local hospice, but also in my lecturer role at the university. Trying to balance the different roles that I played was one of the most exhausting aspects of my multiple roles (Figure 1, p.18). Finding a balance between my roles required constant alertness to recognise how I was positioned by others, as well as how I positioned myself to gain the most out of each situation, which was emotionally draining. Consequently, I required emotion management to remain functional. Reflexivity played a role in my emotion management, as reflecting upon how I felt and the emotions that were engendered helped me to understand what was causing these emotions and how I could manage them in the future. Attending the DProf group meetings, where informal discussions could take place also aided this emotion management. However, this also brought with it its own tensions, as being open and honest can place you in a vulnerable position, especially when the other DProf group members are colleagues. There was a need for trust and confidentiality in this situation to be open to this vulnerability. This took time for relationships and trust to build, but once established was very beneficial.

Doctoral Supervision

Having the DProf group sessions once a month was a real support as my doctoral journey felt isolating at times. I liked this time of discussion, debate, support and guidance. I also used the timeframe between DProf group supervision to give myself deadlines so that I could move forward with my doctoral journey, which provided some relief when the whole journey seemed impossible.

During one of my DProf group supervisions I was introduced to Bourdieu (1998), which gave me a clearer understanding of myself, and the way that I approach education. For example, my social cultural background influences how I learn and the way that I internalise that learning, which can impact upon the outcome of my learning (Tzanakis 2011). Therefore, understanding these issues and attending DProf meetings facilitated my ideas, which opened up new avenues of opportunity and moved me forward in my doctoral journey. They helped me to increase my confidence in discussing my research, understanding different methodologies and how I could apply them, as well as defending my decisions. Interacting with other DProf students was also beneficial as I did not feel so isolated and it provided me with motivation and a sense of competition, as well as unity! In addition, it was a rich environment to learn from each other and see different learning styles being put into practice. From this I reviewed my own learning styles (Honey and Mumford 2006) and looked at my strengths and weaknesses using a SWOT (Strengths, Weaknesses, Opportunities, and Threats) analysis. I learnt from this that I have a habitual systematic way of learning when receiving and processing information. This meant that I was often constrained, limiting my creativity which is required in qualitative research. Therefore, in order to gain the most from my learning I needed to adapt to other learning styles such as a reflector and activist rather than being more of a theorist and pragmatist. In my doctoral journey I felt that this was of enormous benefit, enabling me to see and approach things in different ways and from different perspectives. In addition to this joint supervisions, with my first and second supervisors, were another key component of my learning and development. My dual role of DProf student and physiotherapy lecturer at the

university brought with it some tensions, such as doctoral work not being embraced by some colleagues as part of the lecturer's role.

In my doctoral journey, because of the sensitivity of my research and practice development area, support was essential, both informal (peers and colleagues) and formal (individual and group supervision). This has helped me to self-manage and support emotional labour when managing feelings of unease, discomfort or emotional pain around topics such as death and dying. It has also enabled me to manage relationships and deal with problematic situations with some competence, balancing my insider / outsider position within the research environment. Therefore, the different types of 'self' that I have presented throughout my thesis demonstrates to the reader the authenticity of me 'being there,' so that you as the reader can judge the trustworthiness of my research and practice development through the transparency about the 'goings on' (Carcary 2009).

1.15 Conclusion

This chapter has outlined my research idea and the background to physiotherapists working in palliative cancer care. It has also reflected upon me as the research tool and my doctoral journey to help set the scene before discussing the palliative care literature review that I undertook.

CHAPTER 2: Literature Review

2.1 Introduction

This chapter presents a synopsis of the palliative cancer care literature by focusing on the key discussions and concerns encountered during the literature review that I undertook. To enable the strategies that I used to be placed into context I have commenced the chapter with the role of the literature review within a qualitative framework approach (section 2.2). I have then outlined the key issues (section 2.4.2) and the resultant significant gaps in the literature that I uncovered and addressed. Using a reflexive narrative, I have taken the reader through my journey of the literature review that I undertook. The chapter concludes with my research and practice development project aims and objectives that were developed from the gaps in the literature and which guided my study.

As palliative cancer care is multi-professional in nature I needed to consider a variety of professional journals to find relevant information. I therefore approached the literature review in a systematic way to address this issue, being explicit in my focus, selection, assessment criteria and strategies for combining empirical data (Hawker et al. 2002). Thus, the aim of my literature search was to produce as comprehensible a list as possible of relevant studies on palliative cancer care. The objective of my literature search was to develop a working relationship between research, policy and practice to address both the research and practice development components of my DProf.

My literature search was carried out in three phases:

Phase One: (Following on from my very preliminary literature review presented in chapter 1). Sets the scene placing palliative cancer care services, including physiotherapy and significant policies in 2008-09 and subsequently in 2012-13 into context.

Phase Two: Enabled an in-depth exploration of palliative cancer care services, with a central focus on physiotherapy within palliative cancer care.

Phase Three: (Part of my data collection). Involved selecting key policies and documents in 2008-09 to provide the raw data for exploration into national palliative cancer care standards and best practice recommendations.

2.2 Literature Review within a Qualitative Framework Approach

Literature reviews in qualitative research are carried out at different phases throughout the study to avoid the researcher developing preconceived ideas that could influence what might be discovered (Bluff 2005). However, opinions vary as to the timing of the literature review during qualitative studies (Bluff 2005). Therefore, in my study I chose to carry out the phases of the literature review that I undertook, at the start of my study during the data collection (policy document collection), following my data analysis and after my study's findings, as these seemed key points along my doctoral journey.

2.3 Phase One: Preliminary Literature Search

The purpose of my preliminary literature search was to gain a wider understanding of practice in different areas of palliative cancer care in order to find gaps in the literature. I used two healthcare databases in this process: CINAHL and Medline. Following this I undertook a broad scoping exercise to identify key policies driving change within palliative cancer care, which I have outlined below. Both these activities were carried out in 2008-09 and then again in 2012-13, to present the recent changes. I then explored the latter in more depth across wider databases using a systematic approach in Phase Two of my literature search.

Scoping Exercise

Over the last twenty-six years there have been a number of changes and innovations within the health care system. Policy directives focusing on effectiveness have fuelled this time of change and efficiency and the desire of health care professionals to achieve high-quality care, which has led to the introduction of the quality agenda where innovation and evaluation are central components (Carr et al. 2008). With the publication of the clinical effectiveness agenda (DH 1996) there has been a greater emphasis on development and the

production of evidence based guidelines forming part of the driving force towards implementing research into practice. Changes and innovations within palliative cancer care are occurring on a large scale with government policies being the driving force (NICE 2004a; DH 2005a; DH 2006). This has included the implementation of an end-of-life framework to improve care efficiency, as well as to a commitment to increase investment in this specialist area. A number of challenges however, have arisen for health care professionals in the improvement of end-of-life care, such as the transfer of palliative cancer care expertise from the hospice setting and specialist teams to the wider community and generalist health care professionals. One of the strategies developed in Liverpool by Ellershaw, Wilkinson and Saunders (2003) to assist this process was the end-of-life integrated care pathway (ICP) (Carr et al. 2008), which has been discussed again later in this section under recent changes.

Government Policies and Palliative Cancer Care

Instrumental to revolutionising cancer service delivery in the UK was the Calman Hine report (DH 1995), providing recommendations for the provision and commissioning of cancer care services, which would respond to the needs of service users and their families in England and Wales. One of the main recommendations was to develop cancer networks. The document also recommended health services to integrate a consumer perspective into planning and delivering health care (Jarrett et al. 1999). Five years on from this, 'The NHS Cancer Plan: a plan for investment, a plan for reform' was published by the Department of Health in September 2000. This document built upon the previous Calman Hine Report (DH 1995) and presented a more comprehensive national strategy to direct the cancer networks in the improvement of cancer care services. A number of recommendations were highlighted by this document: save more lives; provide the correct support and care for people living with cancer; offer best treatments; confront inequalities and build for the future through investment in the cancer workforce. A key recommendation was the 'vision for supportive and palliative care' (DH 2000a, ch.7), in which rehabilitation is a major component. 'The Cancer Reform Strategy' (DH 2007) was then published by the Department of Health to build

upon the improvements made under the NHS Cancer Plan (DH 2000a) and to direct the cancer care services over the next five years, up to 2010.

The key recommendations from the NHS Cancer Plan (DH 2000a) were developed further by the National Institute of Health and Care Excellence (NICE), who instigated a campaign to improve the assessment process of people living with cancer. They did this by developing a standardised approach to the assessment of: physical; psychological; social and spiritual needs to be used by all health care professionals (NAO 2005). Thorough assessment of the needs of people living with cancer is viewed as the cornerstone in the provision of quality cancer care, with cancer networks stating that the application of assessment tools is crucial to improving communication (Copp et al. 2007). Following this campaign, the Department of Health commissioned NICE to develop clinical guidelines on supportive and palliative care for adults with cancer, publishing 'Improving Supportive and Palliative Care for Adults with Cancer' (NICE 2004a). In this document guidance is given to a number of cancer care services including: rehabilitation; complementary therapies; psychological support; as well as spiritual and palliative care to adults with cancer. Following this a series of improving outcome guidance documents were developed, linked to the management of specific tumour types such as Breast Cancer (NICE 2000), Haemato-oncology (NICE 2003), Head and Neck Cancer (NICE 2004b). During this process it was acknowledged that some themes linked to more than one or all of the tumour types, one such theme is supportive and palliative care.

In addition to the above the Cancer Care Workforce Team (DH 2003a), along with the National Workforce Development board aimed to recruit and retain a skilled workforce by producing a national strategy to plan and prioritise for additional staffing, which included allied health professionals. This document looked at new ways of working, as well as meeting the continual professional development needs of existing staff. However, although progress has been made in recruiting nursing, radiography and medical staff, the numbers of specialist palliative allied health professionals have not increased in line with other professions (Rankin et al. 2008), even though it quotes the NHS workforce census plan, with a target of 6500 new allied health professionals by

2004. Further to this the Investment in Cancer 2001/02 and 2003/04 (DH 2005b) announced new service developments, which included improvements in lymphoedema services, specifying allied health professionals.

Networks and Organisations

During this scoping exercise there were a number of organisations and collaborations linked to allied health professionals and cancer strategies throughout the UK. These include the Department of Health; National Cancer Action Team (NCAT); Allied Health Professional Leads Forum; Cancer Network Allied Health Professional Lead; Professional bodies; commissioners; providers; hospices; non-statutory organisations; and local authorities.

The National Cancer Peer Review Programme (NCPRP), a quality assurance programme for the NHS cancer care services, developed a set of outcome metrics modelled on the recommendations from the National Institute of Health and Care Excellence (NICE 2004a) in particular chapter ten, improving supportive and palliative care for adults with cancer, which focuses upon rehabilitation. These measures have been published by NCPRP in the 'Manual for Cancer Services Rehabilitation Measures' (NCAT 2008) and a timeline drawn up to co-ordinate the peer review process. The latter is to ensure that the cancer networks were putting the rehabilitation measures in place and to assess the quality of the cancer care services being developed. These measures offered cancer networks guidance, as well as an action plan to implement the rehabilitation recommendations. A significant recommendation from these measures was that each cancer network management team should appoint a lead allied health professional, with clinical experience in rehabilitation. The lead allied health professional would be responsible in driving forward the rehabilitation agenda within their cancer network. In addition, they would set up and chair a network rehabilitation group with allied health professionals (Physiotherapists (PT); Occupational Therapists (OT); Dietiticians; Speech and Language Therapists (SALT); and lymphoedema specialists) and service user representatives.

NCAT was developed to enhance the ability of cancer networks to increase and convey the cancer reform strategy (DH 2007) via robust commissioning to benchmark world-class services. The purpose of NCAT was to: provide quality assurance; implement NICE guidance where appropriate; develop new guidance; develop and train the cancer workforce and support and develop cancer networks. In addition, NCAT would work jointly with the Department of Health, National Health Service improvement, cancer screening service, cancer charities, Royal colleges, specialist professional groups, cancer networks, specialised commissioners, Strategic Health Authorities (SHA) and Primary Care Trusts (PCT), producing a yearly programme of work covering a variety of cancer care services from diagnosis to death (Acreman et al. 2009). NCAT's supportive and palliative care section works alongside the National Cancer Network Allied Health Professionals Leads Forum to increase allied health professional's roles and profiles in cancer care services. This forum was created to provide a connection between allied health professionals leads so that cancer care service developments could be coordinated across the United Kingdom. National and local initiatives were discussed at the forum and progress reports drawn within the cancer networks. The allied lead forum was a component of the programme agenda at the National Development Programme for English Cancer Networks, which occurred biannually.

Recent Changes

The following review provides a contemporary summary of the changes introduced since 2013, until the completion of my research thesis findings. Due to the rate of change occurring in palliative cancer care I am acknowledging that a number of points that I have made here, may well have been superseded.

Since the development of the network groups there have been a number of further changes within palliative cancer care. For example, the Liverpool Care Pathway is no longer seen as fit for purpose due to failings in its implementation, preventing people from having a comfortable and dignified death (NCPC 2013a). It has therefore been recommended by the independent review (Lea 2013) that the Liverpool Care Pathway be replaced with individual care plans over the next year. In addition, 2013 was a decisive year for end of

life care and marked the halfway point of the ten-year End of Life Care Strategy. This strategy is now being reviewed by National Health Service England following on from the independent review of the Liverpool Care Pathway, with the government considering a feasibility review of a 'nation choice offer' to allow people to die at home (NCPC 2013b). There are also a number of future recommendations for palliative care, which the NHS England's National Clinical Director for End of Life Care has identified: having a shared understanding and purpose for end of life care; patients and carers feeling supported and able to cope; professionals feeling supported and able to learn and to care; addressing inequity and variations in practice; developing systems that support efficient and effective palliative and end of life care (NCPC 2013b).

In addition to this the Help the Hospice commission report (Calanzani et al. 2013) has identified five steps that are necessary to guarantee hospices are fit for the future: 1) prepare for significant change in the context of palliative and end of life care; 2) strengthen understanding of the contribution of hospice care; 3) establish hospice care as a solution to future challenges in palliative end of life care; 4) strengthen the connection between hospices and their local health and social care systems and their local communities; and 5) strengthen the leadership of hospice care.

However, the cornerstone to physiotherapy palliative cancer care service provision is the National Cancer Survivorship Initiative (DH 2010a), which has underpinned the main shift from traditional medical led follow up services towards aftercare services, such as palliative cancer care services. There has also been a change in commissioning where strategic health authorities and cancer networks, including NCAT were disbanded in 2013, with the emergence of the new clinical commissioning groups (CCG's) in England. The work carried out by the cancer networks, NCAT and lead allied health professionals should enable commissioners, General Practitioners and providers to consider survivorship, rehabilitation and end of life care in a more insightful and holistic way (Beer and James 2012). In addition to this Improving Outcomes - A Strategy for Cancer (DH 2012a) states that the National Cancer Survivorship Initiative (DH 2010a) will continue to develop specialist services for people with long-term effects of cancer and cancer treatment by developing evidence and

good practice principles. However, there are concerns about the future of cancer care due to the perception that there was inadequate recognition of the significance of survivorship and a lack of importance around integrated care (Beer and James 2012).

My scoping exercise has therefore set the scene for palliative cancer care service provision, which I will now explore further in Phase Two of my literature search.

2.4 Phase Two: Systematic Approach to the Literature Search

The purpose of this systematic approach to the literature search was to gain a more in-depth understanding about the literature relating to physiotherapy service provision in palliative cancer care in the context of palliative rehabilitation, multi-disciplinary team and national palliative care standards and best practice. This search took place during 2008-09 and then again from 2010 to 2013. I used a six step approach (Aveyard 2010) to produce a comprehensive method to my literature search:

Step 1: Describe the topic.

Step 2: Identify concepts.

Step 3: Select search terms to represent concepts.

Step 4: Strategy for inclusion / exclusion criteria of papers.

Step 5: Hand search of grey literature.

Step 6: Recording the literature review and content.

Step 1: Describe the Topic

This study will explore palliative cancer care physiotherapy service for people living with cancer in a specialist palliative cancer care unit. Questions posed from Phase One of the literature review included:

- a) Has the physiotherapy profession kept pace with the development of palliative cancer care services?

- b) Do palliative cancer care physiotherapists meet the national palliative care standards and best practice required for people living with cancer?
- c) Does the physiotherapy palliative cancer care service meet the needs of people living with cancer?

Step 2: Identify Concepts

I developed search terms in order to identify words and phrases that described the concept I was exploring. I achieved this by describing and summarising the topic in Step 1, which was part of the process of defining the scope of Phase Two of my literature search. I have presented my identified words from Step 1 in Table 1. This represents the key concepts forming the academic literature search for my qualitative study.

Table 1: Identification of concepts for the academic literature search

Concept 1	Concept 2	Concept 3
Physiotherapy	Cancer	Palliative Care

Step 3: Select search terms to represent concepts

I used Medical Subject Headings (MESH) terms to focus my academic literature review for MEDLINE, PubMed and Cochran Library. I employed different vocabulary to focus the literature search in CINAHL, where web of science SCOPUS provided keywords appropriate for my concepts (Table 2).

Table 2: Search terms representing concepts for the academic literature review

Search terms describing Concept 1	Search terms describing Concept 2	Search terms describing Concept 3
Physiotherapy	Cancer	Palliative Care
Physical Therapy	Carcinoma	Palliation
Physio*	Oncology	Palliat*
	Onc*	

Once I had obtained a list from MESH words and other appropriate vocabulary my key words were entered in a systematic manner into my chosen databases

(see Table 3). I then sorted my search results by applying my inclusion / exclusion criteria (Table 3) and filtered using the following sections of the articles: title; abstract; key words; full text, as well as identifying any government policies and duplicates within my search results.

Table 3: Inclusion / Exclusion criteria for literature search

Inclusion criteria	Exclusion criteria
From 1995 to date, as well as key pertinent historic papers related to rehabilitation in the context of palliative cancer care	Dates before (other than key historic papers) 1995
Databases; MEDLINE; EMBASE; PubMed; PEDro; AMED; PDQ; Cochran Library; PSYCHINFO; CINAHL; CIRRIE; REHABDATA; ETHOS	Databases that are not cancer specific or health related. Databases which have now become obsolete e.g. CANCERLIT (now subset of PubMed); OVID (MEDLINE)
Palliative Cancer Care services	Palliative care services of other disease specific conditions, such as Neurological (MND; Parkinson's disease etc); Cardiac (e.g. heart failure); Renal (Kidney failure); Respiratory (e.g. fibrosing alveolitis etc)
Hospices and other organisations / day care providing palliative care services for people with cancer	Nursing homes, day care and other organisations not providing palliative care services for people with cancer
Standards or evidence based practice (EBP) / best practice for Palliative Cancer Care	Other palliative care standards / EBP or best practice not related to cancer
Adults with cancer 18 – 75+ years (Cancer Research UK 2011) and their informal carers	Children with cancer (Cancer Research UK 2011) and their informal carers
Palliative Cancer PTs; other AHP and HCPs	Adults with additional needs such as those with learning difficulties or those from ethnic minority backgrounds

Step 4: Strategy for Inclusion / Exclusion Criteria

My rationale for including and regulating papers was considered from Phase One of my literature search, where I concluded that the Calman Hine Report, which was published by the Department of Health in 1995, was the catalyst to the changes now seen to take place in today's palliative cancer care services. However, I have also referred to other historic papers in relation to rehabilitation in the context of palliative cancer care. I included these to address the changing role of the physiotherapist in palliative cancer care and to consider

whether they are meeting national palliative care standards and best practice recommendations.

Step 5: Hand Searches and Grey Literature

I included hand searches to identify references missed by the electronic database searches. This uncovered any new keywords and / or relevant articles that I needed to obtain. I also carried out exploration of grey literature (discussion papers, dissertations, conference proceedings etc).

Step 6: Recording the Literature Review and Content

I recorded the literature review that I undertook, for example: author / s; place of publication; publisher; editor of book; volume and issue of journals; page numbers and the date I accessed websites (Appendix 2). I also compiled a reference list and bibliography from the start of the literature review that I undertook, using EndNote Web for storage and management processes. I then organised the content into themes and linked this to my data collection to form the initial comparison phase of my qualitative approach.

Having described my six step approach to produce a comprehensive method to my literature search, I will now present my critique of the literature, based upon the literatures relevance to my research question. I used the Critical Appraisal Skills Programme (CASP) checklists, (<http://www.casp-uk.net/#!/casp-tools-checklists/c18f8>) until I had achieved a logical case connecting the main concepts rooted in my research question.

2.4.1 Critique of the Literature

Palliative Cancer Care Rehabilitation

There is a dearth of literature on palliative cancer care rehabilitation and cancer rehabilitation in general. However, there is an increasing awareness of the clinical role of palliative rehabilitation (Santiago-Palma and Payne 2001; Michel 2001; Cheville 2005; Kealey and McIntyre 2005), with several studies looking at its efficacy. For example, Oldervoll et al (2006) carried out a quantitative phase 2 pilot study in Norway with thirty-four people (15 males and 19 females) with

advanced cancer to evaluate the effects of physical exercise on physical performance and quality of life over a six-week period. In spite of its limitation of not having a control group, they found that it was feasible for this group to carry out physical exercise and recommended further work to assess its efficacy.

An earlier qualitative study by Belchamber and Gousy (2004) explored the experiences of eight people attending palliative cancer care rehabilitation in a hospice in the South of England. Service users reported a perceived increase in functional ability and reduced anxiety as they felt less abandoned and more in control. The multi-disciplinary palliative cancer care rehabilitation included physiotherapy, which focused on group exercises, non-pharmacological approach to dyspnoea and pain management. Whilst not generalizable, the findings provided evidence of perceived benefit. Previously, in the United States of America (USA), Scialla et al (2000) undertook a quantitative retrospective study into the medical records of 110 palliative cancer care service users who attended an in-patient unit over a thirty-month period. During this time the service users had received comprehensive palliative cancer care rehabilitation by a multidisciplinary team, including a physiotherapist. They found that people with advanced cancer increased in functional status following comprehensive palliative cancer care rehabilitation. Although providing some evidence of effect, improvement in this study may have been due to factors such as spontaneous recovery, the placebo effect, somebody showing an interest and therefore they recommended further work.

So it can be seen that researchers in palliative cancer care rehabilitation are beginning to demonstrate the positive impact upon service users' lives by improving emotional and physical functioning, but more research is required to establish the effectiveness of palliative cancer care rehabilitation and physiotherapy in particular.

Physiotherapy in Palliative Cancer Care Rehabilitation

Santiago-Palma and Payne (2001) indicate that physiotherapy plays an important role from diagnosis to end of life care by providing rehabilitative,

adaptive and supportive interventions. In addition, research on cancer rehabilitation is starting to evidence the efficacy of physiotherapy from a functional perspective, but very little research is available on the efficacy of physiotherapy in palliative cancer care rehabilitation.

Cancer rehabilitation was first researched by Dietz (1969) in the USA who looked at functional improvement in a quantitative study of 1019 cancer service users. Dietz formulated four related categories based upon the cancer service users' functional improvement following rehabilitation: 1) preventative 2) restorative 3) supportive and 4) palliative. Overall, he observed that the cancer service users made a moderate improvement in function. Subsequently, Marciniak et al (1996) used a quantitative assessment of the effects of cancer rehabilitation on functional improvement, after comprehensive inpatient cancer rehabilitation with physiotherapists. Improvements in motor function were retrospectively examined in 159 cancer service users in an American in-patient setting. Significant gains were noted between admission and discharge regardless of variables such as cancer diagnosis, presence of metastatic disease or receiving active treatment. More recently in the USA, Cole et al (2000) carried out a quantitative retrospective, case series (a medical research study), which involved tracking 200 people with cancer who were receiving comprehensive multi-disciplinary in-patient rehabilitation, including physiotherapy, over a 30-month period. Their results supported previous research conclusions with significant gains in function regardless of diagnosis, impairment, disease stage and whether or not service users were receiving cancer treatment at the time of the rehabilitation.

In palliative cancer care there is a lack of international research around physiotherapy (Cobbe and Kennedy 2012). Schleinich et al (2008) designed and piloted a survey at four palliative care sites in Canada. The survey was used to rate the importance of rehabilitation interventions in palliative care and was tested for test-retest reliability. It was administered, initially with 40 palliative cancer care service users and then one week later with 32. They found that there was a lack of palliative cancer care physiotherapists within the multi-disciplinary team, which was considered a barrier to palliative cancer care rehabilitation. However, a limitation to this research was the sample size, which

was too small for statistical analysis. Therefore, it cannot be concluded that any one aspect of palliative cancer care rehabilitation is more important than another. Cobbe et al (2012) used a retrospective chart audit with the aim of profiling palliative cancer care physiotherapy over a six-month period. They looked at 195 palliative cancer care service user discharges (death or transfer to other areas) from a hospice in Ireland following rehabilitation, which included physiotherapy. They found that there was a high referral rate to physiotherapy, which included all levels of functional ability. Palliative cancer care rehabilitation played a major role with physiotherapists treating people up until their last few days of life. The main treatment delivered by physiotherapists was physical activity, but other interventions such as psychological support and education were frequent and routine aspects of physiotherapy care, but were under documented. This study also found that the substantial fluctuations in service users' function, as well as frequent suspension of treatments due to visitors, treatments or deterioration was challenging for physiotherapists. This retrospective research was not able to examine the efficacy of physiotherapy and was descriptive in nature; therefore, conclusions cannot be inferred to other palliative cancer care settings. Thus, prospective research is required to investigate and identify predictors of improvement.

Palliative cancer care physiotherapy within the community setting is not well researched, but could be cost-effective in reducing hospital / in-patient unit admissions and length of stay (Cobbe et al. 2013). Only Mueller and Decker's (2011) research has been published on this topic to-date. In the USA, Mueller and Decker (2011) evaluated physiotherapy intervention using a prospective study of 164 palliative cancer care service users over a one-year period. The service users were receiving rehabilitation from the community hospice, which also included treatments within the home setting. On referral to the physiotherapists a comprehensive assessment was carried out and a patient specific function scale completed with individual goals identified. Seventy-two hours from the initial assessment, a follow-up visit enabled the physiotherapist to assess any functional changes. If required, other interventions were also provided by the physiotherapist such as: non-pharmacological pain management, mobility training and education. Results demonstrated that clinically significant changes were made in at least one of the patient-centered

outcomes for physiotherapy intervention. For example, the palliative cancer care service users had improved in their ability to carry out activities of daily living, mobility, plus improvement in dyspnoea and / or lymphedema. As these results are not transferrable across the sector, further research into rehabilitation in the community is needed.

In Australia, Laakso et al (2003) researched physiotherapy in palliative cancer care to measure the effect of a standard (general) physiotherapy service against an optimised (specialist) physiotherapy service. The quantitative research was carried out in two stages. In the first stage a survey was used to benchmark services. Results from the survey indicated that the quality of service delivery in the standard physiotherapy group was impeded by the lack of time spent (10 minutes) with palliative cancer care service users; delayed or absent referral to physiotherapy; limited resources (e.g. equipment and / or funding) and lack of community-based services following discharge. In the second stage, which was conducted over a twelve-month period in a hospital setting, 40 palliative cancer care service users were randomly allocated to the optimised physiotherapy service and 20 to the standard physiotherapy service. Results demonstrated that there were superior improvements in service user's pain, fatigue and function in those receiving optimal physiotherapy compared to those receiving standard physiotherapy. However, this research is limited by the small sample size weakening the levels of significance, although there were distinct differences between the standard and optimal physiotherapy service, thus indicating the need for further research.

Although research is starting to show evidence for the impact of physiotherapy in palliative cancer care rehabilitation, several barriers have been documented preventing healthcare professionals from referring palliative cancer care service users to physiotherapy. These barriers included: limited understanding of the role of the physiotherapist; perception that physiotherapists lacked the skills required for palliative cancer care (Nelson et al. 2012) and the perception that physiotherapists in palliative cancer care might foster inappropriate hope (Cobbe et al. 2013). Therefore, further research is needed to help health care professionals understand the role and competencies of physiotherapy in palliative cancer care rehabilitation, so that appropriate referrals can be made.

Referral to Physiotherapy in Palliative Cancer Care Rehabilitation

Research indicates that referral to physiotherapy relies heavily on the team's understanding of the role of the physiotherapist. For example, in the USA Montagnini et al (2003) used a retrospective chart review of 100 palliative cancer care service users discharged from a hospital-based palliative care unit, to assess the use of physiotherapy within palliative cancer care rehabilitation. Results indicated that physiotherapists relied upon other health care professionals in the team to refer palliative cancer care service users to them. It was therefore unknown how many service users they might have provided rehabilitation for if they had all been assessed by a physiotherapist. Thus, understanding when to refer palliative cancer care service users to physiotherapy is needed, but this has proved difficult to research.

The evidence around functional status as a point of referral to physiotherapy is ambiguous and extremely difficult to compare across studies due to the variety of different outcome measures used. For example, some studies referred service users who on a number of measures were less able (Addington-Hall and Altmann 2000; Miller et al. 2003; Chen et al. 2003; Ahlner-Elmqvist et al. 2004) and in other studies, the service users referred were fitter and more able (Tang 2003; Peters and Sellick 2006). This is concerning as functional status is a key indicator for referral to physiotherapy. Policies, such as NICE (2004), also suggest that a key criterion for referral to palliative cancer care is an assessment of need and functional status is a characteristic of need, but appears to be poorly researched in this specialist area (Ahmed et al, 2004).

Laakso's (2006) study of a hospital chart audit carried out in a major Australian teaching hospital confirms this trend, stating that although 65% of service users with cancer presented with indications for physiotherapy only 12.8% actually received any physiotherapy input. Other research verifies this oversight of physiotherapy in the delivery of palliative cancer care rehabilitation. For example, in two studies carried out in palliative cancer care units only 26% (Yoshioka 1994) and 37% (Montagnini et al. 2003) of referrals were made to

physiotherapy, but with findings indicating that function had improved following physiotherapy. However, neither study used validated palliative cancer care scales, so there is a lack of evidence to inform best practice in this area. Furthermore, Cobbe and Kennedy's (2012) study suggested that early referral of palliative cancer care service users to physiotherapy would be beneficial, but this needs to be evaluated.

Research is starting to demonstrate that referral to physiotherapy could be beneficial to palliative cancer care service users; however, how this is actually enacted is not clear and researching teamwork may shed some light on this aspect.

Teamwork in Palliative Cancer Care Rehabilitation

The World Health Organisation (WHO) (1990) regarded teamwork as core to palliative cancer care rehabilitation and the number of publications on this topic is increasing (Higginson and Costantini 2002; Head 2002; Crawford and Price 2003; Junger et al. 2007). Hearn and Higginson (1998) carried out a systematic literature review of palliative cancer care rehabilitation teams to ascertain if they improved outcomes in service users. They found that conventional care alone was inadequate for service users with advanced cancer and that a multi-professional team approach in the hospice, community and hospital setting was beneficial. Evidence suggested that such teams could identify more effectively with service users and their families' needs, providing access to other services.

Higginson and Evans (2010) also considered evidence regarding the effectiveness of palliative care teams for people with advanced cancer, following on work from two previous systematic reviews (Higginson et al. 2003; Gysels and Higginson 2004). The results of this more recent review of the literature indicated positive benefits of specialist palliative cancer care rehabilitation teams in key areas, such as improving pain and symptom control, hospital admissions or stays and care giver outcomes. There was also improved satisfaction for service users and their families in some studies, with instances of reduced anxiety and depression. Interestingly, quality of life, when measured, demonstrated fewer differences, but this was hampered by a wide

range of outcome measures used. This was seen as an overall difficulty in defining best practice in palliative cancer care by a number of studies (Hearn and Higginson 1998; Higginson et al 2003; Aspinall et al 2003), due to pertinent palliative cancer care outcomes being hard to establish or measure. Higginson and Evans (2010) concluded that further research was needed to compare service models and the impact of different health care professional mix within palliative cancer care teams, as team composition varied between studies.

Payne et al (2002) in their qualitative research study aimed to identify commissioners and service providers understanding of specialist palliative cancer care in South London. Forty-four commissioners and providers were examined using a formative evaluation framework. Findings indicated that there were a number of issues related to understanding, which included: Lack of agreement relating to the definition of palliative care; inconsistency in referral procedures and a lack of understanding of the difference between generalist and specialist palliative cancer care. A limitation to this study was the usefulness of formative evaluations to others, other than the commissioners and providers in palliative cancer care.

The review of research demonstrates that the effect of palliative cancer care rehabilitation is difficult to measure, that the role of the physiotherapist in palliative cancer care is not clearly understood and that palliative cancer care on the whole needs to be clearly defined. In addition, the majority of the research around physiotherapy in palliative cancer care has been quantitative in approach and carried out in the USA and Australia, therefore more research needs to be undertaken in Great Britain. Also the use of a qualitative approach will enhance how we understand the experiences of physiotherapy within the palliative cancer care team at a local level and how they are responding to national concerns.

2.4.2 Key Issues and Gaps in the Literature

The literature base in palliative care is fairly limited due to the relatively recent interest in palliative cancer care as a discipline, with gaps in the evidence needing to be addressed without delay (Addington-Hall et al. 2009). Therefore,

from the literature review that I undertook I have focused on key areas relevant to palliative cancer care physiotherapy service provision, the service user, the healthcare professionals, the multi-disciplinary team and the physiotherapist.

Service user

The literature documents that it is common for people living with cancer to experience anxiety and depression; the level of which depends upon the disease type, stage and treatment (Bottomley 1997). In advance stages of the disease there is an increase in psychiatric morbidity, incidence of depression and physical debilitation (Bottomley and Jones 1996; Higginson 1997; Breitbart et al. 1998), with the most prevalent symptoms recognised in the end-stages of life as pain; nausea; vomiting; constipation and dyspnoea (Higginson 1997). However, in Belchamber and Gousy's (2004) study, the key symptoms reported in their patient group were, pain, dyspnoea and fatigue. Cancer-related fatigue (CRF) has now been confirmed as one of the most distressing of the cancer symptoms, with people living longer this has been acknowledged as a common side effect of cancer (Donnelly et al. 2010). In Morasso et al's (1999) study of 94 people with end stage cancer, symptom control was perceived to be a key area of unmet need (63%) and professional knowledge; continuity of care; attentiveness; co-ordination of care; partnership; individualisation; rapport and caring were central to those undergoing treatment (Radwin 2001). However, the needs of the majority of people living with cancer remain unmet (Richardson et al. 2005). In addition, people living with cancer have been documented as emotionally demanding, which may have a profound impact upon those caring for them (Fitch et al. 1999; Copp 1999; Odling et al. 2001; Corner 2002).

Health Care Professionals

Health care professionals working in palliative cancer care have long been established as a group at risk of stress (de Carvalho et al. 2005), with some health care professionals perceiving that anxiety from people living with cancer, is a stressful factor in clinical practice (Fitch et al. 1999; Rustoen et al. 2003). Other studies found psychosocial, communication (Sivesind et al. 2003), pain and symptom management (Langton and Blunden 2000) the most demanding

areas of care experienced by health care professionals, with allied health professionals experiencing emotional exhaustion (Fitch et al. 1999).

A significant area of anxiety frequently expressed by health care professionals is associated with a lack of confidence and skills in communicating with people living with cancer (Copp et al. 2007). Considering the NHS Cancer Plan (DH 2000a) highlighted the importance of good communication skills, it is disappointing that evidence indicates that health care professionals continue to encounter difficulties in this area and find it extremely stressful (Corner & Wilson-Barnett 1992; Georgaki et al. 2002; Sasahara et al. 2003; Field and Copp 1999; Cunningham et al. 2006). Furthermore, studies propose that communication skills acquired from communication courses have not been employed in the clinical setting (Kruijver et al. 2000).

Mounting evidence demonstrates that health care professionals working in palliative cancer care continue to receive insufficient education or support (Llamas et al. 2001; Georgaki et al. 2002; Kelly et al. 2006), leading to national educational policies being developed to meet the need for increased knowledge, skills and competencies of health care professionals working in palliative cancer care (Copp et al. 2007). The latter however concentrates upon the education and training of doctors and nurses (DH 2000a; Llamas et al. 2001; RCN 2003) and not so much upon other health care professionals such as physiotherapists, who are often perceived as central to the delivery of quality cancer care (Copp et al. 2007).

Evidence suggests that the health care professional's capability to supply sufficient palliative cancer care to people living with cancer may not be adequate to meet current guidelines (Copp et al. 2007). This may be due to a lack of adequate classroom input to prepare health care professionals for working with people living with cancer (Copp et al. 2007). Thus, a small number of studies have proposed inter-professional education across primary and secondary care as a way to improve the delivery of symptom control for people living with cancer (Leslie et al. 2003). Further to this collaboration between palliative cancer care services, both hospital and community-based has been

suggested as playing a vital role in helping health care professionals to manage symptoms more effectively (DH 1995; Lidstone et al. 2003).

Multi-Disciplinary Team

Evidence has proposed that the success of the multi-disciplinary palliative cancer care team continues to be mired by the uncertainty of the skills and knowledge of the health care professionals involved (Newall and Matthew 1997; Bliss et al. 2000; Seymour et al. 2002; Sasahara et al. 2003). Furthermore, palliative cancer service user's perception of the role of their local palliative cancer care team may be influenced by previous experiences of the team by friends and family from the wider community. Their expectations versus perception of outcome could therefore impact on the confidence in care and compliance to treatment (Jarrett et al. 1999). For example the palliative cancer care service user may decide not to discuss a problem if they think it is not within that particular health care professional's remit (Payne 1990; Sensky 1996), which has been recognised as a potential concern (Jarrett et al. 1999). This may be partly due to the historic background of the hospice movement, which was established for end of life care, whereas the focus is now on holistic symptom control, with care provision prior to and beyond the terminal stages, developing a greater flexibility in the multi-disciplinary team, where stereotypical roles are potentially being challenged (Jarrett et al. 1998).

Physiotherapists

Within the multi-disciplinary team, physiotherapists have a major role to play in the rehabilitation and supportive care of people living with palliative care needs. In order for this to occur perceived barriers in awareness, communication, resources, education and service delivery will need to be addressed. My preliminary literature review has highlighted a number of areas requiring further research around physiotherapy in palliative cancer care including the need to explore:

1. Knowledge, attitudes, beliefs and experiences toward palliative cancer care among health care professionals.

2. Palliative cancer care physiotherapists' skills and competencies.
3. Experiences of palliative cancer care team members with physiotherapists.
4. Service user and caregiver perceptions of physiotherapists.

Further research is also required in order to establish the exact needs and combined learning activities between diverse health care professional groups, which have not been explored in depth to date (Copp et al. 2007). Thus physiotherapy is an evolving profession within palliative cancer care and warrants further exploration and investigation.

Following on from the key issues and gaps identified in the literature review that I undertook, I have set out below the aims and objectives of my research and practice development project.

Aim of Research

To explore the context and provision of a local palliative cancer care physiotherapy service in light of best practice recommendations.

Objectives of Research

1. To identify issues highlighted within palliative cancer care in relation to best practice recommendations (policy document collection).
2. To explore the beliefs, assumptions and perceptions of the role of physiotherapists in palliative cancer care from health care professionals (HCP) and service user (SU) perspectives (semi-structured interviews).
3. To examine physiotherapists performance and behaviour in the palliative cancer care environment (observations).

Aim of Practice Development

To develop a unique private physiotherapy practice for people living with cancer.

Objective of Practice Development Project

To promote patient-centred care, within which care decisions reflect the needs, values and beliefs of the palliative cancer care service users and those providing the care.

I will now take the reader through my reflective journey of the literature review that I undertook, before concluding this chapter.

2.5 Reflexive Narrative

By reflecting in and on (Schön 1983) my experiences during the literature review I ensured that theoretical concepts were measured against my knowledge and experience of both palliative cancer care and physiotherapy practice. The aim of my reflection therefore was to close the gap between theory and practice. This provided me with an internal environment to explore issues that were at times emotionally challenging from both a personal as well as a professional perspective. As I consciously reflected upon my experiences, relating them to the growing body of literature that I had obtained my confidence and understanding of the topic area grew. This process is an integral part of my research as I acknowledged and recognised my limitations and the need to search and review the literature at different stages of my research and practice development journey. By synthesising theoretical concepts against my individual personal experiences, I was then able to reach a deeper understanding. This personal exploration challenged and exposed tacit assumptions, which then led to new understandings and ideas (section 3.17 and 5.6).

I learnt that my personal skills and sensitivity as a research tool (section 1.2) were an important part of the literature review process, as it required careful and accurate reflection. This was personally demanding as it entailed the systematic development of self-knowledge, where I challenged and examined ideas that I had taken for granted. It also gave me the opportunity to develop knowledge that connected with real issues in practice and provided me with the opportunity to try to work out what my new understandings meant within the

boundaries of work, organisations and my research and practice development project.

2.6 Conclusion

This chapter has presented an overview of my scoping exercise and described my systematic literature review, which includes two phases of my literature search and my literature critique. Following Phase Two of my literature search my literature critique has provided an insight into the key issues and gaps in the literature. This has led to my aim and objectives for both my research and practice development project. My reflexive narrative brings the chapter to a close. The next chapter will describe the third phase of my literature search, as it forms part of my data collection. It will also describe how the theoretical framework, methodology, method and analysis were chosen to explore and investigate my aim and objectives, which guided the research documented in this thesis.

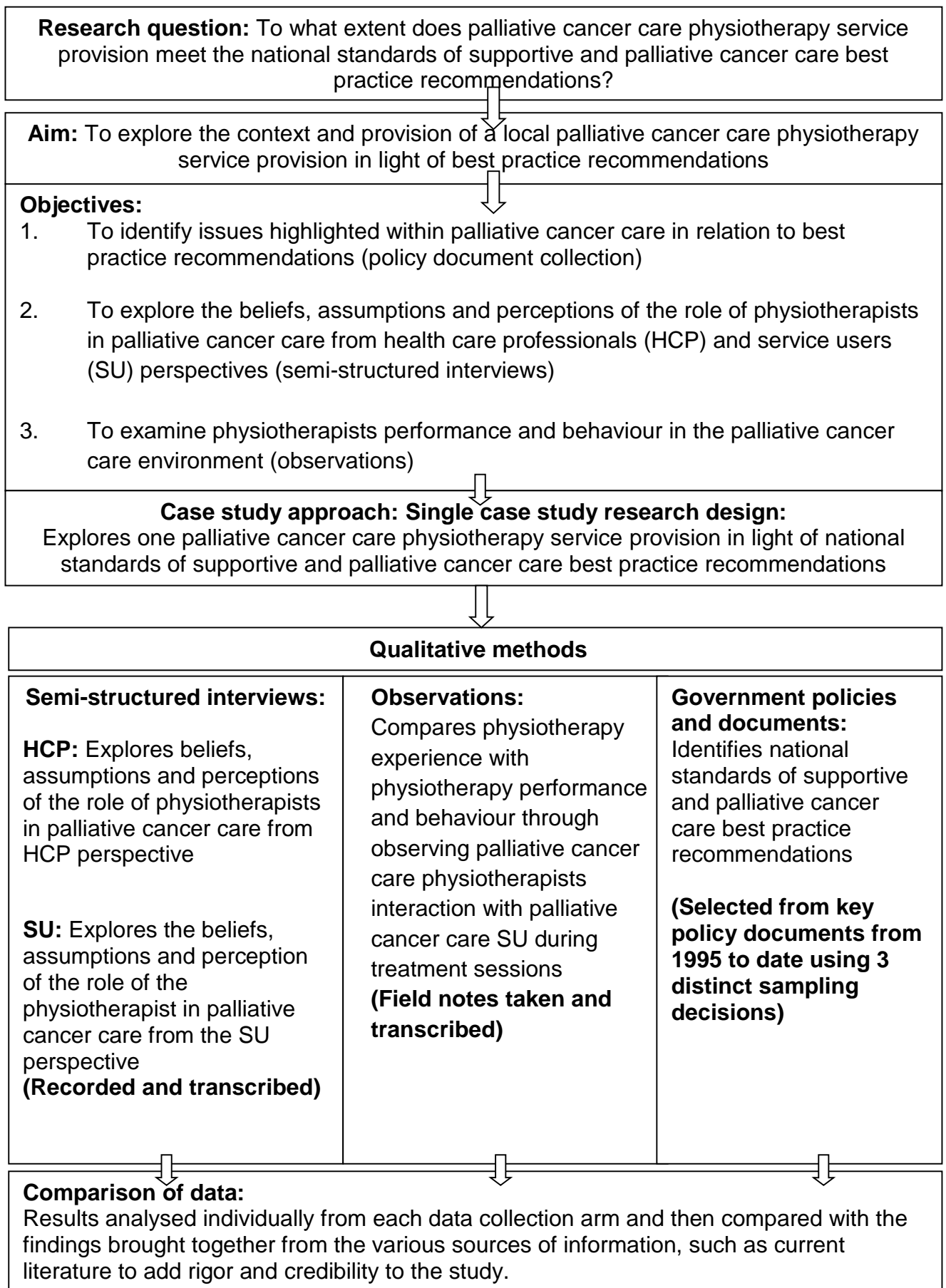
CHAPTER 3: Methodology

3.1 Introduction

I have divided this chapter into three distinct sections: methodology, methods of data collection and method of analysis to describe how the theoretical framework of my qualitative single case study research design was chosen to address the aim and objectives of my research. This chapter will begin by detailing why I used a qualitative approach and case study research design (Figure 2, p.68). In addition, I have documented the theoretical and philosophical foundation of my qualitative case study approach underpinning its application in practice. The chapter concludes with the qualitative methods I used to carry out the data collection and analysis. A reflexive narrative will run through this chapter documenting my methodology journey.

To provide a structure for the reader I have presented a diagram of my overall study in Figure 4 (p.80) in order to highlight the concepts, processes and interrelated elements of my study (Rosenberg and Yates 2007).

Figure 2: Diagrammatic Representation of my Research Study



Section 1: Methodology

Initially I found it difficult to understand the concept of methodology but Hammells' (2006, p.167) definition of methodology as:

“A specific philosophical and ethical approach to developing knowledge, a theory of how research should, or ought, to proceed given the nature of the issue it seeks to address”

helped me to have a clearer insight into the meaning of methodology. It facilitated me in comprehending the importance of my underpinning philosophical and theoretical assumptions, which would provide a bridge between my theory (ideas) and method (doing). My research methodology therefore connects my ontological and epistemological system of beliefs focusing on the most appropriate means for acquiring the knowledge about the world (Denzin and Lincoln 2011). This poses the question, what is the best process of research that will enable me to acquire the knowledge about the world that I seek (Creswell 2007)? I used the paradigms as a tool to help me think about my methodology and help me decide which would be the most appropriate to answer my research question.

3.2 Epistemology and Ontology

My epistemology (theory of knowledge) and ontology (nature of reality) influenced my choice of methodology. In order for me to comprehend the role of methodology within the qualitative research design I needed to understand my 'theory of knowledge,' as this would inform all aspects of my research process. The question was, how may I come to know 'reality?' What is my relationship between the 'knower' and the 'known?' And what are the characteristics, principles and assumptions that guide the process of knowing and the attainment of my research findings (Vasilachis de Gialdino 2009)? The epistemological position that I take as a researcher will have a profound effect upon every aspect of my research process: my chosen subject; the development of my research question; my theoretical lens; my chosen methodology and method. In addition, I would bring to my research my own conscious and unconscious questions, assumptions and beliefs (Hesse-Biber

and Leavy 2006), influencing not only the truths that I searched for in my study but what I believe (Lincoln et al. 2011).

At first I took a very pragmatic stance to my research approach, relating to work carried out by Peirce, William James and Dewey (Smith et al. 2011), applying whichever philosophical or methodological approach fitted most appropriately to my research question. This led to a mixed-method study where I was applying both qualitative and quantitative approaches (Brewer and Hunter 2006). In this philosophical position I was looking at 'truth' with the philosophical lens of 'what works,' therefore testing the feasibility of carrying out my study using both qualitative and quantitative approaches. At this point in my methodological and philosophical journey I was still puzzled, trying to find out where I comfortably stood, what philosophical lens I would use and what would answer my research question. It was at this point in my methodological and philosophical journey that my philosophical stance shifted from a position of pragmatism to a position of social constructivism.

3.3 Constructivism

The approach used in this research is based on social constructivism, where reality is seen as socially constructed (Robson 2004), built upon the principle of the social and cultural nature of human action. This has been defined by Holloway (2005, p.290) as:

"An approach in social science based on an assumption that human beings construct their social reality, and that the social world cannot exist independently of human beings."

In other words:

"All observers view an object of inquiry from their own vantage points in the web of reality, no portrait of a social phenomenon is ever exactly the same as another (Kincheloe and McLaren 2005 p.319)."

From a constructivist's viewpoint, knowledge is built through the reconstruction of these numerous layers of individual or group experiences (Carpenter and

Suto 2008). Multiple constructed realities are therefore formed rather than one single reality, which provides the 'truth' of the phenomenon being researched (Schwandt 2000). Thus the use of semi-structured interviews allowed me to attain numerous perspectives from my research participants, enabling me to understand multiple social constructions of meaning and knowledge around physiotherapy palliative cancer care. These multiple realities or truths can then be understood by exploring the meanings that the participants attribute to their experiences and interactions within the social world. Constructivism, however acknowledges that the researcher and the participants interrelate in a mutual social world (Carpenter and Suto 2008) and so as a research instrument I am constructing knowledge with my participants. This highlights the involvement I have in conferring meanings, the impact on my data generation process and the relationship I form with my research participants. I therefore need to understand how my position as a research instrument in the social world influences my study, which has been addressed through reflexivity.

3.4 Qualitative Research Approach

Qualitative research has its roots in cultural anthropology and sociology and is ideal for studying social processes, exploring how people make sense of themselves in certain contexts (Denzin and Lincoln 2011). It therefore helps us to expand our knowledge of how things came to be the way they are in our social world producing explanations of social phenomena (Hancock et al. 2009). In a health care setting qualitative research is ideal for exploring peoples' views within a real-life context and in particular sensitive subjects such as cancer where flexibility is required to avoid causing distress (Hancock et al. 2009). Qualitative researchers are interested in comprehending the meaning people have constructed, in other words how people make sense of their world and the experiences they have in the world (Merriam 2009). As a qualitative researcher I am therefore studying a topic of interest in the natural environment, attempting to make sense of, or interpret the phenomena in terms of the meanings people bring to them (Denzin and Lincoln 2005). Thus a key characteristic of qualitative research is its inductive approach, where knowledge is generated through observations of everyday life establishing links between social phenomena or suppositions about a situation (Carpenter and Suto 2008), so

developing ideas / understandings rather than testing the theory which would be deductive (quantitative approach).

As a researcher I wanted to be informed by a variety of peoples' viewpoints within palliative cancer care and to gain some understanding of the meaning of situations for these people – constructing meaning from them (Patton 2002; Morse and Richards 2002). I therefore decided to conduct my study in a naturalistic setting, in the palliative cancer care environment in which my phenomenon of interest typically occurs. In addition, I chose observations as Richardson (2006) states that this method can provide insights into how physiotherapists apply knowledge to practice. And lastly I used policy document collection to place the situation in context (Murphy and Dingwall 2003).

3.5 Reflexive Narrative

For me engaging in philosophy at the outset of my research was daunting and reflexivity even more so, as writing in the first person seemed an alien process and yet it is fundamental to qualitative research (Wolcott 2002). In my narrative I have therefore made reflexivity the centre of my 'methodological thinking,' (Seale 1999, p.160) which will enable me to be transparent in my research process removing the barrier between me, the researcher and you, the reader.

Reflexivity is central to qualitative research and closely linked to ethical issues (Carpenter and Suto 2008). Thus, taking a reflexive approach means that I will interrogate my own beliefs and feelings alongside those of my participants. At each stage of my research my impact on relationships in the research environment, access to my data, and how I am identified as the researcher will be documented as part of my analysis process. This should enable you as the reader to make a judgement about how and where I might have influenced the research collection, analysis and dissemination of my findings.

An issue I had to take into account was being an 'insider' which came about through my initial contact with the specialist palliative cancer care unit, where I spent one day a week during a year immersed in the culture of the palliative

cancer care team, prior to starting my data collection. Having had the role of palliative cancer care physiotherapist at the specialist palliative cancer care unit the transition to researcher was not easy. I was now studying members of my own professional group and colleagues who I had been working with. In addition to this, service users were aware of my previous role as a physiotherapist. This required a careful and ongoing negotiation and clarification of the differences between my researcher role and my physiotherapy role to prevent any confusion or expectation, which I have described in depth under ethical issues (Section 3.9).

An advantage to being an 'insider' is that I share a common reality and language that facilitated my interview dialogue enabling me to probe for deeper understandings and meanings. However, as an 'insider' I acknowledge that I do bring certain assumptions and opinions about palliative cancer care, which shaped my data collection and analysis process. I had to learn to listen or observe in a different way, setting aside any biases inherent in my physiotherapy approach to managing symptoms or working in palliative cancer care. I had to stop seeking to predict, explain or manage cancer symptoms and progression. I had to step away from being the expert and focus instead on the expertise of the participant (health care professional or service user) and take the position of learner rather than palliative cancer care physiotherapist.

The credibility and authenticity of my research (Section 3.17) will determine whether my findings can be trusted. I have therefore made efforts to establish confidence in the integrity of my data analysis and interpretation of my findings. Credibility in my research is based on my constructivist assumption that there are multiple realities rather than one single reality and that my participants' experiences are seen as authentic by the individuals.

The transferability of my findings refers to the degree to which my findings inform and facilitate insights within other palliative cancer care environments. Transferability can therefore be made based upon a theoretical understanding of a similar group of phenomena, rather than probabilistic generalisations to a population, as in quantitative research (Green and Thorogood 2004).

During this process, which was complex in nature (Kramer-Kile 2012) I was challenged and stimulated by my supervisors to rethink my methodological approach. This sensitivity to the relationship between the data that was emerging and the initial research question and theoretical framework, helped me to develop qualitative rigour and methodological coherence (Morse et al. 2002).

My methodology grew out of the philosophy that it related to..... or did it? My mind was challenged on numerous occasions about the philosophy and methodology, which underpinned my research, so it is difficult to pinpoint which came first. What I do know is that the challenges posed to me by my supervisors, DProf group and reading made me reflect and question my understanding on this subject numerous times. What I discovered on my journey was that the frontiers between philosophy, methodology and methods are permeable, in other words there was inconsistency in the terminology used in the published literature. I once wrote in my reflective diary that I was “trapped in the web of research terminology” often making me become confused and disorientated at different stages of my philosophical and methodological journey. To add to this, my choice of qualitative research to address my research issues meant that I was faced with copious methodological frameworks (Denzin and Lincoln 2011; Kramer-Kile 2012), each associated with an over-arching philosophy and governed by a specific series of practical methods (Nicholls 2009).

3.6 Methodological Coherence

The research question, design and analysis needs to be closely aligned with my initial theoretical and philosophical assumptions for my study (Hesse-Biber and Leavy 2006). I used the idea of having an overview of the research using diagrams to enable me and the reader to see how all the essential parts of my study connected with each other, “*serving as a strategic, but malleable guide throughout the research experience.*” (Hesse-Biber and Leavy 2006, p.36) I aimed to build a robust understanding through the development of a data analysis strategy, which would be transparent and rigorous in its application. Through this process I would then have a strong line of reasoning to influence

what I understood about the palliative cancer care physiotherapy service provision. This also enabled me to employ rigour to demonstrate trustworthiness in my findings. I therefore decided my qualitative research paradigm would follow a rigorously applied but loosely defined pathway (Nicholls 2009).

Using a case study would allow me to develop a detailed and rigorous knowledge of the palliative cancer care physiotherapy service provision, which would fit my research question: To what extent does palliative cancer care physiotherapy service provision meet the national standards of supportive and palliative care best practice recommendations? Robson (2004), states that 'what?' questions in this context lends itself well to a flexible study design, which reinforced my decision on the use of a case study approach to answer my research question.

Traditionally case studies have been based upon the social constructivism paradigm (Stake 1995; Yin 2009), which would be appropriate for my study as it:

"Recognises the importance of the subjective human creation of meaning, but doesn't reject outright some notion of objectivity. Pluralism, not relativism, is stressed with focus on the circular dynamic tension of the subject and object (Crabtree and Miller 1999, p.10)."

Here I would be using the approach that constructivism is a social construction of reality (Kukla 2002), with the advantage of close collaboration between me, the researcher and the participants, therefore facilitating participants to 'tell their stories (Crabtree and Miller 1999)'. Here, I am claiming that the 'truth' is relative and dependent upon my perspective of the participant's viewpoint, describing their views of reality to improve my understanding of the participants' actions (Carpenter and Suto 2008).

So how does my exploration of the palliative cancer care policy documents fit into my social constructivist stance? By exploring key policy palliative cancer care documents from the past and present I will be able to focus on the political

arena that has shaped the palliative cancer care physiotherapy service provision to date. This will enable me to have a clearer understanding at both a local as well as a national level of the effect that it has had on palliative cancer care physiotherapy service provision and the stakeholders directly responsible for the service delivery within the specialist palliative cancer care unit.

3.7 Case Study Approach

So what is a case study and what is meant by a case study research? Punch (2005) defines a case study as an 'holistic empirical inquiry,' which focuses on preserving and understanding the wholeness and unity of the case, which is important to me when exploring the palliative cancer care physiotherapy service provision within the specialist palliative cancer care unit. A case study would therefore enable me to obtain in-depth understanding through many sources of evidence from my 'contemporary phenomenon' (palliative cancer care physiotherapy service provision), within my real-life situation (specialist palliative cancer care unit), where the context and complexity is recognised (Yin 2009). Key features of case studies include: practice and theoretical development, which fits in well with my practice development; contemporary in nature; case boundaries; transparency of evidence as well as a comprehensive research strategy (Robson 2004). Case studies have a number of strengths: being responsive to dynamic change; progressive focusing on issues; providing policy-makers with insights into situated experiences, which is a requisite of my research (Objective 1) and the ability to capture the complexity of my clinical practice with in-depth understanding of events and issues (Cohen et al. 2007). Case studies can produce large quantities of unmanageable data, which I have addressed through my analytical strategy (Figure 5, p.110) and the addition of boundaries (Figure 3, p.78) to make my data manageable, thus preventing a mass of unreadable evidence (Yin 2009).

I chose a case study design as it is believed to be appropriate for exploratory work providing the development of detailed knowledge about a single case, which enabled me to present an extensive investigation of a single phenomenon of interest (Robson 2004). However, it can involve "*either single or multiple cases and numerous levels of analysis*" and can include qualitative

data only, quantitative only, or both (Yin 2003, p.534). For my case study research design, I chose to follow Stake's (1995) approach rather than Yin's (Yin 1993; Yin 1994; Yin 2003) approach. This was because Stake's (1995) approach is more philosophical, concentrating on qualitative elements (Appleton 2002), which fitted with my methodology and underlying philosophy of social constructivism. In addition, Stake (1995) uses qualitative terminology such as trustworthiness and rigor, which is consistent with social constructivism (Appleton 2002), whereas Yin (1994) uses more quantitative approaches and refers to validity and reliability. Stake (1995) also embraces a naturalistic generalisation, which is more in keeping with social constructivism, while Yin (1994) endeavours to generalise findings to a wider theory (Appleton 2002). Thus, Stake's (1995) view of people learning from single cases fitted with my philosophical underpinning of social constructivism and qualitative case study research design. To answer my research question, I therefore chose a single case study research design because the phenomenon of interest was the exploration of one palliative cancer care physiotherapy service provision, in light of national standards of supportive and palliative cancer care best practice recommendations.

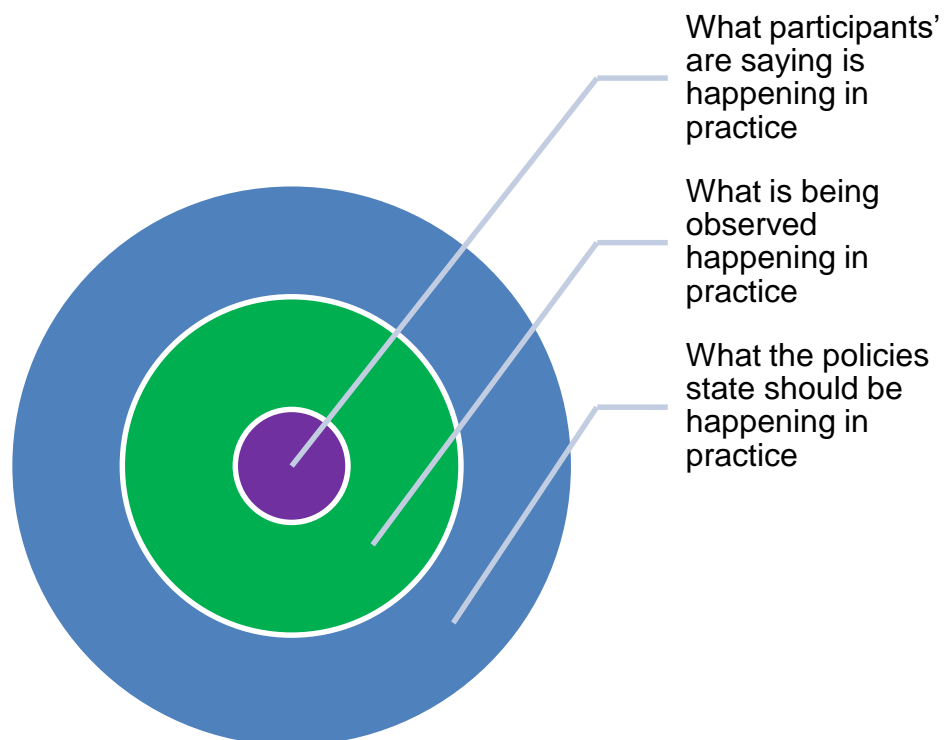
My phenomenon of choice is complex, contextualised and has multiple variables, which lends itself well to case study research (Stake 2000; Yin 2009). This allows a *"detailed, extensive study of a particular contextual and bounded phenomenon that is undertaken in real life situations"* (Luck et al. 2006, p.104), such as the palliative cancer care physiotherapy service provision at the specialist palliative cancer care unit. I therefore chose an instrumental case study research design, where my case is studied to understand related issues or phenomena of interest (Stake 2000; Mills et al. 2010) using a number of qualitative methods. Issues in this context:

"Are not simple and clean, but intricately wired to political, social, historical, and especially personal contexts. All these meanings are important in studying cases (Stake 1995, p.17)."

These issues are therefore essential components in my case study research, which lead to the development of my conceptual framework which guided my research (Baxter and Jack 2008).

It was important that I had a pre-defined boundary for my case study research design to clarify the nature and timeline covered. This included the scope of my case study; social group; organisation; types of data to be collected as well as the priorities for the data collection and analysis (Yin 2009). Therefore, binding my case study could include: time and place (Creswell et al 2003); time and activity (Stake 1995); or by definition and context (Miles and Huberman 1994). I achieved this by establishing my boundaries (Figure 3) in relation to the aim and objectives of my study. Through defining the boundaries of my case study I have made sure that my study will be within a reasonable scope and will indicate the breadth and depth of my study (Baxter and Jack 2008). In addition, by using a theoretical approach to define my case study I will be able to create knowledge that is transferrable to a variety of clinical contexts and behaviours (Crowe et al. 2011). This will result in an informed awareness and understanding of 'how and why' the palliative cancer care physiotherapy service provision (interventions) at the local specialist palliative cancer care unit has developed (Eccles 2006).

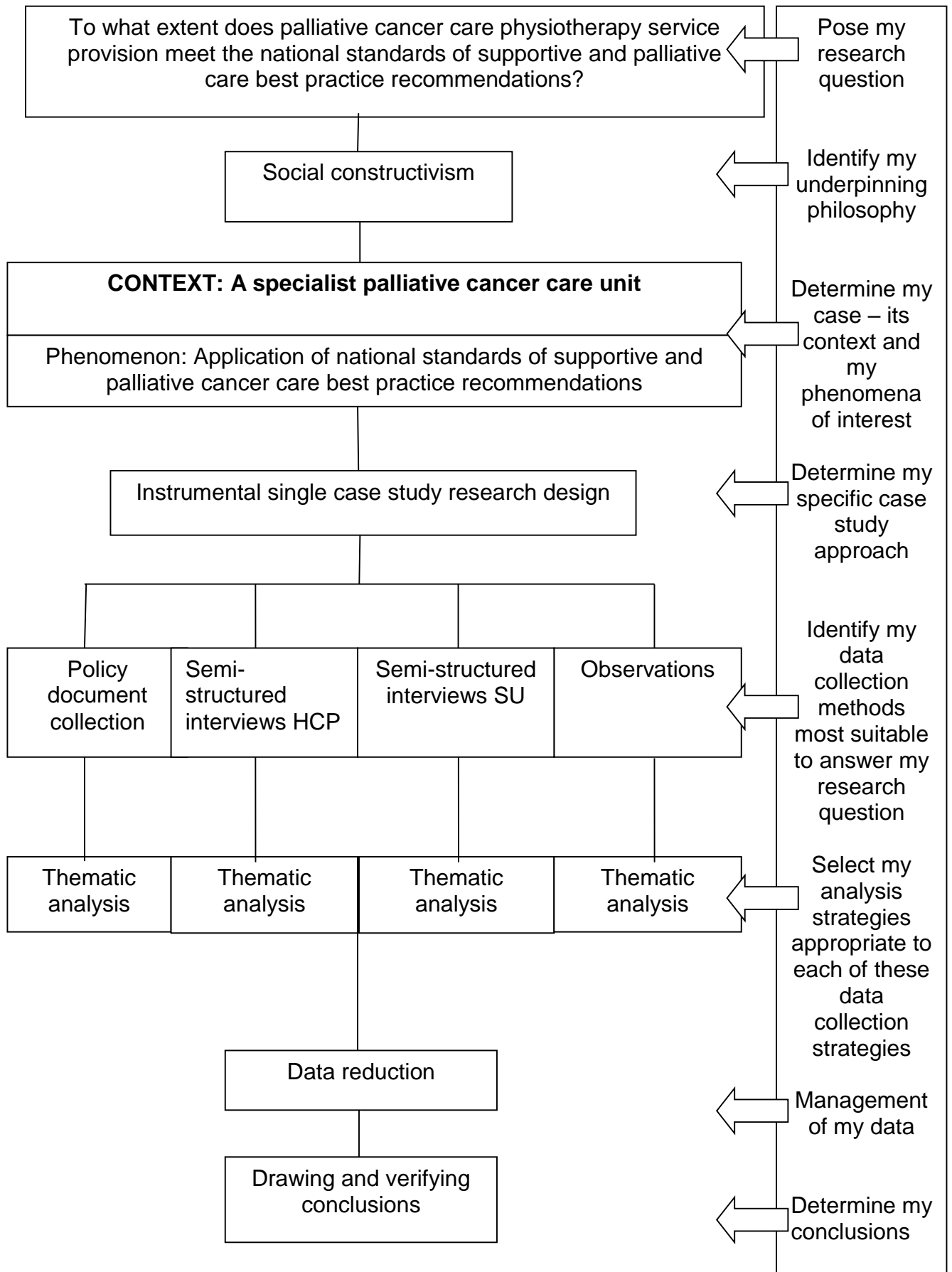
Figure 3: Diagrammatic Representation of my Case Study Boundaries



The nature of a qualitative case study approach meant that it could help me facilitate the exploration of my phenomenon (the palliative cancer care physiotherapy service provision) within the context of the specialist palliative cancer care unit. This qualitative approach therefore allowed me to explore my issue through a single philosophical lens of social constructivism, enabling numerous aspects of the phenomenon to be revealed and understood (Baxter and Jack 2008). My research design incorporated key characteristics such as: rigorous data collection; data analysis and report writing procedures; multiple data collection techniques; detailed methods; evolving design informed by understandings of traditional enquiry; focusing on participant views; me as the data collection tool; presentation of multiple realities; multiple levels of abstraction and verification and accuracy of account given (Creswell 2007). My research therefore captured the essence of the phenomenon by extracting data, which is rich in its explanation and analysis. My case study interviews (semi-structured) relied heavily on the views of the health care professionals and service users and their interaction (observations) with others within the specialist palliative cancer care unit. By using a single case study research design, I could analyse the palliative cancer care physiotherapy service provision at a specialist palliative cancer care unit, based in a local hospice. This is exploratory in nature, in that some conceptual generalisations are possible, where key issues have been identified from the themes and categories.

Figure 4 (p.80) describes my case study in relation to the multiple qualitative data collection methods used setting out my aims, methods and analysis for each qualitative data collection method. In section 2: methods of data collection (p.81) I have laid out Phase Three of my literature search, as it links with my policy data collection method. The method of analysis has been documented in section 3 of this chapter (p.105) and the interpretation of the data will be discussed in full in Chapter 4.

Figure 4: Diagrammatic Representation of my Case Study



Section 2: Methods of Data Collection

I chose qualitative methods with multiple sources of data as they have the ability to capture my case study's complexity (Rosenberg and Yates 2007) and the use of multiple qualitative methods is regarded as fundamental in promoting rigour in case study research (Yin 2009). I have chosen qualitative methods as they are flexible and responsive to the social context of the phenomena I am exploring (Smith et al. 2011) and included semi-structured interviews (health care professionals and service users), observations (physiotherapists and service users) and policy documents, which I analysed using inductive reasoning to provide a variety of sources of converging evidence (Stake 1995) to answer my research question. Following this I reviewed and analysed evidence from the various sources of data and through comparison the outcome are my study's findings (Chapter 4). I have also used quotes and themes in the words of participants to provide evidence of different perspectives (Creswell et al. 2003).

Having provided an overview of my methodology and qualitative method strategy I am now going to describe the ethical approval and then each of the three aspects of data collection:

- 1) Semi-structured interviews with health care professionals and service users.
- 2) Observations of physiotherapists and service users.
- 3) Policy document collection.

3.8 Ethical Approval

I sought ethical approval at the outset of my study by submitting a full research proposal to Bournemouth University Ethics Committee and then through the National Research Ethics Service set up by the NHS (via the Integrated Research Application System (IRAS)), where permission to proceed was granted (Appendix 3) for me to gain access to my participants. Submission to the local Research and Development (R and D) clinical governance committee completed my research governance permissions, with all parties agreeing that my research could commence from March 2010. I kept an ethics log during this timeframe.

The amount of data that I generated and the time it was taking me to transcribe all the interview recordings and observation field notes led me to obtain a minor amendment from the ethics committee. I was granted permission to proceed with a transcriber to complete my transcriptions. To maintain consistency with my transcriptions I provided the transcriber with a transcription template and confidentiality agreement (Appendix 4). In total I alone transcribed the first six service user interviews and the entire observation field notes. As well as gaining ethical approval I also had to consider any ethical issues regarding my research study.

3.9 Ethical Issues

Ethical issues in palliative cancer care are varied and complex making research a challenge in this specialist area, which is perhaps why I found a paucity of research in palliative cancer care. Addressing these unique challenges are therefore essential if physiotherapists are to have an evidence base upon which to make clinical decisions, which can only be achieved through research (Rees 2001). However, I am aware that due to the vulnerability of people with cancer, research is frequently met with resistance. However, this concept of protection may be preventing the individual with cancer the right to receive the best possible care. In addition, I have found that people with cancer often wish to be involved in research, even if it doesn't directly benefit them. People gain comfort in the fact that they may well be benefiting others with cancer in the future (Fine 2003).

I was aware that my qualitative research would be emergent and unpredictable in nature, which would pose me with many ethical challenges on my research journey. My first challenge would relate to the procedures that I was required to carry out for informed consent; my second challenge concerned my relationship between me, the researcher and my participants; my third challenge was the ratio between risk and benefit for my participants and lastly the confidentiality issues associated with my dual role as a palliative cancer care physiotherapist and researcher, all of which I have addressed and described in the semi-structured interviews and observations.

As a qualitative researcher I would not be able to guarantee the direction of my data collection methods, such as in my semi-structured interviews and observations, which is why I sought informed process consent (Ensign 2003). This meant that if my participants had different perceptions about what they considered to be ethical, I could negotiate with them continually (Holloway and Wheeler 2002) throughout the duration of my study. This would provide my participants with a collaborative role in their decision about ongoing participation in my research (Polit and Tatano Beck 2006). There was also a need for me to inform other people within my observational area that an observation was taking place, the purpose of my study and their right not to be involved in my study. I therefore developed information sheets as described by Casey (2004) (Appendices 5 – 8).

I was acutely aware that a potentially exploitative relationship (Houghton et al. 2010) could occur between me and my potential participants. The very nature of my data collection methods (semi-structured interviews and observations) raises significant ethical issues (Hofman 2004), which include: the manner in which my relationships are formed and managed; the nature of the power imbalance between me and my participants and the way my relationship affects my participants psychologically, emotionally and personally (Hofman 2004). I was sensitive to the fact that these boundaries could become blurred as my study progressed, where role confusion could lead to ethical concerns during my exploration (Streubert Speziale and Carpenter 2007). I have therefore made references to the principles of fidelity (honouring the trust placed in me as a physiotherapist / researcher); autonomy (respect for the person's right to be self-governing); beneficence (a commitment to promoting the person's wellbeing); non-maleficence (my commitment to avoiding harm to my participant); justice (the fair and impartial treatment of all people and the provision of adequate services) as well as self-respect (fostering my self-knowledge and care for self) to help alleviate any potential ethical issues (Bulpitt and Martin 2010). In addition, I developed an ethical protocol, as described by Casey (2004) for my study, stating that I would only intervene in patient care in the event of an emergency or if a situation was potentially dangerous.

As I have a professional interest in my study topic and was well known within the palliative cancer care team at the specialist palliative cancer care unit, the separation between my role as a palliative cancer care physiotherapist and researcher was challenging. My main concern was that the participants did not begin to perceive me, the physiotherapy researcher as 'one of their own' and lose sight of the main reason for my presence. This was particularly difficult at the beginning when my role as an honorary physiotherapist working within the palliative cancer care team then changed to the honorary physiotherapy role of researcher. It therefore became necessary for me to explain my new role to the palliative cancer care team so that it could be understood. I did this by organising a meeting with the palliative cancer care team and presenting my proposed study, which helped to reduce any false expectations that they may have had and ensured the integrity of my study (Orb et al. 2001). I also had to deal with a further conflict to the palliative cancer care physiotherapist and research role, that of my physiotherapy lecturer role and the expectation of in-service training that I had been requested to do in my honorary contract role within the specialist palliative cancer care unit. To help resolve some of my conflicting roles I kept a reflective diary which enabled me to have an internal dialogue to analyse and comprehend these important issues within my study. One outcome of these deliberations was to hold regular informal meetings with pertinent gatekeepers, which gave me the opportunity to draw attention to any potential ethical issues that I needed to address.

I adhered to the principles of beneficence and non-maleficence by calculating the risk-benefit ratio of my study, although this is difficult to predict in qualitative research (Cutcliffe and Ramcharan 2002). However, it was important to me that I considered the benefits and possible harm to my participants. I was therefore prepared to stop my semi-structured interview / observation if any of my participants became distressed during the process. I also had a professional at the specialist palliative cancer care unit to whom I could refer my participant following their interview / observation if required, so that they could regain control of the situation (Oliver 2003).

The very nature of my case study research meant that I would be taking an intense interest in personal views and circumstances. Confidentiality was

therefore extremely important to me in order to prevent any risk of exposure or embarrassment to my participants and to prevent disclosure of too much personal information (Stake 2000). I also considered the confidentiality issue associated with the reporting of my detailed case study so that my case study site would not be identified. I therefore put in place robust methods to ensure confidentiality within the design of my case study.

I used pseudonyms and identification codes on the topic guides (Appendix 9 and 10) to maintain confidentiality as described by the Medical Research Council (MRC 2005) recommendations. I also asked the staff involved in the referral of service users to my study to sign a confidentiality form (Appendix 11). In addition to this I completed a data protection form in accordance with the local research and development and I kept hard copies of data locked in a filing cabinet at the research venue. Supplementary to this I password protected all my computer files. The digital recordings that I used in the semi-structured interviews were transcribed anonymously and kept in a secure place and will be destroyed at the end of my study.

Reflexive Narrative

In designing my study, I was concerned with a number of issues, such as being sensitive to the fact that the service users had advanced cancer and were coming to the end of their lives. This required considerate planning, gathering my data with as little disruption to the service users as possible to prevent any undue distress. I was also sensitive to avoiding any unnecessary anguish that my presence as a non-participant observer might cause. I therefore framed my study within a naturalistic paradigm of a case study, which enabled me to construct meaning from my participants (service users and health care professionals) semi-structured interviews and observations (service users and physiotherapists) and place this in the context of policy documents (policy document collection).

3.10 Recruitment of Participants

Semi-Structured Interviews – Service Users

I chose a single local specialist palliative cancer care unit for my case study with the service users participants being of a defined generalised group who met all eligibility criteria (Table 4), which I then applied to select a homogenous sample. A business case development proposal (Rogers 2009) completed prior to data collection stated that 200 patients per annum were referred to the specialist palliative cancer care physiotherapy service provision at the specialist palliative cancer care unit. Therefore, people who were experiencing a variety of cancer symptoms were chosen by me from this cohort.

Table 4: Inclusion / Exclusion Criteria – Service Users

Number	Inclusion criteria	Exclusion criteria
1	The person must have a diagnosis of cancer and experiencing symptoms	The person is not capable of articulating his / her conscious experiences
2	The person must currently be attending the palliative cancer care unit	The person is currently too unwell to participate in a one hour interview
3	The person must be capable of articulating his / her conscious experiences (Creswell 2007)	The person is currently neutropenic
4	The person must currently be having physiotherapy interventions	The person is currently having active radiotherapy or chemotherapy
5	The person must be an adult (over 18 years old)	The person is under 18 years old
6	The person / carer must be English speaking	The person / carer is not English speaking

I accessed my potential service user participants via a referral system from the palliative cancer care physiotherapy service provision at the specialist palliative cancer care unit. By using a service user tally I analysed the number of possible participants. If the potential service user participant fulfilled the inclusion / exclusion criteria for my research, then the potential service user participant was referred to me. I then set up a rapport with the potential service

user participant and explained the study to them, providing them with the semi-structured interview patient information sheet (Appendix 5). I informed individuals that they were free to withdraw from the semi-structured interviews at any time and that this would not affect their care. Time was then given for the service users to explore this information with their families. Once I had established if the service user was interested in being involved in the semi-structured interview I sought verbal consent to protect the rights of the individual. Once verbal consent had been provided, informed consent (Appendix 12) was obtained with process consent occurring throughout the semi-structured interview. This protected the vulnerability of the individual as well as me from any misunderstandings (Ensing 2003). I used a consent check list (Appendix 13) to make sure the service user had received all the information required to make an informed decision.

During a period of a year and nine months from October 2010 to July 2012 service users who fitted the inclusion / exclusion criteria (Table 4, p.86) were referred to my study by the palliative cancer care therapy team, at the specialist palliative cancer care unit. Service users were referred from the following areas: day care centre, community, out-patients and in-patients. In total 37 service users fitting the inclusion / exclusion criteria were referred to my study during the stated period. Out of the total number referred 6 declined as they felt they were unable to sit through the interview, had a history of pain and difficulty concentrating or became too poorly to participate. A further 6 accepted but then became unable to continue due to a deterioration in their condition, admission to hospital or they no longer fitted the inclusion / exclusion criteria due to further treatment. One service user was referred but became too unwell to be eligible for the study and 3 went on to have further treatment, so no longer fitted the inclusion / exclusion criteria. Out of the remaining service users fitting the inclusion / exclusion criteria 8 deteriorated rapidly and subsequently died. My study was therefore based upon 13 service user participants who were able to complete the full study.

Ultimately, 10 of the service user participants referred to my study consented to the semi-structured interviews (Table 5, p.88), from this number 6 were from day care and 4 were from the community. There were no participants recruited

from the in-patients or out-patient areas of the specialist palliative cancer care unit. The length of interview varied from 15 minutes to 1 hour.

Table 5: Participant Demographics: Semi-Structured Interviews Service Users

Pseudonym	Age	Primary diagnosis	Secondary diagnosis	Date of primary diagnosis	Number of Physiotherapy treatments
Mary	93	Ca Colon	None	2009	17
John	69	Acute Myeloid Leukaemia	Metastatic prostate cancer	2011	5
Helen	63	Ca Lung	Spine and liver mets	2011	5
Doris	74	Ca breast	Pulmonary mets	2000	4
Betty	68	Small cell lung cancer	None	2010	13
Tom	86	Ca Bladder Ca Prostate	None	2002 1993	10
Ronald	82	Ca prostate	Bony mets	2008	7
Gary	83	Ca stomach Ca prostate	None	2003 2003	11
Max	79	Adeno-carcinoma transverse colon	Liver mets	2011	5
Henry	80	Ca prostate Cholangio-carcinoma	None	2008 2009	4

Semi-Structured Interviews - Health Care Professionals

I recruited health care professional participants using a defined generalised group who met all eligibility criteria (Table 6, p.89). To gain access to potential health care professional participants I was invited to attend different health care professional meetings in order to present my proposed study and provide information sheets (Appendix 6). I explained that they would be free to withdraw from the semi-structured interviews at any time and that this would not affect their role within the palliative cancer care team. Initially the uptake was slow so it was proposed that I place an advert about my study in the specialist

palliative cancer care unit's newsletter for health care professionals (Appendix 14). Following dissemination of my proposed study potential health care professional participants contacted me either by phone or in person. Once I had established if the health care professional was interested in being involved in the semi-structured interview I sought verbal consent to protect the rights of the individual. Once verbal consent had been provided informed consent (Appendix 15) was obtained with process consent occurring throughout the semi-structured interview. I used a consent check list (Appendix 13) to make sure the health care professional had received all the information required to make an informed decision.

Table 6: Inclusion / Exclusion Criteria – Health Care Professionals

Number	Inclusion criteria	Exclusion criteria
1	The person must currently be working at the specialist palliative cancer care unit	None
2	The person must currently be involved in the specialist palliative cancer care team	The person is not currently involved in the specialist palliative cancer care team
3	The person must be a health care professional (e.g. nurse, physiotherapist, doctor, physiotherapy assistant, health care assistant / therapist)	The person is not a qualified health care professional
4	The person must have been working at the specialist palliative cancer care unit for at least one year	The person has been working for less than a year at the specialist palliative cancer care unit

During a period of eleven months from October 2010 to September 2011 healthcare professionals were able to refer themselves to my study. All those who self-referred fitted the inclusion / exclusion criteria. In total 11 health care professionals were referred for the semi-structured interviews during the stated period. Subsequently 1 was unable to be interviewed due to promotion and no longer worked at the specialist palliative cancer care unit. The length of interview varied from 20 minutes to 1 hour.

Health care professionals were recruited from the following areas of the specialist palliative cancer care unit: day care centre, community, out-patients and in-patients. Of the total number, 6 covered community, in-patients, out-patients and day care and 2 covered in-patients only. Another worked solely in the day care centre and 1 worked in the community. All the health care professional participants referred were female. Demographics of the health care professionals can be seen in Table 7 (p. 91).

Table 7: Demographics: Semi-Structured Interview Health Care Participants

Pseudonym	Profession	Professional qualification	Length of time since qualified	Length of time in palliative care	Length of time working in the specialist palliative care unit
Jackie	Clinical Nurse Specialist	State Registered Nurse	30 years	28 years	28 years
Rachel	Band 6 Physiotherapist	BSc (Hons) Physiotherapy	12 years	7 years	7 years
Emily	Band 6 Physiotherapist	BSc (Hons) Physiotherapy	8 years	7 years	7 years
Chloe	Senior Therapy Assistant	NVQ Therapeutic and Diagnostic Support	8 years	4 years	4 years
Joan	Senior Therapy Assistant	NVQ 3 health ITEC Aromatherapist Massage Therapist	23 years	9 years	3 years
Hannah	Band 6 Physiotherapist	Grad.Dip Physiotherapy	22 years	10 years	10 years
Jessica	Band 6 Occupational Therapist	Diploma in Occupational Therapy	29 years	13 years	3 years
Lizzy	Health Care Assistant	NVQ level 2: Care	11 years	8 years	8 years
Lauren	Acting Clinical Lead	BSc in Adult Nursing	12 years	10 years	10 years
Laura	Nurse	RGN and Dip. Palliative Care	23 years	15 years	15 years

Observations - Service Users

Following the recruitment process for service users as described under the semi-structured interviews, I provided those who had participated in the interviews and who were being treated by the physiotherapy participants (see observations – physiotherapists) with the observation information sheet (Appendix 7). Other service users who fitted the inclusion / exclusion criteria (Table 4, p.86) and who were also being treated by the physiotherapy participants were provided with the observation sheet too. I informed individuals that they were free to withdraw from the observations at any time and that this would not affect their care. Potential participants were given time to discuss this information with their families. Once I had established if the service user was interested in being involved in the observation I sought verbal consent to protect the rights of the individual. Once verbal consent had been provided informed consent (Appendix 16) was obtained with process consent occurring throughout the observations. This protected the vulnerability of the individual as well as me from any misunderstandings (Ensing, 2003). I used a consent check list (Appendix 13) to make sure the service user had received all the information required to make an informed decision.

Out of the 13 service users who were able to complete the study 5 consented to the observations (Table 8, p.93), but only 2 of these had consented to the semi-structured interviews as well. All participants for the observations were recruited from the community at the specialist palliative cancer care unit. There were no participants recruited from the in-patients, out-patients or day care areas

Observations - Physiotherapists

I recruited physiotherapy participants using a defined generalised group who met all eligibility criteria (Table 9, p.93), following the dissemination of my study through informal meetings as well as placing the advert in the specialist palliative cancer care newsletter (Appendix 14). Following consent to the semi-structured interview I provided the observation information sheet (Appendix 8) to the physiotherapists. I informed them that they were free to withdraw from the observations at any time and that this would not affect their role within the

palliative cancer care team. Once I had established if the physiotherapist was interested in being involved in the observation I sought verbal consent to protect the rights of the individual. Once verbal consent had been provided informed consent (Appendix 17) was obtained with process consent occurring throughout the observations. I used a consent check list (Appendix 13) to make sure the physiotherapist had received all the information required to make an informed decision.

Table 8: Participant Demographics: Observation Service Users

Pseudonym	Age	Primary diagnosis	Secondary diagnosis	Date of primary diagnosis	Number of Physiotherapy treatments
Stan	82	Ca prostate	Bony mets	2008	7
Gary	83	Ca stomach Ca prostate	None	2003 2004	11
Henry	80	Ca prostate Cholangio carcinoma	None	2008 2009	4
Ruby	72	Ca ovary	None	2009	2
Paul	85	Ca rectum	None	2010	2

Two physiotherapists who had consented to the semi-structured interviews also consented to the observations (Table 9). Both physiotherapists covered all areas within the specialist palliative cancer care unit.

Table 9: Participant Demographics: Observation Physiotherapists

Pseudonym	Profession	Professional qualification	Length of time since qualified	Length of time in palliative care	Length of time working in the specialist palliative care unit
Rachel	Band 6 Physiotherapist	BSc (Hons) Physiotherapy	12 years	7 years	7 years
Hannah	Band 6 Physiotherapist	Grad.Dip Physiotherapy	22 years	10 years	10 years

The length of observation related to the treatment time and the physiotherapist treating the service user depended upon who they had been allocated during handover and prioritisation of the caseload within the team (Table 10).

Table 10: Observations

Physiotherapist Pseudonym	Service user Pseudonym	Venue	Treatment time
Hannah	Stan	Service user's home	60 minutes
Rachel	Gary	Service user's home	35 minutes
Rachel	Gary	Service user's home	55 minutes
Hannah	Henry	Service user's home	45 minutes
Hannah	Ruby	Service user's home	60 minutes
Rachel	Paul	Service user's home	75 minutes

3.11 Sample Size

Semi-Structured Interviews

The size of my purposeful sample was determined by initially interviewing four to five participants from each of the interview data sets (service users and health care professionals). I applied the key criterion for purposeful sampling, that of 'relevance' (Morse 2000). For example, I selected participants if they were representative of my phenomenon of interest (Yardley 2000), using the following key question to assess the standard of my purposeful samples: Does my sample produce the type of knowledge necessary to understand the structures and processes within which my individuals or situations are located (Morse 2000)? In this way I could increase my use of context as a means of locating lay (service users) and professional (health care professionals) knowledge and understanding subjective meaning. At this point I asked the question: Is there enough data for others outside the sample to relate to the experiences of those within it (Francis et al. 2010)?

The aim of choosing this sample was to gain illumination of 'subjective meanings' – the experiences and situations confronted by the health care professionals and service users involved in my exploration of the palliative cancer care physiotherapy service provision. From a qualitative perspective it was the quality of my sample rather than the quantity that was important to me,

so that I could respect the specificities of each subject's response and the meanings of the response to the subject (Morse 2000). If I let my sample size become too big the aim of my qualitative study would become compromised, as the depth of my description and observation / exploration would be weakened (Addington-Hall et al. 2009).

I made sure that the sample size for my semi-structured interviews was large enough to allow various participant perceptions important to my study to be identified. This prevented my sample from becoming too large and data becoming superfluous, which would be unethical. Guest et al (2006) state that the sample size itself in qualitative research is less relevant as it is the quality of the data arising from the interaction between the researcher and participant that measures its value.

Observations

I worked on the same principles as applied to my semi-structured interviews described above, that my qualitative sample size for my observations must be large enough to obtain the observational information that I required to meet my aim and objectives. I also had to be aware of the practicalities of the time available to me in my studies for data collection and thorough analysis. So I observed 2 physiotherapists carry out 6 treatment sessions between them, each of varying durations depending upon the treatment required by the service user (Table 10, p.94). Six treatment sessions with 5 service users were observed in total. Three treatment sessions were observed for each of the physiotherapists, which included 1 service user being observed twice.

Due to the challenges of recruiting service user participants, I commenced with the health care professional semi-structured interviews and completed 7 by May 2011, prior to commencing my first service user participant interview in June 2011. The semi-structured interviews of the service user and health care professionals then ran parallel until September 2011. The observations of the service users and palliative cancer care physiotherapists commenced in April 2012 to July 2012 and ran parallel with the last 4 service user interviews. It was

during this time that I commenced my policy document collection (Section 3.14) and Phase Three of the literature review that I undertook.

In conclusion when considering my participants for the semi-structured interviews and observations, I concentrated on people living with cancer and health care professionals working in the specialist palliative cancer care unit environment. I anticipated that this would enrich my comprehension of the emergent ideas and thoughts (Finlay and Ballinger 2006) around palliative cancer care physiotherapy service provision and through the source of policy documents, whether physiotherapists were meeting national standards of supportive palliative cancer care best practice recommendations.

Reflexive Narrative

Making a decision about my sample size was not straightforward. As Carpenter and Suto (2008) state, sampling decisions in qualitative research can be difficult to defend, as there is no given formula for determining sample size in qualitative research (Morse 2000). I am therefore going to explain why the depth of data gathered in qualitative research is more important than quantity (Smith et al. 2011). It is crucial to be strategic and meaningful in sample selection (Mason 2002), so I asked the question whether my sample provided me with access to enough data, with the right focus to allow my research question to be addressed. My sample size for the semi-structured interviews, observations and policy document collection therefore had to generate sufficient data to explore processes, similarities and differences, while taking the context into account. Other factors that I took into consideration concerned the scope of my study, the nature of my topic, the amount of useful information that I obtained from each participant or policy document and my methodology and methods that I used in my study design (Morse 2000). Thus the quality or depth of the data obtained from each of my sources enabled me to decide on the sample size required (Carpenter and Suto 2008). The processes that I took for obtaining sample size have been described under each method.

3.12 Semi-Structured Interviews

Semi-structured interviews are extensively used in flexible designs, such as case study research where they are combined with other methods (Robson 2004). Semi-structured interviews are also appropriate for my study as they gather information on attitudes and beliefs (Fox 2009), which addressed Objective 2 of my study: *To explore the beliefs, assumptions and perceptions of the role of physiotherapists in palliative cancer care from health care professionals and service users' perspective*. In addition, I was able to develop my semi-structured interview questions (open-ended) in advance of my interviews, which were designed around my research question: *To what extent does palliative cancer care physiotherapy service provision meet the national standards of supportive and palliative cancer care best practice recommendations?*

I devised the semi-structured interviews for my study following the literature review of Phase One of my literature search in 2008-09 (Chapter 2, p.41), where I identified gaps in the literature. From this I developed a loose structure or topic guide (Appendix 9 and 10), which consisted of a list of topics related to my research question (Table 11 and 12). It also meant that I could develop prompts for each question on my interview topic guide for clarification if required. This provided me with some structure and clarity to my open-ended questions, which is a requisite in qualitative research (Cohen et al, 2007).

My open-ended questions defined the topic (Tables, 11 and 12) being explored and allowed me and my participants to search the topic in more detail (Fox 2009). I also had prompts in case my participants only answered me briefly or were not sure of the question. I was then free to explore my participant's views further if a new line of inquiry arose (Fox 2009), which enabled my participants some liberty to offer me a variety of views and proffer new insights (Addington-Hall et al. 2009).

Table 11: Semi-Structured Interview Topic Guide – Service User

Number	Topic guide
1	Expectations of the palliative cancer care physiotherapy service pre and post attending the specialist palliative cancer care unit
2	Description of the palliative cancer care physiotherapy service received
3	Description of the communication between the palliative cancer care physiotherapist and other health care professionals
4	Quality of life pre and post palliative cancer care physiotherapy interventions
5	Benefits if any of receiving palliative cancer care physiotherapy interventions
6	Improvements if any to the palliative cancer care service provision
7	The most difficult part of their illness to cope with and if any of the palliative cancer care physiotherapy interventions had helped them to deal with this more effectively?

Table 12: Semi-Structured Interview Topic Guide – Health Care Professional

Number	Topic guide
1	Understanding of the role of palliative cancer care physiotherapy
2	Expectations of the palliative cancer care physiotherapy service
3	Description of the palliative cancer care physiotherapy interventions that their patients had received
4	Description of the communication between the palliative cancer care physiotherapists and other health care professionals
5	How they felt the palliative cancer care physiotherapists had managed their patient's cancer journey
6	Their thoughts on the quality of life of their patients pre and post palliative cancer care physiotherapy intervention
7	What they felt had benefitted the patients who had received palliative cancer care physiotherapy interventions
8	Improvements that they would make to the palliative cancer care physiotherapy service provision
9	The most difficult part of service users illness that they had to cope with and if any of the palliative cancer care physiotherapy interventions had helped them to manage this area more effectively?

By using a topic guide I could also detail the procedure to ensure consistency across both the health care professional and service user interviews (Robson 2004) during the time span they were conducted. The semi-structured interviews which I recorded, took place in a quiet room at the specialist palliative

cancer care unit away from the work place or treatment environment. This provided an atmosphere free from distraction, whilst still being within the culture of the specialist palliative cancer care unit. Interviews were also arranged at times most suitable for the participants, so that it fitted in with either their work schedule or treatment plan. These considerations placed participants at ease, allowing a more productive interview to take place and richer data to be gathered (Gill et al. 2008).

3.13 Observations

I chose observations as a research method for my study as they are one of the key research methods for studying small groups, in natural settings. They are therefore perfect for studying 'social worlds,' such as the palliative cancer care physiotherapy service provision. In other words:

"those groupings of individuals bound together by networks of communication or universes of discourse and who share perspectives on reality (Lindesmith et al. 1991 p.282),"

Furthermore, the data I obtained from my observations could be compared with data gathered from other methods (Robson 2004), which is ideal in my case study research where multiple data collection methods have been used. My comparisons enabled me to pick up any discrepancies between what people say that they have done or will do, and what they actually did, or will do (Robson 2004), in line with my case study boundaries (Figure 3, p.78).

Therefore, my observations were able to add richer data to the responses obtained from my semi-structured interviews. My observations addressed Objective 3 of my study: *To examine physiotherapists performance and behaviour in the palliative cancer care environment.*

Observations took place in individual homes of service users who had been referred to the specialist palliative cancer care unit and palliative cancer care physiotherapy service, using the inclusion / exclusion criteria (Table 4, p.86) and sampling plan described previously. Observations involved me observing six physiotherapy treatments of varying durations, which I collected using field notes and which were recorded consistently. I recorded observations of

physiotherapists and service users, both verbal and non-verbal using field notes which I then transcribed. To ensure a high level of trustworthiness and authenticity I took a structured approach in the design of the observation. This procedure provided me with a framework and direction on what I would observe, so that I only attended to the specified areas relevant to my research question. I therefore had an observation guide (Table 13, p.102) which directed my observations and provided the structure required to meet my studies objectives.

Preparing for my observation involved determining the purpose in relation to research Objective 3, as well as identifying who was going to be observed. I had to consider the accessibility of my participants and the venue where I would observe the physiotherapist treating the service user. This inevitably was determined by the service user participant as to whether they were receiving physiotherapy in the community, on the ward or within day care at the specialist palliative cancer care unit. Once the site had been established a time of day and date was agreed and the treatment time acknowledged, as this varied between participants depending upon their needs. Following this I had to consider how I would present myself, both in terms of my appearance and my purpose. To avoid confusion, I wore mufti rather than a physiotherapy uniform. I then gained sufficient rapport and empathy with the physiotherapist and service user to enable the observation to be conducted (Pope and Mays 2000). This allowed me to establish my situational identity (Angrosino 2005) with the participants, meeting ethical approval of being open and transparent (Robson 2004). During the observation I was then a familiar and accepted presence, but aware that I might stimulate modifications in behaviour and action (Pope and Mays 2000).

During my observations I used the observation guide (Table 13, p.102) and wrote field notes to record my observations, which I transcribed as soon as possible (within 24 hours of my field notes being written) so that the richness of the experience was not lost. I expanded my notes into rich descriptions following each observation (Appendix 18), which involved describing what happened and what I learnt. I used clearly labelled columns to separate my

observations, interpretations and personal comments. This enabled me to gain an in-depth understanding of social interaction within this context.

Table 13: Observation Guide

Category	Categories	Research notes
Appearance	Clothing, age, gender, physical appearance	Anything that might indicate membership or is of interest to the study, such as profession, social status, socioeconomic class, religion or ethnicity
Verbal behavior and interactions	Who speaks to whom and for how long: who initiates interactions; languages or dialects spoken; tone of voice	Gender, age, ethnicity and profession of speakers; dynamics of interaction
Physical behavior and gestures	What people do, who does what, who interacts with whom, who is not interacting	How people use their bodies and voices to communicate different emotions; what individuals' behaviours indicate about their feelings toward one another, their social rank, or their profession
Personal space	How close people stand to one another	What individuals' preferences concerning personal space suggest about their relationships
Human traffic	People who enter, leave and spend time at the observation site	Where people enter and exit; how long they stay; who they are (ethnicity, age, gender); whether they are alone or accompanied; number of people
People who stand out	Identification of people who receive a lot of attention from others	The characteristics of these individuals; what differentiates them from others; whether people consult them or they approach other people; whether they seem to be strangers or well known by others present

(Mack et al. 2011)

3.14 Policy Document Collection

I chose policy document collection as my third research method, as it addressed Objective 1 of my study: *To identify issues highlighted within palliative cancer care in relation to best practice recommendations*. Over the last two decades the use of qualitative research to explore policy issues has grown, underpinned by the constant requirement to comprehend the complex behaviours, needs, systems and cultures in social policy fields (Ritchie and Spencer 2002), such as in palliative cancer care. However, in the past one of the inhibiting factors for using qualitative methods in social policy was the lack of an audit trail for the research process, especially in the conduct of qualitative data analysis (Ritchie and Spencer 2002). I have therefore addressed this in my study through the application of a qualitative software package (Section 3, p106) using a framework and analytical strategy (Figure 5, p.110) to provide transparency of how my findings were obtained. This important element underpins my qualitative research, providing the basis for policy makers and practitioners to make informed judgements and actions to commission services.

My methodological review of my policy documents forms Phase Three of my literature search, which followed the same steps as Phase Two (Chapter 2: 2.4, p.49) in terms of concept (Table 14) and search term development (Table 15), this time focusing on policy documents; palliative cancer care standards and best practice taken from Step 1 of Phase Two of my literature search.

Table 14: Identification of Concepts for the Policy Literature Search

Concept 1	Concept 2	Concept 3
Physiotherapy	National Cancer Standards	Palliative Care

Table 15: Search Terms Representing Concepts for the Policy Literature Search

Search terms describing Concept 1	Search terms describing Concept 2	Search terms describing Concept 3
Physiotherapy	National Cancer Standards	Palliative Care
Physical Therapy	Best Practice in Cancer	Palliation
Physio*	Cancer Guidelines	Palliat*
	Onc* Guidelines	

As described in Phase Two of my literature search I entered key words in a systematic manner into my chosen databases (Table 3, p.51) and my search results were presented in a table format following the same inclusion / exclusion criteria (Table 3) and filtering system. During my academic literature search in Phase Two, a few key policy documents were identified during my filtering stage, which were then added to my policy literature search results. Once my policy search had been completed I used a purposive sampling technique to choose my policy sample for analysis (Table 16). I used three distinct sampling decisions: Decision 1: Purposive sampling technique – to choose sample based on titles having similar characteristics, for example importance in driving change, Decision 2: This related to the issues and dates of the documents, Decision 3: Content of the documents to be coded, which I have described in full in the ‘stages of analysis’ (p.111) in the following section and presented in Appendix 19.

Table 16: Policy Documents

Policy document	Issue date	Publishing body
Calman-Hine Report	April 1995	DH
NHS Cancer Plan	September 2000	DH
Improving Supportive and Palliative Care for Adults with Cancer	March 2004	NICE
Cancer Reform Strategy	December 2007	DH
End of Life Care Strategy	July 2008	DH
Manual for Cancer Services 2008 – Rehabilitation Measures	December 2008	NCAT
Common Core Competencies for End of Life	September 2009	DH
National Cancer Survivorship Initiative	January 2010	DH
Improving Outcomes – a Strategy for Cancer	January 2011	DH
Commissioning End of Life Care	June 2011	NCPC
Cancer Commissioning: Making the Reforms Work for Patients	June 2012	2020health.org
Improving Outcomes – a Strategy for Cancer	December 2012	DH

Section 3 – Method of Analysis

My case study research is underpinned by a research framework (Figure 4, p.80) where my analytical strategy (Figure 5, p.110) used key stages that identify my themes and categories. This provided me with authentication of my theoretical propositions and is therefore fundamental to the rigour of my case study research (Stake 1995; Yin 2009). In order for me to accomplish this it was necessary for my case study to have defined boundaries (Figure 3, p.78) to prevent my large quantity of data becoming unmanageable (Luck et al, 2006). I approached this through the development of my diagrammatic representations (Figures 2-5, p.68, p.78, p.80, p.110). By selecting a data analysis strategy and making sure it linked with my chosen data collection methods I implemented methodological rigour (Polit and Tetano Beck 2004). My analytical stages (Figure 5, p.110) demonstrate how diagrams can present a systematic and rigorous means of organising large amounts of data from multiple sources (Miles and Huberman 1994) and was used in my research to allow the data to be considered in a manner conceptually consistent with each of the elements of palliative cancer care physiotherapy service provision, whilst maintaining an inductive process of analysis.

Qualitative computer assisted analysis software, such as NVivo provided me with a tool for transparency and efficiency: logging the movement of my data; coding patterns; mapping conceptual categories; keeping memos of thoughts enabling all stages of my analytical process to be traceable and transparent (Figure 5). This process produced an audit trail for my study, an essential element of trustworthiness and plausibility (Bazeley 2009) leaving me 'firmly in charge' (Fielding and Lee 1998). This allowed me to produce a more detailed and comprehensive audit trail, which would not have occurred if I had completed it manually. Therefore, the aim of the data analysis strategy (Figure 5) within NVivo was to provide rigour to my case study research. My objectives were: to apply a rigorous data management system using open and hierarchical coding through NVivo; to attach descriptive and explanatory accounts throughout my analytical process using NVivo memos and annotations providing an audit trail; to test, validate and revisit analytical memos to self-audit proposed findings and verify theoretical propositions and lastly, to maintain an

NVivo project journal to provide a reflective narrative of my data analysis journey.

This was an interactive process that occurred between me, the data collection and data analysis. I then analysed all my qualitative data individually using a thematic approach following my analytical strategy (Figure 5, p.110).

3.15 Thematic Analysis

This was used to analyse all four data sets: Thematic analysis is used widely as an analytical method in qualitative research, yet is inadequately defined (Roulston 2001; Tuckett 2005; Braun and Clarke 2006). One might argue that it should be the underpinning method for qualitative analysis, due to the generic skill of identification of thematic meanings across qualitative data analysis (Holloway and Todres 2003) and is a method which allows identification, analysis and reporting of patterns (themes) within the qualitative data set (Braun and Clarke 2006).

A key advantage to thematic analysis is that it provides an easy and flexible approach to qualitative data analysis (Braun and Clarke 2006) and is therefore ideal for researchers, such as myself in an early qualitative research career. Determining themes and prevalence is an advantage of the flexibility of thematic analysis and whilst it can be done in a variety of ways, it must remain consistent throughout the data analysis (Braun and Clark 2006).

Thematic analysis can also be used within different theoretical frameworks, such as constructivism. However, any theoretical framework holds a variety of assumptions regarding the nature of the data and its representation of reality, the world and how this is unpicked or unravelled, so the latter needs to be made transparent to produce a good quality thematic analysis (Braun and Clarke 2006).

I chose thematic analysis to analyse my data as it is compatible with constructivism paradigms and its flexibility provides an effective research tool enabling rich, detailed but nevertheless complex accounts of the data (Braun

and Clarke 2006). It enabled me therefore to organise and describe my data sets providing a rich detailed account of my case study data.

A lack of transparency around thematic analysis is a disadvantage (Antaki et al. 2002), as it can hinder researchers working on related studies in the future (Attride-Stirling 2001). It is therefore important for the reader to understand how I analysed my data, or what assumption informed my analysis, in this way my research can be evaluated. Once this has been achieved comparisons with other studies on palliative cancer care can be made.

A social constructivist approach provided me with a framework for inquiry within my study. I then needed a way to argue what I know based on the process by which I came to know it (Kukla 2002). For this reason, I chose thematic analysis, where data is grouped into themes and is a core skill in qualitative research. Thematic analysis has the ability to identify analyse and report patterns (themes) within data and across data sets and can be applied in different theoretical approaches, as well as being extensively used in qualitative research (Braun and Clark 2006). Situating the thematic analysis within my data analysis helped me to frame the process and provide a rationale to my analysis, which I have made transparent by using visual, systematic methods and procedures (Figure 5, p.110). By adopting a generic qualitative approach, I can enhance the credibility of my research findings, because I will be more concerned with the accuracy of describing my participants' experiences, staying close to the data and ensuring my interpretations are transparent (Sandelowski 2000). Thematic analysis would therefore engage my involvement and interpretation of the data, where I focus on *"identifying and describing both implicit and explicit ideas within the data, that is, themes (Guest et al. 2011 p.11),"* followed by a number of stages, as described in my analytical strategy (Figure 5). Hence, I chose this process because it can produce rigorous qualitative data analysis that could eventually be influential to policymakers, other researchers and funders (Guest et al. 2011).

3.16 Stages of Analysis

The analytical strategy (Figure 5) was developed by me to manage the large quantity of data collected (verbatim transcriptions of interviews, observation field notes, policy documents and literature) for analysis, providing me with a coherent structure that preserves my original accounts and observations (Ritchie and Spencer 2002) obtained from my qualitative data collection. In addition, my analytical strategy was designed to facilitate a systematic analysis within the demands and constraints of my case study. I included five stages in my analytical strategy for my study to achieve the aim and objectives of my research (Figure 2, p.68). My five stages of analysis followed the key stages of qualitative data analysis, which included; familiarisation; identifying a thematic framework; indexing; charting; mapping and interpretation (Bazeley 2009). Each stage is an analytical, logical process that interconnects, but continues to rely on me as the analyst to apply a creative and conceptual ability to determine meaning, with flexibility for reworking ideas if necessary, as the analytical process is both documented and accessible (Ritchie et al. 2003).

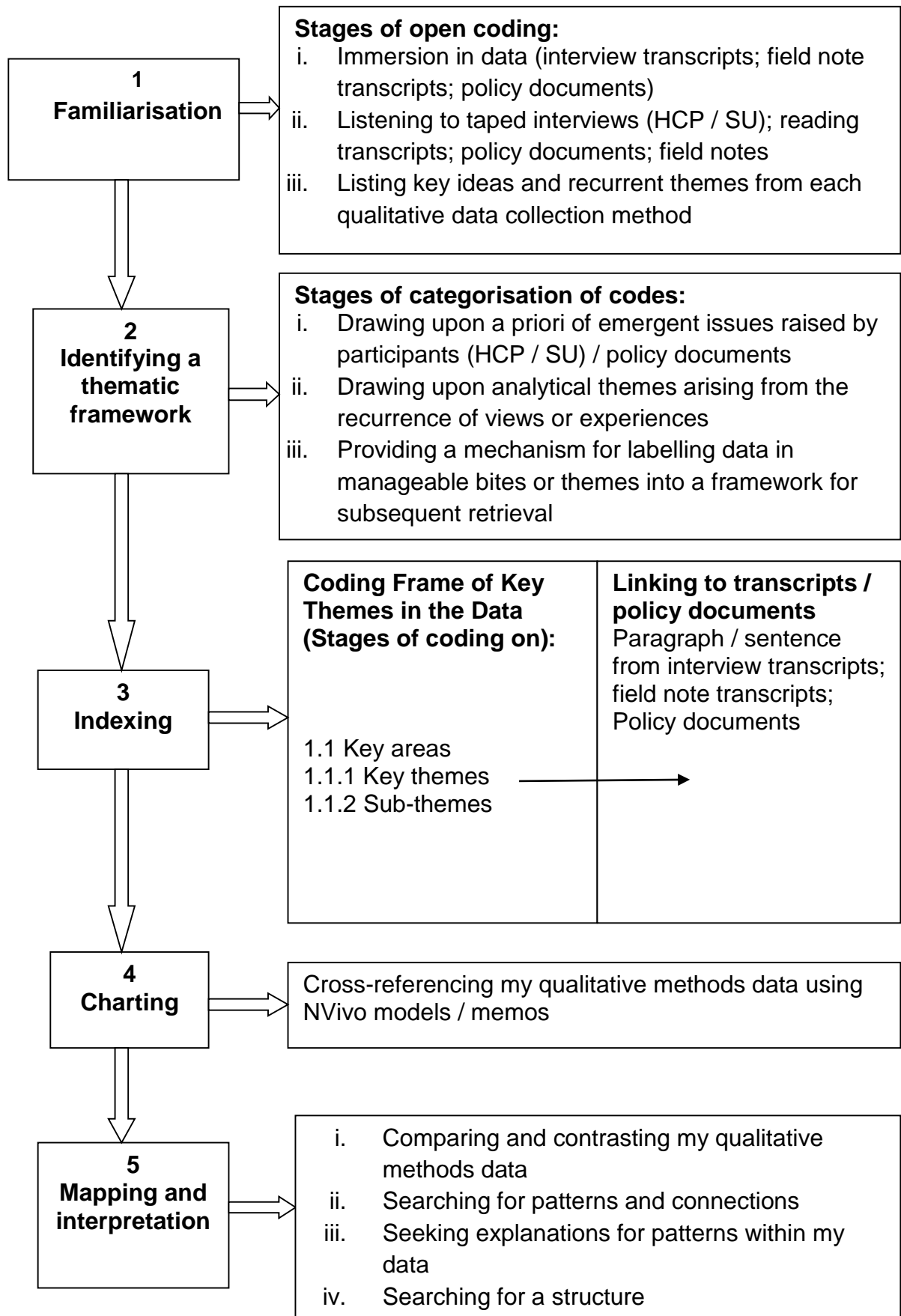
Being an inductive approach allowed my study to evolve naturally and for me to become a 'research tool' (Denzin and Lincoln 2011), with the participants being central to this process, mirroring the 'patient-centred care' approach in practice. In this way the participants could describe what is important to them and what is necessary in their cancer journey / health care professional journey.

Reflexive Narrative

My reflexivity within my study is a continual process of reflection on my interpretations of both my experience and the phenomena being explored, moving my knowledge and understanding about this particular research outcome forward (Finlay and Gough 2003). Therefore, acknowledgement of my experience, pre-judgements and fore-understandings will be explicit in my narrative, while recognising that narrating my experience either during my reflexive account, semi-structured interviews or observations will only provide one version, my interpretation of the data. This recognition will prevent prejudices dominating my research findings. I therefore had an ongoing conversation about my experience, while simultaneously living in the moment

(Finlay and Gough 2003). This moving back and forth between experience and awareness has enabled me to become immersed in multiple layers of meaning (Denzin and Lincoln 2011).

Figure 5: Diagrammatic Representation of my Data Analysis Strategy



The following five stages of data analysis were applied individually to each of my four data sets (semi-structured Interviews – health care professionals; semi-structured interviews – service users; observations – physiotherapists and service users; and policy document collection). The order in which the stages were carried out can be seen in Table 17 (p.114).

Stage 1: Familiarisation

This is the stage that I became familiar with the range and diversity of my data by becoming totally immersed, gaining an overview of the bulk of the information, so placing ideas in context. This process involved; re-listening to my recordings and reading the transcripts from my health care professional and service user interviews; re-reading my field notes and reading the transcripts from my observations; and reviewing my policy document collection. From this I was able to gain an idea of the richness, depth and diversity of my data, whilst starting to list key ideas and recurrent themes leading to the start of abstraction and conceptualisation (Appendices 20 - 23).

Stage 2: Identifying a Thematic Framework

During this stage I made notes and recorded the variety of individual replies to the semi-structured interview questions, responses to treatment and policy recommendations by noting any recurrent themes and issues which emerged and were of importance to the participants or policy makers. I then reviewed the selected text, notes, key issues and identified and referenced concepts and themes. Following this I identified and constructed a framework so that the key issues, concepts and themes could be separated and arranged. This stage involved a number of issues including: my original research aim, emergent issues from the participants and analytical themes evolving from the recurrence or 'patterning' of certain views or experiences. I then made judgements about meaning in order to refine my thematic framework, which involved both logical and intuitive thinking around the relevance and importance of the issues and my connections between ideas (Appendices 20 - 23).

Stage 3: Indexing

My indexing arose from the priori of issues described previously providing a mechanism for labelling my data, which made it more manageable with the ability to retrieve and explore my data. I kept a common index for the different data being analysed, so enabling me to identify common and divergent themes. As in Stage 2, I continued to make judgements around the meaning and significance of my data at this stage, which is subjective in nature. However, by using a system of annotations within NVivo my process is visible and accessible to others and assumptions can be reviewed by me. I then carried out a refining process where I looked at the overview of the categories I had developed in Stages 2 and 3, so allowing for further interpretation of my analysis by refining the contents of each category (Appendices 24 - 27).

Stage 4: Charting

At this stage I had applied a thematic framework to each of my individual qualitative data collection sets, and in order for me to represent my data as a whole; I considered the various attitudes and experiences for each theme. Here I highlighted the data from the original context and cross-referenced it with the appropriate thematic reference. I have documented this under headings and subheadings drawn from my thematic framework and presented it using NVivo models. I have drawn up NVivo models for each of my key areas demonstrating individual responses (Appendices 28 - 31). I maintained a consistent order in the models so that I could make comparisons within and eventually across my data sets (Table 17, p.114).

Stage 5: Mapping and Interpretation

On completion of Stage 4 I then mapped and interpreted key areas of my data; physiotherapy profession; physiotherapy service; quality of life. In order to do this, I returned to my study objectives, as well as the key feature of my qualitative analysis (defining concepts, mapping range and nature of phenomena and finding associations and comparisons. This process was guided by my research question, as well as the themes and associations that emerged from my data. I reviewed the charts, NVivo memos and then

compared and contrasted the perceptions, accounts and experiences from the four data sets. Patterns and connections were then sought from the explanations embedded in my data. From this I identified and mapped the nature of my research phenomenon (Appendices 32 - 34).

Table 17: Integration of the Four Data Sets During Analysis

Key: Green shading: analysis WITHIN the data set / Orange shading: analysis ACROSS the data sets

Date	Semi-structured interviews Health Care professionals (data set 1)	Semi-structured interviews Service user (data set 2)	Observations Physiotherapists and service users (data set 3)	Policy document collection (data set 4)
January – March 2012	Stage 1: Familiarisation - coded transcript 1 to 3 within the data set			
April - May 2013	Stage 1: Familiarisation - coded transcript 4 to 10 within data set Stage 2: identifying a thematic framework completed -Amalgamation of some sub-themes within the data set	Stage 1: Familiarisation - commenced coding transcript 1 within the data set		
June – July 2013	Stage 3: Indexing commenced within the data set	Stage 1: Familiarisation - coded transcript 1 to 10 within the data set Stage 2: identifying a thematic framework - Amalgamation of some sub-themes within the data set	Stage 1: Familiarisation - commenced coded transcript 1 within the data set	Stage 1: Familiarisation – commenced coding document 1 - 3 within the data set
July – August 2013	Stage 3: Indexing completed and reviewed – some sub-themes merged within the data set	Stage 3: Indexing commenced within the data set	Stage 1: Familiarisation – Coded transcript 2 to 6 within the data set	Stage 1: Familiarisation – completed 4 – 12 within the data set Stage 2: identifying a thematic framework commenced - Amalgamation of some sub-themes within the data set
August – September 2013	Stage 4: Charting commenced – memoing within the data set	Stage 3: Indexing completed and reviewed within the data set Stage 4: Charting commenced – memoing within the data set	Stage 2: identifying a thematic framework - Amalgamation of some sub-themes within the data set Stage 3: Indexing commenced within the data set	Stage 3: Indexing commenced and reviewed within the data set
October – November 2013	Stage 4: Charting completed within the data set	Stage 4: Charting completed within the data set	Stage 3: Indexing completed and reviewed within the data set Stage 4: Charting commenced - memoing within the data set	Stage 4: Charting commenced - memoing within the data set
December 2013 - January 2014			Stage 4: Charting completed within the data set	Stage 4: Charting completed within the data set
February 2014 – March 2014	Stage 5: Mapping and interpretation across the data sets	Stage 5: Mapping and interpretation across the data sets	Stage 5: Mapping and interpretation across the data sets	Stage 5: Mapping and interpretation across the data sets

3.17 Reflexive Narrative

In order to maintain trustworthiness (Carcary 2009; Nicholls 2009; Bazeley 2009) of my data I compared my sources (health care professionals, service users and policy documents), methods (semi-structured interviews, observations and policy document collection), and myself (values, beliefs and assumptions) as the research tool. Being conscious of my influence upon my interpretations of the data I attempted to recognise personal assumptions and biases to remind myself of my own values, beliefs and assumptions (4.8). In addition, I explained to my research participants (health care professionals and service users) that their personal experience was being requested and valued. Therefore, by explaining the intention of my research and ensuring confidentiality and anonymity I optimised my participant's disclosure and enabled my participants to be more open, rather than just providing professionally or patient / therapist acceptable responses or actions (3.9). During the writing up of my findings I have reinforced the trustworthiness of my data through the use of direct quotes.

Using memos throughout my data analysis enabled me to reflect upon my thinking and decision-making during interpretation and comparison of my data sets (4.8), providing transparency for the reader. Reflexivity has therefore enabled me to explore my role and perspective in the process of generating and interpreting my data, which is demonstrated in examples taken from my observation field note transcriptions, as I tried to make sense of my data:

"I believe reminiscing is an important part of this gentleman's quality of life" (observation: personal comments: April, 2012).

Here, my assumption led me to focus on the specialist physiotherapist's reaction to the 'story' the service user was telling and whether any key aspect of the 'story' would be tailored to personal goal setting. I was therefore continually referring back to my own experiences and responses in similar situations and then reflecting on my observations constructing layers of meaning (Denzin & Lincoln, 2011).

Being invited into the service users' home during the observations offered me an additional layer to my reflections. This provided me with a sense of the service user's environment, as well as the ability to share in the experience of their emotional journey in palliative cancer care. Participating in the interviews and observing specialist physiotherapists treating service users also immersed me in the:

"Physical emotional and psychological experience of being in the field." (Watson 1999, p.2)

At times this was difficult for me as I wanted to put my practitioner's hat on and treat the service user myself. I therefore had to learn to take a step back referring the service user to the appropriate practitioner at the end of the interview. Furthermore, I often debriefed with the specialist physiotherapist after the observations, especially when it had been a particularly emotional experience. This helped us both to reflect on our specialist area and made sure that the service user had the best possible support available. Although this was not an easy process, my immersion and reflection enabled me to capture multiple layers of meaning to make sense of my multi-dimensional phenomena (Santasier and Plack 2007). However, due to the complexity of my data I found that I needed to shape and reshape (James 2012) my research themes over time to make sense of how all the data came together (4.8).

3.18 Conclusion

I have established and documented the concept of my qualitative case study approach at the beginning of this chapter in conjunction with its appropriateness as a theoretical framework to explore my research aim and objectives of my study. My reflective narrative has been woven within this chapter to highlight key areas of my methodological journey. The main body of this chapter has explored my case study's qualitative data collection and analysis methods in depth and the next chapter will discuss my findings.

CHAPTER 4: Findings

4.1 Introduction

The aim of my study was to explore the context and provision of a local palliative cancer care physiotherapy service provision in light of best practice recommendations. Three research objectives were set, the first to identify issues highlighted within palliative cancer care in relation to best practice recommendations; the second to explore the beliefs, assumptions and perceptions of the role of physiotherapists in palliative cancer care from health care professionals and service users' perspectives and the third to examine physiotherapists' performance and behaviour in the palliative cancer care environment. To meet my aim and objectives, data were collected through four data sets: semi-structured interview of service users and health care professionals; observations of service users and physiotherapists and policy document collection, which were then analysed as described previously in Chapter 3 (Figure 5, p.110).

In this chapter I have presented the overarching theme of metamorphosis that was identified from my case study findings. I have also outlined my initial findings from my policy documents, interviews and observations, followed by an in-depth discussion of my key themes and sub-themes that I identified in my data analysis. In important areas of the findings I have added my interpretation and at the end of the chapter I have included a summary of the key findings of my research. The chapter is completed with a reflective narrative of my findings journey. In addition, I have simplified the following titles throughout the chapter to allow for ease of reading:

1. The palliative cancer care service user has been referred to as service user.
2. The specialist palliative cancer care physiotherapist has been referred to as specialist physiotherapist.
3. The specialist palliative cancer care physiotherapy community service provision has been referred to as the new physiotherapy community service.

4.2 Metamorphosis

My findings indicated that metamorphosis was occurring in palliative cancer care physiotherapy service provision. I have used the metaphor of metamorphosis due to the sudden nature of the change and also the new form that the physiotherapy profession was taking within cancer care services. Physiotherapists were starting to emerge into a different form, like a butterfly emerging from its chrysalis.

This fast pace of change has been instigated by policy makers in response to: demographic changes; population changes; and improvements in cancer treatment. People with cancer were living longer with more complex conditions and side effects of their treatments. Hence, the needs of the palliative cancer care community were changing (DH 2007).

The improvements in cancer treatment and demographic movement were leading to organisational and transformational change within the National Health Service and voluntary sectors, with new developments in service provision, such as the new physiotherapy community service. The development of local innovative services was something that policy makers sought to strive for, stating that an aim was:

“To empower local organisations and professionals to deliver the freedoms to innovate and to drive improvements in services which deliver care of the highest quality for all patients and service users.” (PDC: DH 2011a, p.2)

The new physiotherapy community service at the specialist palliative cancer care unit responded to this challenge and was prompted by the changing needs of the service user, where the side effects of their cancer treatments were impacting upon their lives. The improved treatment regimens for cancer, although enabling service users to live longer, were seen by local practitioners to be having increased side-effects, and generalist physiotherapists were not meeting their needs. Subsequently, service users were being frequently admitted to the wards at the specialist palliative cancer care unit, where specialist physiotherapists were expected to carry out crisis management. The need for new ways of dealing with this problem and preventing these

admissions therefore became evident to the specialist physiotherapists. This was highlighted by policy makers, as a potential issue that needed to be addressed:

“Some patients will be left with ongoing side effects from treatment..... we want to see better recording of the late effects of cancer treatment, improved information for patients and access to specialist services for the late effects of cancer treatment.” (PDC: DH 2011a, p.53)

My findings have therefore provided additional evidence to support good practice principles in the context of a newly developed physiotherapy community service. These have been discussed in more detail later in the chapter. Before discussing these I have highlighted contextual issues from each of my data sets to ‘set the scene’ for the later findings.

4.3 Initial Findings

An overview of my initial findings from each data set have been discussed in this section without the use of quotes to gain a sense of my data analysis as a whole. In the next section, I have followed this with more in-depth discussions around my key themes and sub-themes that I identified in my data analysis, which have supporting evidence in the form of quotations.

Policy Documents

The key messages arising from the policy documents included a number of uncertainties, which have emerged from the metamorphosis of the palliative cancer care landscape. The main uncertainty highlighted within recent policy documents were the concerns around the removal of the cancer network. This organisation was seen as key in the future developments of palliative cancer care services and a major driving force in improvements to practice. A crucial component was the monitoring of treatment outcomes, including the implementation of service changes. This is thought to potentially have an effect upon the future development of total care pathways, as the networks provided an environment for collaboration and development of best practice. Due to the

removal of this opportunity for health care professionals to meet there is now concern over professional communication across organisational boundaries. Another uncertainty was the unease of palliative cancer care health care professionals relating to the instigation of the new clinical commissioning groups and how this might impact upon the future delivery of palliative cancer care.

As well as the metamorphosis within the palliative cancer care organisations, the changing needs of the service user have been highlighted within the policy documents. A more skilled and flexible cancer workforce will be required, where complex communication is essential and the development of guidelines by professional bodies on the level of expertise and support required to manage common cancers a necessity. In addition, health care professionals will need to have the necessary skills, expertise and competencies including knowledge, skills and attitudes related to care of the dying. Through mapping palliative cancer care services, the policy makers aim to identify models of good practice, which can then be used to support workforce and guideline development. This will identify current support and gaps in palliative cancer care service provision. However, there was little discussion of physiotherapy service provision directly, although recent policy documents did mention that extensive physiotherapy is a requirement of cancer rehabilitation. There was also appreciation that as physiotherapy was commissioned locally, funding may not exist or local waiting times maybe lengthy.

It was also highlighted within recent policy documents that service user empowerment should be encouraged through service user involvement and patient-centred care. It was suggested that this should be translated into service user training to boost confidence when representing service users at meetings. Although there was discussion on wellbeing and prevention of cancer there was no mention of the person's quality of life when living with cancer until the acknowledgement of rehabilitation in the context of palliative cancer care in the National Institute of Health and Care Excellence (NICE 2004a) guidance. More recently it was also included as a domain in Improving Outcomes, a Strategy for Cancer (DH 2012a). However, in order for service users to become empowered and be involved in their care they will need to have an

understanding of professional roles and rehabilitation in the context of palliative cancer care.

Service User Interviews

Service users were confused regarding who the different professions were within the palliative cancer care rehabilitation team, thus demonstrating a lack of awareness of the role of the specialist physiotherapist. Service users therefore did not have any expectation of the new physiotherapy community service when they were first referred to the specialist palliative cancer care unit and often stated that they didn't think physiotherapy could help them. Prior to the specialist physiotherapy input, service users described feeling restricted and bereaved. Restrictions were due to issues such as fatigue, dyspnoea, loss of confidence, lack of strength, pain, anger, frustration and resentment. Bereavement was described as loss of self, abilities, control, and changes in loved ones' relationships and future plans.

Once the service users had received specialist physiotherapy within the multi-disciplinary rehabilitation team they described feeling more supported, enabled, connected and satisfied. They expressed that they felt empowered to take up new activities and to become more positive in their outlook leading to a sense of acceptance. They described an improved quality of life, where they felt that they were living rather than just surviving and were more likely to have come to terms with their situation.

Health Care Professional Interviews

The new physiotherapy community service was viewed by the health care professionals interviewed as an evolving service, where recent changes in service delivery had occurred to meet the policy maker's requirement of working closely together to ensure continuity of care and responding to the needs of the service user. The new service delivery was a community based specialist palliative cancer care service providing prompt and timely physiotherapy input to service users. A number of service issues were highlighted by all of the health care professionals interviewed including: constraints to the development

of the new physiotherapy community service due to physiotherapy staffing hours, tensions between expectations of specialist physiotherapy input on the wards at the specialist palliative cancer care unit, versus palliative cancer care physiotherapy input in the community setting.

Specialist physiotherapists were seen by the health care professionals interviewed as having a key role within the multi-disciplinary palliative cancer care rehabilitation team. The three specialist physiotherapists interviewed described their role in detail and this has been documented under my key themes. Sharing of information was seen by the specialist physiotherapists as a central and important component of this role. It was perceived that the most difficult part of this role was facing death and dying and being aware of their own mortality. There were many adaptations, which were needed and reported by the specialist physiotherapists, assumptions were challenged, different mindset noted, flexibility, adaptability, peer support and complex communication applied, as well as adjusting and revising knowledge and expertise to meet the service user's needs.

Physiotherapy input was described by the specialist physiotherapists and other health care professionals interviewed as beneficial, supporting the quality of life of the service user through enabling acceptance, generating feelings of wellbeing and fostering service users hope through realistic goal setting. In contrast to this, prior to having specialist physiotherapy in the community setting, service users were seen by all the palliative cancer care health care professionals interviewed as vulnerable, at risk of falls leading to emergency admissions where crisis management was instigated, rather than being able to provide responsive management.

Observations

Specialist physiotherapists were observed to have a strong patient / therapist relationship where problem solving was a key component to symptom management. There was also ongoing involvement of the service user's carer or relative. Communication was a strong influencing factor that threaded its way through these elements and culminated in reinforcement of the assessment

and treatment plan, so that it appeared to be clear to the service user and their families / carers. During this process it was observed that the specialist physiotherapist had to adjust to a variety of environmental and emotional factors as part of their role, with humorous banter often used by the service user to communicate sensitive information. This was all delivered in a professional manner, making sure consent and confidentiality were adhered to. A number of service users' showed their sadness, discomfort, stress, anxiety and frustration, through both verbal and non-verbal communication. The specialist physiotherapists were observed to connect and react to these expressed emotions in differing ways during the assessment and treatment process. Some of these situations were challenging to the specialist physiotherapists and required complex communication to reach a positive outcome. This was often achieved through valuing and acknowledging the service user's emotions allowing them ownership of the situation and therefore the ability to take control. Humour and reminiscence in relation to the service user's condition and past life was also observed as meaningful and played a role in the service users' rehabilitation. This was perceived to enhance quality of life and to be a useful tool in supporting some of the service users' expressed emotion described earlier.

4.4 Key Themes and Sub-Themes

Having discussed the contextual issues from each of my four data sets (interviews of service users and health care professionals, observations and policy document collection) and provided an overview of my initial findings. I have discussed in-depth below the key themes and sub-themes that I identified from the thematic analysis of my four data sets. Each key theme and sub-theme has been supported by quotes. A coding pattern has been used for the policy document collection and has been referred to as PDC. Pseudonyms have been used for the semi-structured interviews for health care professionals and service users, as well as observations for service users and physiotherapists. I have started with an overview – metamorphosis of cancer treatments nationally.

4.5 Metamorphosis of Cancer Treatments Nationally

Due to new cancer treatments becoming available nationally, analysis of my policy documents revealed that there has been a metamorphosis within the palliative cancer care community where people with a diagnosis of cancer are living longer. There is therefore a requirement by health care professionals to respond to the long term needs of people living with cancer and the side effects of treatment:

“With more people surviving cancer there is now a greater recognition of the need for rehabilitation to deal with the late effects of treatment or the physical effects of the disease itself.” (PDC, DH 2011a, p.52)

This brings with it a number of issues for physiotherapists, such as the necessity to have the competencies and knowledge to address the long term side effects of cancer treatments and how to manage the service user's needs, which can change on a daily basis. For the service users this means coming to terms with their diagnosis / prognosis, learning how to live with their condition and knowing how to manage their symptoms effectively, all of which can be supported through rehabilitation, however:

“Some patients are not getting access to rehabilitation services, either because their needs are unrecognized by front-line staff or because of a lack of allied health professionals who are adequately trained in the care of patients with cancer.” (PDC, NICE 2004a, p. 12)

In addition to this, the metamorphosis of rehabilitation within cancer care has not yet been fully established within palliative cancer care:

“Rehabilitative approaches are just beginning to evolve for other groups, such as people whose disease is progressively deteriorating.” (PDC, NICE 2004a, p.135)

Therefore, the metamorphosis of cancer treatments nationally is having a major impact upon service delivery, where:

“Survivorship and palliative care were not felt to be as embedded in the whole pathway as they might be.....patients could easily become bewildered, frustrated and sometimes receive inadequate treatment and support.” (PDC, Beer and James 2012, p.26)

These issues were identified in my case study, which I have explored in detail in my key themes: metamorphosis of physiotherapy service provision (4.6) and metamorphosis of the physiotherapy profession (4.7, p126).

4.6 Metamorphosis of Physiotherapy Service Provision

Historically palliative cancer care physiotherapy service provision has developed and grown as a speciality within the hospice environment. Its movement within the hospital environment however, has been viewed by therapy managers as an anomaly because it has sat outside the core specialist areas and was consequently an unknown entity. It hasn't been recognised as a speciality in its own right within the hospital setting and therefore not one of the core areas of physiotherapy, such as orthopaedics; cardiovascular or respiratory. This has meant that specialist palliative cancer care physiotherapy service provision has been under the umbrella of other physiotherapy services, such as care of the elderly or neurology. This was an issue reflected upon by one of the specialist physiotherapists:

“Palliative care always tags onto another area um it was part of the elderly team where I worked before and before that it was tagged onto neuro.” (HCP interview: PT: Emily)

This has meant that there has been a lack of specialist physiotherapists within the hospital setting and consequently the community setting. Service users in the local community to the specialist palliative cancer care unit were previously referred to the generalist community physiotherapy service from the local hospital. This was not ideal as generalist physiotherapists would prioritise their work load to other service user groups who they felt required their services sooner than the palliative cancer care service user group, therefore not meeting the latter group's needs. This is perhaps why the generalist physiotherapy service was described as unsatisfactory by one clinical nurse specialist who stated that the generalist physiotherapists:

“Just sent a letter to patients who were virtually moribund, saying that there was a ten week wait, so I would ring up and say that they would be dead by then! It causes a lot of unnecessary distress.” (HCP interview: SRN: Jackie)

The generalist physiotherapy community service was therefore not meeting the rapidly changing needs of the service users in the community around the specialist palliative cancer care unit. The generalist physiotherapists' lack of knowledge in treating service users also meant that service users were not receiving optimum treatments:

“Although they (generalist physiotherapists) are very good they don't tend to work that brilliantly with palliative patients who are getting worse all the time.” (HCP interview: SRN: Jackie)

Response time from the generalist physiotherapists' community service to assess the palliative cancer care service user group was also poor. This meant that the palliative cancer care service users rapidly changing needs were not being met and crisis management would be undertaken by the specialist physiotherapists on the wards at the specialist palliative cancer care unit. This was not sustainable and so the specialist physiotherapists responded by moving their service out of the specialist palliative cancer care unit into the community, treating the service users in their own homes. From the clinical nurse specialist's perspective this new physiotherapy community service seemed to be able to meet the needs of the service users:

“Our team (specialist palliative cancer care physiotherapists) are aware that our patients just go downhill so rapidlyreferrals have to be next day.” (HCP interview: SRN: Jackie)

Through the new physiotherapy community service, rehabilitation seemed to promote quality of life in people with advanced cancer coming to the end of their lives by improving their strength, dyspnoea, fatigue and pain. Consequently, this increased their mobility, preventing falls and unnecessary admissions to the specialist palliative cancer care unit, which enabled the service users to remain within their own homes for longer:

“Some people do improve for quite some time, like this guy ... he has had a period over the last six months where they (specialist physiotherapists) worked with him a lothe has been going around the garden, he’s been into the village, he’s done all sorts of things so, that’s on the back of him having great confidence in him having physio.” (HPC interview: SRN: Jackie)

However, transferring the specialist physiotherapy service provision away from the wards into the community setting highlighted a number of issues:

- a) Lack of outcome measures needed to evaluate this transition.
- b) Overall sense of vulnerability by the specialist physiotherapists and senior therapy assistants in proving their worth in the new physiotherapy community service, as well as obtaining funding and future commissioning.
- c) Confusion from the ward staff at the specialist palliative cancer care unit regarding the new physiotherapy community service.
- d) Confusion from the service users regarding the role of the specialist physiotherapists.

These issues have been explored under my sub-themes:

4.6.1 Outcome measures and commissioning: vulnerability (a and b).

4.6.2 Service users and health care professional’s confusion (c and d).

4.6.1 Outcome Measures and Commissioning: Vulnerability

There was a lack of outcome measures to evaluate the transition of the specialist physiotherapy service provision from the wards at the specialist palliative cancer care unit into the community setting. This has meant that the specialist physiotherapists have been unable to evaluate the effectiveness of their new service provision. Policy makers have stated that outcome measures are the cornerstone of service development and evaluation, especially where radical change in service delivery has occurred:

“It is vital to monitor outcomes of treatment and the implementation of changes in services.” (PDC, DH 1995, p.23)

Cancer Networks were therefore set up to help drive forward improvements in cancer care practice, including the development and implementation of outcome measures:

“The networks were perceived to have a real role in developing outcome measures.” (PDC, Beer and James 2012, p.24)

However, the application of outcome measures in specialist palliative cancer care physiotherapy service provision has been historically difficult due to the nature of the service users’ deteriorating condition. This was confirmed by two of the specialist physiotherapists:

“Outcome measures are very difficult.” (HCP interview: PT: Rachel) and “we don’t actually take an outcome measure to know what they (service users) were doing before (specialist physiotherapy)” (HCP interview: PT: Emily)

The Cancer Networks were starting to address this issue prior to disbanding at a crucial time within the metamorphosis of the physiotherapy service provision. They were aiming to standardise the outcome measures used in palliative cancer care through collaboration with health care professionals locally and nationally. This was something that the specialist physiotherapists felt would be extremely beneficial in demonstrating the effectiveness of their new physiotherapy community service:

“If you could have something standardised and nationally recognised, so that you could really use it to prove the need of the service.” (HCP interview: PT: Emily)

The policy makers have documented that this struggle with the use of outcome measures is not confined solely to physiotherapists working in palliative cancer care, but in cancer care provision as a whole:

“Patient friendly outcome measures are thought not to be in place, so it is difficult for patients to assess the performance of their clinical team. This view was frequently expressed with

regard to commissioning and seems to be an issue that must be addressed urgently.” (PDC, Beer and James 2012, p.27)

Due to the organic nature of the metamorphosis within palliative cancer care the most recent phase of change has been the disbanding of the Cancer Networks and at the same time the emergence of the clinical commissioning groups. This has brought with it uncertainty regarding the effects of change on future palliative cancer care service provision, including physiotherapy. It appears that outcome measures have not been dealt with adequately within the new physiotherapy community service, leaving a major gap in best practice recommendations. This will be problematic and possibly detrimental to this new palliative cancer care physiotherapy community service provision, as outcome measures will be required for obtaining future commissioning of the service. Unless the physiotherapy service can demonstrate its worth whilst enabling other healthcare professionals to become aware of this, then the new physiotherapy community service may not be commissioned, as the need for physiotherapy in palliative cancer care highlighted by the policy makers will not be sufficient. This vulnerability was reflected by one of the senior therapy assistants:

“We don’t know (pause) what funding issues there will be, they (funding body) can understand, see how well we are doing and I think that they would do their utmost to keep our positions open.”(HCP interview: STA: Joan)

This concern over funding resonated in the policy documents:

“The cancer centre, whilst knowing of the imperative (need for funding), cannot influence local providers or GPs and does not hold the purse strings.” (PDC, Beer and James 2012, p.26)

The fragility of this metamorphosis of physiotherapy service provision was beginning to be felt by the specialist physiotherapists and senior therapy assistants:

“Going from a permanent contract to a temporary contract was quite a big undertaking” (HCP interview: STA: Joan)

Although outcome measures haven't been used by the specialist physiotherapists to evaluate their new physiotherapy community service, there has been an audit demonstrating the key changes in the transition of the service from the specialist palliative cancer care unit to the community setting:

"We've done an auditat the beginning sometimes it would take three or four weeks from a referral for us to get out now we are doing it within days, 24 hours." (HCP interview: STA: Joan)

This suggests that the metamorphosis of the physiotherapy service provision was being consistently responsive to the rapidly changing needs of the service users in the local community, as recommended by the policy makers for people:

"With advanced cancer on a 24 hour, seven days a week basis and that equipment can be provided without undue delay." (PDC, NICE 2004a, p.10)

In addition to the audit the specialist physiotherapists had a data base of activities, which provided a record of the need for the new physiotherapy community service. Concerns around funding were also reducing as collaboration through the Gold Standards Framework (Walshe et al 2008), promoting high quality end of life care through the seven 'C's (communication, co-ordination, control of symptoms, continuity, continued learning, carer support and care in the dying phase) (Amass, 2006) provided some insight for General Practitioners (GP's) (key players in the clinical commissioning groups) of the value of the new physiotherapy community service:

"We do have Gold Standards Framework meetings with GPs and district nurses." (HCP interview: SRN: Jackie)

The Gold Standards Framework, implemented at the specialist palliative cancer care unit as part of the metamorphosis of the specialist physiotherapy service, brings the best advances made in hospice care out into the community setting. This was in response to the need to prevent out-of-hours crises in the community, as well as providing a forum for health care professional collaboration and sharing of ideas. The need to work more collaboratively to prevent such crises has led to more cohesive rehabilitation team working in the

community setting. However, I identified in two of my data sets (interviews of service users and healthcare professionals) confusion around the role of the specialist physiotherapist from the service users' perspective, as well as confusion relating to the role of the new physiotherapy community service from the perspective of the health care professionals working on the wards of the cancer care unit.

4.6.2 Service User and Health Care Professional Confusion

It was apparent from the service user's interviews that service users were unaware on referral to the specialist palliative cancer care unit that they may require physiotherapy, or that it would be of benefit to them in the palliative cancer care setting:

*"I had no idea at that stage that I needed physiotherapy at all."
(SU interview: Mary)*

This lack of awareness by the service users of the availability and need for physiotherapy in the palliative cancer care setting was echoed by the acting clinical lead:

"I think sometimes they (service users) get quite surprised that physios are even around in this sort of setting." (HCP interview: ACL: Lauren)

It was perceived however by the specialist physiotherapists that once they had met the service users and carried out a thorough assessment explaining their role, that it was much clearer to them:

"Once we have explained our role they (service users) do have an understanding of what we can maybe bring for them. It could be a number of different things just to improve their sort of wellbeing and their mindset really" (HCP interview: PT: Emily)

The specialist physiotherapy assessment, which covered an interview, objective and system-based information gathering, was described by the specialist physiotherapists interviewed as key to recognising service user's needs. This was confirmed by one palliative cancer care service user:

“Well until, let’s put it like this I didn’t know what my needs werethe physiotherapist made me aware of my needs in terms of what she talked to me about, the exercises, the positions.” (SU interview: Henry)

This then appeared to determine the role of the new physiotherapy community service:

“In that first structured assessment that gives you an idea into what maybe your role is with that patientYou act in whatever role you feel appropriate for that patient sometimes being the patient’s advocate, which ever circumstance that might be in terms of liaising with the MDT or the family, or however they want you involved really.” (HCP interview: PT: Rachel)

From my interpretation patient advocacy was seen by the specialist physiotherapists as an important part of ethically sound professionalism. The specialist physiotherapists therefore felt ethically obliged to take action following their assessment of the service users’ needs. Advocacy in this instance implied recognising when service users required referrals to other members of the palliative cancer care rehabilitation team in order to optimise their quality of life. The role of identifying the service user’s needs through the specialist physiotherapy assessment was perhaps key to the specialisation of palliative cancer care physiotherapists. This then enabled the physiotherapist to treat the service users effectively alongside successful team working to provide the best possible rehabilitation outcome. The clinical nurse specialist saw this as a beneficial addition to nursing skills:

“Physios bring something different to it (palliative cancer care rehabilitation) (pause) so it is an add-on to the nursing skills really.” (HCP interview: SRN: Jackie)

Nevertheless, there was a lack of understanding of the role of the new physiotherapy community service from the ward staff at the specialist palliative cancer care unit. This lack of understanding was probably due to the fact that prior to the metamorphosis of the physiotherapy service provision, the specialist physiotherapists were spending the majority of their time on the wards. This was due to the crises management required when the service users were being

referred to the generalist physiotherapists. However, with the metamorphosis of the physiotherapy service provision the specialist physiotherapists were spending the majority of their time in the community setting, treating service users in their own homes. This responsive management rather than crisis management has meant that the specialist physiotherapists' presence on the wards had reduced considerably:

"Sometimes the consultants and nurses of the in-patients are annoyed about the time it takes for the therapy teams to get around to seeing the patients because they are too busy seeing the community patients." (HCP interview: SRN: Jackie)

This lack of awareness regarding the role of the new physiotherapy community service triggered the need for team reflection. One of the senior palliative cancer care therapy assistants described how the specialist physiotherapists addressed this issue:

"Our first team reflection was all about what our team did and what was involved and how we are hoping to evolve the team. We felt that they (ward staff) didn't really know where our role was" (HCP interview: STA: Joan)

This led to the introduction of a link person between the ward and the community to help explain the role of the new physiotherapy community service:

"I think I've been able to hopefully help the ward staff understand our roles as a therapy team." (HCP interview: STA: Joan)

However, it was perceived by one of the specialist physiotherapists that the full role of the new physiotherapy community service was not clear amongst the palliative cancer care health care professionals as a whole:

"Quite often we will get referrals through for one sort of issue... but you go in (service user's home) and there are a lot more things that you could be doing with that person that perhaps isn't recognised, so I think the general sort of education for the rest of the team across both the ward and the community" (HCP interview: PT: Emily)

Thus, with the current changes in palliative cancer care, the need for the recognition of the role of the specialist physiotherapist is becoming apparent. My findings may provide some insight into this, where I identified from two of my data sets (interviews of health care professionals and observations) the metamorphosis of the physiotherapy profession within palliative cancer care.

In this section the metamorphosis of the physiotherapy service has been identified, moving from crisis management to responsive management, within a community setting. The next section has discussed how this has impacted upon the physiotherapy profession.

4.7 Metamorphosis of the Physiotherapy Profession

The metamorphosis of the physiotherapy profession has occurred due to the very nature of palliative cancer care within which there are a wide range of ethical issues that need to be considered on a regular basis. The National Council for Palliative Care (NCPC) believes that the values of all those involved (practitioners, service users and family members) should shape the ethical framework of service provision (NCPC 2014). Within the new physiotherapy community service this involved complex communication with the palliative cancer care multi-disciplinary team at the Gold Standards Framework meetings. Each individual service user's case was then discussed on its own merit and decisions were made by balancing duties, rights and ethical principles. Through this system the specialist physiotherapists have adjusted their individual treatment plans accordingly to meet the service user's needs:

“You’re looking at what treatment you should give and thinking whether ethically you should be giving or offering that treatment.” (HCP interview: PT: Rachel)

This included knowledge and skills relating to service users' treatments, such as chemotherapy and radiotherapy, which impacted upon the specialist physiotherapy treatment planning:

“it is not only the disease that they are going through but it’s quite often the treatments they are having as well which can limit therapy.” (HCP interview: PT: Emily)

In addition to this the specialist physiotherapists were required to:

“Have the necessary knowledge, skills and attitudes related to care for the dying.” (PDC, DH 2008a, p.12)

However, policy makers have stated that there is a requirement for a more skilled and flexible cancer workforce within palliative cancer care to ensure that the service user’s needs are being met:

“The NHS will need a skilled and flexible workforce.....if it is to meet the cancer challenges of the future.” (PDC, DH 2007, p.124)

The specialist physiotherapists working in palliative cancer care have therefore had to transform their thinking, skills and knowledge to meet the needs of the service user. This has occurred by metamorphosing from a bio-medical model of health care (Engel 1977; Wade and Halligan 2004), to a bio-psycho-socio-cultural-spiritual model of health care (Puchalski et al. 2009; Periyakoil 2014) to align with the hospice ethos. Here, the primary focus of health care has moved away from symptom control to a rehabilitative approach involving an integrated multi-disciplinary team. This extends beyond the service user to include the family, community and the spiritual and cultural aspects of health care. Effective communication, including comprehension of both psychosocial as well as biological aspects of health care delivered in an ethical manner is essential to this model of health care.

Through this metamorphosis of health care delivery, team working and the Gold Standards Framework meetings, the specialist physiotherapists in my case study have been able to develop their skills and knowledge in palliative cancer care. However, this has brought with it a number of issues, the need to:

- a) Develop a different mindset to treatment planning.
- b) Integration of professional boundaries.
- c) Develop specialist palliative cancer care skills and knowledge.
- d) Emotionally adjust to caring for people who are dying.
- e) Find ways of dealing with difficult situations.

These issues have been explored under the sub-themes:

4.7.1 Shift in mindset and treatment planning (a).

4.7.2 Integration of professional boundaries and skill development (b and c).

4.7.3 Emotional adjustment (d and e).

4.7.1 Shift in Mindset and Treatment Planning

A shift in mindset was identified in the specialist physiotherapist's treatment planning as well as the service user's reaction to the treatment they were receiving, where the patient / therapist relationship had a strong influence on each other.

It was perceived by all the health care professionals interviewed that physiotherapists working in palliative cancer care were different to physiotherapists working in other areas of health care. It was felt that physiotherapists went through a shift in mindset to overcome certain challenges and assumptions in order to meet the needs of the service user:

"They just have a completely different mindset to other physios they have had to go through this mental process where they go backwards with the patients instead of forwards and that's a huge switch I think for physiotherapists." (HCP interview: SRN: Jackie)

From my interpretation describing 'going backwards' suggested that historically the physiotherapists role is perceived to provide treatments and goals to promote physical health through rehabilitation that leads to recovery or maintenance. In contrast, in palliative cancer care the physiotherapists role is to provide treatments and goals that reduce physical and emotional issues through adapting rehabilitation in parallel to the deterioration of the person's condition until discharge or death. This may include maintenance, as well as windows of opportunity where physical progress can be made. The specialist physiotherapists interviewed supported this view and described their shift in mindset in terms of how they worked with the service user:

“Probably the big difference in palliative care is that it doesn’t really lend itself as well to a medical model there are much more sort of emotional details, ethical, spiritual, um, just emotional support issues coming in.” (HCP interview: PT: Rachel)

This switch in mindset from the primary focus of physical aspects of health care to the psychosocial and spiritual aspects of health care has occurred through the bio-psycho-socio-cultural-spiritual model of health care (Puchalski et al, 2009; Periyakoil, 2014) within the palliative care setting. This then transferred to the delivery of palliative cancer care rehabilitation where the specialist physiotherapist carried out shared decision making in their treatment planning, as encouraged by the policy makers:

“Patients, families and other carers should play the central role in making decisions about the care they receive.... therefore underpin good supportive and palliative care.” (PDC, NICE 2004a, p.21)

This inclusion of service users and families in the shared decision making and goal planning was confirmed by one of the specialist physiotherapists:

“We try and work with the patient and work with the family while trying to achieve what they want to achieve realistically.” (HCP interview: PT: Emily)

This switch in mindset in treatment planning and goal setting enabled service users to become more involved in their rehabilitation, as described by one of the service users:

“She (physiotherapist) certainly makes you feel part of the decision making process.” (SU interview: Henry)

The specialist physiotherapists listened to the carer’s views, as well as those of the service users. This allowed the specialist physiotherapists to gain further insight into the service user’s life and how the carer and service users were managing. In so doing, they were able to pick up on the carers’ emotional and physical needs as well as the service users, acting upon them in an appropriate manner:

“PT is now considering the treatment plan in relation to the participant’s and son’s goals.” (PT and SU observation: Hannah and Ruby)

The specialist physiotherapists were therefore supporting the carer as well as the service user in the shared decision making. This was perceived by one of the physiotherapists as providing a sense of hope, not only to the service user but also to the carer:

“It might not just be them (service users), it might be the carers or family have felt more support throughout the treatment and know that they can do something for that person to give them a bit more hope in a way that they are going to get through that next day. They (carers) like to know they (service users) are achieving their goals, not just for the patient, but for themselves as well to know that they are improving them.” (HCP interview: PT: Emily)

This sense of hope was also noted by the clinical nurse specialist in relation to goal setting:

“They (specialist physiotherapists) do give hope to the patient, but they give them (pause) achievable goals. They (specialist physiotherapists) are very positive with the patients and very realistic.” (HCP interview: SRN: Jackie)

From my interpretation hope in this context suggested that the service users felt that receiving specialist physiotherapy would enable them to achieve physical activities, which they had been struggling with, such as walking short distances and / or managing their dyspnoea through breathing techniques. By picking up key emotional and physical issues through the physiotherapy assessment, the specialist physiotherapists were then able to consider the service user’s expectations. This provided a platform for the service user’s rehabilitation where it was possible to bridge the gap between the service users, carers and specialist physiotherapist’s goals, so that a compromise could be made:

“I think his quality of life was quite poor when he came to see me, he could walk a few steps but he clearly wanted to be doing all the things he was doing before. The gap between what he

*wanted to achieve and what he could achieve was massive.”
(HCP interview: SRN: Hannah)*

The specialist physiotherapists have therefore learnt through a shift in mindset to adapt their goal setting to meet the needs of the service users:

*“We always adapt our goals to what the patient wants, no matter what level of impairment we find. We will always adapt our goals to what the patient’s potential, personal goals are I think that is where the flexibility and the adaptability comes in.”
(HCP interview: PT: Rachel)*

In order for this to be successful the specialist physiotherapists needed to be one step ahead of the service user’s deteriorating condition. This required a shift in mindset from a focus on progressive physical aspects of goal setting to a focus on quality of life aspects of goal setting:

*“You’re not focusing on progressive goals in terms of what we want to achieve We’re looking at qualitative things rather than quantitative... we are modifying our goals in that way.”
(HCP interview: PT: Rachel)*

In addition to this the clinical nurse specialist described a shift in mindset from a focus on health promotion to a focus on positive thinking, promoting service users’ feelings of well-being:

“All physios are very good at making you feel good about yourself and promoting health and getting better and all those things but there is a subtle switch isn’t there? They (specialist physiotherapists) still manage to make people feel great about themselves, even though they are getting worse (smile).” (HCP interview: SRN: Jackie)

The specialist physiotherapists’ ability to improve the service users’ sense of bodily health and control even though they were deteriorating was seen to be key to palliative cancer care rehabilitation:

“We can see a change in their motivation.....you can see their mood lifting.” (HCP interview: PT: Emily)

This shift in the service users' mood was perceived by the clinical nurse specialist to be occurring through the specialist physiotherapists' goal setting and treatment planning:

"It's (specialist physiotherapy) very beneficial, it helps the patients physically and very much mentally really, you know it is kind of, they (specialist physiotherapists) are very good on a psychological level." (HCP interview: SRN: Jackie)

Working with psychological issues was confirmed by one of the specialist physiotherapists as a core part of palliative cancer care rehabilitation, where emotional issues were addressed prior to physical issues:

"I think it has got a lot to do with their (service users) mindset and the way they feel yes physically we can improve people but it's not necessarily its more sort of managing the level they are at, at the moment and I think they can benefit from that advice to improve them physically. But then also their mood will improve them physically as well. So I think a lot of it is how they're feeling and thinking about things." (HCP interview: PT: Emily)

Some of the psychological issues that the specialist physiotherapists were required to address prior to the physical assessment were described by one of the senior therapy assistants:

"There's fear, there's worry, there's upset, there's depression. All those very highly charged, emotional things going on with somebody, as well as all the physical problems." (HCP interview: STA: Lizzy)

Therefore, during the interview assessment the specialist physiotherapist would explore the service user's emotional and spiritual needs. The patient / therapist relationship offered the opportunity to discuss the service user's values and beliefs, which helped to gain insight into spiritual needs. This included considering how the service user's emotional and spiritual thoughts might be impacting upon the perception of their condition and symptoms:

"The physiotherapist now uses the information regarding the spirituality and the discussion around the palliative care team to

offer the participant a referral to members of the team that could help with his emotional journey.” (PT and SU observation: Rachel and Gary)

Through integrated rehabilitation team working this information was then documented by the specialist physiotherapist and provided to the service user's key worker, as well as being disseminated at the Gold Standards Framework meeting. The initial specialist physiotherapy assessment therefore provided the specialist physiotherapists with spiritual, emotional, and physical information required to adapt and tailor their treatment plan to individual service users:

“We approach every case from that initial assessment you need to modify that sometimes when you treat each patient. Some patients will not tolerate the full assessment some patients you can get a very in-depth picture.” (HCP interview: PT: Rachel)

The psychological aspect of the specialist physiotherapy interview assessment was observed as crucial in terms of progressing physiotherapy treatment and improving the service user's overall emotional and functional well-being. During the treatment session it was further observed that the specialist physiotherapists encouraged the service user to lead rather than the physiotherapist, which is a huge switch in mindset. This transfer of power promoted self-management and ownership of the service user's rehabilitation:

“Interesting to see patient choice and also reaffirming the positive patient / therapist relationship. The physiotherapist also acknowledged this and encourages the participant to take the lead in his treatment.” (PT and SU observation: Hannah and Henry)

Service users were therefore observed to take ownership of their rehabilitation through shared decision making. This way the service users were able to guide their treatment to a place of their choosing. The specialist physiotherapists were observed to adapt the service user's rehabilitation to follow this through, giving back a sense of control to the service user:

“Participant is obviously keen to be outside for his activities as he is guiding his discussion towards this.” (PT and SU observation: Rachel and Gary)

The service users also voiced self-management and ownership of their rehabilitation by giving themselves reminders of their treatment plan:

“I’ve written it on my calendar.....I’ve put if you feel good, pace yourself.” (SU interview: John) and ‘It’s something that you’ve got to try for yourself.” (SU interview: Mary)

This confirmed the policy makers comment that:

“Patients can also play a central role in their own rehabilitation, and many take an active role through self-management.” (PDC, NICE 2004a, p.135)

However, even though shared decision making, self-management, ownership and a strong patient / therapist relationship has enabled the specialist physiotherapists to adapt the service user’s goals and treatment planning to meet their needs, this has involved integrated team working, drawing upon the diverse skills available within the palliative cancer care rehabilitation team to be able to provide the best outcome for the service user:

“The PT is trying to explore this further so that she can clinically reason how to help and who she could refer this participant to, to help him with these emotions.” (PT and SU observation: Hannah and Henry)

The specialist physiotherapist therefore made robust connections with the palliative cancer care rehabilitation team to meet the needs of the service user:

“It’s just working with the patients and working with the rest of the team to be able to control them (emotional and physical issues) as much as you can really and getting the timing right (pause) which is not always easy (smile).” (HCP interview: PT: Emily)

This cohesive rehabilitation team working within the bio-psycho-socio-cultural-spiritual model of health care (Puchalski et al. 2009; Periyakoil 2014) has led to an integration of professional boundaries and physiotherapy skill development.

4.7.2 Integration of Professional Boundaries and Physiotherapy Skill Development

Integration of professional boundaries and skill development was identified in three of my data sets (service user and health care professional's interviews and observations). This was described in terms of palliative cancer care rehabilitation team working, where the transfer of basic physiotherapeutic skills to other members of the team was seen to be important:

“Making sure that you’ve got good handover therapy wise of moving and handling.” (HCP interview: PT: Rachel)

Other skills discussed by the specialist physiotherapists as potential for crossover or integration of professional boundaries within the palliative cancer care rehabilitation team included:

“Pain management, exercise prescription, exercise delivery, positioning, provision of walking aids, and those sort of basic things that could be done at weekends, all things that potentially we could be looking to advise and educate a bit on, so certainly a patient shouldn’t be sort of left in bed from a Friday to a Monday.” (HCP interview: PT: Rachel)

The main integration of professional boundaries described occurred between the specialist physiotherapists and the specialist palliative cancer care occupational therapists. This was reflected in the level three technicians who were therapy assistants rather than being assigned to palliative cancer care occupational therapy or palliative cancer care physiotherapy. One of the specialist physiotherapists described this integration of boundaries:

“You know if a member of our teams been off in terms of OT the physio has responded. There definitely is a blurring of boundaries. I suppose we do a little bit of everything sometimes” (HCP interview: PT: Rachel).

There was also a close liaison described between the specialist physiotherapists and the palliative cancer care nursing staff. This lent itself well to providing a platform from which to learn from each other and develop and share skills to meet the needs of the service user, re-enforcing integration

of professional boundaries to achieve quality palliative cancer care rehabilitation:

"We do link up with nursing staff. Sometimes we do treatments with them as well. Especially like I said we do work together." (HCP interview: STA: Chloe)

Working in this cohesive manner was seen by the acting clinical lead to be a vital part of palliative cancer care rehabilitation, stating that if the specialist physiotherapists were not part of the rehabilitation team then:

"Quality of life would reduce, patients wouldn't be able to be mobilised as much, we wouldn't be able to learn the techniques that help with breathlessness, etc." (HCP interview: ACL: Lauren)

Other areas described by one of the specialist physiotherapists around cohesive rehabilitation team working and integration of boundaries included the management of lymphoedema:

"I think there has been cross boundaries in the areas of lymphoedema management. I think that is potentially an area that needs to be more of a multi skill mix." (HCP interview: PT: Rachel)

From my interpretation, multi-skill mix in this context was referring to a number of health care professionals working in palliative cancer care and having the skills and knowledge to manage service users' lymphoedema. This skill mix within the palliative cancer care rehabilitation team meant that the service users also described palliative cancer care health care professionals as a team that was not defined by professions. This reinforces the integration of professional boundaries and integrated rehabilitation team working. This seamless palliative cancer care rehabilitation team working was reflected by one of the service users, when he struggled to remember which health care professional had been involved in his care:

"I hadn't really thought about individual bits (referring to the different professions)." (SU interview: Max)

Communication and team working was therefore seen to be central to palliative cancer care rehabilitation. The specialist physiotherapists would make referrals to other members of the palliative cancer care rehabilitation team as appropriate. This then optimised the outcome of rehabilitation and therefore quality of life for the service user:

“Physiotherapist is trying to look at alternative ways to maintain the participant’s quality of life through adaptations and considering other members of the palliative care team who could help.” (PT and SU Observation: Hannah and Stan)

When service users were deemed at risk of falls, the specialist physiotherapists were observed to offer walking aids and exercise prescription, adapting activities of daily living to maintain the service user’s safety within their home environment. This was described by one of the service users:

“When I do my leg exercises, and that’s good, because you need those more than anything and I can do it at home.” (SU interview: Doris)

Referral to the specialist palliative cancer care occupational therapists was also made when specialist equipment was required:

“The PT must have been thinking about the above situation and finds a solution regarding the bathroom handles. With this positive affirmation by the participant the PT goes onto consider further equipment that may be of help. A referral to the OT has been consented.” (PT and SU observation: Hannah and Ruby)

The specialist physiotherapists perceived that their skills and knowledge enabled them to assess psychosocial and physical issues related to cancer pain, dyspnoea and fatigue that might be impacting upon the service user’s quality of life. They then considered treatment techniques that could be used to enhance that person’s quality of life:

“We would be able to identify the areas that are affecting their (service users) quality of life, whether that be breathlessness, pain, function, pacing activity, breathlessness management positioning and breathing.” (HCP interview: PT: Rachel)

This ability to identify areas affecting the service user's quality of life was observed in relation to cancer related pain:

"Pain is a problem for this lady, which the PT picks up on and investigates further." (PT and SU observation: Hannah and Ruby)

One of the service users linked the skills and knowledge of the specialist physiotherapists to goal setting and confirmed the cohesive rehabilitation team working to meet his needs:

"Our goal was clear, to keep one pain free, keep as mobile as possible and as I say communicating any matters that she (specialist physiotherapist) felt other people (MDT) ought to know in a very professional way." (SU interview: Henry)

In addition, dyspnoea was observed to restrict palliative cancer care service users both emotionally and physically, with two of the service users stating that it was the most difficult part of their illness to manage:

"Worse part of the job that I've got" (referring to dyspnoea) (SU interview: Mary) and "Participant mentions breathlessness as being his main gripe" (PT and SU observation: Hannah and Stan)

The specialist physiotherapists confirmed that dyspnoea was both emotionally, as well as physically debilitating, which required specialisation of key physiotherapy cardiovascular respiratory skills:

"I have seen someone recently with breathlessness that was so panicked about breathlessness they didn't move, but they wanted to get around the home.....their panic levels were so high that they almost felt rooted to the spot" (HCP interview: PT: Rachel)

Using a non-pharmacological approach to breathlessness, which has been specifically developed to treat service users, the specialist physiotherapists were able to address panic attacks using distraction techniques such as the calming hand (Appendix 35):

“I would hope to say that the quality of life (pause) improves after contact with us just by doing the calming hand. They can now feel that they’ve got enough self-control over their breathlessness.” (HCP interview: PT: Rachel)

The ability of the palliative cancer care physiotherapists to enable the service users to cope with their dyspnoea was confirmed by the acting clinical lead:

“We have a lot of breathlessness patients so that when people have a panic attack they (specialist physiotherapists) can teach them to handle things like that.” and “Quite a few of our patients need chest physio, ones that are in bed and obviously that’s positively a life-threat, that’s possibly a life-threatening thing if secretions build up.” (HCP interview: ACL: Lauren)

As well as treating the psychosocial and physical disabilities of dyspnoea, the specialist physiotherapists were observed to work with the spiritual, emotional and physical aspects of pain experienced by service users. Prior to treating the physical aspect of pain using the non-pharmacological approach to pain management, the specialist physiotherapists explored the psychological aspects, often using education to help relieve any anxieties that the service user might have been experiencing:

“The PT uses education to explain to the participant why he is experiencing pain.” (PT and SU observation: Rachel and Paul)

In the treatment of physical aspects of pain Transcutaneous Electrical Nerve Stimulation (TENS) was an electrotherapy modality observed to be used by the specialist physiotherapist:

“I went in and gave a lady a TENS machine recently and went through positioning and use of the TENS machine and her (service user) pain level went down for a large amount of time.” (HCP interview: PT: Rachel)

Observations confirmed that the use of TENS to treat cancer related pain was found to be beneficial to both the service user and carer:

“PT discusses TENS machine and participant states that he has it on and points to where the TENS is situated on his body. Partner comments that is great the TENS.” (PT and SU observation: Hannah and Stan)

Another modality observed to be used by the specialist physiotherapists to treat the physical aspects of cancer related pain was ice:

“PT advised on the use of ice. Participant explains that he puts ice on at night time.” (PT and SU observation: Rachel and Gary)

However, it was noted by one of the service users that:

“Physio can control pain to a point.” (SU interview: John)

This confirms the need for a multi-disciplinary skill mix and integration of professional boundaries within the palliative cancer care rehabilitation team to meet the needs of the service user. In addition, it required the specialist physiotherapists to use active listening skills during assessment and /or treatment sessions to pick up on key issues that needed to be addressed. The specialist physiotherapists were often observed to comfort distressed service users as part of their assessment and / or treatment. Humour was observed to be used frequently by the service users and the specialist physiotherapists to cope with these difficult situations. For example, when it became apparent to the service users and or the carers that the service users’ goals would need to be modified to be achieved:

“Humorous banter between all parties seemed to be part of this participants coping strategy.” (PT and SU observation: Hannah and Stan)

Managing complex emotional situations as part of the specialist physiotherapist’s repertoire of skills has meant that they have had to emotionally adjust to working in palliative cancer care.

4.7.3 Emotional Adjustment

A number of emotional adjustments have been made by the specialist physiotherapists in the metamorphosis of the physiotherapy profession. One area of emotional adjustment perceived to be challenging was responding to:

“Some of the difficult questions, the really emotionally draining questions that you have to answer.” (HCP interview: PT: Emily)

These questions often revolved around the service user’s anxieties in relation to death and dying and were seen to occur during the majority of the treatment sessions observed. For example, one service user said:

“I’m not going to lose the battle am I?” (PT and SU observation: Hannah and Stan)

Another episode observed, involved a service user who had seemed preoccupied throughout his treatment session. The specialist physiotherapist picked up on this emotion and explored it as part of his treatment. It came to light that the service user’s neighbour had completed a bike ride to raise money for cancer and had given the service user the number with the service user’s name on it, that his neighbour had worn during the bike ride. Unfortunately, under the number and the service user’s name ‘in memory of’ had been blanked out, but was still readable:

“The participant realised that his neighbour had completed this cycle ride in good faith, but had not been sensitive around the participant’s feelings when he had given him the cycling number.....The realisation of his situation seems to be coming to the surface.” (PT and SU observation: Hannah and Henry)

The specialist physiotherapists reflected upon this emotional adjustment to meet the needs of the service users:

“I think because we’re often doing a lot of one to one work with patients, they will often open up to you in a way that they might not open up to another health care professional necessarily.” (HCP interview: PT: Rachel)

This patient / therapist relationship was therefore seen to be used by the service users as an opportunity to talk about sensitive information. From my interpretation this demonstrated how comfortable service users felt about divulging confidential information to the specialist physiotherapists and indicated that the patient / therapist relationship provided a sense of security. It also meant that through this process the specialist physiotherapists became more aware of their own mortality:

“That clinician/patient relationship is probably the hardest thing. I would say it impacts you both psychologically and emotionally. Especially when there are children involved and again I suppose you are drawing parallels with your own life.” (HCP interview: PT: Rachel)

This meant that specialist physiotherapists had to come to terms with their own emotions in relation to death and dying. A process that involved time and experience to optimise emotional adjustment. One of the senior therapy assistants reflected upon this process and described it as a consciousness enlightenment of the need to make the most of your life:

“You almost feel sort of, not panicky but you sort of think there is so much you want to do that you don’t know what is round the corner and you want to grab every opportunityit’s made me realise that life is such a thin thread.” (HCP interview: STA: Joan)

The clinical nurse specialist perceived that the specialist physiotherapists found emotional adjustment to death and dying one of the most difficult areas of the metamorphosis of the physiotherapy profession:

“It’s actually very hard for physios to work with people who don’t get better.” (HCP interview: SRN: Jackie)

Treating service users of similar age and background was perceived by the specialist physiotherapists and therapy assistants as one of the most difficult areas of emotional adjustment to deal with:

“What I found hard personally is someone sort of closer to my own age with young children who’s obviously not got long to live and that has been very hard (pause) to sort of cope with (pause).” (HCP interview: STA: Chloe)

This personal identification triggered stronger emotional responses that were perceived to be more complex to manage:

“How it really impacts the rest of the family how it impacts them emotionally.....there are always cases that you draw parallels withthat you maybe get more emotionally involved with.” (HCP interview: PT: Rachel)

These emotional adjustments were perceived by one of the specialist physiotherapists as an ongoing process:

“A lot of people say that you learn to adapt you know to working in end of life caresome people are still going to pull on your heart strings.” (HCP interview: PT: Emily)

The specialist physiotherapists were seen to have developed a variety of strategies to manage their emotional adjustment. Experience, networking and teamwork were perceived as helpful in enabling them to work effectively in palliative cancer care rehabilitation:

“I do feel that I’ve got good peer support and, and there’s another physio who had been involved with this particular patient quite closely too. We were able to sort of bounce things off each other quite well.....It is those isolated cases and I think when we get that we do work quite closely as a team.” (HCP interview: PT: Rachel)

An important part of this peer support was the ability to debrief. This process provided the specialist physiotherapist and therapy assistants with a fuller understanding of the situation. It often offered an alternative perspective and was perceived to help with their emotional adjustment. However, due to time constraints this debriefing process was not always possible:

“To talk through things which is really important to be able to talk about how you’re feeling, but it’s difficult sometimes if you see several patients one after the other.” (HCP interview: PT: Emily)

A strong sense of peer support was therefore observed amongst the specialist physiotherapists and senior therapy assistants. They were seen to be creative in managing their emotional adjustment by learning through each other's experiences:

*"Sometimes you can use situations to help other people out or maybe help them to see things from a different perspective."
(HCP interview: STA: Joan)*

The length of time working in palliative cancer care was also perceived to be advantageous in supporting areas of emotional adjustment, including life experience as a whole:

"I think, life experiences has helped me along the way and empathy" (HCP interview: STA: Joan)

However, the emotional adjustment to working in palliative cancer care took time, and the length of time varied between individuals as described by one of the senior therapy assistants:

"(Colleague) kept saying to me you'll get a wall where you think everybody has got cancer everybody is dying. You know (laughs) I think I went through that wall a lot later than they expected me to" (HCP interview: STA: Joan)

This senior therapy assistant also commented that peer support was not always suitable as a coping mechanism and that alternative ways of managing emotional adjustment should be made available:

"Sometimes you don't really want to talk about it to your colleagues, you know because they might think why did she find that upsetting? Or why was she angry about that situation?" (HCP interview: STA: Joan)

This meant that occasionally managing emotional adjustment was sought outside the health care environment, rather than using peer support:

"I think obviously if you are a religious sort of person you can turn to your chaplain." (HCP interview: STA: Joan)

Other ways that the specialist physiotherapists and senior therapy assistants have creatively managed their emotional adjustment was through sharing cases and being aware of each other's needs:

"We've had certain situations where one person is really quite difficult for us to deal with emotionally then the other person will perhaps lead on it or go and see the patient just on their own if it is really quite difficult so we try and help each other like that."
(HCP interview: PT: Emily)

A more official form of peer-support provided by the specialist palliative cancer care unit was also available to the specialist physiotherapists and senior therapy assistants, but time constraints often prevented physiotherapists from attending:

"They do a sort of support session on the unit monthly (pause) um, and again it is sort of at a time inaccessible to me." (HCP interview: PT: Rachel)

The ability of being able to talk about different cases and support each other was seen to be of paramount importance, as it was perceived by one of the specialist physiotherapists that if these opportunities were not available then the physiotherapist or senior therapy assistant would no longer be able to cope with working in palliative cancer care:

"I think it could be something that you can definitely burn out with if you didn't have the chance to be able to talk about it."
(HCP interview: PT: Emily)

The specialist physiotherapists therefore had to emotionally adjust to these diverse situations and come to terms with and accept the dying process. Emotional adjustment to working in palliative cancer care rehabilitation was therefore perceived to be part of the metamorphosis of the physiotherapy profession:

"I certainly don't feel in an emotional turmoil all the time.I have accepted that and I have worked with that for quite a long time." (HCP interview: PT: Rachel)

However, one of the senior therapy assistants perceived emotional adjustment to be the hardest part of working with service users and described a spiritual aspect to this adjustment:

“It is difficult for me to accept that every patient that I see will pass away at some stage.....when I am with a person who passes away I never just think oh, that’s another one, you know I’m not a religious person, but you always pass a little prayer.”
(HCP interview: STA: Joan)

The policy makers acknowledged the challenge of this emotional adjustment and have emphasised the need for the appropriate training and development to manage this area successfully:

“Caring for those approaching the end of life is one of the most important and rewarding areas of care. Although it is challenging and emotionally demanding if staff have the necessary knowledge, skills and attitudes, it can also be immensely satisfying.” (PDC, DH 2008a, p.12)

These skills, knowledge and attitudes have been developed by the specialist physiotherapists through their shift in mindset and treatment planning, integration of professional boundaries and skill development, as well as emotionally adjusting to working in palliative cancer care. This has all occurred through the metamorphosis of the medical model of health care to the bio-psycho-socio-cultural-spiritual model of health care (Puchalski et al 2009; Periyakoil 2014) to meet the needs of the service users. This was confirmed by the service users who commented that physiotherapy had enhanced their quality of life, as they felt they were able to do more and were living rather than just surviving:

“I’ve got a reasonably good quality of life, yeah. I do the things I want more or less....it’s trying to balance it. I’m enjoying myself.” (SU interview: John) and *“I’m doing the best that I can with the help of physiotherapy. The care they (specialist physiotherapists) gave me was the ability they gave me to get up and move around.”* (SU interview: Mary)

In this section I have identified the metamorphosis of the physiotherapy profession within palliative cancer care in response to ethical issues and the

side effects of cancer treatment'. I will now summarise my key findings, before reflecting upon how I as a research tool may have influenced the interpretation of my data to develop themes.

4.8 Summary of Key Findings

Review of policy documents and my own practice have highlighted that there has been a metamorphosis (a sudden and widespread change) within the palliative cancer care community. Many people with a diagnosis of cancer are more likely to be treated and are living longer with a diagnosis of cancer and surviving from cancer.

Physiotherapy provision is needed which supports people to live well with the side effects of the cancer and its treatment. Previously in this setting, physiotherapy services have been left behind and mainly general physiotherapy services were available. Within the case, department physiotherapists had developed specialist skills to work with people living with cancer. These skills were all intertwined and influenced each other, where physical needs were met through exploring the psychological and spiritual needs to develop person-centred goals. However, a large part of the development of the role of physiotherapy was becoming a skilled team member. For example, embracing the bio-psycho-social-cultural-spiritual model of health care (Puchalski et al 2009; Periyakoil 2014), shifting mindsets and sharing decisions. The final key area was developing the ability to recognise and manage their own emotions in light of potentially distressing situations.

Alongside direct patient care in the New NHS, practitioners (not just managers) needed to develop entrepreneurial skills to sell their service. They also needed to be able to provide appropriate evidence / outcome measures to show the need for the involvement of specialist physiotherapists.

Overall, in this study I have been able to highlight the key skill set for physiotherapists enabling them to respond appropriately and as specified by policy documents, when working with people with cancer.

4.9 Reflexive Narrative

Representing my findings was an ethical concern for me as I felt I had a duty to present the service users and healthcare professional's experiences and opinions accurately, reflecting upon the context in which these were generated. This was steeped in my palliative cancer care background of meeting ethical principles and best practice, as well as being true to my profession. However, as I embarked upon interpreting my data to develop themes, I pondered on how I would do this. Used to logical step by step procedures I struggled with the freedom I now had to interpret my data, which felt overwhelming. The complexity of interpreting data from my four data sets added to this:

*"It's like a maze, I go down one way expecting to find the right direction only to find that I am completely lost once again!"
(Diary entry: October 2013)*

Interpretation of my data was not a simple process and involved more than just following the various stages of my data analysis. I found that my mind would continually think and re-think what was being said or observed. This enabled me to immerse myself in the data, explore and be challenged by my supervisors, which eventually enabled creativity and the ability to write thick descriptions (James 2012). This creativity emerged slowly as I collected data and then in the time period following my data collection, where I would often get lost in the minutiae of my data. It was only after I re-emerged from the depths of the data that I was able to view it from a higher level and gain a clearer understanding. Part of this difficulty was my attention to detail and being anxious that I would miss key information and partly because I have high expectations of myself and therefore have a tendency to perfectionism. This has its advantages and its disadvantages. The advantage being that I am thorough and conscientious, the disadvantage being that it was constraining, which is why my creativity was initially curbed. Eventually with my supervisors help, I learnt to develop the ability to pull out key themes and sub-themes

across my data sets to provide the framework for writing up my research findings. This refinement process opened up more creative possibilities (Sennet 2008), where I was then able to 'read beyond the data' and to see what was absent as well as present and explain why (Mason 2002). I have discussed this further in my practice development and discussion chapter. During this process I drew upon my own implicit knowledge as a research tool in order to come to understand my data and present it to the reader, which I have explored in light of the current literature in my discussion chapter.

Reflecting on the interpretation of my data was therefore an activity, which raised my conscious awareness of the process, where assumptions were challenged and my appreciation of the phenomena changed. At times my own knowledge and experience became a barrier to interpretation, where I focused on palliative cancer care rehabilitation rather than looking at the nuances embedded within the interview responses, policy documents and observations. What had become part of my own metamorphosis into a specialist physiotherapist initially hindered my interpretation of my data as it seemed obvious and apparent to me, rather than new and evolving. It was only after reflecting back to a generalist physiotherapist that I was able to lift this veil and use my knowledge and experience to interpret these nuances, so that the role and metamorphosis of the specialist physiotherapist could be understood more fully:

"Finally I can see the light! Now I can start to describe what was intuitive. I can see the areas where physiotherapy has metamorphosed in this specialist area and start to unpick and make sense of it." (Diary entry: August, 2014)

What was an unexpected revelation in the metamorphosis of the physiotherapy profession were the responses by the specialist physiotherapists in relation to the interview question:

"What is the most difficult part of service users' illness that you have had to cope with? Describe which area of the service user's illness is the most difficult for you to manage." (HCP interview topic guide: Appendix 9)

I assumed the specialist physiotherapists would respond with something like managing pain or dyspnoea, rather than coping with death and dying. However, I could relate to the specialist physiotherapists metamorphosis in this area, as I had been through a similar process, which would ultimately influence my decision making and interpretation of this phenomena. However, this concept played on my mind and challenged my values, beliefs and assumptions. Was I still focused on the physiological pathology to describe illness and the effectiveness of treatment rather than the subjective dimension of illness?

“Was I defining illness in a different way to the specialist physiotherapists? Could I be seeing death and dying as the natural course of life rather than a ‘symptom’ of illness.” (Diary entry: July 2012)

I concluded this challenge of ideas by reflecting upon one of the goals of palliative rehabilitation, which is to reduce suffering, but it is not the only goal and perfect achievement, for example a full recovery is not expected. Death is delayed, but not indefinitely. Therefore, palliative rehabilitation aims to support and enable a good life and a good death (DH 2008a) and both the specialist physiotherapists and service users have had to come to terms with this in order to obtain the best outcome / relationship forming a different picture of their traditional assumptions about the professional role of the physiotherapist. This understanding eventually made sense of the specialist physiotherapist’s response to my interview topic guide question and an important element in their metamorphosis.

Comparing across my four data sets, outcome measures were seen as an important link in the metamorphosis of the new physiotherapy community service and future commissioning. The fact that the specialist physiotherapists were not using any outcome measures to measure their impact upon enhancing quality of life for people living with cancer reinforced the need to explore this issue further. My decision making around outcome measures however, was undoubtedly influenced by the findings from my MSc research in palliative rehabilitation (Belchamber and Gousy 2004):

“Outcome measures are an issue.... this resonates with my MSc research.....the complexities of measuring the impact of rehabilitation in a palliative care setting is challenging...this needs to be explored further.” (Diary entry: July, 2013)

Initially I was disappointed to find that this issue around outcome measures still hadn't been addressed in palliative cancer care. However, through the literature review that I undertook it became more apparent why this was such a struggle, deepening my understanding of the complexities of implementing outcome measures, which I will explore in my discussion chapter.

The lack of understanding of the role of the specialist physiotherapists amongst my other physiotherapy colleagues, first triggered my desire to research this area of practice, which could be seen as an influencing factor in my decision making and interpretation of my data when developing my themes. With this experience I was not surprised that the specialist physiotherapists interviewed felt that their role was not fully understood by other health care professionals. However, this role confusion also linked to the service users' interviews, and was reflected in my observations where the responses to the following interview question, did take me by surprise:

*“What were your expectations of the physiotherapy service before you arrived at the specialist palliative cancer care unit? Explain your thoughts about being treated by a physiotherapist.”
(SU interview topic guide: Appendix 10)*

The service users had no expectations of the physiotherapy service, having only preconceived ideas of physiotherapy from past experiences in other settings. By unpicking this phenomenon, I started to see the links between the specialist physiotherapist's assessment and the service users understanding of their care, which then led to the links with the integrated rehabilitation team working. The other thread of confusion around the role of the new physiotherapy community service provision was entwined within this and reinforced by the grouping of allied health professional's roles within the policy documents (Table 16, p.104).

The puzzling aspects of my data as I developed my themes were the complexities of the transformation of the physiotherapy profession, as well as the intricacies of palliative rehabilitation team working, within the new physiotherapy community service provision. Eventually separating these key themes out as they both intertwined enabled the pieces of the puzzle to finally fit together. The characteristics of my findings have therefore emerged through my own motivations, as well as recognising the importance of echoing as many voices as possible (Denzin and Lincoln 2011) in my research findings, while capturing the essence of the phenomenon. In writing up my findings I have therefore learnt to trust the qualitative research process, resisting temptation to force meaning, but instead allowing it to emerge from deep immersion in my data and experience in the research field (James 2012). My own willingness to relinquish some control over the process eventually enabled this to happen. Through interpretation of the themes that have emerged from my study, implications for the future physiotherapy profession, palliative cancer care service delivery and policy decisions have been documented in my discussion chapter. Therefore, reflecting upon my data generated, my experiences and my research question constructed an understanding of the provision of a local palliative cancer care physiotherapy service provision in light of best practice recommendations.

In my reflexive narrative I have voiced my assumptions that reside in my cultural background and knowledge of palliative cancer care physiotherapy. It is these assumptions that have shaped my thoughts and constitute my cognitive boundaries of firmly held beliefs. My background, training and assumptions have therefore inevitably had an effect on my research process. I recognise that the interpretation of my data to develop my findings are value laden, as I have been directly involved in my data collection and interpretation. Responding to these potential biases, I have used reflexivity as a form of self-appraisal to uncover and present my subjective stance. In addition, I hope the dynamic process of thematic analysis (Creswell 1998) has enabled me, after many transformations to put across to the reader a coherent and interesting report of my research phenomenon.

4.10 Conclusion

In this chapter I have discussed and reflected upon the findings of my case study. I will now move on to share what I have learnt from my practice development project. This will be followed by my discussion chapter, which will bring together my research and practice development components of my doctor of professional practice. A reflexive narrative will continue to run throughout these chapters.

CHAPTER 5: Practice Development

5.1 Introduction

The majority of Healthcare in the United Kingdom is now provided through the National Health Service (NHS), a free public system funded by the tax payer. However, there remains a private system, funded by medical insurance or on a pay as you go basis. In some cases, service users will access both systems to meet their individual needs (Barbiere et al. 2011). An increasing number of service users are now accessing the private healthcare system, either through private activity within the NHS and / or through the independent sector (Mulvaney et al. 2005). Publication of the policy document NHS plan (DH 2000b), has contributed to the growing entrepreneurial culture of the NHS, providing more autonomy and accountability, with expectations of quality and efficiency (Turner et al. 2013). Womack et al (2007) states that efficiency generated through quality underpins best practice in a healthcare enterprise culture and for an enterprise improvement to be successful there must be a framework of robust processes, empowered people with a purpose that is clear and quantifiable. The process must be designed and applied to meet the service user's demand, which is a key criterion of best practice (Turner et al. 2013).

Practice development plays a key role in changes to health care culture and services (Scott et al. 2003; NHS 2013) and therefore runs parallel with the current metamorphosis within the palliative cancer care landscape. This has brought about challenges to physiotherapy practice and the delivery of patient-centred care. There is an emphasis on patient-centred care in the current political agenda (Beer and James 2012) and it is questionable whether the Chartered Society of Physiotherapy (CSP) has responded to this in a strategic manner (Kell and Owen 2008), as core standards of practice (CSP 2005; WCPT 2008) now clearly state a patient-centred approach. Trede and Higgs (2008) describe a patient-centred approach as a model where the health care professional is proactive in the sharing of knowledge, power and decision making with their service users, however it could be argued that physiotherapy has always been patient-centred, as rehabilitation promotes a partnership between the health care professional and the service user. On the other hand, traditionally physiotherapists have perceived themselves as experts and are

therefore seen not to share power. Nevertheless, this patient / therapist partnership empowers physiotherapists to identify gaps in services through reflection in and on practice (Schön 1983), often leading to practice development, which mirrors my personal, professional and research journey. Addressing these challenges however, requires thorough practice-based research and robust methodologies to transform individuals and practice, enabling research knowledge to be applied appropriately to deliver effective practice (McSherry and Warr 2006; Hamer and Page 2009).

In the last decade significant time and effort has been placed in finding effective ways of engaging health care professionals in improving service users' experiences and outcomes (Dobson et al. 2003; Greenhalgh et al. 2004a; Manley 2000; Rycroft-Malone et al. 2002; Rycroft-Malone et al. 2004; Walsh et al. 2005). Theoretical and empirical work around transformational practice development has recently emerged (Manley and McCormack 2004; Manley et al. 2008) and may provide a positive way forward (Crisp and Wilson 2011). However, for practice development to be a success Manley (2004) states that there must be effective facilitation of the individual, team and organisation's attributes, which have been identified as vital components of successful workplace cultures.

Policies introduced as part of the National Health Service modernisation agenda (DH 2013) highlighted the requirement for healthcare professionals to research effective ways to deliver healthcare. This included the evaluation and dissemination of ideas for service improvement, with continuing professional development encouraged to build upon the necessary skills to achieve this goal (Gerrish 2001). Practice development embraces the aim of the modernisation agenda (DH 2013), as it is a process of continual improvement towards effective person-centred care (McCormack et al. 1999; Garbett and McCormack 2002). However, the definition of practice development within the literature is ambiguous (Hanrahan 2004), for example, a concept analysis of practice development described three attributes of practice development: 1) Identification of service user need; 2) demonstration that improvement in practice is necessary; and 3) facilitation of change (Unsworth 2000; Garbett and McCormack 2002).

These attributes are consistent with service improvement and are an intrinsic part of practice development (McSherry and Kell 2007). I have therefore described my practice development as the overarching term for a) the development of my private practice and b) subsequent service improvement. In order to make this clearer to the reader I have used the terms private practice framework and improvement framework to distinguish between the two key areas of my practice development project.

In this chapter I have presented my practice development project (private practice and practice improvement); practice development framework; physiotherapy private practice; rationale behind my practice development and the practical frameworks that I used to build up my private practice and practice improvement within a hospice setting. To reflect upon my progress as a practice development facilitator I have chosen a practice development framework proposed by Crisp and Wilson (2011), described under my reflexive narrative (5.6), with stages of facilitation skills presented in Table 18 (p.204).

5.2 Physiotherapy Private Practice

Physiotherapy practice such as massage, hydrotherapy and exercise was first documented during Hippocrates time in 460 BC (Higgs et al 2009). It was not until the 1890s that physiotherapy practice emerged in the form of 'medical rubbing' delivered by nurses (Jones and Sheppard 2008) and by 1894 the Society of Trained Masseuses (STM) was established (Thornton 1994; CSP 2015). In the 1900s massage was being taught in the private healthcare sector through the Private Practitioners Association established in 1928, with medical gymnastics introduced in 1930 (Mullis and Takagi 2002). In 1944 the Private Practitioners Association went on to influence the development of the Chartered Society of Physiotherapy (CSP). Three years later the minister of health instructed all physiotherapists to join the recently founded National Health Service (Kelly and Lewis 2012). However, some physiotherapists opted to remain in private practice and a year later formed the National Association for Private Practitioners (NAPP), and the Organisation for Private Practitioners (OPP). At the same time licensing for private practices in London was enforced (Kelly and Lewis 2012). The NAPP and OPP then merged to form one private

practice organisation and in 1952 the organisation of the Chartered Physiotherapists in private practice (OCPPP) was born. Rebranding of the OCPPP commenced in 2006 and two years later the name was changed to PhysioFirst (Kelly and Lewis 2012). Having been a member of PhysioFirst since 2009, physiotherapy private practice seems to be dominated by sports and musculoskeletal physiotherapy specialists, however in recent years there have been a growing number of private physiotherapists offering rehabilitation for neurological conditions, with the most recent addition of rehabilitation for children. Private physiotherapists do see some service users with respiratory and / or diagnosis of cancer, however there are no private physiotherapists who specialise in these areas.

The aim of my practice development was to develop a unique private physiotherapy practice for people living with cancer; Physiotherapy Cancer Care (www.physiocancercare.co.uk). However, my main concern regarding setting up a private practice for people living with cancer was the subject of payment. Due to my nature, the traditional culture of working in the National Health Service and the ethos behind the hospice movement made this situation an uncomfortable one for me. This led to many discussions with colleagues in private practice, as well as considering how best to manage this situation. I therefore sought provider recognition from key health insurance companies and was successful in provider recognition through Standard Life (Appendix 36) and WPA (wpa.org.uk) (Appendix 37). This meant that people with this insurance cover could claim back the cost of their treatment with Physiotherapy Cancer Care.

My private practice, however took a totally different direction to the one that I envisaged. Physiotherapy Cancer Care has not followed the traditional physiotherapy private practice route and rightly so, as supporting people with palliative cancer care needs requires a multi-disciplinary team, as confirmed by my research findings. Although aligning myself with a large local private physiotherapy practice that offered holistic treatments that my potential clientele could access, it was still not optimal to best practice. However, when I was offered a contract between Physiotherapy Cancer Care and a local hospice, this met best practice principles and removed my dilemma regarding people with

cancer paying for their treatments. This contract involved managing and developing a breathlessness clinic for palliative cancer care service users and led to the improving practice element of my practice development.

The objective of my practice development (private practice and practice improvement) was to promote patient-centred care, where care decisions reflected the needs, values and beliefs of the palliative cancer care service users and those providing the care, (for example, in the practice improvement, me as the physiotherapist and my key worker, a nurse by profession). In my research I explored the beliefs, assumptions and perceptions of the role of the physiotherapists in palliative cancer care from health care professionals and service users' perspectives. This helped to identify any issues that required action and highlighted areas where values and practice did not appear to match, providing relevance and quality to my research and practice development, informing democratic principles of citizenship, accountability and transparency (NIHR 2012).

I linked my practice development project through my private practice framework (Section 5.4) and subsequently my practice improvement framework (Section 5.5) to improve practice within a local hospice, managing and developing a breathlessness clinic. I gained views from the hospice's chief executive, medical director, board of trustees and clinical governance to take my practice development forward, which was critical to its success and sustainability. This involved individual and group meetings as well as board reports, which I have described in detail later in the chapter. My research and practice development project has therefore run concurrently, exploring both my practice development and case study in unison.

5.3 Rationale for Practice Development

In order to develop an idea for my practice development project I immersed myself in the culture of palliative cancer care having an honorary contract at a local hospice, as well as networking with palliative cancer care teams. I also carried out a scoping exercise in palliative cancer care, which highlighted innovation and evaluation as critical elements of change within the health care

system (Carr et al. 2008), with the development and production of evidence based guidelines to drive forward the implementation of research into practice (DH 2006).

This exploration of palliative cancer care triggered a revival of an idea that I had considered six years prior to starting my doctorate, that of setting up a unique physiotherapy private practice for people living with cancer. At the time there seemed to be a gap in the market, as I was often asked by service users and their families if I provided private physiotherapy. As both research and practice development progressed and I started to analyse my data, this need for specialist palliative cancer care physiotherapists was re-enforced.

5.4 Research Informed Practice Development

Specific aspects of my case study research findings informed my decisions in the development of my practice development project, for example; In order to fulfil the research findings of an integrated team approach, I aligned the private practice element of my practice development project to a large local private physiotherapy practice (3. Operations and Outcomes, p.181). For the improvement element of my practice development project the decision to have a contract with a local hospice provided an integrated team approach (Business contract, p.192). Additionally, my research findings indicated that the non-pharmacological approach to dyspnoea and pain management were key aspects of care, so I incorporated them into my private practice treatments, including other key findings around treatment delivery (3. Operations and Outcomes, p.181). Furthermore, my research findings indicated that there was a lack of outcome measures used to evaluate the new community physiotherapy service, so I sought to explore and implement outcome measures to evaluate the private practice element of my practice development (3. Operations and outcomes, p.181), as well as the improvement element of my practice development (Breathlessness clinic manager, p.192). My research findings also demonstrated that treating people with cancer in their own homes was beneficial and best practice. I therefore, decided to offer domiciliary visits, as well as clinic based treatments, in the private practice element of my practice development (3. Operations and outcomes, p.181). Finally, my research

findings relating to the bio-psycho-socio-cultural-spiritual model of health care (Puchalski et al 2009; Periyakoil 2014) influenced my choice of framework used in the improvement element of my practice development project (Person-Centredness, p.194).

Reflexive Narrative

First of all, I networked with local NHS and voluntary palliative cancer care physiotherapists and then explored local private practices and hospitals (private and NHS) to see what services were available for palliative cancer care service users. There were no specialist palliative cancer care physiotherapists available in the private healthcare sector at this time and only a few in the NHS sector. This lack of specialist palliative cancer care physiotherapists was something I wanted to address across the whole of the United Kingdom healthcare system, not only the NHS and voluntary sectors, but also the private healthcare sector. The advantage of this was that I would gain a better insight into the United Kingdom's healthcare system as a whole. Having worked in the NHS, private and voluntary sectors this would add to my knowledge base and understanding. The disadvantage was that I was not familiar with setting up a physiotherapy private practice and what it would entail. In addition, I was unsure about how to go about the costing especially around such a sensitive area as palliative cancer care. However, these issues were resolved pragmatically, as discussed earlier in the chapter.

I will now discuss my private practice framework:

5.5 Private Practice Framework

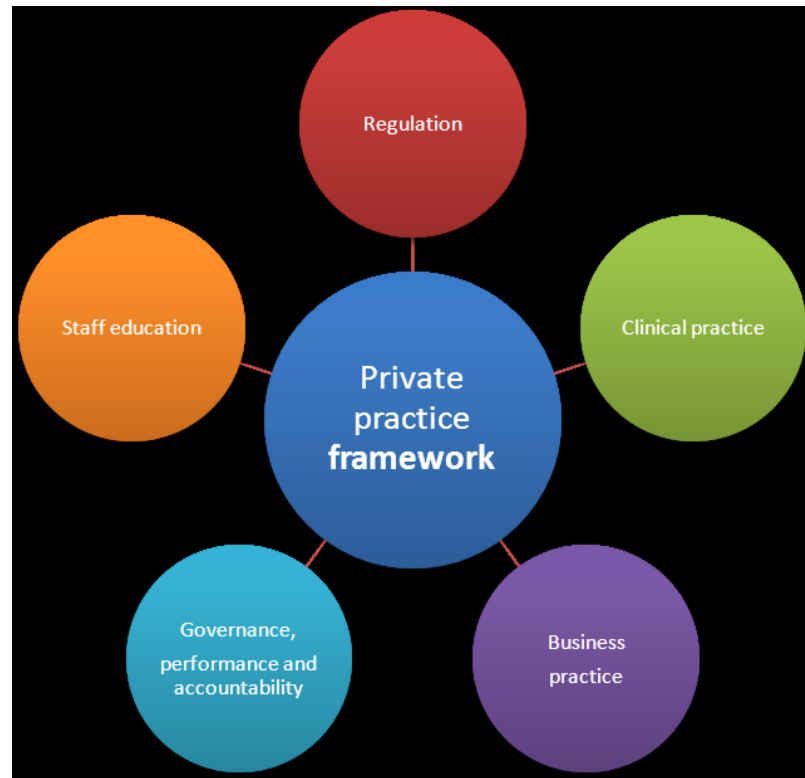
When setting up my private practice, I needed to be aware of issues related to business practice; regulation; governance; performance and accountability; clinical practice and staff education (Figure 6, p.172). This was not an easy process as there was a dearth of literature on the topic of physiotherapy business planning (Wassinger and Baxter 2011). Considering the background to private physiotherapy practice in the United Kingdom this was disappointing. Literature that I did find on physiotherapy private practice originated from

Australia, New Zealand or America. Within these countries the healthcare system is either entirely private (USA) or a mix of public / private (Australia / New Zealand), which perhaps contributes to this finding? Information however was available to me through PhysioFirst (2007), the Chartered Society of Physiotherapy (CSP 2000; CSP 2003b; CSP 2011) and the Government website on setting up in business (Gov.uk 2014).

Devising a business plan is an essential element of starting up and running a successful business and is vital when developing a new business enterprise (Gov.uk 2014). For a new private physiotherapy practice this is one of the fundamental documents to be prepared and needs to be 'fit for purpose' (Wassinger and Baxter 2011). My business plan therefore had to be comprehensive, describing in detail all aspects of my idea for a new business enterprise for palliative cancer care, including the concepts and issues for physiotherapy, such as the service that I would be providing for people living with cancer.

The concept that underpins business planning initially looked straight forward to me however private physiotherapy practices often fail within the first year (PhysioFirst 2007). Issues leading to failure were linked to the physiotherapist neglecting to address and plan for key aspects of starting up a private physiotherapy practice (Wassinger and Baxter 2011). I therefore addressed these issues in my business plan (Appendix 38) and then within my private practice website (www.physiocancercare.co.uk). This ensured that my private practice physiotherapy service provision was in accordance with relevant policies, legislation and regulations and developed with an academic understanding of these issues.

Figure 6: Private Practice Framework Used to Develop Physiotherapy Cancer Care



(Reproduced with permission of the Department of Health, Queensland Government: DH 2014a).

The business model that I used for my private practice development consisted of three parts: strategic imperative; patients and demand; operations and outcomes; which will be described under business practice (p173). I chose this model as it was developed to support business planning, implementation and change management (DH 2014a).

When planning my private physiotherapy practice, I therefore considered the 'added value' that my practice would bring beyond that which was already available to people living with cancer. Offering a unique physiotherapy cancer care service provided a point of difference with current services available for people living with cancer. For example, my private practice would be offering a specialist private physiotherapy service rather than a generalist private physiotherapy service. Wassinger and Baxter (2011) state that the uniqueness of the business is a key issue and should be clearly communicated in the business plan in conjunction with a strong mission statement.

Business Practice

In this section I have discussed the methods, procedures and processes that I followed in the development of my private practice and in pursuit of the aim and objectives for my practice development. To do this I employed the three business model components mentioned earlier.

1. Strategic Imperative

The aim of my private practice was to provide quality physiotherapy service provision to people living with cancer. My two objectives were: 1) to align my private practice to policy commitments and 2) to align my private practice to research evidence. In order to develop this, I needed to set out an action plan where I considered: how many hours I could work part time; how much capacity my practice would have to fill; how much income I would generate; my current earnings from Bournemouth University; the types of treatment that I would provide; and the marketing and promotional activities that I would need to carry out. In my strategic planning, I also considered how I was going to assess the strengths and weaknesses of my practice development. To do this I decided to use a Strength, Weaknesses, Opportunity and Threats (SWOT) analysis, as it is seen as the foundation of successful business planning enabling in-depth evaluation of a new business enterprise (Taylor 2013). The outcome of my SWOT analysis was that: a) I had the clinical skills to provide specialist cancer care, but would need to update these independently; b) gaining a clientele would need strategic marketing skills that I would need to acquire; c) balancing workload and commitments would need serious consideration if the practice development project was to thrive. The main threat identified was that I had no staff to cover me during illness or annual leave. The SWOT analysis also linked well to my critical reflection of the progress of my skills as a practice development facilitator (Table 18, p.204), during the improvement aspect of my practice development.

2. Patients and Demand

A significant issue that I needed to consider when planning my private physiotherapy practice was the local competition. This needed to be carefully researched and measured, obtaining crucial information about my main competitors and how they might impact upon my new business enterprise (Wassinger and Baxter 2011). Following this it was important for me to identify the 'geographical area of relevance' and the target population and size (Gov.uk 2014), as well as the strengths and weaknesses of my competitors.

Marketing is essential to a successful business venture (PhysioFirst 2000a; PhysioFirst 2000b; PhysioFirst 2000c) and establishing a 'market angle' will differentiate my private physiotherapy practice from others (Wassinger and Baxter 2011). My 'market angle' was my specialist knowledge and expertise in palliative cancer care, which results in improved quality of care as highlighted in my findings.

I carried out market research (PhysioFirst 2000d) to explore the need for a private physiotherapy practice specialising in cancer care. Initially I reviewed telephone and internet listings of private physiotherapy practices, checking directories such as the PhysioFirst website (www.physiofirst.org.uk), which incorporates a search facility 'Find a Physio,' for the general public to help them locate a physiotherapy member with a given speciality. Looking through this directory confirmed that my local area was saturated with private physiotherapy practices, offering services in musculoskeletal, neurology and sports, but not one specialising in cancer care. I also researched the Health and Care Professions Council website (www.hcpc-uk.org), as well as the Chartered Society of Physiotherapists interested in Oncology and Palliative Care website (www.acpopc.csp.org.uk). From this I concluded that I had a unique idea and had spotted a niche in the physiotherapy private practice market.

In addition to researching key websites, anecdotal evidence from working in cancer care for a number of years had suggested to me that there was a gap in the market in this specialist area. Since I have started my private practice I have found this to be the case, one such enquiry stated:

“I am trying to find her (mother) a physio specialising in cancer, in the area. It is amazingly hard! All anyone seems to be able to do is recommend a general physio.....It's amazing how scarce this all is (and a bit sad!)” (SU: carer: E-mail: June 2014).

Having established there was a niche in the private physiotherapy market I now needed to find out if setting up a private practice for people living with cancer would be a viable option. The next step therefore was to develop a marketing plan (Morley and Rennison 2011). The definition of marketing is the provision of products or services which people need (Business Bureau 2002), and because I was undertaking my doctorate I had the opportunity to consider the cancer care service user's point of view, which was obtained in one of my data collection sets, service user interviews. I found that the non-pharmacological approach to dyspnoea and pain management were key aspects of care, which specialist physiotherapists can provide. However, in the context of today's health care the word 'need' is now promoted as patient choice (Dixon et al. 2010), therefore, in order to be part of the patient choice, marketing my private practice will be a survival tool over competitors contending for the same patient group (Business Bureau 2002). Competition and choice was also growing in the United Kingdom from the recent Government health care reforms (Morley and Rennison 2011; DH 2010c) and the emergence of Clinical Commissioning Groups (CCGs). CCG's in England have a duty to promote integrated healthcare around service users' needs, so I had the responsibility to develop a client-centred approach to service delivery (Morley and Rennison 2011). I also needed to understand the potential growth or decline of my market and be able to react to it accordingly in order for my private practice to survive (Business Bureau 2002). For this I needed to develop a range of marketing skills to manage the uncertainties of the changing health care environment (Morley and Rennison 2011).

Gaining marketing skills was not an easy process as I had not had any undergraduate or postgraduate training in this area. Searching the academic literature was a start as well as accessing information from PhysioFirst (PhysioFirst 2000e) which provided some guidance. So where to start? Reading an article on a physiotherapist's experience of marketing private practices provided me with some ideas how best to approach this task (Spencer

2003). Advice was given on networking and writing to local consultants which was viewed as an effective, as well as low cost option for promoting my private practice. The downside to this however, is that it is time consuming (Spencer 2003). It was recommended that marketing opportunities should be sought using three basic principles:

- 1) To measure the response of the market to my marketing efforts.
- 2) To improve my marketing efforts dependent upon that response.
- 3) To be creative in directing those improvements.

(Spencer, 2003)

The type of marketing also needed to be considered, for example, advertising in the yellow pages is a very passive medium and doesn't spread the word, whereas active media such as leaflets does (Spencer 2003). From my networking with colleagues in private practice I was directed to Vistaprint (www.vistaprint.co.uk), an online company which provides marketing materials at a reasonable cost. This enabled me to develop the following: flyers; business cards; leaflets; promotional offers (Appendices 39 – 42); complementary slips and headed paper for my private practice. I also bought some promotional pens as part of my marketing strategy.

I distributed my leaflets and promotional offers within a large locally established physiotherapy private practice reception area who had agreed to rent out a room to me on an ad hoc basis (Appendix 43). I also sought other venues to advertise, such as the local library, the patient information centre at the local National Health Service Foundation Hospital and two local private hospitals. These all drew a blank as I was unable to advertise in these areas due to conflicts of interest, therefore I sent letters to three oncology consultants at the local private British Medical Institution (BMI) hospital (Appendix 44). Responses were mixed, but one consultant did provide a positive reply (Appendices 45 – 46) and agreed to refer private cancer care service users to me, who might benefit from the unique palliative cancer care service provision I was offering.

However, we are now living in an advancing digital world where websites are powerful marketing and communication tools (Lynott 2010; Lombardi 2012), with services users likely to search the internet for healthcare services (Fried 2010; Lombardi 2012). Therefore, establishing a presence on the internet was paramount for the success of my private practices (Lombardi 2012) which would also provide alternative communication lines such as e-mail to potential clients (Fried 2010; Lynott 2010). Being a member of PhysioFirst (<http://www.physiofirst.org.uk>) I could advertise on their website and in the yellow pages, however, I felt that another marketing tool was required, which led to the development of my own website for my private practice Physiotherapy Cancer Care (www.physiocancercare.co.uk). Since its launch I have been contacted by Therapy Directory (<http://www.therapy-directory.org.uk>) and now also have a profile on their website (<http://www.therapy-directory.org.uk/therapists/caroline-belchamber>). This was a new directory launched in 2012 and was free to subscribe to with the following criterion:

“Every therapist on the site who provides their full profile must send a copy of their qualifications and insurance cover to us, or must be registered with a professional body online with recognised codes of ethics and practice. This way those searching for a therapist on our site can feel safe, and our members know they are listed among other professionals.” (E-mail: February, 2012: Therapy Directory Team)

For the development of my website I chose Visual web developer 2008 and then updated to 2010 express edition (<http://microsoft-visual-web-developer-2010-expr3.software.informer.com/>) as the preferred learning tool to develop the website for my private practice. This tool is free to download from the Internet and allows beginners to build and design their own websites. Registering with the visual web developer took a minimal amount of time, but the actual learning process of developing the website took about two months and has been ongoing ever since. I used guidance provided by the visual web developer, academic literature (Fried 2010; Lynott 2010; Lawton 2010) and assistance from my husband to aid my learning, presenting a poster of my website development at the Third Annual Postgraduate Research Conference at Bournemouth University in 2011.

The development of my website was a time consuming process as there was a lot of administrative work involved in getting my private practice onto the internet. This included choosing a domain name and renewing my registration on an annual basis. Fried (2010) states that a domain name performs three functions, providing: 1) a license to build a website on the Internet; 2) a unique identifier for my website and 3) a route through which I can send and receive e-mails. However, when choosing my domain name it needed to be memorable and easy to type into a browser's address box (Fried 2010). I also had to ensure that the navigation system was consistent and provided website visitors with adequate information to make an easy and effective choice (Lynott 2010). It is therefore recommended that in the design of a website the layout should be simple, making the home page relevant and concise, so that visitors to the site will want to explore it further (Lawton 2010). With this in mind designing my website took time, as it was necessary to have the right balance between making my website look attractive, but keeping it user friendly. To avoid key pitfalls in the design of my website I also made sure that I had a clear definition and purpose, taking time to discuss my ideas with my husband, so that he knew what I was trying to achieve (Lynott 2010).

Once I had completed the design of my website the next step was to launch it, which required a host. Fried (2010) recommended using a search engine to research the kudos and complaints of various hosts (Hosting review <http://hosting-review.com/?gclid=CIOI39aBt6QCFUNM5QodRnhXyw>) and to check out reviews from respected sites such as 'Top 10 Web hosting' (www.top10webhosting.com), which provides details of each host and its ranking. This enabled me to make an informed choice and selected Pipeten (<https://domains.pipeten.com>) as the host for my website. I then considered my Internet marketing strategy, which included raising the ranking of my website on the search engine, known as 'search engine optimisation' (Lawton 2010). To do this I used meta-tags, which are words and phrases describing the contents of my website and the nature of my practice (Lynott 2010). This simplified the process for search engines and potential clients (Lynott 2010) directing more traffic to my website (Lawton 2010).

The ongoing maintenance of my website was another consideration due to my time constraints. However, I needed to remember that to attract attention to potential clients it was vital to consider the type of information and content that I would add to my website. This required thinking about the audience using my website such as service users, media and policy makers, who would be looking for information relevant to their needs (Lawton 2010). In addition, as I was using my website as a marketing tool it needed to be kept dynamic with current information (Fried 2010; Lawton 2010). I therefore learnt to link my resources to established and well known websites, such as Macmillan and my professional bodies so that my potential clients would have up to date and appropriate information. Initially I had many requests from American health insurance companies relating to mesothelioma, who wanted to be added to my resource page, one such request is cited here:

*"I was browsing through a number of community wellness websites and was impressed by the information you had listed. You have a great website and it is very easy to navigate through..... I noticed that you provide resources on this page of your website:
<http://www.physiocancercare.co.uk/Resources.aspx>. I was hoping that you would consider adding our link information as well."* (E-mail: September 2011, outreach manager: Mesothelioma Prognosis.net)

I soon learnt that this was a marketing strategy used by many organisations and placing a link on my resource page would increase their client numbers! I was also inundated with requests to advertise my private practice on well-known websites such as the Guardian:

"You might think that advertising Physiocancercare on such a massive site as the Guardian would be cost-prohibitive. But you'd be wrong! Webwindows has an ongoing contract with the Guardian which enables us to offer (first time) online advertisers a truly affordable package." (E-mail: September 2011: Webwindows)

At first I was flattered by these requests, however I soon learnt to say no as recommended by PhysioFirst (2000f), who advised private practitioners to consider if such advertising would benefit their practice and in the case of media

advertising to put themselves in the position of the client and ask if they would use this information to select a physiotherapist?

As my private practice evolved I started to attract other enquiries. These included some consultancy work for BUPA Home Healthcare (<http://www.bupa.co.uk/home-healthcare>), to provide advice on their proposed Palliative and End of Life Specialist Rehabilitation Pathway.

“I hope you don’t mind me contacting you....We are looking to develop a new service to support patients in the palliative stage of their life, through offering a palliative physiotherapy and occupational therapy service. To ensure that we map out the best proposition and service possible, we are looking to engage with a palliative physiotherapist who may be able to help us in our understanding of the assessment and treatment needs of palliative care patients. To date, I have been really struggling to find somebody appropriate, as it does seem to be quite a niche field.” (Proposition development lead: BUPA Home Healthcare: e-mail: May 2012).

When I responded to the request I was asked to provide my thoughts and reflections on two documents: 1) proposed service model for palliative and end of life specialist rehabilitation and 2) proposed flow diagram of how the service would work. BUPA Home Healthcare had completed the background and scoping work in preparation for a tender from a clinical commissioning group in the Midlands. However, they needed to build their understanding of specialist physiotherapy in palliative cancer care in order to proceed with this tender. A brief was therefore provided to me as a guide so that I could prepare my responses (Appendix 47).

This consultancy work linked with my MSc research into rehabilitation in the context of palliative cancer care (Belchamber and Gousy 2004), as well as my DProf research, where a deeper understanding of specialist palliative cancer care was obtained. In addition, this proposed tender was based in the community and my case study research explored the shift of a specialist palliative cancer care service provision from the specialist palliative cancer care unit into the community setting. Establishing a private practice had also provided me with some experience in business planning and what was required

for the development of a new evidence-based palliative cancer care service provision. I had by now gained three years' experience as a practice development facilitator through my private practice and service improvement elements of my practice development project. Previous to this I had experience of facilitating and evaluating the development of an oncology physiotherapy in-patient service at a local hospital. I therefore felt well enough equipped with the skills and expertise that BUPA Home Healthcare required to act as a consultant for them.

This consultancy work was an unexpected turn of events, which I hadn't anticipated when developing my private practice. My private practice was therefore taking shape organically, first with the contract between Physiotherapy Cancer Care and a local hospice and now with the consultancy work. My physiotherapy private practice was original not only in the treatment of people living with cancer, but also from the way it was evolving in the delivery of its services.

3. Operations and Outcomes

For my private practice operations procedure, I accessed key documents from the Chartered Society of Physiotherapy on private practice (CSP 2011): Insurance (CSP 2003b); Record keeping and access to health records (CSP 2000); as well as standards of physiotherapy practice (CSP 2005). This ensured that I was developing my private practice within a legal and professional framework. I also accessed documents from Government on the data protection act (DH 1998b); the protection and use of patient information (DH 2003b); and access to health records (DH 2010d). Further information was gained from PhysioFirst regarding data protection and access to medical records (PhysioFirst 2002; PhysioFirst 2001), again ensuring I was following correct policies and procedures. I then put these policies and procedures in place to provide a quality physiotherapy service to my potential clients.

The next operational procedure was to consider my product description for Physiotherapy Cancer Care, which was linked to my marketing strategy (Patients and Demand, p.174), running alongside the development of my

website. My research findings were also taken into account regarding the type of treatments that would be appropriate for my potential clients and the format in which I would deliver these treatments. Key findings relating to treatment delivery included: exercises; gait re-education; moving and handling techniques; non-pharmacological approach to pain management; non-pharmacological approach to dyspnoea management; fatigue management and emotional support. My product description therefore contained these key treatments and have been outlined in my business plan (Appendix 38) and placed on my website (<http://www.physiocancercare.co.uk/Services.aspx>).

Once my product description had been established I needed to develop clinical documentation that would be fit for practice and which would enable me to evaluate my service provision. This was not an easy task as my research findings indicated that outcome measures were difficult to implement in this specialist area. I therefore researched physiotherapy specific and palliative cancer care outcome measures (Appendix 48) to see if there were any that I could trial in relation to my product description. This included attending relevant study days held by the local Cancer Network and local Patient Recorded Outcome Measures (POMRs) and quality of life as described under governance, performance and accountability. Following these activities, the outcome measures that I opted to trial were: Medical Research Council (MRC) breathlessness scale (Stenton 2008); dyspnoea (Bausewein et al. 2008); pain (Wilkie et al. 1990; Farrar et al. 2003) and fatigue (Chalder et al. 1993); visual analogue scales (VAS) and the Karnofsky performance scale (Yates et al. 1980; Abernethy et al. 2005).

After completing my clinical documents, I outlined a treatment and fee protocol within my business plan and then gave more clarity to this on my website (<http://www.physiocancercare.co.uk/Payment.aspx>). The next step in my operations process was to consider the venue from which Physiotherapy Cancer Care would operate from. Initially I planned to buy or rent premises, but this proved to be expensive and would not be sustainable in the start-up of Physiotherapy Cancer Care. Also, from my research findings treating people with cancer in their own homes was seen as beneficial and best practice with

the current changes in health care (NICE 2004a; DH 2007; DH 2008a; DH 2011a). I therefore decided to offer domiciliary visits and developed a lone working policy. In order to do this, I gathered information from my colleagues working in private practice, as well as researching NHS and Government lone working policies (NHS 2009a; NHS 2009b; DH 2011b; HSE 2013) and gaining advice from PhysioFirst on risk assessments (PhysioFirst 2001). I then used the standard model template for loan workers (NHS 2009a) to develop my loan working policy, taking into account: identification of risks; likelihood of incident; control measures required; and actions to be taken (Appendix 49).

Further to the offer of domiciliary visits, I decided that it would be advantageous to potential clients and me if I was to align Physiotherapy Cancer Care with a large local private physiotherapy practice, enabling potential clients to have access to a wider health care team. This team included Chartered physiotherapists offering clinical pilates; aromatherapists; and nutritionists. This addressed an element of best practice, identified from my research, where access to a multi-disciplinary team is an important part of care for palliative cancer care service users (NICE 2004a). I therefore rented a room on an ad hoc basis to minimise costs and in this way potential clients could have the choice of domiciliary or clinic based treatments. In addition, the local private practice would benefit from my expertise in palliative cancer care and this might generate further referrals to Physiotherapy Cancer Care. I would also benefit from the local physiotherapy private practice's years of experience in private health care with opportunities for peer-review as described here:

"I am so glad that you feel that you could work from here. We will do as much as we can to support your venture because we do feel that your approach is very professional and caring and just the kind of service we want to have working from here. Just to say that tonight's meeting is now at 7pm. So I would recommend that you come along for 6.30pm (ish) and meet us and perhaps, if you could say a few words as to what you do it would be helpful." (E-mail: June 2009: Manager of a Large Private Physiotherapy Practice).

Regulation

Professional regulation was considered in the development of my private practice, researching: standards of proficiency (HCPC 2013); conduct performance and ethics (HCPC 2012); physiotherapy practice (WCPT 2008); and quality assurance (CSP 2012). From this I took into account my professional responsibilities, such as maintaining my state registration through the Health and Care Professions Council (HCPC) as well as making sure that I was delivering a quality and professional service that was ethically sound. I therefore organised regular peer and professional support to maintain competence and emotional wellbeing, as highlighted as a necessity in my research findings. I approached this issue through my special interest group, the Association of Chartered Physiotherapists interested in Oncology and Palliative care (www.acpopc.org.uk) and the Multi-Disciplinary Association of Supportive Care in Cancer (www.mascc.org). I was then able to develop this peer and professional support further during the improvement element of my practice development, within a hospice setting.

Further regulation included seeking advice from professional bodies, such as the Chartered Society of Physiotherapy and the Health and Care Professions Council, including the local private physiotherapy practice, for the use of their logo on my website. Here is the response from the Chartered Society of Physiotherapy:

"Thank you for contacting the CSP, you can certainly use the CSP membership badge logo, this is the one that is shaped like a lozenge. You cannot use our corporate logo which is the CSP letters without prior permission from our Publications Unit. I have attached a file with the badge logo for your use. I have listed below the contact details of the officer who you should apply to for permission to use the CSP corporate logo." (E-mail: June, 2009. CSP Graphic Designer)

On completing my draft website design, I approached three local hospices to obtain feedback on its contents. Gaining access to key people (the Chief Executive of one hospice and consultants from the other two hospices) that I needed to speak to was made easier by the fact that I had worked in all three hospices in the past and was well known to them. Appointments were booked

in June 2009 and face to face meetings were held at each of the hospices. Prior to the meetings I provided access to my draft website, so that it could be viewed by the Chief Executive and consultants enabling them to make notes before the meeting took place. On the whole the feedback on my website was very positive and linked with the academic writing on good web design as described earlier.

However, there was one conflict of interest voiced by the Chief Executive relating to the services my private practice outlined, which were seen to be competitive to the hospice, in particular to the breathlessness clinic. The primary care trust awarded on an annual basis a percentage of money to the running of the breathlessness clinic at the hospice and the Chief Executive was concerned that this money would be at risk if some of the cohort of patients went to my private practice for breathlessness management instead. In response to this concern I was asked if I would consider a contract between the hospice and my private practice to manage and develop their breathlessness clinic. This was an issue that I had to think through carefully, leading to further meetings and discussions with the Chief Executive before making a final decision. The outcome of this is described later in the chapter. The consultants I spoke to were also able to give me feedback from a private practice perspective, as they either currently worked in this area or had done so in the past. I then spoke to my line manager at Bournemouth University to make sure that there were no conflicts of interest in setting up a physiotherapy private practice alongside my physiotherapy lecturing post. Once I had positive feedback from all parties and had placed a copyright footnote on my website, I launched it with the search engines in July 2009. Since then I have maintained and updated my website allowing it to evolve as my research and practice development project progressed.

The next step having developed my business plan, marketing plan and website was to register with the Government for self-employment, which I did online (online.hmrc.gov.uk). I was also entitled to a small earnings exception certificate, which I applied for through Her Majesty's Revenue and Customs regarding class 2 national insurance contributions. Following this I set up a

spreadsheet to keep track of my finances, which included completing a self-assessment tax return form for each tax year.

Governance, Performance and Accountability

I have maintained my professional responsibilities and obligations through the Chartered Society of Physiotherapy (CSP). As a member of my professional body and being registered with the Health and Care Professions Council (HCPC) I am bound by the rules of professional conduct as described under Regulation. Further peer and professional support has been gained through the local hospice governance system where my practice improvement took place; as well as through my honorary contract with another local hospice. Key documents mentioned under 'Regulation' have been adhered to for performance and accountability and documented in my business plan. They have also been listed on my website (<http://www.physiocancercare.co.uk/Responsibilities.aspx>). This reassures potential clients of the high quality and standard of the treatments offered by Physiotherapy Cancer Care.

All client records are held on a secure computer and comply with the Data Protection Act (DH 1998b). The software used includes an audit trail that identifies any changes made to the text, as in a written record. I then save the client's electronic records regularly on a flash key, which is kept in a locked filing cabinet. The client files are password protected and will not allow access until I have entered my identity and password. These records are retained in accordance with the Chartered Society of Physiotherapy core standard, documentation, 14 and 15 (CSP 2005), which sets out the need to retain records in accordance with existing policies and current legislation. Information from PhysioFirst regarding the Data Protection stated that on the 1st March, 2000 any PhysioFirst member who stores service user details on a computer must register with the Data Protection Agency (www.dpr.gov.uk) (PhysioFirst 2002). I therefore followed this up and registered online with the Information Commissioner's Office (http://ico.org.uk/for_organisations/data_protection/registration) and it is published on the public register of data controllers

([http://ico.org.uk/what we cover/register of data controllers](http://ico.org.uk/what_we_cover/register_of_data_controllers)). PhysioFirst also advised to beware of bogus e-mails, which some PhysioFirst members had received and were under investigation by the Data Protection Agency (PhysioFirst 2002).

On the advice of the Chartered Society of Physiotherapy, when client's records have been generated by computer, a hard copy should be printed off and signed each time a treatment was given. This practice will continue until case law for computer-generated records are accepted in court. I have also put in place a procedure if clients wish to access their records (Appendix 50). This is in line with the Department of Health (DH 1998b; DH 2010d) and PhysioFirst (PhysioFirst 2002; PhysioFirst 2001) recommendations. This information has also been made available to the public through the private practice website (www.physiocancercare.co.uk/Records.aspx).

Reflexive Narrative

I ensured that I remained up to date in my mandatory training on an annual basis by completing: information governance; health and safety; COSHH; fire safety; infection control; basic life support; manual handling; safeguarding vulnerable children; protection of vulnerable adults; complaints handling and conflict management; and lone worker safety awareness training. This training was provided through Physio First and more recently through ABL training and consultancy Ltd (www.abltraining.co.uk), which was delivered in the hospice setting. I also carried out continuing professional development (CPD) to ensure my competencies remained up to date and evidence-based. Attending study days with the Association of Chartered Physiotherapists interested in Oncology and Palliative Care (ACPOPC), I covered topics such as pain in cancer assessment and management, confirming the knowledge I had on this topic around modalities such as Transcutaneous Electrical Nerve Stimulation (TENS) for use in cancer related pain, which was also confirmed in my findings and in the literature. Other topics included INSPIRED breathlessness pathway (<http://nliah.com/compendiums/Articles.aspx?ArticleID=2&SiteID=1>), which linked with my knowledge of the non-pharmacological approach to

breathlessness and reinforced the work that I had been involved in as part of the lung cancer guideline development group (NICE 2005).

Attending the improving cancer pain study day in 2009 confirmed my findings from my MSc research on rehabilitation in the context of palliative care (Belchamber and Gousy 2004). This included barriers to pain control and the World Health Organisation (WHO) pain ladder continuing to be the main guide to the administration of analgesia. Clinical aromatherapy and the non-pharmacological approach to pain management were also confirmed as useful approaches to the management of pain. Key outcome measures (Brief Pain Inventory (BPI); Edmonton classification system for cancer pain (ECS-CP) (Fainsinger et al. 2010; Fainsinger and Nekolaischuk 2008); Visual Analogue numerical pain score (Hjermstad et al. 2011); Short form McGill Pain Questionnaire (Melzack 1975), had been reviewed for use in cancer care by Breaking Barriers: management of cancer-related pain CD ROM program (Von Gunten 2009) and this was helpful in considering the outcome measures that I would use in my clinical documents for my private practice.

It was stated by the Westminster Forum in 2014 that an unprecedented scale of change was required to manage the increasing numbers of people who will require palliative cancer care in the future. Funding for local clinical commissioning groups and educationalists was paramount with different levels of involvement and development of services. There were concerns however that this would introduce further disparity in service provision. This information was relevant to my academic, as well as my professional practice as it will impact on both. Its relevance to academia concerns the ability to transfer this learning into the new physiotherapy curriculum so that physiotherapy students are fit for practice in this fast changing National Health Service. Its relevance to my professional practice relates to the learning around partnership between hospice and other stakeholders to transfer knowledge and skills to improve palliative cancer care service provision.

Clinical Practice

I developed clinical documents outlined below with appropriate outcome measures as described under operations and outcomes for assessments of people living with cancer to evaluate the effectiveness of my treatment modalities and interventions. This involved further literature search into key cancer symptoms that I had initially explored in my MSc (Belchamber and Gousy 2004) and which were noted in my DProf research (data collection and analysis): dyspnoea, cancer related fatigue and cancer related pain. Using evidence-based practice around physiotherapeutic interventions and modalities as explored below, I then developed assessment forms for: breathlessness; cancer related fatigue; cancer related pain; and rehabilitation. All of which have outcome measures embedded within them.

Physiotherapy interventions such as massage, soft tissue manipulation, heat pads and TENS have been documented by Twycross (2004) and Charlton (2005) as helpful for the management of pain in people living with cancer. With this in mind the non-pharmacological approach to pain management should be delivered using the total pain model of care defined by Dame Cicely Saunders, advocating a comprehensive, patient-centred approach to pain assessment and management (Ong 2005). A more recent development however, focuses on the conceptualisation of physiotherapy in palliative cancer care pain management and the 'mechanism-based' classification of pain (Kumar and Saha 2011). Here the person living with cancer's clinical presentation is identified in relation to the symptoms, which is vital for instigating the correct therapeutic strategy for pain relief (Kumar 2011).

Physiotherapy treatment modalities have also been reported to be beneficial for cancer-related fatigue (Watson and Mock 2004); prostate cancer (Clay et al. 2007); older women with cancer (Mackey and Sparling 2000); breast cancer (Molinaro et al. 1986; Keays et al. 2008) and breast cancer related lymphoedema (Megens and Harris 1998; Bicego et al. 2006); colorectal cancer (Courneya et al. 1999) and cancer therapy-related hyperthermia (Iuk et al. 1986). There is further evidence that group exercise therapy (Belchamber 2009), energy conservation techniques and frequent physical activity can be

beneficial in the management of cancer-related fatigue (Narayanan and Koshy 2009).

Manual handling techniques and the provision of equipment to aid activities of daily living can also improve palliative cancer care service user's functional ability (O'Sullivan and Schmitz 1988; King et al. 2005). Instructions on the use of equipment to the palliative cancer care service user and carer through advice, support and education by the physiotherapist can prevent falls, improve balance and maintain independence (Javier and Montagnini 2011).

The non-pharmacological approach, which involves breathing techniques, relaxation, positioning, coping strategies, pacing strategies and exercise prescription to manage dyspnoea is advocated by Hately et al (2001; 2003); Syrett and Taylor (2003); and NICE (2005). More recently the National Cancer Team pathways identified the non-pharmacological approach as best practice with potential to prevent unnecessary anxiety, panic and reliance on pharmacological input in the early stages of lung cancer (NCAT 2009). These interventions are helpful in enabling palliative cancer service users to be in control of their breathlessness (Hately et al. 2001; Hately et al. 2003; Vora 2004) and have a cognitive effect on depression and changes in mood (Dubbert 2002). In addition, breathing techniques, such as pursed lip breathing can improve the person's ability to manage their breathlessness more effectively (LeGrand 2002). It is advised that palliative cancer care service users attend three sessions of the non-pharmacological approach, as this is deemed to have better outcomes than those only receiving one session (Barton et al. 2010).

Through a meta-analysis of 30 randomised control trials non-pharmacological interventions were acknowledged as favourable in the management of people living with cancer. Psychological and physical activity-based interventions are being established as enhancing quality of life for people with cancer-related fatigue (Jacobsen et al. 2007; Belchamber and Gousy 2004). In conclusion, non-pharmacological physiotherapy interventions cover a wide range of treatment options for symptom control, improving quality of life for people living with cancer and receiving palliative rehabilitation (Kumar and Jim 2010; Belchamber and Gousy 2004).

Staff Education

Physiotherapy Cancer Care is run solely by me at the present time, but may employ staff in the future, if required. However, under the contract between Physiotherapy Cancer Care and the local hospice I have provided staff education. The main reason for taking on this role was to promote the breathlessness clinic and disseminate the non-pharmacological approach to breathlessness to other health care professionals. In this way more palliative cancer care service users could either be referred to the breathlessness clinic or benefit from the coping strategies and techniques for managing their dyspnoea. I have learnt that although the breathlessness clinic had been established since 2000, it was still poorly recognised by a number of health care professionals in the local area. However, through education, awareness of the breathlessness clinic has grown and consequently referrals have increased, with more palliative cancer care service users benefitting from this treatment.

I have transferred my knowledge and skills to provide education to BSc (Hons) physiotherapy students in cardiovascular respiratory and supportive and palliative care, as well as to postgraduate staff interested in cancer care. In addition I have been invited to: present a Continuing Professional Development workshop in 2009 at Bournemouth University on physiotherapeutic management of cancer; present a workshop at the End of Life Conference: breathlessness the way forward, held at Bournemouth University in 2011; present my DProf research at the local Cancer Network Rehabilitation Subgroup in 2011 and asked if I would like to be the research link for this group; write a profile of myself for the Journal of Supportive Care in Cancer in 2011 (Belchamber 2011a) present an interactive session on the benefits of exercise at the Breast Cancer Care's Younger Women's Forum in Brighton in 2012; join the international corresponding reference group for JBI COnNECT plus Cancer Care Node (<http://connect.jbiconnectplus.org/>) to assist with developing evidence-based practice guidelines in supportive care in 2012; write a post for the European Association of Palliative Care (EAPC) blog (<http://eapcnet.wordpress.com/2013/06/13/fostering-hope-through-palliative-rehabilitation/>) in 2013 and present approaching and managing breathlessness in cancer patients as part of the program for practical approaches to cancer and

end of life care for allied health professionals in Southampton in 2014. Physiotherapy Cancer Care therefore offers presentations (www.physiocancercare.co.uk) to groups of people living with cancer and organisations interested in the physiotherapy service provision that I offer (<http://www.physiocancercare.co.uk/Information.aspx>). I have followed advice from PhysioFirst regarding making presentations, as part of my marketing strategy (PhysioFirst 2000g).

Business Contract

As mentioned previously gaining advice and feedback from the local hospices about my practice development and website development led to one local hospice proposing a business contract with Physiotherapy Cancer Care to come and manage their breathlessness clinic.

This was an exciting opportunity offered to me as the hospice was going through major change, having a new build with the addition of an in-patient unit. I therefore discussed the proposed contract at length with the hospice's Chief Executive to establish that this would be an appropriate step forward for my practice development, as well as being beneficial for the hospice and its service users. I obtained advice from Bournemouth University Business Centre on drawing up a contract between my private practice, Physiotherapy Cancer Care and the local hospice. Following this, the original contract (Appendix 51) was agreed and signed by myself and the chief executive of the hospice, once it had been approved by the hospice's board of trustees and clinical governance group. I have since updated the contract between Physiotherapy Cancer Care and the local hospice on an annual basis.

Breathlessness Clinic Manager

I commenced as the breathlessness clinic manager at the local hospice in January 2010 with a remit to develop and expand the breathlessness clinic service provision for palliative cancer care service users with primary and secondary lung cancer. I was originally involved in the setting up and running of the breathlessness clinic in 2000 at the local hospice following the successful

completion of a pilot study (Hatelly et al. 2001; Hatelly et al. 2003) and the retirement of the physiotherapist who was involved in the data collection. I had also been involved in some of the data collection towards the end of the pilot study and consequently was given the role of disseminating the findings. I was therefore familiar with the workings of the clinic having been involved in the birth of the first breathlessness clinic in the South and spending the next three years establishing the clinic within the local area.

On commencing my new post as breathlessness clinic manager I could see that little had changed in the delivery of the breathlessness clinic service since I left to gain experience in acute oncology at a local hospital in 2003. The breathlessness clinic documentation was the same and some of the outcome measures used in the initially pilot study were still being collected. These included the Rotterdam symptom checklist (de Haas et al. 2012), Visual analogue scales and 'things that improve breathlessness,' used in the original research on the non-pharmacological approach to dyspnoea by Corner and colleagues (1996). I therefore decided that I would start the improvement element of my practice development by reviewing the breathlessness clinic notes, outcomes, as well as the clinic's policy and procedures to bring them in line with best practice recommendations.

In order to improve practice within the breathlessness clinic I explored different practice development frameworks to find one that I felt would be fit for purpose. Through my literature search I came across a few practice development frameworks that have been specifically developed by different disciplines, such as paediatric oncology (Gibson et al. 2000). However, there were no practice development frameworks specific to physiotherapy or hospice services. I therefore chose the practice development framework developed for the National Health Service, with its aim to improve quality and service (Wall et al. 2013). The main reason for choosing this framework was its appropriateness for improvement initiatives such as implementing national standards and developing improvements locally (Wall et al. 2013), both of which my case study research and practice development encompassed.

5.6 Improvement Framework

This framework consists of six elements: person-centredness; evidence; improvement processes; enabling and sustaining change; leadership and facilitation; learning and development. All the improvement elements link together and I have included a diagrammatic representation (Figure 7) of these links, central to which is practice development. I have used the six elements as subheadings to discuss how each was addressed in my service improvement of the breathlessness clinic.

Figure 7: Improvement Framework



(Reproduced with permission of HealthCare Improvement Scotland: NHS 2013)

Person-Centredness

Person-centredness is becoming recognised in both research and health care practice (Hebblethwaite 2013) and has been highlighted in international and national policy documents (WHO 2008; DH 2010c; Bikker et al. 2012). In addition, the concept of person-centredness is pertinent and consistent with the prerequisites of allied health professionals (Hebblethwaite 2013), such as physiotherapy. However, in palliative cancer person-centred care I have

included relationship-centred care (MacDonald 2002; McCormack 2001; Hebblethwaite 2013), as it expands upon person-centredness to incorporate the palliative cancer care service user's family and carers. This relationship-centred care also includes health care professionals and the wider community (Nolan et al, 2004). This concept therefore fits well with the bio-psycho-socio-cultural-spiritual model of health care (Puchalski et al 2009; Periyakoil 2014) as described in my findings.

One of the aims of practice development is to facilitate person-centred care, so that decisions made reflect the needs, values and beliefs of the people receiving the care in this case palliative cancer care service users and the health care professionals delivering the care (the physiotherapist) (Crisp and Wilson 2011; Hebblethwaite 2013), which links with my practice development project objective. I therefore gained mutual respect and insight into other people's beliefs and values through the development of relationships, which included: palliative cancer care service users; health care professionals working in palliative cancer care; carers of people living with cancer and other agencies. Service users and health care professional's values and expectations were acquired through my DProf research and rather than just focusing on my patient-therapist relationship. I also looked wider at the inter-professional and multi-disciplinary relationships (McCormack 2004) to encourage meaningful involvement (Hebblethwaite 2013) in the development of the breathlessness clinic as described under 'improvement process.'

Evidence

The evidence supporting my service improvement came from a number of sources: initial and subsequent literature searches; professional opinion; policy documents, standards and guidelines; and my DProf research findings, which have been discussed and referred to throughout this section.

Improvement Process

The breathlessness clinic had an average of 250 service users attending the clinic per annum with the clinic appointments available three days a week. This level of service needed to be sustained to cover a minimum of three appointments per service user, as described as best practice (Hatley et al. 2001; Hatley et al. 2003; Barton et al. 2010). With my other commitments it was not feasible to achieve this independently, so through discussions with the Chief Executive it was agreed that I could recruit a key worker to the clinic with the view to developing their skills and competencies, which I have described under 'Leadership and Facilitation.'

I chose a collaborative nurse / physiotherapist approach as a model of best practice for the non-pharmacological approach (Syrett and Taylor 2003), as it was feasible within the local hospice budget and staff mix. A nurse working in day care who had attended my two-day study day at the hospice in 2001 on the non-pharmacological approach to breathlessness indicated a keenness to develop her skills in this area. I therefore put the nurse's name forward to the Chief Executive and Nursing Director, who both agreed that the nurse would make an ideal key worker for the clinic. Part of the breathlessness clinic improvement process therefore involved writing a job description and specification for the key worker in conjunction with the Director of Nursing. Terms and conditions of the key worker's employment were then determined between the Director of Nursing and the Chief Executive.

To promote the relationship-centred care to service improvement I became a member of the local Cancer Network breathlessness sub-group between 2010 until 2013, after which it disbanded due to the introduction of the new clinical commissioning groups. I have since become involved in a new group, which is being piloted in 2014 to continue to network and standardise respiratory care within the local area. This group is called the (region) Respiratory Physiotherapy Network and includes physiotherapists from local services in hospitals, communities and hospices. This will enable health care professionals to build upon previous good work and share our expertise to improve future respiratory practice within the local area.

In order to develop and improve the breathlessness clinic practice, I initially researched national and local initiatives, such as the lung cancer guidelines (NICE 2005; NICE 2011; SIGN 2008; SIGN 2014; BTS 2001; BTS 2010) and more recently improving and integrating respiratory services (IMPRESS 2012a; IMPRESS 2012b) and the London Cancer Alliance (LCA) lung cancer clinical guidelines (LCA 2013). This gave me an insight into the services available locally who might potentially make referrals to the breathlessness clinic and whom I could approach. It further confirmed that the non-pharmacological approach to dyspnoea within a breathlessness clinic setting continued to be gold standard best practice in managing breathlessness in people with primary and secondary lung cancer (Hatley et al. 2001; Hatley et al. 2003; NICE 2011). This literature review also highlighted the fact that the non-pharmacological approach could support people with cancer who were breathless but did not have lung metastases (Bauswein et al. 2008) as well as other chronic lung conditions, such as chronic obstructive pulmonary disease (COPD) (Bauswein et al 2008; IMPRESS 2012a; IMPRESS 2012b) and those with heart failure (Bauswein et al. 2008). I have therefore revised and widened the referral criteria for the breathlessness clinic over the last five years to include these conditions. This change paralleled the hospice transformation from a focus on palliative cancer care service users to opening its doors to other palliative conditions as recommended by the National Council for Palliative Care (NCPC 2005).

I reviewed existing data from the breathlessness clinic such as statistics on the number of referrals, which healthcare professionals were referring to the clinic, the number of appointments that were attended by the palliative cancer care service users and reasons for non-attendance. This provided me with a baseline and an idea of whether service users were being referred early enough in their disease trajectory. It also provided me with an idea of which healthcare professionals I needed to approach to develop relationship-centred care in order to improve practice and awareness of the clinic. This was actioned and is described under 'Leadership and Facilitation' (p.200). I then reviewed and updated the documentation for the breathlessness clinic, such as protocol and procedure, statistic collection and outcome measures, using the information I

had gained from my literature search, as described previously including a review of existing data.

As the clinic developed I used clinical audit cycles to monitor the implementation of the revised clinic notes and the outcome measures incorporated into the updated documentation. These included: The Medical Research Council (MRC) dyspnoea scale (Stenton 2008); chronic obstructive pulmonary disease (COPD) Assessment Test (CAT) (Dal Negro et al 2014) and the Nijmegen questionnaire (Van Dixhoorn 1985) to assess for dysfunctional breathing patterns due to behavioural and psychological issues. I liaised with the Medical Director, Director of Nursing and the local hospices clinical governance and board of trustees regarding any new developments or issues. This was achieved through quarterly reports covering statistical information, clinic hours, clinic referrals, developments, issues and action plan.

As healthcare professionals became more aware of the breathlessness clinic the referral numbers rose. This led to the main issue of being unable to expand the clinic services further due to the current staffing levels and lack of funding to be able to introduce a pulmonary rehabilitation program for people with an MRC of 4-5, who were unable to attend pulmonary rehabilitation at other centres due to their deteriorating condition. Another area of clinic development that was being restricted related to domiciliary visits for those service users who were too unwell to attend the hospice. This was because it took up more clinic staff time reducing the number of service users who could be seen within the clinic. This was disappointing as this was one of the clinic developments that was now at risk of being lost and of which my research findings had demonstrated as best practice, meeting the palliative cancer care service user's needs.

I referred to NCAT care pathways to see where the breathlessness clinic sat and if the service was meeting best practice. I used the allied health professions cancer care toolkit, which was developed on behalf of the strategic allied health professions leads group (SAHPLE) as part of the Quality, Innovation, Productivity and Prevention (QIPP) agenda (DH 2012b) as guidance. This was appropriate as it was evidence-based and provided

information on commissioning principles, which would help in the future when liaising with the clinical commissioning groups.

Enabling and Sustaining Change

At the heart of practice improvement is enabling and sustaining change (Wall et al. 2013). To do this effectively staff should be involved at all levels as early as possible, through facilitation to improve the success of implementation and sustainability (Meyers et al. 1999). It was therefore vital that I used creative and innovative ways to engage my colleagues at the hospice, as well as those in the community in the breathlessness clinic improvement process. Before I could do this it was essential for me to consider who the change would affect directly and indirectly, including what the drivers and barriers to change might be. Those affected directly included the staff in day care, as the breathlessness key worker leaving day care would mean a change in staff numbers and the need to recruit. It also affected the key worker moving into a new role and the Nursing Director, who would be involved in supporting these changes. Indirectly this change would have an effect on the board of trustees, hospice clinical governance, the Chief Executive and eventually the Medical Director when he was appointed to the hospice. The main drivers to change were clinical guidelines (NICE 2005; NICE 2011; SIGN 2008; SIGN 2014; BTS 2001; BTS 2010) and the main barrier to change was funding, as the hospices main funding source which was being absorbed by the new build, came from donations and legacies. Other barriers included time required to complete bids, such as applying to Macmillan for service development funding, as well as other commitments that hospice staff had to the development of the new build. Space also became a factor especially when moving out of the current hospice building into temporary accommodation for two years while the new hospice was being built. This caused many distractions and priority was focused on the smooth transition of current services across to the temporary accommodation and then back to the new build with as little disruption to the palliative care service users as possible.

Once I had gathered this information I was then informed as to whom I should involve, consult or notify. This also gave me insight into how the dynamics and cultures of the teams I would be working with might affect the success of the

improvement process. My main hurdle at the start of the improvement process was to achieve a shared vision for the breathlessness clinic. This required a number of learning and development skills as described under 'Practice Development Frameworks' (Sections 5.4 and 5.5). Areas, that I identified for further development were addressed through attendance at appropriate master classes, workshops, facilitation from colleagues, DProf facilitators and supervisors. I also sought the hospice's support in communicating good practice and development projects as part of the movement within the new build.

Leadership and Facilitation

In order for me to carry out the improvement process to develop the breathlessness clinic I needed to be able to inspire, enable and transform others (Wall et al. 2013). This meant that I would be required to facilitate and support change, including the development of staff (Crisp and Wilson 2011). I therefore took on the role of mentoring the breathlessness clinic key worker. However, each mentoring relationship is unique, with mentor and mentee entering the mentoring relationship and process with individual values and expectations (Naidoo 2006).

For effective professional mentorship Hansen and Matthews (2002) advocate a replacement of traditional power roles, for example, physiotherapist / student, with collegial-peer relationship, which fitted with my practice development concept of relationship centred care. This enabled identification of any problems, problem solving, promoting openness and trust (Hansen and Matthews 2002). Using a structural paradigm (Muth et al. 2001) I provided clear intended learning outcomes to actively engage the key worker (Muth 2002). This included weekly de-brief sessions, observation sessions with feedback, action plans, peer-review and case study discussions. Once I had established this in the first year of working at the clinic, I then encouraged the key worker to apply for the Respiratory Assessment and Diagnosis post graduate course at Edge Hill University, which she completed in 2013. During this time, I was invited by the university to be the key worker's mentor / assessor with an expectation that the key worker achieved the clinical outcomes of the Master of Science (MSc) module. This involved me assessing the breathlessness key

worker against a number of performance statements. On successful completion of this course the key worker was recognised as a specialist nurse, which I endorsed with the hospices Director of Nursing in May 2014.

I also acted as a role model for others as part of the service improvement. This included inviting other health care professionals, such as hospital and community physiotherapists, district nurses, consultants and general practitioners, as well as physiotherapy and occupational therapy students from Bournemouth University to visit the breathlessness clinic and to observe the treatments delivered. This led to the development of a student volunteer protocol (Appendix 52), which was agreed by the Chief Executive and board of trustees, but put on hold while the restructuring of the volunteer process took place. These practice development initiatives improved the local health care professionals understanding of the clinic and the student's knowledge in treating people in a palliative care setting. Visiting the breathlessness clinic is now a key part of the district nurse's induction program and there is a heightened awareness of the breathlessness clinic locally. All of these initiatives have consequently improved the amount of referrals made to the clinic. In addition, there has been international interest in the breathlessness clinic with a recent visit of a palliative medicine specialist from Australia, who is keen to set up a breathlessness clinic:

"I spent a day with (specialist nurse) and physiotherapist Caroline Belchamber, and was grateful for the consent and co-operation of the patients and carers who allowed me to observe their clinic appointments. I was very impressed by the expertise and experience, which provided me with several ideas to improve care of our patients in Geelong." (E-mail: Information for hospice newsletter: palliative medicine specialist: August, 2014)

I now oversee the clinic as the specialist nurse is competent in the week by week running of the clinic. I have since been asked by the hospice to develop the physiotherapy service provision for the new in-patient unit within the hospice, which I will take on with the new skills and knowledge that I have gained through my research and practice development components of my

DProf. My new skills relating to facilitating change and mentoring staff will be particularly helpful.

Learning and Development

The application of learning is central to the success of ongoing improvements to practice (Wall et al. 2013). This is where my combined roles of education, research, enterprise and practice development fuse together, in line with the Bournemouth University's Strategic Plan for Fusion (BUSP, 2012 - 2018).

The whole practice development process has been a steep learning curve for me. It has enabled me to use my diverse physiotherapy skills and expertise in palliative cancer care, my educational skills and knowledge from my physiotherapy lecturing role, including other skills such as research skills and palliative rehabilitation skills developed during my MSc and DProf.

5.7 Reflexive Narrative

Skilled facilitation is seen to be the cornerstone of successful practice development, where innovation and sustainable change is required (Harvey et al. 2002; Rycroft-Malone et al. 2004). With the current challenges in the delivery of patient-centred care strong leadership is necessary along with rigorous practice-based research and the development of robust methodologies to transform health care professionals and practice, enabling research knowledge to be applied appropriately for effective practice (Manley and McCormack 2003; FitzGerald and Armitage 2005; McSherry and Warr 2006; Hamer and Page 2009).

As skilled facilitation is core to transformational practice development I decided to use the Practice Development Framework proposed by Crisp and Wilson (2011). This framework is ideal as it provides a structure for reflection on self-development with potential approaches to improve. This is essential, as successful transformational practice development is dependent upon effective facilitation of health care professionals, teams and organisations to produce effective workplace cultures (Manley 2004). This framework includes three stages of facilitation skills: 1) Preliminary; 2) Progressive and 3) Propositional

(Table 18, p.204). I have used these stages as sub-headings to navigate the reader through my personal development.

Table 18: Stages of Facilitation Skills

Preliminary	Progressive	Propositional
Egocentric engagement with practice development	Values remain bound by concrete perceptions of practice development reality	Values associated with practice development encompass many personal and social possibilities
Limited awareness of self and impact on others in this engagement	Awareness of self, interpersonal relationships and emotional investments result in attachments to other practice developers	Embracing the potential ongoing transformation of practice development
Perceptions and actions based on naïve assumptions about practice development	Rules surrounding practice development can be changed by consensus	Freeing from a fixed notion of practice development – practice development reality is located within a range of ways of working
Imitating others – non-reflective action in evolving practice development reality	A step by step process of practice development is followed without generalisation of learning	Transformational thinking employing hypotheses and reasoning with regards to what is possible through practice development
Transforming practice reality to meet own needs	Interpersonal relationships with other practice developers are inherently co-operative in nature	
Forms of engagement with practice development are motivated by own evolving needs	Movement away from rules to more flexible ways of working – both in terms of practice development activities and their goals	
The rules of practice development are sacred and must be followed	Learning is related to the broader context of practice development and how that plays out in practice	
Learning based on repeated actions and experiences	Reality transformed by means of internalised actions that are grouped and coherent (perceptions based on internalised representations of practice development)	

(Reproduced with permission of Crisp and Wilson 2011)

Preliminary

In the preliminary stage I began with literature searches around practice development to understand its methodology and facilitation. My behaviour and thoughts were therefore centred on my personal development and the need to fulfil the practice development aspect of my DProf. Throughout my literature search I found that continuing professional development was seen as a vehicle for the development of practice, but was also seen as the consequence of practice development activity, as it results in enhancing the knowledge and skills of the health care professionals through its implementation.

Mallett et al (1997) described professional and practice development as a continuous process, which can be separated into two different areas; Professional development focusing on knowledge, skills and values, and practice development focusing on the implementation of the latter into quality patient-centred care. Joyce (1999) confirms the idea that practice and professional development are two separate concepts. An awareness of either a better method of service / care delivery or an awareness of a specific client need seems to be the trigger for practice development activity, similarly there is evidence that many developments in practice happen due to continuous professional development activity (Unsworth 2000).

Health care professionals tend to merge their interest in developing the service with a personal interest in their career progression and personal award (Carr 2000), which I can identify with. Nonetheless, whichever is the catalyst any health care professional intending to initiate practice development should ensure that the proposal is in harmony with the aims of the organisation, so that change can occur successfully. This has been possible through my honorary contract, immersion in the palliative cancer care environment and contract between Physiotherapy Cancer Care and the local hospice. Clarke (1998) states that the development of practice is integral to professional care; both care for the individual service users and the systematic enhancement of services and the professional role to meet the needs of service users. This stands true today where a strong link between continuing professional development, practice development and change are evident especially within

the developing palliative cancer care services and is reflected in my practice development project and research.

The early interactions between myself and practice development work established a sound foundation for creating a meaningful practice development reality (Crisp and Wilson, 2011), where I integrated new knowledge with personal theories, motivations and characteristics. In doing so, I have critically examined my responses establishing a firm basis for ongoing development and transparency for the reader. Critical reflection (Johns 1998; Maggs and Biley 2000); action learning (McGill and Brockbank 2004); active learning (Dewing 2008); and critical creativity (McCormack and Titchen 2006) are all strategies that a practice development facilitator can use to improve their development of expertise (Crisp and Wilson 2011). I have used a mixture of these strategies at different stages of my practice development.

At this preliminary stage I had embraced the role of practice development facilitator, with the assumption that I would be able to easily follow practical frameworks on private practice and practice improvement. These assumptions arose from reading around practice development, as well as having facilitated the development of an oncology physiotherapy in-patient service at a local hospital a number of years ago. I also had previous experience of being self-employed, delivering evidence-based oncology and palliative cancer care courses around the South West of England. As a consequence, I was very pragmatic with my practice development and was therefore relatively unaware of the impact my practice development was having on those around me.

However, this preliminary stage of practice development challenged my assumptions as I started to gain a deeper understanding of facilitation activities and what it involved. I learnt how to apply theories underpinning practice development activities and started to comprehend the role that I played as a facilitator.

Progressive

This stage took me longer than the preliminary stage, as it incorporated a number of complex and integrated elements of practice development. As a consequence, the majority of my expertise in practice development evolved during this progressive stage. Crisp and Wilson (2011) describe this stage in three phases: 1) Early, 2) middle and 3) latter phases.

My values as I entered the early phase of my development were anchored to my perceptions of practice development, nurtured through literature and past experiences. Reflecting back on this now I can see that I only had a surface understanding of what contributes to practice development. For example, a key principle of practice development is the engagement of participants in learning and action (Crisp and Wilson 2011). I thought that by providing information about my practice development to private practitioners, consultants and my line manager I would be meeting that principle! I have since learnt that it is the collaboration and active involvement of others that takes practice development forward in a positive and constructive way.

In the early phase I was following a step by step process, as described in the two practical frameworks that I chose for my practice development: 1) private practice framework and 2) improvement framework. This provided me with confidence and security, where I had internalised rules regarding the role of the facilitator (Crisp and Wilson 2011). For example, I followed the frameworks in a logical manner, ticking off accomplished tasks. Eventually I realised this was quite constraining and I needed to be more flexible in my approach as a facilitator. This required negotiation, exchanging of ideas and using the frameworks as a guide, rather than to the rule.

During the middle phase of my development I became more aware of myself and my learning. I realised that being more flexible and open to ideas, as described earlier provided a deeper awareness of my learning style and my approach to practice development. This led to a desire to link up with other practice development facilitators with similar experiences to reflect upon progress and aid problem solving. DProf peers and facilitators offered this

connection and support for me, providing co-dependent relationships (Crisp and Wilson 2011). For example, discussing the connection between my research and practice development project enabled me to take forward best practice recommendations into practice. This helped with the development of my private practice documentation and then the subsequent documentation in my practice improvement part of my practice development project. These changes and developments were required to provide quality palliative cancer care service provision.

Through the latter phase of my development my co-dependent relationships with my DProf peers and facilitators reduced as I became more competent in my practice development facilitator skills. This freed me from my internalised rules, allowing me to work more flexibly as I gained support from colleagues at the hospice, especially my key worker to improve practice within the breathlessness clinic. For example, providing mentorship to my key worker and guiding her in her studies, as well as listening to her ideas and suggestions for service improvement. At this point I wasn't only concerned about my own learning and development, but was now considering my colleagues learning and their ideas for practice improvement. This initiated a seminar on the breathlessness clinic at the local hospice, where myself and the key worker, developed the presentation materials and worked together, sharing our skills and expertise to deliver the session. Even though I was becoming more aware of those around me and working more flexibly, I still facilitated using processes, which although resulting in me learning about the essentials of facilitation, restricted me in the ability to transfer my skills to other areas (Crisp and Wilson 2011). This was because I felt that I needed to increase my confidence in facilitation and consolidate my learning and skills first, before I could transfer them to other areas.

Propositional

Moving into the propositional stage my knowledge, skills and theoretical understanding were merging to produce an integrated sense of self as a facilitator (Crisp and Wilson 2011). Here I had learnt to be flexible in my thoughts and actions, where I came to realise that my values and beliefs

surrounding practice development covered a variety of personal and social possibilities. This came about through my interactions with others, learning to problem solve from one another and seeing how different people approach problems in different ways. My surface understanding of principles, theories, actions and outcomes of practice development had therefore become deeper understandings and I had started to embrace potential and ongoing practice development transformations by changing my own thinking, creating hypothesis and developing logical and reliable opinions about what is possible and what is not in practice development. For example, what is possible is the engagement and development of practitioners, such as my key worker and myself, consequently improving practice for service users in a real healthcare setting. However, what is not possible is the success of practice development if practitioners are not working with the service users and are not engaged in the process. Core to practice development is patient-centred care and service user's needs do not cease at the boundaries of departments or clinics. Collaboration therefore needs to be extending beyond these boundaries for practice development to be truly successful, promoting creative potential. If this occurs, practice development can be collaborative, evolutionary and transferable to other areas of healthcare.

During my research and practice development project I metamorphosed in a number of ways: professionally I changed in form, from a health care professional to a researching professional; from an employee to an employee and entrepreneur; and from a physiotherapist to a facilitator of change, mentor and consultant. Personally I changed in form, from working rigidly to rules to working more flexibly; from lack of confidence in my new practice development and research skills to increased confidence in my new practice development and research skills; from a novice in research and practice development software packages to being competent in research and practice development software packages. The whole metamorphosis of palliative cancer care has therefore impacted upon me as the research tool and practice developer and changed my form over the last six years, opening my eyes to my own profession and questioning the health care provision for people living with cancer. All of these changes have been driven by policy documents over this

time frame and are the catalyst for the metamorphosis of palliative cancer care as a whole.

5.8 Conclusion

This chapter has set out the practice development component of my DProf and explained how it links in with my practice improvement, my DProf research and personal development. It has discussed how the two components of my DProf, research and practice development project have run concurrently and how each has informed the other. The next chapter will discuss my research findings, as well as my practice development project outcomes and their implications on the future practice of physiotherapy palliative cancer care, central to which, is the national standards of supportive and palliative care best practice recommendations.

CHAPTER 6: Discussion

6.1 Introduction

Research and Practice Development Aims Revisited

The overall aim of my doctorate was to explore the developing role of physiotherapists within the palliative cancer care settings. My research findings and practice development project outcomes do not stand as independent entities, but rather were influenced by each other, demonstrating the complexity of the phenomenon that I studied.

6.2 Metamorphosis

My work demonstrates that specialist physiotherapists have responded to the changing healthcare system, through the metamorphosis of their service provision and by addressing two out of three key policy recommendations i) service quality and ii) innovation (DH 2010e; DH 2014b). However, in my findings the specialist physiotherapists had not yet responded to the third key policy recommendation iii) measurement of service quality and innovation (DH 2010e; DH 2014b). I therefore attempted to address this gap in my practice development outcomes and have discussed the reasons for the difficulties in implementing this key policy recommendation later in the chapter. My work also identified key constituents that shaped the metamorphosis of physiotherapists working in palliative cancer care, demonstrating new ways of working and being.

Two key areas that emerged from my work were 1) development of physiotherapy service provision and 2) development of physiotherapy as a profession. I have framed the first key area around the key policy recommendations mentioned above: i) service quality; ii) innovation and iii) measurement of service quality and innovation. I have then gone onto the second key area, where I have discussed the chief constituents that shaped the development of physiotherapy as a profession.

6.3 Development of Physiotherapy Service Provision

6.3.1 Service Quality

A significant research finding in the development of physiotherapy service provision was the 'bottom up' approach that the specialist physiotherapists took to implement policy into practice. This was triggered by the gradual decline of service quality for palliative cancer care service users in the community, which was due to two overriding factors 1) the increasing numbers of palliative cancer care service users in the community and 2) the lack of palliative cancer care skills and input from the generalist physiotherapists. This trigger is an important factor in the future development of physiotherapy service provision and policy implementation, because commissioners and service providers lack an understanding between the generalist's and specialist's roles (Payne et al. 2002). This could be detrimental in the commissioning of future services for people living with cancer. This lack of understanding is not surprising as specialist providers within the voluntary sector often adopt different roles depending upon resources available to meet the complex needs of palliative cancer care service users (Robbins 1998). In addition, individual healthcare professionals, such as physiotherapists, bring different skills and characteristics to the palliative cancer care setting. These are then enhanced through continuing professional development around palliative cancer care competencies. This lack of understanding by the commissioners between the generalist and specialist roles may be detrimental to the care of palliative cancer care service users in the future and may reduce their quality of life. This issue needs to be addressed urgently, as there is an increasing emphasis in policies (DH 2010b; DH 2012c) for generalist physiotherapists rather than specialist physiotherapists providing palliative cancer care in the community, as this is seen as a cost effective way of moving forward.

In the UK a major focus of health policy has been around improving generalist palliative and end of life care (Higginson 2015) and specifically workforce development including education and training for generalists, as well as specialists (DH 2008b). However, generalists are identified as providing care for service users with less complex needs, while specialists focus on complex symptom management, which includes spiritual, psychological, cultural, grief

and loss support for the service user and their family (Higginson 2015). My work identified that this was a crucial part of the service users' care and has been discussed further in 6.4. My work also demonstrates that with service users living longer the complexity of their needs is increasing with generalist physiotherapists being unable to fulfil these needs. As a consequence, education of the generalist physiotherapist is required urgently, so that they are able to identify the increasingly complex needs of service users and meet policy recommendations. It is widely recognised that specialists should provide this education and support for generalists, but the nature and level of support is undefined (Higginson 2015) and with a lack of specialist physiotherapists (Copp et al. 2007; CSP 2010; CGSPC 2012), this will be difficult to implement. Therefore, how the community workforce is developed and up-skilled will need to be carefully considered to ensure generalist physiotherapists and service users have the support that they require. In addition, increasing the number of generalist and specialist physiotherapy posts is a prerequisite to managing the growing demand for palliative cancer care service user aftercare to ultimately improve service quality.

In my work to improve service quality the specialist physiotherapists acted as change agents and consequently policy champions. In healthcare reform the role of the change agent and their decisions during a window of opportunity (known as a critical juncture) has been shown to be vital (Capoccia and Kelemen 2007) and can make a significant impact on the outcome of service quality (Cerna 2013). In my work this occurred through networking and transformational leadership (discussed in section 6.4) where key stakeholders were identified to enable successful implementation of policy into practice. The specialist physiotherapists were capable of doing this due to their knowledge and involvement in local palliative cancer care physiotherapy service provision, where they could identify issues and put a case across for the need for change. My work demonstrates that this action requires flexibility, so that adaptations can be made for local difficulties and any contextual factors (Cerna 2013). Therefore, policy-makers will need to take into account local autonomy when implementing policies in the future. My work demonstrates how, within the 'new' NHS, service change might come about through this model of service

development, where the dominant hierarchical system of the NHS is changing to individuals and teams 'on the ground' leading the way.

In contrast to the above, the top down approach to policy implementation has tasked CCGs in England and local authorities (such as local health boards in Wales) to commission community or home based services (DH 2010c) in order to prevent unnecessary hospital admissions. However, there is a tension between a) a request for generalist rather than specialists in the community and b) a request for reduced costs and hospital admissions. In my research findings it could be interpreted that hospital admissions had increased, due to the crisis management occurring on the wards, which was perhaps because of the generalist's lack of palliative cancer care competencies. Therefore, hospital admissions may not reduce if the skills required to manage people with cancer are not available in the community. As a consequence, service quality may decline and costs may rise. Furthermore, even if generalists had the required palliative cancer care competencies there are not enough of them in the community (Copp et al. 2007; CGSPC 2012) to meet policy recommendations. My research findings demonstrate that having specialist physiotherapists rather than generalist physiotherapists, could reduce hospital admissions through this new model of working. This may cost more upfront, but actually it will be cheaper in the long term, as hospital admissions reduce. However, reliance on specialist physiotherapists may possibly lead to disempowerment of generalists, with the belief that only specialists can provide 'proper palliative care' (Murray et al. 2008).

The bottom up approach to the development of physiotherapy service provision therefore seems to be the way innovation and service development is happening in the UK healthcare system. My work is living out what the policies are stating, that best practice and community service models are recommended to address the changes occurring across the healthcare system (NICE 2004a; DH 2010c; DH 2012c). Physiotherapists therefore need to be a) aware that they can do something about their service, for example, empower people so that they can make change happen and b) have an understanding of current policies in order to make a case for change. My work is leading the way in this new way of working.

I will now discuss where my work fills gaps in the literature, under the second key policy recommendation, ii) innovation.

6.3.2 Innovation

In recent decades there has been a great deal written about links between research, policy and practice (Nutley et al. 2010). In spite of this, it has been recognised that there is still a major translational gap between these disciplines (Nutley et al. 2010). My work has addressed this translational gap in two ways: 1) a bottom up approach to policy implementation and 2) an entrepreneurial approach to physiotherapy service provision. However, identifying where the gaps are in the market requires entrepreneurial skills, which not all physiotherapists have but which NHS physiotherapists will require in order to develop and have their services commissioned in the future. This need links with the business model that the 'new' NHS has embraced and physiotherapists will need entrepreneurial skills to survive in this changing healthcare system.

The need for innovation in service provision has been high on the political agenda for decades. However, it has been acknowledged that implementation of innovations remains challenging (Barnett et al. 2011), with a lack of understanding regarding the role and attributes of policy champions in the innovation process (Locock et al. 2001). In my work these challenges were addressed through an innovation decision process, which included: knowledge; persuasion; decision; implementation and confirmation (Rogers 1995) and was facilitated by key specialist physiotherapists acting as champions (Greenhalgh et al. 2004b). This enabled specialist physiotherapists to develop innovative services, implementing national policy from a bottom up approach. Therefore, the most novel aspect of my work has resulted from the specialist physiotherapists identifying and addressing the palliative cancer care service users' complex needs, rather than from the policy documents per se. This supports the policy makers and academics who champion the need for healthcare professionals to not only be clinically competent, but also to have sufficient skills and knowledge to enable them to acknowledge, assimilate and act upon political, financial and governance issues (Hartley and Benington 2010; Shapiro and Rashid 2011). However, this radical change in service

provision and policy implementation has implications on how physiotherapists see their own roles in the way care is provided and received (DH 2010c), which I have discussed in Section 6.4.

The academic foundation to guide community palliative cancer care service provision is under developed (Murray et al. 2008; Cobbe et al. 2013) with only Mueller and Decker's (2011) study published on this topic to date. The novel approaches I have reported in relation to the development of community physiotherapy service provision and implementation of policy into practice therefore provides an original contribution to knowledge in this area.

I will now discuss how innovation is dependent up the third key policy recommendation: iii) measurement of service quality and innovation.

6.3.3 Measurement of Service Quality and Innovation

A significant research finding in the development of physiotherapy service provision was the lack of measurement of service quality and innovation by specialist physiotherapists. This may be due to the fact that when the business model was implemented into the 'new' NHS, physiotherapists were not well prepared. They have therefore had to adopt strategies, such as audits and evidence-based practice to evaluate their services in line with national standards of care and best practice recommendations.

Since 1997, within healthcare policies there has been a change in focus in the assessment of service quality from processes or targets to outcomes, with a lack of evidence to support either system in providing a true reflection of service quality and innovation (Roland and Ranson 2011). Outcome measures have been widely used as a measure of quality (Starfield and Shi 2007; Chow et al. 2009) and are dependent upon a number of features including, but not limited to the process and structure of healthcare (Campbell et al. 2000; Rubin et al. 2001). However, the use of outcome measures to measure quality and innovation is limited as some outcomes are difficult to measure, such as physical disability and rehabilitation (Castle and Ferguson 2010), which poses a major problem for physiotherapists. Furthermore, there are inherent difficulties

in implementing outcome measures in palliative cancer care: Firstly, palliative cancer care rehabilitation is a 'reverse' process to 'traditional' rehabilitation making it even more difficult to measure; secondly, outcomes, including patient reported outcome measures (PROM) are described as the main indicator of quality and yet the role of NICE in developing these outcomes suggests that process is equally important (DH 2010c); finally, outcome measures historically have not been included in the data collected around specialist palliative cancer care and commissioners will need to adopt both process and outcome measures to address this gap (CGSPC 2012).

For specialist physiotherapists, measuring service quality and innovation is complex as there is a tension between a) working within the team and b) working in a team approach and highlighting what additional things specialist physiotherapists bring to palliative cancer care because they are part of that team, making it very difficult to identify the contributions they are making. This is complicated further by the number of stakeholders involved, each of whom place different values on the diverse attributes and components of quality and frequently hold varying viewpoints on what constitutes quality (Campbell et al, 2000; Nakkeeran and Thiagarajan 2010). For example, the healthcare providers may focus on the processes of care, while the service users are more concerned with the accessibility or continuity of care, with healthcare managers focusing on efficiency of care, and purchasers of healthcare on costs, which might not be valued as much by the service users. As a consequence, the concept of quality is often viewed from the perspective of one stakeholder rather than from a collective view point (Campbell et al. 2000; George and Sanda 2006), which can cause conflict in goals and priorities and therefore requires different approaches to quality assessments (Buttall et al. 2008). Specialist physiotherapists will therefore need to find evidence that healthcare commissioners will respond to, which includes processes as well as outcomes to develop a business case. Using a business model approach, physiotherapists will need to see CCGs as customers and market their service in order for CCGs to consider purchasing it. The 'new' NHS is therefore becoming more privatised, which is not surprising as the modernisation process was based upon the private sector model of healthcare. Thus, my work is pioneering this new way of working.

One of my practice development outcomes was to attempt to measure service quality and innovation. However, this was not an easy process due to the inherent difficulties of implementing palliative cancer care outcome measures as highlighted. Part of this difficulty I have now realised, is due to looking at outcome measures from a profession specific perspective, rather than from an integrated perspective, which my findings demonstrate is key to service quality in palliative cancer care. I will therefore need to revisit the way I measure service quality and innovation in my practice development project and consider it within an integrated framework. The importance of integration will be discussed in the next section along with the other chief constituents that shaped the development of physiotherapy as a profession.

6.4 Development of Physiotherapy as a Profession

A significant research finding in the development of physiotherapy as a profession was the change in mindset of the specialist physiotherapist. My research findings showed that specialist physiotherapists are reinventing their identity and role, as knowledge agents of their service users' conditions and what they do in practice. As a consequence, new ways of working are recasting traditional perceptions of what it means to be a professional (Brown and Crawford 2003) and in particular what it means to be a physiotherapist. Consequently, physiotherapists' identities and professional practice are in a situation of change, as they reconstruct their roles and identity (Baxter 2011; Hammond et al. 2015). It could therefore be argued that the role of the professional body, such as the Chartered Society of Physiotherapy, which was once a dominant force, has been weakened. This is because multiple stakeholders have been created in the 'new' NHS representing organisational agendas, which now contribute and compete in the formation of professional roles (Jones and Green 2006; Grant et al. 2009). Therefore, in the 'new' NHS, professionals have to mediate between these stakeholders in order to interpret and shape their work (Moffatt et al. 2013) and with the introduction of any provider of healthcare meeting care quality commission standards of service provision, they will be able to bid for contracts (DH 2010c). However, this will require adequate outcome measures and processes to demonstrate the quality of their service provision.

In my work integrated teamwork was seen to be the cornerstone of enhanced service quality, a key recommendation of the NICE guideline on improving supportive and palliative care for adults with cancer (NICE 2004a). My work demonstrates that integrated teamwork and interdisciplinary collaboration brought about effective and efficient work, providing a seamless service improving service quality for palliative cancer care service users in the community. A number of essential characteristics of integrated teamwork were uncovered that enabled this to occur, where specialist physiotherapists changed their mindset and adopted new ways of working, which include: psychosocial-spiritual-cultural model of health care; sharing of skills, patient-centred care and service user involvement in decision making, which I will now discuss.

Historically, physiotherapists have favoured a more biomedical model of healthcare, modelling its professional practice on medicine (Henderson 2002; Nicholls and Gibson 2010). As a consequence, physiotherapists are usually very protective of their identity (Sparks 2002), preventing full integration into the multi-disciplinary team. The majority of physiotherapists remain protective of their skill set, which has been confirmed by the literature (Baxter 2011; Kreindler et al. 2012). Thus, core principles of medicine such as aetiology and the requirement for scientific neutrality still permeates throughout physiotherapy professional values (Nicholls and Gibson 2010). This negative side of healthcare professionals, where there is a pursuit of power, has been observed as a major inhibitor to NHS reforms over the past twenty-five years (Currie et al. 2008) in particular to inter-professional working (Robinson and Cottrell 2005). As a result, it is one of the biggest hurdles that the physiotherapy profession will have to overcome in order to meet policy and best practice recommendations. My work demonstrates that the specialist physiotherapists were able to overcome this hurdle by embracing the hospice ethos and philosophy of recognising the importance of integrating the psychosocial, spiritual and cultural aspects of care applying the essential characteristics of integrated teamwork. Reflection was key to developing the essential characteristics of integrated teamwork. By reflecting upon their own and the service user's mortality, specialist physiotherapists were much more in tune with their cultural and spiritual side of care, which then transferred to their colleagues. This eroded barriers and promoted collegiality, removing any threats and meeting on a

human level. This negated the power struggle often seen between healthcare professionals, where they are trying to protect their identity. The positive outcome of this was the ability to share skills between professions for the benefit of the service user. Through this process, specialist physiotherapists have changed their mindset and reflected upon their own spirituality producing a connectedness not only with the service users but also with other members of the multi-disciplinary team. This act of reflection enabled the specialist physiotherapists to provide meaning to their work through a process of continuous readjustment of their principles and ideals (Banks 2010). This highlights the importance of reflective practice in continuous professional development in both education and practice (Clouder 2000; Paget 2001). It also has wider implications for physiotherapists in other areas of practice.

Specialist physiotherapists have found the need to explore and reflect upon the depths of their own being, particularly in relation to death, which is seen as part of their personal and professional growth. This is a journey which they felt they should not avoid, no matter how traumatic and difficult it might be, as it was an important part of their understanding of the service users' own journey. Consequently, this attendance to the 'whole' person was seen to promote a deeper, more complete rehabilitation than physical care in isolation. This enabled the specialist physiotherapists to recognise and respond to the service user's individual needs, becoming more patient-centred. Specialist physiotherapists have been open to this challenge, where an intrinsic link between personal and professional spirituality has gone beyond professional practice, incorporating the wider service user community. Specialist physiotherapists have therefore learnt to respect the human spirit and its potential. Spiritual care in this instance is the person to person care, based upon a partnership, which recognises an essential component of humanity shared by service users and health care professionals alike. This is the essence of humanisation, where partnership affects all facets of care, ensuring service users are not just a number (Todres et al. 2009; Galvin and Todres 2013). Therefore, specialist physiotherapists have a tacit knowledge developed by reflecting in and on practice (Schön 1983), creating learning in action through experience and maturity. This know-how is extremely valuable, as it is most likely to lead to innovation in thinking and performance with a resultant

improvement in service quality (Bevan and Fairman 2014). My work verifies this statement.

By adopting the psychosocial-spiritual-cultural model of health care, where all components of this model intertwine, the specialist physiotherapists were able to explore spiritual pain in a similar way to physical pain. This was achieved through the presence of compassion, empathy, fostering of hope, touch, healing and providing spiritual care, as confirmed by Belchamber (2011b) and Belchamber et al (2013). Central to palliative cancer care rehabilitation for both the healthcare professional and service user is the promotion of a sense of belonging, meaning and purpose. This integration or 'wholeness' is perhaps what translates into the multi-disciplinary team, breaking down any tensions or barriers that might have prevented integration and sharing of skills. Hence, the transparency of the aim and process of palliative cancer care have prevented any inter-professional power struggles (Hunter and Segrott 2008; Dalley and Sims 2001; Fox et al. 2003). This is supported by Neumann et al (2010) who state that a prerequisite for effective teamwork and patient-centred care are clear goals and operational policies.

This shift in physiotherapy perspective was fundamental to my work and is important to physiotherapy as a whole, where physiotherapists are hesitant to include spirituality in patient care, due to lack of perceived time, training and overall discomfort with the spiritual domain (Oakley et al. 2010; Sargeant et al. 2012). However, by seeing people as people rather than service users or healthcare professionals they are able to integrate successfully as a team, from a human to human perspective. This makes a huge difference in service quality, is highly significant and a powerful influence as it underpins humanisation, eroding barriers such as protecting roles and identity as previously highlighted. The specialist physiotherapists were therefore seeing themselves as people first with physiotherapy skills and relating at that level. This enabled integrated teamwork and consequently the power imbalance that normally occurs began to disappear, facilitating patient-centred care. Thus, this new way of working, coming from a spiritual background of people living with cancer, could be transferred to other areas of physiotherapy where we were able to relate to people on a human to human level with our particular skills,

rather than feeling we need to protect our own professional identities. Two key benefits arose from this new perspective: 1) the ability to truly integrate teamwork and 2) the ability to comprehensively address service user's complex needs. This is what the policies are about and my work demonstrates that specialist physiotherapists are carrying this out in practice. This suggests that physiotherapy education should include training in spiritual care and humanisation, so that they become comfortable in the spiritual domain forming a natural part of practice.

In my work another essential characteristic of integrated teamwork was the sharing of skills. My work revealed that specialist physiotherapists had high levels of competency within a well defined knowledge base, which has been described as professional maturity (Finfgeld-Connett 2008). In this context professional maturity and experience has enabled the specialist physiotherapists to integrate and share skills (Axelsson and Axelsson 2009) and has been described as cross-boundary, unbounded or third space professionals who are best placed to *“build strategic advantage and institutional capacity”* (Whitechurch 2008, p.382). This maturity and experience was seen to link directly to the specialist physiotherapist's capability to cope with the physical, psychological and emotional demands of their clinical work. Experience and maturity therefore share common attributes and are an important element of the individual's social competency within the professional role (Boshuizen and Schmidt 2000). Adam et al (2011) state that for therapists to cross boundaries and be effective in practice they need to acquire maturity and professional judgement in order to meet the needs of complex service users. This maturity has been identified in therapists working in emotionally demanding areas of clinical practice (Gray and McPherson 2005). The specialist physiotherapists in my study demonstrated this maturity and experience enabling them to integrate and cross-boundaries to meet the palliative cancer care service users' complex needs and provide a seamless service.

A further essential characteristic of integrated teamwork noted in my work was joint decision making. This was seen to develop through the psychosocial-spiritual-cultural model of health care, which encouraged ownership of care. In contrast to this, generalist physiotherapists who are still embedded in the bio-

medical model of healthcare (Henderson 2002; Nicholls and Gibson 2010) and / or are inexperienced might prevent service users from disclosing important concerns and feelings. This may be due to over-emphasising the clarification of physical concerns and then moving swiftly on to provide advice and reassurance. Alternatively, they may be able to identify the service user's spiritual needs, but feel ill-equipped to be able to respond, due to a number of personal and / or professional reasons. This lack of being equipped for the task is a major failing of physiotherapy education and a hindrance to future practice, especially with the recent focus on the Francis report (2013). There is therefore an urgent need to recognise this issue as a requirement for continuing professional development in order to support this process of change for qualified generalist physiotherapists, as well as specialist physiotherapists in other areas of care, such as neurology and respiratory. In addition, the dominance of the medical model of healthcare in physiotherapy may be preventing service users taking ownership of their own care.

To reduce these barriers to integrated teamwork the profile and importance of inter-professional education needs to be raised within undergraduate education. The majority of the literature on inter-professional education emphasises the cultivation of collaboration and preparation of the individual professional to improve services (Barr et al. 2006). These aims are interdependent in driving forward effective teamwork and consequently service and care (Barr et al. 2006). However, an improvement in teamwork through inter-professional education in established community teams was found to deteriorate overtime, due to institutional constraints and / or self-protection and self-interest (Cashman et al. 2004). Therefore, sustained efforts will be required to maintain a change within the physiotherapy profession. In addition, policies will need to promote awareness between healthcare professional's needs and in particular the needs of palliative cancer care service users, to help break down any barriers. In my work the model that has functioned really well is the specialist physiotherapists working as a human being, alongside another human being with particular skills. This challenges the way we think of inter-professional and multi-professional working, where we focus on whether healthcare professionals know enough about each other's professions, rather than working on a human level. We therefore need to find common ground, for example, we are all

human beings who have different skills, removing threats and barriers that can be built up through the traditional view of inter-professional and multi-professional working. This humanistic view point enabled healthcare professionals to feel safe and explore other areas of care.

Thus, my work shows that physiotherapists have emerged like a butterfly from a cocoon, with a new skill set, coping strategies and integration within the multi-disciplinary rehabilitation team. However, the number of physiotherapists within these teams across the healthcare system remains scarce. This is partly due to the fact that there have recently been severe cuts to commissioned physiotherapy undergraduate training places, despite increasing demand for physiotherapy services (CSP 2010). It is also due to the skills and expertise of specialist physiotherapists not being recognised, with only a small number of specialist physiotherapists available in palliative cancer care. Furthermore, in the hospital setting the bio-medical model of health care is slow to change, as undergraduate physiotherapists are not receiving the education and training that they need to develop their clinical expertise in cancer care. This lack of education in palliative cancer care has been acknowledged by the Commissioning Guidance for Specialist Palliative Care (CGSPC) (2012), who suggests the development of e-learning tools to address this gap. There are therefore, still areas in physiotherapy education and training that need to be addressed as palliative cancer care continues to change. Only Macmillan, Marie Curie and a minority of universities are currently providing post-graduate education and training. For the physiotherapist this is limited and will not be adequate in the future to address the growing needs of palliative cancer care service users. Moreover, the new ways of working that have been discussed, could be applied more widely in physiotherapy to benefit other service user groups.

Another significant research finding in the development of physiotherapy as a profession was the transformational change that occurred through the specialist physiotherapist's facilitation of others, encouraging connection of ideas and knowledge, where a collective leadership style was important to sustain change. This style of leadership has been described as the direction in which service change and improvement should be going in the 'new' NHS, replacing the

traditional dominant model of leadership (Bevan and Fairman 2014). Furthermore, with the rapidly changing healthcare system the need for clinical, administrative and policy leadership to improve palliative care service quality is critical (Weissman 2003; Walshe 2008; Murray et al. 2008). In my work the specialist physiotherapists were seen as both effective leaders and policy champions (discussed in 6.3.1), where the energy and passion of the champion was translated into effective change using key leadership qualities. This included marketing the new service through: passion and advocacy for the service user; clear vision with defined goals; ability to implement change; ability to select and develop staff with knowledge of current and future roles; transparent and honest communication; and knowledge of educating and mentoring others. These leadership skills are transferrable and could have wider implications for physiotherapists, enabling transformation into lead clinicians for a variety of services. With the current changes in the UK healthcare service, opportunities such as these are becoming readily available and physiotherapists should make the most of these chances to remain fit for practice in a changing healthcare landscape. Therefore, the specialist physiotherapists in my work are at the forefront of this change in leadership style.

This leadership style has emerged from a change in the specialist physiotherapist's mindset, as discussed under my first significant research finding in this section. Bevan and Fairman (2014) describe this as 'dialogic,' where change is created through ongoing organisational conversations that influence people's thoughts and actions, bringing new understanding. This has opened up opportunities to involve the service users and their families, as well as the wider community in new ways, such as integrated teamwork. The specialist physiotherapists' change in mindset has also enabled them to embrace the psychosocial-spiritual-cultural model of healthcare, discussed earlier, rather than the bio-medical model of healthcare. In a similar way this exposure to 'dialogic ideas' has moved the specialist physiotherapists away from the 'diagnostic' method of dealing with change, which is akin to seeing the healthcare organisation as if it were a biological system, rather than one that is a *"socially co-constructed reality"* (Bevan and Fairman 2014, p.28).

Cancer networks were seen as part of this ability to be 'dialogic', as it enabled healthcare professionals with similar professional backgrounds and interests to come together across diverse areas of service delivery. Bevan and Fairman (2014) state that for transformational change to occur on a large scale, cohesive networks connecting disparate individuals and groups are required in order to increase diversity of contribution and thought. Perhaps then, in the rapid changes that have occurred in palliative cancer care, the disbanding of the cancer networks has been short-sighted and may slow down large scale change within this specialist area. Specialist physiotherapist will therefore need to embrace this transformational model of leadership in the future, in order to meet best practice recommendations and implement policy into practice.

Through facilitation of transformational change, I was able to expand and develop the breathlessness clinic and consequently improve service quality. This was achieved using a collective leadership style as described earlier, which sustained the changes that I made in the improvement element of my practice development project. Service quality was improved by introducing a skill mix to support people with chronic lung conditions using a nurse / physiotherapist model (Syrett and Taylor 2003). Mentoring the key worker in the main skills of the non-pharmacological approach to dyspnoea, especially around breathing techniques enabled the sharing and transference of skills between professions. This outcome resulted in the key worker metamorphosing into a respiratory nurse specialist. This achieved the aim of my contract with the hospice; however, physiotherapists might argue that this outcome would warrant the protection of physiotherapy identity rather than the encouragement of skill mix. Hence, this new way of working is developing other healthcare professional's skills to meet the needs of the service user and celebrates patient-centred care. Transferring skills and learning from each other is a new way of working that reflects the 'new' NHS where healthcare professionals won't be able to remain within their own professions, but will need to mentor, support and learn from other professions to meet the service users' needs. This adds to the mixture of new ways of being as a physiotherapist.

Due to the number of changes recommended within the policies and the speed in which the changes are occurring, it is vital that a much greater awareness of

potential risks to clinical care is highlighted especially with regard to palliative cancer care service users. Professional bodies, such as the Chartered Society of Physiotherapy should be at the forefront of these changes. My work can provide some answers as to how these issues might be addressed, which I have discussed under implications and future practice and research recommendations.

6.5 Implications and Future Practice and Research Recommendations

My work has uncovered a number of issues that warrant further exploration. Firstly, the bottom up approach to policy implementation, integrated teamwork, sharing of skills, humanisation and transformational leadership are areas of increasing interest within the healthcare system and policy documentation. Secondly, the allied health professional workforce development and in particular physiotherapy has lagged behind in the rapid metamorphosis of palliative cancer care service provision in a number of areas, such as training and education, business planning and measurement of service provision. In order to develop practice in the future these issues need to be addressed with the introduction of cancer care into the physiotherapy curriculum, so that physiotherapy graduates have a better understanding of managing people with cancer and picking up signs and symptoms of cancer that might otherwise be missed. Additionally, post-graduate training in cancer care is a necessity for generalist physiotherapists, who have a growing workload of cancer care service users requiring rehabilitation. There is also a need for a recognised career pathway for physiotherapists in cancer care to enable capacity building within the palliative cancer care workforce. Therefore, the implementation of a business model; the model of rehabilitation assessment and support levels 1 to 4, (NICE 2004a) and the psychosocial-spiritual-cultural model of healthcare into the physiotherapy curriculum would provide a basis to develop certain skill sets (a - e), which I have discussed below.

a) Business Skills

Introducing a business approach to service delivery is vital for undergraduate and post-graduate physiotherapists due to the importance of this topic in

relation to clinical practice and future commissioning of services. This is especially important in relation to cancer care services, which may be lost if this is not addressed imminently. Business planning for future physiotherapy cancer services is a key business skill for the setting up of services or practice development projects. Therefore, future research is needed to determine the current level of business expertise, the skill set needed and the best way to help physiotherapists develop these skills, so that physiotherapists are able to successfully develop and market their services to commissioners. This skill set, however, needs to be developed alongside specific clinical skills.

b) Specific Clinical Skills

Key physiotherapy clinical cancer skills, such as the non-pharmacological approaches to pain, fatigue and dyspnoea management need, to be available in both undergraduate and post-graduate training. In addition to this the psychosocial and spiritual aspects of care needs to be addressed with the introduction of the psychosocial-spiritual-cultural model of healthcare delivery within the curriculum. This will provide the foundation for comprehending the delivery of palliative cancer care rehabilitation and the need for complex communication skills.

c) Psychological and Communication Skills

There is a requirement for communication skills to be taught using multiple layers of communication to achieve the complexity required when working in cancer care and developing new services. Graduating physiotherapists will need the communication skills to provide them with the competence to discuss challenging questions from service users, families, relatives and / or carers, as well as the ability to influence stakeholders in developing new services. Therefore, future research is required in mapping and developing the most effective way to enhance the communication skills of physiotherapists to support a whole person approach in practice. Additionally, physiotherapy students will need to learn personal strategies to manage their own emotional and spiritual adjustment, enabling them to comprehend the dying process. This will involve knowledge around integrated team working and humanisation.

d) Teamwork Skills

Introducing a culture of change in professional teamwork is a necessity for the delivery of a seamless service in cancer care. Understanding each other on a human level and exploring basic transferable skills between professions will provide additional skill sets to all health care professionals. Introducing this concept of integration of healthcare professionals into the curriculum would therefore enable capacity building within the palliative cancer care workforce. Consequently, future research is required around integrated working from a humanistic viewpoint using Human Inquiry, such as a co-operative inquiry (Heron and Reason 2001) approach to deepen our understanding of the human skills that are required to enable healthcare professionals to work in an integrated way. This would also require evaluation of the palliative cancer care service provision.

e) Outcome Measures and Audit Skills

Physiotherapy undergraduate and postgraduate training is required to address cancer care outcome measures and auditing. This is specifically essential to palliative cancer care outcome measures that can be applied effectively by physiotherapists to assess their service delivery. By introducing this skill set into the curriculum, as well as in practice, physiotherapists working in cancer care will be able to demonstrate their worth. However, this will require further research to find appropriate outcome measures for physiotherapists to use in cancer care service delivery that are standardised and meaningful.

In future practice development, policy makers need to take into account the bottom up approach and transformational leadership skills in developing patient-centred services, rather than relying on traditional hierarchical dominant leadership skills and top down approach to policy implementation. Specialist physiotherapists also need to promote their skill base to the policy makers and be more explicit about their changing identity and role within the 'new' NHS. Education, as described earlier is a powerful way of changing practices and policies and physiotherapists are in a strong position to accomplish this. However, this will require creativity and innovation in implementing skill sets (a – e) into undergraduate and post-graduate physiotherapy training to enable a

deeper understanding of this metamorphosis. For example, practice-centred models of learning may be the answer to enhance quality palliative cancer care physiotherapy service provision, supporting physiotherapy practice and producing appropriate outcome measures. This may provide a platform for enhanced transformative learning, where physiotherapists and other palliative cancer care professionals are connected by common practice-centred needs and learning goals. As a continuing professional development resource, web-based activities developed by motivated specialist palliative cancer care physiotherapists, acting as educational champions, could support these communities of learning. These activities would be purposefully designed to develop practice-based competencies and address continuing professional development needs. Future research using a methodology such as appreciative inquiry would be required to study the efficacy of this model of learning and its impact upon the quality of palliative cancer care physiotherapy service provision.

Having discussed implications and future practice and research recommendations, I will now present the strengths and limitations of my work.

6.6 Strengths and Limitations of my Work

The major strength of carrying out a DProf, is the principal focus on professional practice, which has enabled me to learn from my own experience and forge new relationships leading to stronger links with the university where I work, the palliative cancer care physiotherapy profession and work based practice partners, each one informing and developing the others leading to an outcome which is greater than the sum of its parts (Gesalt approach).

The key strength of my work was uncovering the complex phenomena within my case study: Palliative cancer care physiotherapy service provision, in light of national standards of supportive and palliative cancer care best practice recommendations. A case study can aid researchers in comprehending complex issues (SPPC 2011). Therefore, my case study has provided me as the research tool and you as the reader, with a deeper understanding of the phenomenon of physiotherapists working in palliative cancer care.

A further strength of my research is the multiple sources of data that a case study can provide, which has allowed me to present numerous perspectives from: healthcare professionals' interviews; service users' interviews; service user and physiotherapist observations; as well as my policy document collection, giving a rich, deep understanding of the current situation for physiotherapists. In addition, observations have been documented in the literature as supplying valuable understanding of the effectiveness of palliative cancer care services, particularly in the community setting (Black 1996; Stroup et al. 2000). My case study has also enabled me to explore a real-life situation, where my findings can be used as a basis for the application of ideas and extension of methods (SPPC 2011).

Difficulties in the process included the amount of data generated by my case study with the time required to transcribe, analyse and compare my data, including my competence in carrying out the analysis and its interpretation of meaning. There were also major challenges in undertaking palliative cancer care research from both an ethical as well as from a practical perspective, such as engaging with people who are coming to the end of their life. Also, the number of health care professionals involved in palliative cancer care rehabilitation can make it difficult to explore one profession in isolation. There are however, some limitations of case study research, such as not being generalizable. For example, I cannot claim that my case study is typical of all specialist palliative cancer care units, as I have no way of empirically knowing if my case study is similar or different. Nevertheless, my case study can provide transferability (Hodkinson and Hodkinson 2001). For example, through my description of the context of data collection and analysis of my case study the reader can judge the relevance of my findings to other situations. To bring this chapter and my thesis to a close I will now reflect upon my DProf journey.

6.7 Reflexive Narrative

I have developed and changed as an individual during my doctorate, through a journey of self-re-construction (Scott et al. 2004), transforming my multiple roles

(Figure 1, p.18) in a variety of ways. The process of fusion between my roles has opened my eyes to links between theory and practice, demonstrating to me gaps in my own practice and skill set (education, practice and research). As a consequence, my doctoral journey has impacted upon and influenced my disposition, professional attitude and confidence. This has brought with it a rollercoaster of emotions, where at times I have felt vulnerable, confused, disorientated, and then confident and assured only to return to my previous emotions, as I was taken in and out of my comfort zones. A necessary learning and developing process (William and Glasby 2010; Williams 2011) in helping me to implement change both personally and professionally (Barker and Cole 2007; Paton et al. 2008).

According to Forbes (2008) doctoral learning provides opportunities for reflexivity, characterised by the experience of epistemological uncertainties of which being reflexively self-aware is paramount. Therefore, reflection on practice (Schön 1983) and planning has been a necessary prerequisite of my DProf, due to the complexity and unpredictability of the professional contexts within which my doctoral research and practice development took place. Reflection and planning therefore became an inherent and ongoing process, which I will reflect upon under key headings of disposition, professional attitude and confidence.

Disposition

One of my characteristics is to be well organised, with a love of order and the use of tables to present my ideas. There were disadvantages and advantages to this characteristic. Firstly, it was an advantage in the fact that being organised helped me to manage the complexity and unpredictability of my research and practice development project. Secondly, I found it to be a major hindrance in carrying out my qualitative research, especially when it came to analysing my data and writing up my findings. Becoming more qualitative in nature was probably the most difficult area of my doctoral journey to overcome. I tried different ways to conquer these major hurdles with the help of my supervisors, who encouraged me to emerge from the depths of my research data and look at the whole picture. However, even when I had succeeded in

passing these hurdles it led me to the biggest mountain I had to climb – writing my discussion chapter. This seemed like an insurmountable wall preventing me reaching my goal. It was almost as if the pressure of nearly completing my doctoral journey was too much and I wanted to stop, like a marathon runner who has run out of energy within the last few miles of the finish line. Even so I kept a positive and professional attitude towards my doctoral work and endeavoured to problem solve, which is at the very heart of physiotherapy.

Professional Attitude

This awareness of my quantitative nature demonstrated to me how my professional attitude and behaviours played a deeper role in my professional development than I had realised. For example, I had worked in palliative cancer care since 2000 and had immersed myself in the psychosocial-spiritual-cultural model of health care, moving away from the medical model of health care and yet my quantitative nature still emerged in other areas, such as my research. This surprised me as I had carried out qualitative research for my Master's degree, so was naïve enough to assume that I had a good grasp of qualitative research. However, I soon came to realise during my doctoral journey that I had a lot more learning to do! This included being able to let go, to write freely and be creative, all of which seemed so alien to me! To do this I needed to understand my own belief systems and overcome any barriers to my learning. My belief system, which is the foundation of my professional attitude and behaviours, has changed over time. This has occurred through questioning my own predispositions and responses to situations, as I have developed my scope of practice from a novice physiotherapist to a qualified physiotherapist; from a respiratory physiotherapist to a palliative cancer care physiotherapist; from a clinician to a lecturer; from a lecturer to an entrepreneur and researching professional. This has all culminated in my doctoral journey, a journey of learning and self-realisation. A journey where I have questioned the ideals of my professional practice through the exploration of physiotherapist's behaviour in palliative cancer care and observing how physiotherapy practice needs to change. A journey where I have questioned my own learning style; physiotherapy education and practice through reflexivity, which has consequently had an impact upon confidence in my own belief system and

professional attitudes. Therefore, the more I understood about what I was trying to achieve and the disposition that would help or hinder me the more I gained confidence in the likely outcome. This knowledge management enabled me to engage in a process of innovation and improvement in practice (Williams 2011).

Confidence

The whole doctoral journey has had an effect on my confidence, the confidence in my own physiotherapy profession, practice and education. I have questioned who and what we are and how we as a profession are relating to the changes of the health care system? I have questioned our current educational process in preparing physiotherapists to be fit for practice in this changing health care system. Through my doctoral journey I have found confidence in the authenticity of my own views of physiotherapy practice and education, which gave me motivation to negotiate and collaborate confidently in the workplace and will help me in disseminating my research findings and practice development project outcomes in the future. Due to this doctoral process and having ‘insider’ knowledge of palliative cancer care I was ideally placed to make changes and manage my practice development project (Cameron and Green 2009). I have been able to shape physiotherapy culture in the workplace via my practice development project and research findings, whilst fostering professional autonomy and continuing professional development. I hope in doing so I will assist in the survival and blossoming of physiotherapy in the future health care system.

Thus, my confidence has been dynamic in nature throughout my doctoral journey, a maturing personal belief in the physiotherapist’s role, scope of practice and significance of the profession (Holland et al. 2012). This has enabled me to develop and foster professional confidence in a number of areas, such as my practice development project, research and education, which has sparked a passion to continue to move forward with my work.

6.8 Conclusion

The specialist physiotherapist's way of being needs to be embraced by the profession if physiotherapy is to remain fit for practice in the 'new' NHS. My thesis therefore provides a framework and unique perspective within which the physiotherapy profession can focus its attention on how physiotherapy needs to change in the future. Suggestions include nurturing: mentorship skills; entrepreneurial skills; leadership skills; policy champion skills; essential characteristics of integrated teamwork; humanisation; psycho-social-cultural-spiritual model of healthcare and self-reflection, all of which relates to my case study so readers may wish to draw upon their own conclusions as to how the findings correlate with their specific setting particularly in the field of palliative cancer care.

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APPENDICES

Appendix 1: Funding letter of support

(County) CANCER NETWORK

Address removed for
confidentiality

13th November 2009

Research Administrator
Dimbleby Cancer Care
4th fl Management Offices
Bermondsey Wing
Guy's Hospital
Great Maze Pond
LONDON SE1 9RT

Dear Sir / Madam

Caroline Belchamber, doctor of professional practice (DProf) research

Mrs Belchamber is currently researching for her doctorate on the subject of Physiotherapy and whether it meets National Care Standards.

As you will be aware, Living With and Beyond Cancer is a major feature of the Cancer Reform Strategy and the survivorship and palliative care agendas are a priority in delivering quality care to cancer patients. Therapies which support palliative care, in particular helping to maintain a good quality of life for cancer patients, are becoming increasingly important and are viewed as an integral part of the treatment pathway. It has been acknowledged that physiotherapy has core skills that can support the person living with cancer by enabling people to adapt to their changing condition through realistic goal setting and patient-centred care. In addition the rehabilitative care physiotherapy can provide aims to maximise independence by reducing the extent to which symptoms can interfere with the persons physical, psycho-social and spiritual functioning. The latter includes provision of coping skills and strategies, which assist in the management of the changing physical status of disease progression playing an important role in the management of breathlessness, anxiety and pain management as well as other more complex conditions. There are therefore numerous benefits to both the patient and carer as well as cost benefits to the Trusts in preventing unnecessary hospital admissions through physiotherapy interventions. However, further research is needed to assess patients' understanding of the benefits of physiotherapy, as well as the perceptions of health care professionals.

Mrs Belchamber's important research will address all of these issues and link them to the National Standards. Without her research it will be difficult to assess and quantify gaps in the physiotherapy service that we provide to our patients and to subsequently rectify these gaps. The (county) Cancer Network is therefore fully in support of Mrs Belchamber's research and we hope that funding will be provided to her.

Should you wish to discuss any aspects of my letter, please contact me at the above address.

Yours faithfully

A handwritten signature in dark ink, appearing to read 'J Lawry', with a stylized flourish at the end.

Jan Lawry MA
Service Improvement Facilitator
(County) Cancer Network

Appendix 2: Example summary of articles and critique

Author /s	Title of paper	Country of origin	Year	Method	Sample size	Sample	Key findings	Critique
Connors S; Graham S; Peel T.	An evaluation of a physiotherapy led non-pharmacological breathlessness programme for patients with intrathoracic malignancy	England	2007	Quant	169 14 completing full 4-week programme	Aged 80 and over Female and Males	<p>The 155 patients who did not complete the programme had a short median survival (95 days) and tended to have cancer related breathlessness</p> <p>In a group whose natural history is a relentless deterioration over a period of months, pre and post-intervention symptom scoring is difficult to achieve</p>	<p>A qualitative approach might be more sensitive at identifying which aspects of the service are most appropriate for this patient group</p> <p>Breathlessness programme was PT led, who had only attended a 3 day education programme based on the Corner model in 1997</p> <p>Study compared to Bredin et al 1999 and Corner et al 1996 studies – higher drop out found in this study, likely reason being in the patient selection</p> <p>Only seven references, which did not include Hatley et al 2001 – also PT led</p>
Copp G; Caldwell K; Atwal A; Brett-Richards M; Coleman K.	Preparation for cancer care: perceptions of newly qualified HCPs	Scotland	2007	Quant cross-sectional postal survey design	50 graduates from each professional category in nursing, occupational therapy, physiotherapy, and social work were sampled yielding a total sample of 200	Twenty-eight (33%) respondents stated that they were currently involved in working with people with cancer. These were as follows: 5 nurses, 8 PTs, 9 OTs	<p>A positive link between HCPs' educational input and experience of working with people with cancer was found e.g. confidence, communication skills, decrease in anxiety and application of knowledge gained in classroom to professional practice</p>	<p>Findings of this study clearly have implications for education and practice</p> <p>There is a positive trend with regard to cancer education and learning in practice for professionals, nonetheless, they highlight the gaps in our present knowledge about the effectiveness of shared teaching and learning across and between the different professional groups; in particular the perceived lack of sufficient classroom input to prepare health professionals for working with cancer patients</p> <p>Future studies will need to determine the</p>

						and 6 social workers	Most respondents learnt about caring for cancer patients through practice rather than classroom teaching	specific needs and collaborative learning activities between different HCP groups, an area which have been largely ignored to date
Donnelly CM; Lowe-Strong A; Rankin JP; Campbell A; Allen JM; Gracey JH.	Physiotherapy management of cancer-related fatigue: a survey of UK current practice	Germany	2010	Quant Postal questionnaire	223 out of 341 (65%) response rate	PTs who are members of the UK Association of Chartered PTs in Oncology and Palliative Care (ACPOPC)	<p>Findings show therapists feel their practice is affected by the lack of exercise guidance for the cancer population</p> <p>Results found that physiotherapy undergraduate education regarding CRF was rare</p> <p>The current findings suggest that physiotherapy practice would greatly benefit from specialist training opportunities in facilitating exercise with cancer patients</p> <p>Cancer survivors show a high level of interest in physical activity counselling</p>	<p>Only members of ACPOPC were surveyed; therefore, a sampling bias exists and findings cannot be generalised to wider PT practice</p> <p>The closed response format of the survey may have led to different interpretations of questions between respondents</p> <p>This study highlights the need for structured learning opportunities across settings, so that all patients with fatigue treatable by physiotherapy are identified</p> <p>Further research is required to establish the optimal types, timing, intensity, frequency and duration of exercise across all stages of the disease trajectory</p> <p>Promoting the role of PTs in managing CRF to other health professional groups and health care commissioners, as well as research determining cost-effective methods of exercise delivery, is necessary</p> <p>The most effective method of delivering exercise counselling should be investigated with the aim that this could become standard practice for PTs in all comprehensive cancer centres</p>

Appendix 3: Ethics letter of approval

NHS
National Research Ethics Service
Berkshire Research Ethics Committee
Building L27
University of Reading
London Road
Reading
RG1 5AQ
Telephone: 0118 918 0550/1
Facsimile: 0118 918 0559

14 December 2009

Mrs Caroline A Belchamber
Physiotherapy Lecturer
Bournemouth University
Royal London House, R601
Christchurch Road
Bournemouth
BH1 3LT

Dear Mrs Belchamber

Study Title: Palliative care: Are we meeting the standards?
REC reference number: 09/H0505/108
Protocol number: 1

Thank you for your letter of 20 November 2009, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>
Where the only involvement of the NHS organisation is as a Participant Identification

This Research Ethics Committee is an advisory committee to South Central Strategic Health Authority

The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England

Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter		29 July 2009
Email from CI to REC		31 July 2009
REC application	1	29 July 2009
Investigator CV		28 July 2009
CV: Dr E Carr		29 July 2009
CV: Dr J Warr		28 July 2009
Protocol	1	28 July 2009
CERES Leaflet		
GP/Consultant Information Sheets	App 8, v1	28 July 2009
Consent Check List	App 4, v1	28 July 2009
Confidentiality Form	App 5, v1	28 July 2009
General Risk Assessment Form - Domiciliary Visits for private practice: Physiotherapy Cancer Care	App 11, v1	28 July 2009
General Risk Assessment Form - Interviews with palliative care service users	App 10, v1	28 July 2009
Interview Agenda - Health Care Prof	App 13, v1	28 July 2009
Interview Agenda - Service User	App 12, v1	28 July 2009
UMAL Indemnity Cover		01 August 2008
Peer Review		20 April 2009
Letter from Trust re: Honorary Contract		16 October 2008
Response to Request for Further Information		20 November 2009
Participant Information Sheet: Service User - Interviews	2	20 November 2009
Participant Information Sheet: Health Care Professional - Interviews	2	20 November 2009
Participant Information Sheet: Service User - Participant Observation	2	20 November 2009
Participant Information Sheet: Participant Observation Leaflet	2	20 November 2009
Participant Information Sheet: Physiotherapy - Participant Observation	2	20 November 2009
Participant Information Sheet: Participant Observation Leaflet	2	20 November 2009
Participant Consent Form: Form 2: Service User, Interview	2	20 November 2009
Participant Consent Form: Form 3 - Health Care Prof, Interviews	2	20 November 2009
Participant Consent Form: Form 4: Service User, participant observation	2	20 November 2009
Participant Consent Form: Form 1: Physiotherapist, Participant Observation	2	20 November 2009
UMAL Insurance cover	01.08.09 - 31.07.10	01 August 2009
Hon Contract Letter		12 November 2009

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Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

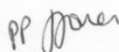
The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk

09/H0505/108

Please quote this number on all correspondence

Yours sincerely

PP 

Professor Nigel Wellman
Chair

Email: scsha.berksrec@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: Sponsor - Dr. B. Gail Thomas, Bournemouth University

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Appendix 4: Transcription confidentiality agreement

Confidentiality form

Title: **Are physiotherapists meeting National Palliative Care Standards? A case study approach**

Confidentiality and anonymity will be the main priority in protecting those participating in a study of this nature. Although anonymity cannot be fully guaranteed, it is imperative that the transcriber involved in the study agrees to the following:

- Any information gained through the interviews will not be divulged to anyone not involved in the study.
- All recorded data will be kept locked away when not being transcribed.
- The transcriber's guidelines will be followed at all times.
- Interview transcripts will be completed and transcribed only by the transcriber appointed by the researcher.
- The transcripts will remain with the transcriber during transcription until returned to the researcher.
- Pseudonyms will be used to provide anonymity for the participants in the transcripts.
- An Id code will be used for all interview data transcribed.

Signature of transcriber _____ **Date** _____

Please print name _____

Appendix 5: Service user information sheet – Interviews

Service User Information Sheet - Interviews

Date:.....

Study Title: Are physiotherapists meeting National Palliative Care Standards? A case study approach

You are being invited to take part in a research study, which is being carried out as part of an educational qualification. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends and relatives if you wish. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for taking time to read this information sheet.

1. What is the purpose of the study?

The purpose of this study is to provide an understanding of the complex world of physiotherapists working in palliative care. It will explore your views, ideas and experiences of physiotherapy in palliative care. You as a participant will be able to provide valuable information regarding this through semi-structured interviews. In addition healthcare professionals and physiotherapists' views, ideas and experiences will be explored. The researcher will then use the information collected to help clarify the contribution physiotherapists make in helping you to manage your symptoms. This will be looked at in conjunction with the National Institute of Clinical Excellence Guidelines (NICE), and other relevant department of health (DH) documents.

2. Why have I been chosen?

You have been chosen because you are attending the palliative care venue and are being treated by the physiotherapist. You also fit the requirements of the inclusion / exclusion criteria for the study. (Please talk to the study physiotherapist if you would like this explained).

3. Do I have to take part?

No you do not have to take part in the study. I have provided you with this information sheet so that you can make an informed decision as to whether you wish to take part or not in the study. Taking part in this study is voluntary and deciding whether or not to take part will not affect your care. During the interviews you will not be required to answer any specific questions if you chose not to and have the option to withdraw at any time from the interview or study and the tape destroyed.

4. Who is organising the study?

The study is being organised by Caroline Belchamber (Physiotherapy Lecturer, Bournemouth University) as a research dissertation for a doctor of professional practice (DProf), at Bournemouth University.

The study is being funded by the Association of Chartered Society of Physiotherapists in Oncology and Palliative care (ACPOPC) research grant and the Chartered Society of Physiotherapy Charitable Trust fund. The study will run for three years in total, with collection of information over a twelve-month period.

5. What will happen to me if I take part?

Your care at the palliative care venue will continue as usual. The researcher will arrange a date and time convenient for you for the interview to take place. This will be organised on a day that you are able to attend and can be changed if you are feeling too tired or unwell. The interview will take place in a quiet room and will last approximately one hour. During the interview you and the researcher will be the only people present. A tape recorder will be used to tape the interview and the researcher will make notes during the interview.

6. What do I have to do?

If you decide to take part in this study then you will be offered an interview consent form to sign, agreeing that you would like to participate in the study interviews. A separate participant information sheet about the studies participant observations has also been given to you. If you decide to take part in the participant observation, then you will be offered a participant observation consent form to sign as well

7. Are there any disadvantages in taking part in this study?

There are no significant disadvantages in taking part in this study, however you might find the interview process tiring, as this will occur over a one-hour period. The researcher is also sensitive to your needs and will order the interview questions in such a way as to not cause you any discomfort. However should you have any concerns about any of the questions the researcher will be able to offer to assist in answering these in a sensitive manner or if necessary refer you to an appropriate member of staff. A prompt response will then be offered to you. You can contact the study physiotherapist on (01202 962158) if you have any concerns about the study.

8. What are the possible risks of taking part?

The semi-structured interviews are lengthy and will last about one hour. You may find this exhausting. If there is a change in your condition, or if the multi-disciplinary team decide it is no longer appropriate for you to take part in the study then the following action will take place.

- The study physiotherapist will discuss the situation with you
- You will be given the option to continue or drop out of the study if you still fit the inclusion / exclusion criteria, which includes; people with a diagnosis of cancer; currently attending the palliative care unit; capable of articulating his / her conscious experience; requiring physiotherapy treatment
- The study physiotherapist will explain why you should no longer participate in the study if you no longer fit the inclusion/exclusion criteria

If at any time the study physiotherapist considers it in your best interest, she will withdraw you from the study. The study physiotherapist will explain the reasons and arrange for your care to continue.'

9. What are the possible benefits of taking part?

By focusing on the care you have received from the physiotherapy service at the palliative care venue you may benefit from increased understanding of the effect that care has had on your symptoms. The study will also provide you with a chance to express your opinion and views on palliative physiotherapy. It is also an opportunity to take part in a study that aims to have a positive impact on any future developments relating to the palliative physiotherapy service.

10. What happens when the study stops?

It is hoped that the information gathered in the interviews will help to improve the service currently offered to you by the palliative care physiotherapists.

The researcher will store hard copies of the interview notes and the tape recordings in a locked filing cabinet in the researcher's office in Bournemouth University. These will remain confidential with only the researcher and the researcher's supervisors having access to them. Interview notes will be transcribed and will have a unique code on them so that your name cannot be ascribed to it.

When the study stops excerpts of the taped interview will be given in the researcher's final dissertation paper. The taped interview will not be shared by anybody other than the researcher and the researcher's supervisors of the study. All excerpts / quotations of the taped interview given in the final dissertation paper will remain anonymous and you will not be identified as a participant.

The researcher will retain the taped interview until completion of the study for a period of 6 to 12 months and then it will be destroyed. The tape will be destroyed in accordance with Data Protection and the Records Management Code of Practice (DH, March, 2006).

11. Are there any restrictions on what I might eat or do?

No, there aren't any restrictions.

12. What if something goes wrong?

If taking part in this study harms you, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action. Regardless of this, if you have any cause to complain about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms are available to you. Any complaints can be made through the usual procedures at the palliative care venue.

13. Confidentiality - who will know I am taking part in the study?

All information, which is collected, about you during the course of the research will be kept strictly confidential. Any information about you, which leaves the palliative care venue, will be anonymised so that you cannot be recognised from it. Any information gained through the interview will not be divulged to anyone not involved in the study. All data will be kept locked away in an assigned filing cabinet and only those involved in the study will have access to the key. Interview transcripts will be completed and transcribed by the researcher. The transcripts will remain either with the researcher during transcription and data analysis, or held in an assigned locked filing cabinet at the palliative care venue. Pseudonyms will be used to provide anonymity for the participants in the transcripts and an identification code will be used for all interview data collection.

14. What will happen to the results of the study?

The results of the study will be written up in the study physiotherapist's dissertation. A copy will be submitted to Bournemouth University, the Director of the palliative care venue, IRAS and a further copy will be submitted to the association of chartered physiotherapist in oncology and palliative care (ACPOPC), the study physiotherapist will also keep a copy. Please let the study physiotherapist know if you would like to read a brief summary of the study.

Wider dissemination of the research results will include conference presentations and future publications. The study may also evolve to set up a private practice for people living with cancer.

15. Who has reviewed the study?

The Bournemouth University School Postgraduate Committee and Bournemouth University Research Governance and Ethics have reviewed the study and this study was given a favourable ethical opinion for conduct by the Berkshire Research Ethics committee.

16. Contact for further information

If you require further information you should contact;

Caroline Belchamber, Physiotherapy Lecturer, Royal London House, R601, Christchurch road, Bournemouth, Dorset, BH1 3LT

Tel No: 01202 962158

E-mail: cbelchamber@bournemouth.ac.uk

Or alternatively contact the researcher's supervisor:

Dr Jerry Warr, reader, Bournemouth University, School of Health and Social Care, Centre for practice development, 1st floor, Royal London House, Christchurch Road, Bournemouth, Dorset, BH1 3LT

Tel No: 01202 962788

E-mail: jwarr@bournemouth.ac.uk

....., Senior Clinical Leader at the palliative care venue is an independent person who can also provide you with advice and information concerning this study.

The study physiotherapist, the multi-disciplinary team, and the Director of the palliative care venue would all like to thank you very much for your participation in this study.

You will be given a copy of the patient information sheet and a signed consent form to keep.

Appendix 6: Healthcare professional information sheet

Health Care professional Information Sheet - Interviews

Date:.....

Study Title: Are physiotherapists meeting National Palliative Care Standards? A case study approach

You are being invited to take part in a research study, which is being carried out as part of an educational qualification. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with colleagues and other Health Care Professionals if you wish. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for taking time to read this information sheet.

1. What is the purpose of the study?

The purpose of this research is to explore palliative care physiotherapy service provision against best practice in relation to their contextual situation. In order to do this I will need to involve the multi-disciplinary team at the palliative care unit. I will require both service user and health care professional participants in order to gather data about views, ideas and experiences of physiotherapists in palliative care. You as a participant will be able to provide valuable information regarding this through semi-structured interviews. In addition service users' views, ideas and experiences will be explored. The researcher will then use the information collected to help clarify the contribution physiotherapists make in helping service users manage their symptoms. This will be looked at in conjunction with the National Institute of Clinical Excellence Guidelines (NICE), and other relevant department of health (DH) documents.

2. Why have I been chosen?

You have been chosen because you are part of the Health Care Professional team at the palliative care venue and are treating service users who fit the requirements of the inclusion / exclusion criteria for the study. (Please talk to the study physiotherapist if you would like this explained).

3. Do I have to take part?

No you do not have to take part in the study. I have provided you with this information sheet so that you can make an informed decision as to whether you wish to take part or not in the study. Taking part in this study is voluntary and deciding whether or not to take part will not affect your employment status. During the interviews you will not be required to answer any specific questions if you chose not to and have the option to withdraw at any time from the interview or study and the tape destroyed.

4. Who is organising the study?

The study is being organised by Caroline Belchamber (Physiotherapy Lecturer, Bournemouth University) as a research dissertation for a doctor of professional practice (DProf), at Bournemouth University.

The study is being funded by the Association of Chartered Society of Physiotherapists in Oncology and Palliative care (ACPOPC) research grant and the Chartered Society of Physiotherapy (CSP) Charitable Trust Fund. The study will run for three years in total, with collection of information over a twelve-month period.

5. What will happen to me if I take part?

The lead for the palliative care team will be notified of your participation in the study. Your employment at the palliative care venue will continue as usual. The researcher will arrange a date and time convenient for you for the interview to take place. This will be organised on a day that you work at the palliative care venue and can be changed if your workload changes or you are ill. The interview will take place in a quiet room and will last approximately one hour. During the interview you and the researcher will be the only people present. A tape recorder will be used to tape the interview and the researcher will make notes during the interview. During your working day on the ward you may see the researcher writing field notes about conversations and observations, which will remain confidential and be anonymous. Only Physiotherapists who have consented to take part in the participant observations will be observed and field notes taken. A leaflet explaining the participant observations will be distributed in the immediate vicinity so that service users and staff are aware of the participant observations taking place. If you would like to see the participant observation leaflet, please request one from the researcher.

6. What do I have to do?

If you decide to take part in this study and have stated this verbally to the researcher then you will be offered an interview consent form to sign agreeing that you would like to participate in the study.

7. Are there any disadvantages in taking part in this study?

The researcher is sensitive to your needs and will order questions appropriately so that you will feel comfortable responding to them. However should you have any concerns about any of the questions the researcher will be able to offer to assist in answering these in a sensitive manner or if necessary refer you to an appropriate member of staff. A prompt response will then be offered to you. You can contact the study physiotherapist on (01202 962158) if you have any concerns about the study.

8. What are the possible risks of taking part?

The semi-structured interviews are lengthy and will last about one hour. You may find this difficult to fit into a very busy workload. Workload and availability will be the main issues and these will be addressed by organising interviews during quiet periods, which will be identified by the palliative care team. If there

is a change in your workload, or if the palliative care team decide it is no longer appropriate for you to take part in the study then the following action will take place.

- The study physiotherapist will discuss the situation with you
- You will be given the option to continue or drop out of the study
- The study physiotherapist will explain why you should no longer participate in the study

If at any time the study physiotherapist considers it in your best interest, she will withdraw you from the study. The study physiotherapist will explain the reasons and arrange for the lead of the palliative care team to speak to you.

9. What are the possible benefits of taking part?

By reflecting on the physiotherapy service provided at the palliative care unit you may benefit from increased understanding of the effect that physiotherapy has had on service users symptoms. The study will also provide you with a chance to express your opinion and views on palliative physiotherapy. It is also an opportunity to take part in a study that aims to have a positive impact on any future developments relating to the palliative physiotherapy service.

10. What happens when the study stops?

It is hoped that the information gathered in the interviews will help to improve the service currently offered to service users by the palliative care physiotherapists.

The researcher will store hard copies of the interview notes and the tape recordings in a locked filing cabinet in the researcher's office in Bournemouth University. These will remain confidential with only the researcher and the researcher's supervisors having access to them. Interview notes will be transcribed and will have a unique code on them so that your name cannot be ascribed to it.

When the study stops excerpts of the taped interview will be given in the researcher's final dissertation paper. The taped interview will not be shared by anybody other than the researcher and the researcher's supervisors of the study. All excerpts / quotations of the taped interview given in the final dissertation paper will remain anonymous and you will not be identified as a participant.

The researcher will retain the taped interview until completion of the study for a period of 6 to 12 months and then it will be destroyed. The tape will be destroyed in accordance with Data Protection and the Records Management Code of Practice (DH, March, 2006).

11. Are there any restrictions on what I might eat or do?

No, there aren't any restrictions.

12. What if something goes wrong?

If taking part in this study harms you, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for legal action. Regardless of this, if you have any cause to complain about any aspect of the way you have been approached or treated during the course of this study, the normal staff complaints mechanisms are available to you.

13. Confidentiality - who will know I am taking part in the study?

All information, which is collected, about you during the course of the research will be kept strictly confidential. Any information about you, which leaves the palliative care venue, will be anonymised so that you cannot be recognised from it. Any information gained through the interview will not be divulged to anyone not involved in the study. All data will be kept locked away in an assigned filing cabinet and only those involved in the study will have access to the key. Interview transcripts will be completed and transcribed by the researcher. The transcripts will remain either with the researcher during transcription and data analysis, or held in an assigned locked filing cabinet at the palliative care venue. Pseudonyms will be used to provide anonymity for the participants in the transcripts and an identification code will be used for all interview data collection.

14. What will happen to the results of the study?

The results of the study will be written up in the study physiotherapist's dissertation. A copy will be submitted to Bournemouth University, the Director of the palliative care venue, IRAS and a further copy will be submitted to the association of chartered physiotherapist in oncology and palliative care (ACPOPC), the study physiotherapist will also keep a copy. Please let the study physiotherapist know if you would like to read a brief summary of the study to read. Wider dissemination of the research results will include conference presentations and future publications. The study may also evolve to set up a private practice for people living with cancer.

15. Who has reviewed the study?

The Bournemouth University School Postgraduate Committee and Bournemouth University Research Governance and Ethics have reviewed the study and this study was given a favourable ethical opinion for conduct by the Berkshire Research Ethics committee.

16. Contact for further information

If you require further information you should contact;

Caroline Belchamber, Physiotherapy Lecturer, Royal London House, R601, Christchurch road, Bournemouth, Dorset, BH1 3LT

Tel No: 01202 962158

E-mail: cbelchamber@bournemouth.ac.uk

Or alternatively contact the researcher's supervisor:

Dr Jerry Warr, reader, Bournemouth University, School of Health and Social Care, Centre for practice development, 1st floor, Royal London House, Christchurch Road, Bournemouth, Dorset, BH1 3LT

Tel No: 01202 962788

E-mail: jwarr@bournemouth.ac.uk

....., Senior Clinical Leader at the palliative care venue is an independent person who can also provide you with advice and information concerning this study.

The study physiotherapist, the multi-disciplinary team, and the Senior Clinical Leader of the palliative care venue would all like to thank you very much for your participation in this study.

You will be given a copy of the Health Care Professional Information sheet and a signed consent form to keep.

Appendix 7: Service user information sheet: Participant observation

Service User Information Sheet – Participant observation

Date:.....

Study Title: Are physiotherapists meeting National Palliative Care Standards? A case study approach

You are being invited to take part in a research study, which is being carried out as part of an educational qualification. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends and relatives if you wish. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for taking time to read this information sheet.

1. What is the purpose of the study?

The purpose of this study is to provide an understanding of the complex world of physiotherapists working in palliative care. In order to do this the study will explore your experiences of physiotherapy treatment in palliative care. You as a participant and the physiotherapist treating you will be able to provide valuable information regarding this through notes being taken during participant observations. The researcher will then use the information collected to help clarify the contribution physiotherapists make in helping you to manage your symptoms. This will be looked at in conjunction with the National Institute of Clinical Excellence Guidelines (NICE), and other relevant department of health (DH) documents.

2. Why have I been chosen?

You have been chosen because you are attending the palliative care venue and are being treated by the physiotherapist. You also fit the requirements of the inclusion / exclusion criteria for the study. (Please talk to the study physiotherapist if you would like this explained).

3. Do I have to take part?

No you do not have to take part in the study. I have provided you with this information sheet so that you can make an informed decision as to whether you wish to take part or not in the study. Taking part in this study is voluntary and deciding whether or not to take part will not affect your care. During the participant observation you will not be required to answer any specific questions if you chose not to and have the option to withdraw at any time from the participant observation or study and the field notes destroyed.

4. Who is organising the study?

The study is being organised by Caroline Belchamber (Physiotherapy Lecturer, Bournemouth University) as a research dissertation for a doctor of professional practice (DProf), at Bournemouth University.

The study is being funded by the Association of Chartered Society of Physiotherapists in Oncology and Palliative care (ACPOPC) research grant and the Chartered Society of Physiotherapy (CSP) Charitable Trust Fund. The study will run for three years in total, with collection of information over a twelve-month period.

5. What will happen to me if I take part?

Your care at the palliative care venue will continue as usual. The researcher will arrange a date and time convenient for you and the physiotherapist for your treatment and the participant observation to take place. This will be organised on a day that you are able to participate and can be changed if you are feeling too tired or unwell. The participant observation will take place on the ward and will commence at the beginning of your treatment session and finish at the end of your treatment session. During the participant observation you and your physiotherapist will be observed from a distance so as not to be intrusive. People on the ward will be given a leaflet (see Appendix A) explaining that a participant observation is taking place. A note pad will be used to take notes of the participant observation and these will remain confidential and be anonymous.

6. What do I have to do?

If you decide to take part in this study then you will be offered a participant observation consent form to sign. A separate patient information sheet about the study interviews has also been given to you. If you decide to take part in the interview then you will be offered an interview consent form to sign as well.

7. Are there any disadvantages in taking part in this study?

There are no significant disadvantages in taking part in this study. Your physiotherapy treatment will occur as would have been provided to you if you had not taken part in the study. The experienced palliative care physiotherapist will know when to bring the treatment to a finish so you should not find the experience tiring. The researcher is sensitive to your needs and will be as discrete as possible during the participant observation. However, should you have any concerns about any of the participant observations then the researcher will be able to offer to assist in answering these in a sensitive manner or if necessary refer you to an appropriate member of staff. A prompt response will then be offered to you. Contact details are, (name removed) from the family support team at the palliative care unit, who can be contacted through the palliative care sisters (Tel No. removed). You may also wish to contact the study physiotherapist on (01202 962158) if you have any concerns about the study.

8. What are the possible risks of taking part?

Your physiotherapy treatment will be carried out as per the palliative care physiotherapist's guidelines and standards, the only difference being the researcher taking notes during this treatment time. However if there is a change in your condition, or if the multi-disciplinary team decide it is no longer appropriate for you to take part in the study then the following action will take place.

- The study physiotherapist will discuss the situation with you
- You will be given the option to continue or drop out of the study if you still fit the inclusion / exclusion criteria, which includes; people with a diagnosis of cancer; currently attending the palliative care unit; capable of articulating his / her conscious experience; requiring physiotherapy treatment
- The study physiotherapist will explain why you should no longer participate in the study if you no longer fit the inclusion / exclusion criteria

If at any time the study physiotherapist considers it in your best interest, she will withdraw you from the study. The study physiotherapist will explain the reasons and arrange for your care to continue.'

9. What are the possible benefits of taking part?

By focusing on the care you have received from the physiotherapy service at the palliative care venue you may benefit from increased understanding of the effect that care has had on your symptoms. It is also an opportunity to take part in a study that aims to have a positive impact on any future developments relating to the palliative physiotherapy service.

10. What happens when the study stops?

It is hoped that the information gathered in the participant observations will help to improve the service currently offered to you by the palliative care physiotherapists.

The researcher will store hard copies of the field notes from the participant observations in a locked filing cabinet in the researcher's office in Bournemouth University. These will remain confidential with only the researcher and the researcher's supervisors having access to them. Field notes will be transcribed and will have a unique code on them so that your name cannot be ascribed to it.

When the study stops excerpts of the field notes will be given in the researcher's final dissertation paper. The field notes will not be shared by anybody other than the researcher and the researcher's supervisors of the study. All excerpts / quotations of the field notes given in the final dissertation paper will remain anonymous and you will not be identified as a participant.

The researcher will retain the field notes until completion of the study for a period of 6 to 12 months and then they will be destroyed. The field notes will be destroyed in accordance with Data Protection and the Records Management Code of Practice (DH, March, 2006).

11. Are there any restrictions on what I might eat or do?

No, there aren't any restrictions.

12. What if something goes wrong?

If taking part in this study harms you, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action. Regardless of this, if you have any cause to complain about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms are available to you. Any complaints can be made through the usual procedures at the palliative care venue. Informal complaints concerning minor issues can be initiated with the Patient Advice and Liaison Service (PALS), contact (name removed), PALS Co-ordinator (e-mail address removed), (name of hospital removed) Hospital or front line staff and it will be dealt with as far as possible at that level. Where dissatisfaction persists, PALS staff advise of the option to pursue a formal complaint, which may be raised in writing with the Trust's complaints manager, Mr Simon Dursley, Complaints and Legal Services Manager, (name) Hospital.

13. Confidentiality - who will know I am taking part in the study?

All information, which is collected, about you during the course of the research will be kept strictly confidential. Any information about you, which leaves the palliative care venue, will be anonymised so that you cannot be recognised from it. Any information gained through the participant observation will not be divulged to anyone not involved in the study. All data will be kept locked away in an assigned filing cabinet and only those involved in the study will have access to the key. Observation field notes will be completed and transcribed by the researcher. The transcripts will remain either with the researcher during transcription and data analysis, or held in an assigned locked filing cabinet at the palliative care venue. Pseudonyms will be used to provide anonymity for the participants in the transcripts and an identification code will be used for all observation and field note data collection.

14. What will happen to the results of the study?

The results of the study will be written up in the study physiotherapist's dissertation. A copy will be submitted to Bournemouth University, the Director of the palliative care venue, IRAS and a further copy will be submitted to the association of chartered physiotherapist in oncology and palliative care (ACPOPC), the study physiotherapist will also keep a copy. . Please let the study physiotherapist know if you would like to read a brief summary of the study. Wider dissemination of the research results will include conference presentations and future publications. The study may also evolve to set up a private practice for people living with cancer.

15. Who has reviewed the study?

The Bournemouth University School Postgraduate Committee and Bournemouth University Research Governance and Ethics have reviewed the study and this study was given a favourable ethical opinion for conduct by the Berkshire Research Ethics committee.

16. Contact for further information

If you require further information you should contact;

Caroline Belchamber, Physiotherapy Lecturer, Royal London House, R601, Christchurch road, Bournemouth, Dorset, BH1 3LT

Tel No: 01202 962158

E-mail: cbelchamber@bournemouth.ac.uk

Or alternatively contact the researcher's supervisor:

Dr Jerry Warr, reader, Bournemouth University, School of Health and Social Care, Centre for practice development, 1st floor, Royal London House, Christchurch Road, Bournemouth, Dorset, BH1 3LT

Tel No: 01202 962788

E-mail: jwarr@bournemouth.ac.uk

....., Senior Clinical Leader at the palliative care venue is an independent person who can also provide you with advice and information concerning this study.

The study physiotherapist, the multi-disciplinary team, and the Director of the palliative care venue would all like to thank you very much for your participation in this study.

You will be given a copy of the patient information sheet and a signed consent form to keep.

Appendix A

Participant observation leaflet

This study is being carried out as part of an educational qualification

Title of Project: **Are physiotherapists meeting National Palliative Care Standards? A case study approach**

The following information has been provided to notify you that participant observation is being carried out in the immediate vicinity. This is part of a study, which will help the researcher, Caroline Belchamber (physiotherapy lecturer at Bournemouth University) to explore the physiotherapy service being offered to patients.

What is participant observation?

Participant observation is looking, listening and generally experiencing a situation, which helps the observer to understand action: as to how and why practices and relations change.

The observer (Caroline Belchamber) records her experiences in order to understand the cultural environment in which the subjects being observed occupy. These observations are then written as notes, which will eventually be used in the study to convey the observations to a wider audience. All the notes taken will be anonymised so that the people involved cannot be identified.

Will I be involved?

No you will not be involved and no notes will be taken on your actions / activities either verbal or non-verbal on the ward. Only the physiotherapist and the patient being treated who have given consent to participant observation will be involved.

How long will it take?

The participant observation will occur for the duration of the physiotherapy treatment, which could be as little as ten minutes to an hour depending on the individual's requirements.

Further questions

If you have any concerns / questions regarding participant observation then the researcher (Caroline Belchamber) will be available to answer any of these questions / concerns prior to the participant observation taking place.

Or alternatively you can contact the researcher's supervisor;
Dr Jerry Warr, reader, Bournemouth University, School of Health and Social Care, Centre for practice development, 1st floor, Royal London House, Christchurch Road, Bournemouth, Dorset, BH1 3LT

Tel No: 01202 962788

....., Senior Clinical Leader at the palliative care venue is an independent person who can also provide you with advice and information concerning this study.

Thank you for taking time to read this information leaflet

Appendix 8: Physiotherapist information sheet: participant observation

Physiotherapy Information Sheet - participant observation

Date:.....

Study Title: Are physiotherapists meeting National Palliative Care Standards? A case study approach

You are being invited to take part in a research study, which is being carried out as part of an educational qualification. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends, relatives and colleagues if you wish. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for taking time to read this information sheet.

1. What is the purpose of the study?

The purpose of this study is to provide an understanding of the complex world of physiotherapists working in palliative care. In order to do this the study will explore your physiotherapy treatment in a palliative care setting. You will be able to provide valuable information regarding this through notes being taken during participant observations. The researcher will then use the information collected to help clarify the contribution physiotherapists make in helping service users to manage their symptoms. This will be looked at in conjunction with the National Institute of Clinical Excellence Guidelines (NICE), and other relevant department of health (DH) documents.

2. Why have I been chosen?

You have been chosen because you are a physiotherapist working at the palliative care venue and have experience in treating palliative care service users.

3. Do I have to take part?

No you do not have to take part in the study. I have provided you with this information sheet so that you can make an informed decision as to whether you wish to take part or not in the study. Taking part in this study is voluntary and deciding whether or not to take part will not affect your employment. During the participant observation you will not be required to answer any specific questions if you chose not to and have the option to withdraw at any time from the participant observation or study and the field notes destroyed.

4. Who is organising the study?

The study is being organised by Caroline Belchamber (Physiotherapy Lecturer, Bournemouth University) as a research dissertation for a doctor of professional practice (DProf), at Bournemouth University.

The study is being funded by the Association of Chartered Society of Physiotherapists in Oncology and Palliative care (ACPOPC) research grant and the Chartered Society of Physiotherapy (CSP) Charitable Trust Fund. The study will run for three years in total, with collection of information over a twelve-month period.

5. What will happen to me if I take part?

Your job at the palliative care venue will continue as usual. The researcher will arrange a date and time convenient for you and the service user to be treated so that the participant observation can take place. This will be organised on a day that you work at the palliative care unit and in conjunction with your workload and prioritisation list. If you are unable to participate due to illness or other personal issues then a new date and time can be arranged. The participant observation will take place on the ward and will commence at the beginning of the planned treatment session and finish at the end of the treatment session. During the participant observation you and your service user will be observed from a distance so as not to be intrusive. People on the ward will be given a leaflet (see Appendix A) explaining that a participant observation is taking place. A note pad will be used to take notes of the participant observation and these will remain confidential and be anonymous.

6. What do I have to do?

If you decide to take part in this study then you will be offered a participant observation consent form to sign. A separate Healthcare professional information sheet about the study interviews has also been given to you. If you decide to take part in the interview then you will be offered an interview consent form to sign as well.

7. Are there any disadvantages in taking part in this study?

The researcher is sensitive to your needs and will be as discrete as possible during the participant observation so that you will feel comfortable carrying out your physiotherapy treatment. However, should you have any concerns about the participant observations the researcher will be able to offer to assist in addressing these in a sensitive manner or if necessary refer you to an appropriate member of staff. A prompt response will then be offered to you. You can contact the study physiotherapist on (01202 962158) if you have any concerns about the study.

8. What are the possible risks of taking part?

The physiotherapy treatment will be carried out as per the palliative care physiotherapist's guidelines and standards, the only difference being the researcher taking notes during this treatment time. However if there is a change in the service users condition, or if the multi-disciplinary team decide it is no longer appropriate for you to take part in the study then the following action will take place.

- The study physiotherapist will discuss the situation with you
- You will be given the option to continue or drop out of the study
- The study physiotherapist will explain why you should no longer participate in the study

If at any time the study physiotherapist considers it in your best interest, she will withdraw you from the study. The study physiotherapist will explain the reasons and arrange for the lead of the palliative care team to speak to you.

9. What are the possible benefits of taking part?

By focusing on the treatment you have provided for your service user you may benefit from increased understanding of the effect that care has had on your service users symptoms. This could help support your clinical reasoning, continued professional development and lifelong learning. It is also an opportunity to take part in a study that aims to have a positive impact on any future developments relating to the palliative physiotherapy service.

10. What happens when the study stops?

It is hoped that the information gathered in the participant observations will help to improve the service currently offered to service users by the palliative care physiotherapists.

The researcher will store hard copies of the field notes from the participant observations in a locked filing cabinet in the researcher's office in Bournemouth University. These will remain confidential with only the researcher and the researcher's supervisors having access to them. Field notes will be transcribed and will have a unique code on them so that your name cannot be ascribed to it.

When the study stops excerpts of the field notes will be given in the researcher's final dissertation paper. The field notes will not be shared by anybody other than the researcher and the researcher's supervisors of the study. All excerpts / quotations of the field notes given in the final dissertation paper will remain anonymous and you will not be identified as a participant.

The researcher will retain the field notes until completion of the study for a period of 6 to 12 months and then they will be destroyed. The field notes will be destroyed in accordance with Data Protection and the Records Management Code of Practice (DH, March, 2006).

11. Are there any restrictions on what I might eat or do?

No, there aren't any restrictions.

12. What if something goes wrong?

If during the participant observation the researcher observes any mal-practice then the researcher would be required to report this to the palliative care team lead. If the service user is harmed due to someone's negligence, then the service user may have grounds for legal action. Regardless of this, if the service user has any cause to complain about any aspect of the way they have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms are available to them.

13. Confidentiality - who will know I am taking part in the study?

All information, which is collected, about you during the course of the research will be kept strictly confidential. Any information about you, which leaves the palliative care venue, will be anonymised so that you cannot be recognised from it. Any information gained through the participant observation will not be divulged to anyone not involved in the study. All data will be kept locked away in an assigned filing cabinet and only those involved in the study will have access to the key. Observation field notes will be completed and transcribed by the researcher. The transcripts will remain either with the researcher during transcription and data analysis, or held in an assigned locked filing cabinet at the palliative care venue. Pseudonyms will be used to provide anonymity for the participants in the transcripts and an identification code will be used for all observation and field note data collection.

14. What will happen to the results of the study?

The results of the study will be written up in the study physiotherapist's dissertation. A copy will be submitted to Bournemouth University, the Director of the palliative care venue, IRAS and a further copy will be submitted to the association of chartered physiotherapist in oncology and palliative care (ACPOPC), the study physiotherapist will also keep a copy. . Please let the study physiotherapist know if you would like to read a brief summary of the study.

Wider dissemination of the research results will include conference presentations and future publications. The study may also evolve to set up a private practice for people living with cancer.

15. Who has reviewed the study?

The Bournemouth University School Postgraduate Committee and Bournemouth University Research Governance and Ethics have reviewed the study and this study was given a favourable ethical opinion for conduct by the Berkshire Research Ethics committee.

16. Contact for further information

If you require further information you should contact;

Caroline Belchamber, Physiotherapy Lecturer, Royal London House, R601, Christchurch road, Bournemouth, Dorset, BH1 3LT

Tel No: 01202 962158

E-mail: cbelchamber@bournemouth.ac.uk

Or alternatively contact the researcher's supervisor:

Dr Jerry Warr, reader, Bournemouth University, School of Health and Social Care, Centre for practice development, 1st floor, Royal London House, Christchurch Road, Bournemouth, Dorset, BH1 3LT

Tel No: 01202 962788

E-mail: jwarr@bournemouth.ac.uk

....., Senior Clinical Leader at the palliative care venue is an independent person who can also provide you with advice and information concerning this study.

The study physiotherapist, the multi-disciplinary team, and the Senior Clinical Leader of the palliative care venue would all like to thank you very much for your participation in this study.

You will be given a copy of the patient information sheet and a signed consent form to keep.

Appendix A

Participant observation leaflet

This study is being carried out as part of an educational qualification

Title of Project: **Are physiotherapists meeting National Palliative Care Standards? A case study approach**

The following information has been provided to notify you that participant observation is being carried out in the immediate vicinity. This is part of a study, which will help the researcher, Caroline Belchamber (physiotherapy lecturer at Bournemouth University) to explore the physiotherapy service being offered to patients.

What is participant observation?

Participant observation is looking, listening and generally experiencing a situation, which helps the observer to understand action: as to how and why practices and relations change.

The observer (Caroline Belchamber) records her experiences in order to understand the cultural environment in which the subjects being observed occupy. These observations are then written as notes, which will eventually be used in the study to convey the observations to a wider audience. All the notes taken will be anonymised so that the people involved cannot be identified.

Will I be involved?

No you will not be involved and no notes will be taken on your actions / activities either verbal or non-verbal on the ward. Only the physiotherapist and the patient being treated who have given consent to participant observation will be involved.

How long will it take?

The participant observation will occur for the duration of the physiotherapy treatment, which could be as little as ten minutes to an hour depending on the individual's requirements.

Further questions

If you have any concerns / questions regarding participant observation, then the researcher (Caroline Belchamber) will be available to answer any of these questions / concerns prior to the participant observation taking place.

Or alternatively you can contact the researcher's supervisor;
Dr Jerry Warr, reader, Bournemouth University, School of Health and Social Care, Centre for practice development, 1st floor, Royal London House, Christchurch Road, Bournemouth, Dorset, BH1 3LT

Tel No: 01202 962788

....., Senior Clinical Leader at the palliative care venue is an independent person who can also provide you with advice and information concerning this study.

Thank you for taking time to read this information leaflet

Appendix 9: Topic guide: Healthcare professional

Participant No.....

Id code _____

Title: **Are physiotherapists meeting National Palliative Care Standards? A case study approach**

Time of interview:

Date:

Place:

Interviewer:

Interviewee:

Position of interviewee:

Questions:

1. What do you understand about the role of physiotherapy in oncology and palliative care?

Prompt: Explain your thoughts about oncology and palliative care physiotherapy.

2. How would you describe your expectations of the oncology and palliative care physiotherapy service?

Prompt: Explain to me what you expect service users to gain from having physiotherapy interventions.

3 How would you describe the oncology and palliative care physiotherapy that service users have received?

Prompt: Describe your feelings on how you see service users cared for by the oncology and palliative care physiotherapy service.

4 How would you describe the communication between the oncology and palliative care physiotherapy service and other health care professionals you communicate with?

Prompt: How would you describe the way the oncology and palliative care physiotherapy service and health care professionals have managed service user's cancer journeys?

5 How would you describe service users' quality of life before receiving interventions from the oncology and palliative care physiotherapy service?

Prompt: How would you describe service users' lives before having the care provided by the oncology and palliative care physiotherapy service?

6 How would you describe the quality of life of service user after receiving interventions from the oncology and palliative care physiotherapy service?

Prompt: How would you describe service users' lives after having care from the oncology and palliative care physiotherapy service?

7 Describe what you feel has benefited service users by having oncology and palliative care physiotherapy interventions?

Prompt: How beneficial do you think is the care offered to service users by the oncology and palliative care physiotherapy service?

8 Describe what improvements you would make to the oncology and palliative care physiotherapy service.

Prompt: What if anything would you change about the care service users have received by the oncology and palliative care physiotherapy service?

9 What is the most difficult part of the service users' illness that you have had to cope with?

Prompt: Describe which area of the service users' illness is the most difficult for you to manage.

10 Has any of the care offered by the oncology and palliative care physiotherapy service helped you to manage this area of the service users illness more successfully?

(This form will have one question to each A4 sheet to allow for note taking during the interview.)

Format taken from Creswell J S (1998, p.127)

Appendix 10: Topic guide: Service user

Participant No.....

Id code _____

Title: Are physiotherapists meeting National Palliative Care Standards? A case study approach

Time of interview:

Date:

Place:

Interviewer:

Interviewee:

Position of interviewee:

Questions:

1. What were your expectations of the physiotherapy service before you arrived at (venue) unit?

Prompt: Explain your thoughts about being treated by a physiotherapist.

2. How would you describe your expectations now?

Prompt: Explain to me what you now expect to gain from having physiotherapy treatment.

3. How would you describe the physiotherapy you have received?

Prompt: Describe your feelings on how you have been cared for by the physiotherapist

4. How would you describe the communication between the physiotherapist and other health care professionals you are involved with?

Prompt: How would you describe the way the health care professionals have managed your cancer journey?

5. How would you describe your quality of life before receiving physiotherapy?

Prompt: How would you describe your life before having the care provided by the physiotherapist?

6. How would you describe your quality of life since receiving physiotherapy?

Prompt: How would you describe your life since having care from the physiotherapist?

7. Describe what you feel has benefited you by having physiotherapy treatment?

Prompt: How beneficial have you found the care offered to you by the physiotherapist?

8. Describe what improvements you would make to the care you have received by the physiotherapist.

Prompt: What if anything would you change about the care you have received by the physiotherapist?

9. What is the most difficult part of your illness to cope with?

Prompt: Describe which area of your illness is the most difficult for you to manage.

10. Has any of the care offered by the physiotherapist helped you to manage this area of your illness more successfully?

(This form will have one question to each A4 sheet to allow for note taking during the interview.)

Format taken from Creswell J S (1998
p127)

Appendix 11: Confidentiality form

Title: Are physiotherapists meeting National Palliative Care Standards? A case study approach

Confidentiality and anonymity will be the main priority in protecting those participating in a study of this nature. Although anonymity cannot be fully guaranteed, it is imperative that those involved in the study agree to the following:

- Any information gained through the interview or participant observation will not be divulged to anyone not involved in the study.
- All data will be kept locked away in an assigned filing cabinet and only those involved in the study will have access to the key.
- Interview transcripts and participant observation field notes will be completed and transcribed by the researcher.
- The transcripts will remain either with the researcher during transcription and data analysis, or held in an assigned locked filing cabinet at the palliative care venue.
- Pseudonyms will be used to provide anonymity for the participants in the transcripts.
- An Id code will be used for all interview, observation and field note data collection.

Signature of professional _____ **Date** _____

Appendix 12: Consent form: Service user: Interview

Consent form 2: Service user, Interview

Service User Number:.....

Service User Identification Number for this Study:.....

Title of study: **Are physiotherapists meeting National Palliative Care Standards? A case study approach**

Name of researcher: **Caroline Belchamber**

		Please initial box
1	I confirm that I have read and understood the information sheet dated [.....] for the above study and have had the opportunity to ask questions.	
2	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.	
3	I understand that sections of any of my medical notes may be looked at by responsible individuals from [the palliative care venue] or from regulatory authorities where it is relevant to my taking part in research. I give permission for these individuals to have access to my records.	
4	I understand that notes and recordings taken during the Interview at the palliative care venue will be anonymous and used for the sole purpose of the study.	
5	I understand that I will be interviewed by the study physiotherapist (researcher) and these will be anonymous and used for the sole purpose of the study	
6	I understand that consent will be obtained from me before any pictures are used on the website and that quotes used will be anonymised.	
7	I agree to take part in the above study.	

Name of Patient:Date:.....Signature:.....

Name of Person taking Consent (if different from researcher)

Date:.....Signature:.....

Researcher:.....Date:.....Signature:.....

1 for patient; 1 for researcher; 1 to be kept with medical notes

Appendix 13: Consent check list

Consent checklist

Adapted from a document prepared by Christopher Hodges and Christine Bendall

McKenna & Co, Solicitors, London EC1A 4DD

To assist compliance with Good Clinical Practice in the European Union issued by the Committee of Proprietary Medicinal Products, 1990 and Reports of the Royal College of Physicians, 1990 and 1986 and Health Service Circular HC (90) 22 and Health Service Guidelines HSG (91) 5.

Questions marked with an asterisk () are relevant to research in patients only.*

Research project name No. Date

Participant name Sex DOB

Name of investigator obtaining consent.....

1. Have you given the participant an oral explanation of the proposed research project?

..... Yes / No

1.1 Have you given the information sheet to the participant? Yes / No

1.2 Have you told the participant that he/she will be kept informed of all relevant information, which becomes available during the course of the

study?..... Yes / No

2. Did your oral explanation to the participant include:

2.1 That this is a research project? Yes / No

2.2 Participation is voluntary? Yes / No

2.3 The aims of the project?..... Yes / No

2.4 The likely duration of the participant's involvement? Yes / No

2.5 The expected benefits to the participant* and/or others? Yes / No

- 2.6 The expected nature of the drug, device or intervention being tested?...Yes / No
- 2.7 The procedures which will be involved in participation?Yes / No
- 2.8 That the participant may instead receive a reference treatment or placebo?
..... ..Yes / No
- 2.9 What alternative standard medical therapy is available? *Yes / No
- 2.10 What risks¹, inconvenience, discomfort or distress may reasonably be anticipated for
this participant: the level and the likelihood?Yes / No
- 2.11 That there may be some unforeseen risks?..... ..Yes / No
- 2.12 That a refusal to participate may be given without reasons and will not affect
the care which will be given to the participant*?Yes / No
- 2.13 That the participant may be withdrawn from the study if the investigating
physician considers this is necessary in the best interests of the participant?
..... ..Yes / No
- 2.14 That personal information may be scrutinised during audit by competent
authorities and properly authorised people, but all personal information will
be treated as strictly confidential and will not be made publicly available?
..... ..Yes / No
- 2.15 That information generated by the study may be published but that no details
will be divulged from which the participant could be identified?Yes / No
- 2.16 That some such information will be retained for a period after the end of the
trial?..... ..Yes / No
- 2.17 What compensation arrangements are available?Yes / No
- 2.18 Whom to contact in an emergency and how?.....,.....,Yes / No

2.19 What activities if any must be avoided during participation (e.g. driving, operating machinery, drinking alcohol, sport, pregnancy, breast feeding), after participation (e.g. blood donation, participation in another trial) and for what period? Yes / No

3. Has the participant given authorisation to approach his/her GP and for permission for the GP to disclose medical information?..... Yes / No

4. Is or has the participant been involved in any other research studies?..Yes / No

5. Is or has the participant recently been taking, or does he/she intend to take, any other medicines or preparations? Yes / No

6. Have you allowed the participant sufficient time to consider the matter on his/her own, to discuss with others if wished, or ask you questions? Yes / No

7. In your opinion, has the participant understood and consented to take part in this research?

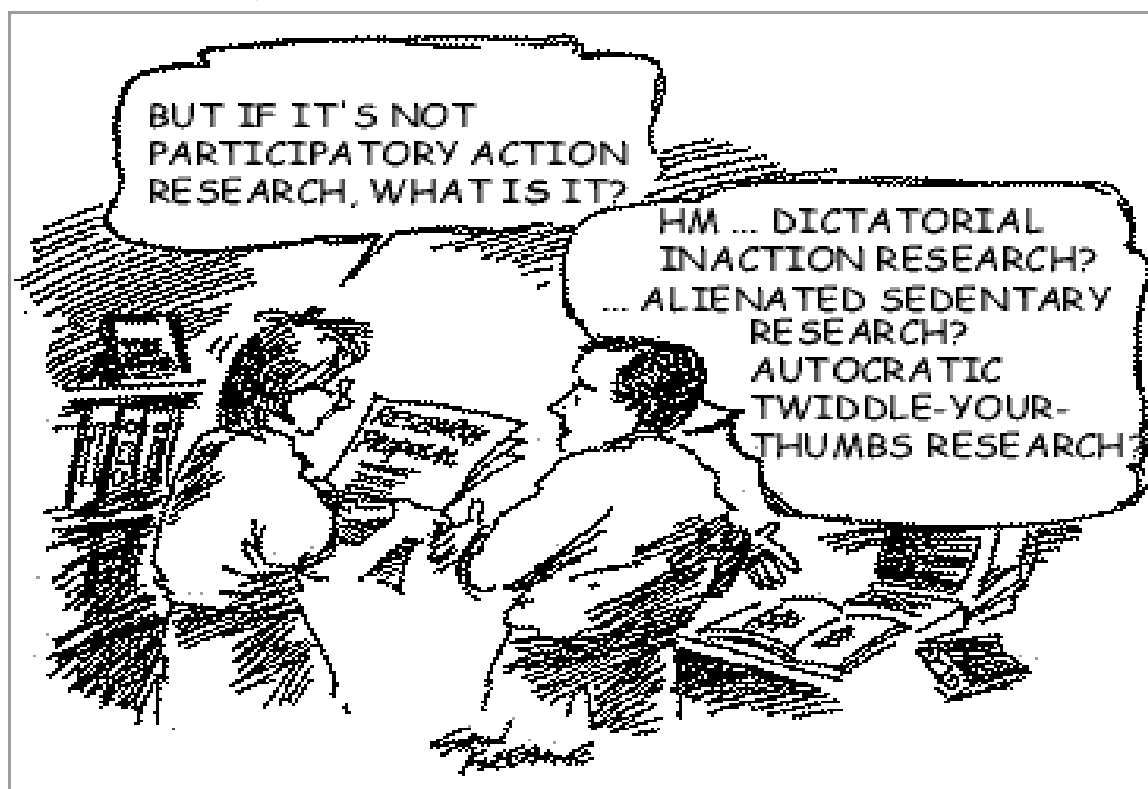
..... Yes / No

¹Healthy volunteers should know all, even remote, risks. Patients should, as a minimum be made aware of all material risks.

Appendix 14: Study advert

Placed in the specialist palliative cancer care unit's news letter for health care professionals

Research, what research?



Come and find out what research is happening at Unit and how you can be involved

Venue: Seminar room, Unit

Date: Friday 16th April 2010 Time: 2 – 3.30 pm

Speaker: Caroline Belchamber

Contact details: cbelchamber@bournemouth.ac.uk

Thank you

Appendix 15: Consent form: Health Care Professionals: Interview

Patient IdentificationNumber for this Study:.....

Title of study: **Are physiotherapists meeting National Palliative Care Standards? A case study approach**

Name of researcher: **Caroline Belchamber**

		Please initial box
1.	I confirm that I have read and understood the information sheet dated [.....] for the above study and have had the opportunity to ask questions.	
2.	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my participation in the multidisciplinary team or legal rights being affected.	
3.	I understand that audits and medical notes may be looked at by the study physiotherapist (researcher) or from regulatory authorities where it is relevant to my taking part in research. I give permission for these individuals to have access to the above.	
4	I understand that notes and recordings taken during the Interview at the palliative care venue will be anonymous and used for the sole purpose of the study.	
5	I understand that I will be interviewed by the study physiotherapist (researcher) and these will be anonymous and used for the sole purpose of the study	
6	I understand that consent will be obtained from me before any pictures are used on the website and that quotes used will be anonymised	
7	I agree to take part in the above study	

Name of HCP:**Date:**.....**Signature:**.....

Name of Person taking Consent (if different From researcher):-

Date:.....**Signature:**.....

Researcher:.....**Date:**.....**Signature:**.....
1 for HCP; 1 for researcher

Appendix 16: Consent form: service user, participant observation

Service User Identification..... Number for this Study:.....

Title of study: **Are physiotherapists meeting National Palliative Care Standards? A case study approach**

Name of researcher: **Caroline Belchamber**

		Please initial box
1	I confirm that I have read and understood the information sheet dated [.....] for the above study and have had the opportunity to ask questions.	
2	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.	
3	I understand that sections of any of my medical notes may be looked at by responsible individuals from [the palliative care venue] or from regulatory authorities where it is relevant to my taking part in research. I give permission for these individuals to have access to my records.	
4	I understand that notes taken for the participant observations during my physiotherapy treatment at the palliative care venue will be anonymous and used for the sole purpose of the study.	
5	I understand that field notes will be taken by the researcher and these will be anonymous and used for the sole purpose of the study	
6	I understand that consent will be obtained from me before any pictures are used on the website and that quotes used will be anonymised	
7	I agree to take part in the above study	

Name of Patient: **Date:**..... **Signature:**.....

Name of Person taking Consent (if different from researcher):-

Date:..... **Signature:**.....

Researcher:..... **Date:**..... **Signature:**.....
1 for patient; 1 for researcher; 1 to be kept with medical notes

Appendix 17: Consent form: Physiotherapist, participant observation

Service User Identification Number for this Study:.....

Title of study: **Are physiotherapists meeting National Palliative Care Standards? A case study approach**

Name of researcher: **Caroline Belchamber**

		Please initial box
1	I confirm that I have read and understood the information sheet dated [.....] for the above study and have had the opportunity to ask questions.	
2	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my participation in the multidisciplinary team or legal rights being affected.	
3	I understand that audits and medical notes may be looked at by the study physiotherapist (researcher) or from regulatory authorities where it is relevant to my taking part in research. I give permission for these individuals to have access to the above.	
4	I understand that notes taken for the participant observations during the delivery of my physiotherapy treatment to the service user at the palliative care venue will be anonymous and used for the sole purpose of the study.	
5	I understand that field notes will be taken by the researcher and these will be anonymous and used for the sole purpose of the study	
6	I understand that consent will be obtained from me before any pictures are used on the website and that quotes used will be anonymised	
7	I agree to take part in the above study	

Name of PT:Date:.....Signature:.....

Name of Person taking Consent (if different from researcher):-

Date:.....Signature:.....

Researcher:.....Date:.....Signature:.....

1 for PT; 1 for researcher

Appendix 18: Example of observation transcriptions from field notes

Su ID code: 105 / **PT ID code:** 1 (002)

Site: Community

Data collector: Caroline Belchamber

Date of data collection: 9th July 2012

Data collection method: participant observation / Observation No: 1

Transcriber: Caroline Belchamber

Date and time of computer data entry: 30th July 2012: 10:45

10:05: Introductions occurred at the start with signing of the observation consent form with a further Q and A session before beginning the observation.

Time	Objective observations	Interpretations	Personal comments
10:10	<p>The participant is an elderly gent who demonstrates that he was once well dressed. Currently wearing an old suit and slippers. His sitting room is situated just off the hall way a little way from the front door.</p> <p>Participant is sitting on armchair in sitting room. The PT is on her knees to talk to the participant and to be at the same eye level.</p> <p>The participant gets out a handkerchief and wipes his nose and states that his 'legs generally get tired.' He also mentions that fatigue is a problem.</p> <p>The PT discusses calories and asked if the participant was 'still on steroids?' Apparently he never has been. The PT looked a little flustered at this response.</p> <p>The participant pats his knees and the PT is now in a shallow squat. The participant describes tightness in his thighs as he rubs them. The PT moves her left leg backwards into a lunge, while she examines his legs. The participant explains about his walking and the PT listens and confirms, enquiring if it is 'just with a stick?'</p>	<p>Considers being well presented important and perhaps has dressed for the physiotherapist arriving?</p> <p>The PT is using her non-verbal communication to gain a positive patient / therapist relationship.</p> <p>The participant seems to have a cold or at least a problem with a runny nose. His main concern seems to be his legs and fatigue.</p> <p>The PT has picked up on these cues and starts to clinically reason the cause of his symptoms, checking his nutritional intake and medication – although either the participant is unaware that he is taking steroids or the PT has not looked at his medication list and is mistaken.</p> <p>As well as the subjective information the PT is now gathering objective information as she assesses his legs, while continuing to listen to the participant.</p>	<p>This gentleman lives alone and I wonder if he needs some support as there is quite a strong unpleasant smell in the air – not sure if this is incontinence or inability to wash himself adequately enough?</p> <p>This gentleman obviously likes to look smart, from the clothes he has chosen to wear.</p> <p>There is a piano in the room so I presume he has a musical background of some kind. Looks like the piano is still being used as music is on the stand.</p> <p>The PT demonstrated some discomfort around her question about steroids – looking at the notes the participant was not on steroids, confirming that the participant was correct.</p>

Time	Objective observations	Interpretations	Personal comments
10:15	<p>The participant lifts up his left leg again and while rubbing the tops of his legs he states that they are 'weaker'</p> <p>The participant starts to dribble and wipes his mouth with his handkerchief.</p> <p>The participant then states that 'if I have alcohol they become much weaker?' The PT acknowledges this but doesn't probe and instead asks the participant to explain how he is getting onto his bed.</p> <p>The participant is now moving his left leg up and down, mentioning that he gets pain on the top of his legs. At this point the PT moves forward and requests consent to move the participant's leg. The participant nods in agreement. The PT straightens the participant's leg and then places his foot on the floor. She then starts to palpate the top of his leg.</p> <p>The PT remains at eye level with the participant and now asks him about his exercises and stretches. The participant mentions that the stretch on the bed was 'impossible' The PT enquires whether or not the participant is able to 'hold his leg behind him?'</p> <p>The PT goes on to explain that the quadriceps muscle is made up of four muscles and explains where they insert and says she will check his squats. The PT explains further that the tightness might cause the pain in the front of his knee.</p>	<p>More information is now being given by the participant about his condition.</p> <p>This information has been acknowledged by the PT, but it is difficult at this point to know whether she will act upon this information or not?</p> <p>The PT is focused on his muscle strength and range of movement. Probably checking for any apparent disabilities. She is gaining further information through palpation and looking to see if that causes any signs of pain either verbally or non-verbally.</p> <p>The PT is gaining further subjective information to help her with clinical reasoning. She has moved onto the prescribed exercises to see if they are appropriate or helping?</p> <p>The PT gathers that some of the exercises have not been achievable and uses education to explain to the participant why this might be so and why he is experiencing pain.</p>	<p>The participant doesn't seem to be concerned about his dribbling. I wonder if this has been investigated by the PT in her previous visits?</p> <p>I start to consider if alcohol is a problem for this gentleman?</p> <p>This could be due to depression, not coping, 'managing' his pain independently, being lonely causing risk of falls and deterioration in living conditions.</p> <p>Pain is another symptom that the participant is complaining of, which links in with his previous concerns.</p> <p>It is interesting that with this PT's background her emphasis is around her knowledge of musculoskeletal skills. I wonder if other areas are being missed as she is so musculoskeletal focused? However her skills here are very appropriate and might not have been so thorough carried out by another PT with a different skill set.</p>

Time	Objective observations	Interpretations	Personal comments
10:20	<p>The PT considers modifying stretches and explains that she will send the updated exercises to him. The PT then pauses to think and then asks the participant if he is able to cross his legs. The participant tries but is unable to so the PT says 'I'll have to have another think about an exercise'</p> <p>The PT is now on one knee and starts to check the participant's social life. He mentions that he 'pops out to the pub' and then asks 'Am I going to get weaker?' He explains his difficulty getting into the car and bed. 'I flop onto the bed, especially after alcohol' The PT explains that alcohol will be a relaxant and will have a negative effect on his mobility.</p> <p>The PT then checks the participant's alcohol intake. The participant admits to three double whiskies, which he has done for a long time. The PT clarifies whether he has any 'peaks and troughs?'</p>	<p>Through clinically reasoning the PT is considering an alternative way to stretch this gentleman's quads to reduce the tight band. However this is proving difficult for the PT to find an exercise that he will be able to do independently that will give the desired result.</p> <p>The PT has taken this opportunity to ask about the participant's social life, which leads back to the mention of alcohol earlier. Using education again the PT explains why the participant is having difficulty with ADL's following alcohol intake.</p> <p>The PT is exploring as to whether alcohol is becoming a problem for this gentleman.</p>	<p>The PT is struggling to find an appropriate exercise.</p> <p>There doesn't seem to be any outcome measures used for the previous exercises provided.</p> <p>The participant obviously enjoys his drink, but I wonder if this has gradually increased over time?</p> <p>I feel relieved that the PT is exploring this further.</p> <p>It is encouraging that the PT considers referring this gentleman to the day care centre as I feel it would benefit him greatly.</p>
10:30	<p>The PT continues to have good eye contact with the participant and starts to discuss attending day centre one day a week. Mentioning that 'you can have your whisky there you know!'</p> <p>The PT then suggests watching the participant do his exercises and the participant gets up quickly from the chair using his walking stick in his right hand.</p> <p>Example shown up to this point as 8 pages in total</p>	<p>The PT demonstrates here that she is concerned about this participant's isolation and encourages him to attend the day centre.</p> <p>The PT will now be able to see objectively what this gentleman is able to achieve independently</p>	<p>The PT has built up a good rapport and this has enabled her to explore other areas of this gentleman's well being.</p>

Appendix 19: Policy document sampling decision

Policy document	Calman- Hine Report	NHS Cancer Plan	Improving supportive and palliative care for adults with cancer	Cancer Reform strategy	End of Life Care strategy
Policy documents having similar characteristics e.g. Importance of driving change	The aim of this report is to create a network of care in England and Wales which will enable a patient, wherever he or she lives to be sure that the treatment and care received is of a uniformly high standard. It is not a blueprint but a strategic framework to help commissioners and providers of cancer services to make well informed and wise decisions.	This Cancer Plan sets out the first ever comprehensive strategy to tackle the disease. It is the first time any government has drawn up a major programme of action linking prevention, diagnosis, treatment, care and research.	Cancer service guidance supports the implementation of <i>The NHS Cancer Plan</i> for England, and the NHS Plan for Wales <i>Improving Health in Wales</i> . The service guidance programme was initiated in 1995 to follow on from the Calman-Hine Report, <i>A Policy Framework for Commissioning Cancer Services</i> .	the Cancer Reform Strategy was published with aims to: save more lives; improve patients' quality of life; reduce inequalities; build for the future; enable cancer care to be delivered in the best place at the right time and achieve maximum value for money.	It recognised that the delivery of quality end of life care services to individuals, their families and carers will require nothing less than a cultural shift in attitude and behaviour within the health and social care workforce.

Issues and dates of the documents	April 1995	September 2000	March 2004	December 2007	July 2008
Content of the documents	<p>This report will serve to outline the direction in which cancer services in England and Wales should be developed. Discussion locally and nationally with purchasers, providers and professional bodies will be needed before they can be implemented. The EAGC are working with the Clinical Outcomes Group in England and the professions to develop more specific disease-related guidelines starting with the commoner cancers. Subsequent reports will be concerned with other aspects of cancer care.</p>	<p>This Cancer Plan sets out a programme of investment and reform to tackle these problems and deliver the fastest improving cancer services in Europe. It takes forward the work in the NHS Plan – increasing the number of doctors, nurses and other staff and providing more equipment for cancer care, but also modernising the NHS too, through new national standards and new ways of working to prevent and treat cancer. It sets out our approach to tackling health inequalities and perhaps most important of all, it puts the patient at the centre of cancer care.</p>	<p>The focus of the cancer service guidance is to guide the commissioning of services and is therefore different from clinical practice guidelines. Health services in England and Wales have organisational arrangements in place for securing improvements in cancer services and those responsible for their operation should take this guidance into account when planning, commissioning and organising services for cancer patients. The recommendations in the guidance concentrate on aspects of services that are likely to have significant impact on health outcomes. Both the objectives and resource implications of implementing the recommendations are considered. This guidance can be used to identify gaps in local provision and to check the appropriateness of existing services.</p>	<p>The Cancer Reform Strategy acknowledges that national guidance will continue to play a vital role as cancer services develop over the next five years. Much of this guidance has been developed by the NICE and predecessor bodies.</p>	<p>The Department of Health, working with the NHS End of Life Care Programme, has commissioned three foundation projects based on the core common requirements for workforce outlined in the strategy to start taking this work forward:</p> <ul style="list-style-type: none"> • Developing competences and core principles • Producing a suite of e-learning modules • Identifying related communication skills training at all levels

















Policy document	Manual for cancer services 2008 – rehabilitation measures	Common core competences for end of life	Survivorship initiative	Improving outcomes – a strategy for cancer
Policy documents having similar characteristics e.g. Importance of driving change	This revised Manual of Cancer Services is an integral part of the NHS Cancer Plan, Cancer Reform Strategy and modernisation of cancer services. It will support quality assurance of cancer services and enable quality improvement.	Supports the National End of Life Care Strategy	The dramatic improvements in survival rates mean that we need to challenge widespread beliefs about cancer. Cancer is increasingly an illness which might not be cured or which might have the characteristics of a long term or chronic condition that people can live with for many years.	The Coalition Government has set out a simple aim: to deliver health outcomes that are among the best in the world. To achieve this aim, we have set out radical plans for the health and social care services. These plans are underpinned by three, mutually-reinforcing principles: <ul style="list-style-type: none"> • to put the patient or service user at the heart of the public services – transforming the relationship between citizen and service through the principle of <i>no decision about me without me</i>; • to orientate the NHS, public health and social care services towards delivering the improvements in outcomes which matter – rather than measuring processes which do not; and • to empower local organisations and professionals to deliver the freedoms to innovate and to drive improvements in services which deliver care of the highest quality for all patients and service users.
Issues and dates of the documents	December 2008	September 2009	January 2010	January 2011
Content of the documents	Improving Outcomes Guidance (IOG) for cancer services now covers the vast majority of all cancers. Implementation of this guidance, which involves the establishment of multidisciplinary teams and reconfiguration of some complex services is now well advanced for many cancers and is scheduled to be complete for less common cancers by 2010.	The main purpose in developing competences and principles is to support workforce development, in its broadest sense, to ensure all workers are confident and able to work with people at the end of their lives. They	Our vision is that cancer survivors are supported to live as healthy and active a life as possible for as long as possible. For some, cancer can be an 'acute illness' which can be cured by initial treatment. Being 'cured' however does not mean one is necessarily well. Chronic consequences of treatment may need to be managed over the following months and years, consequences which often have a devastating impact on daily life. For	This is the first of a number of outcomes strategies which will set out the ways in which we will meet our aim of delivering healthcare outcomes as good as anywhere in the world. Outcomes strategies set out, for a particular service area: our ambitions for the quality of services we want to make available to patients and service users, and to their carers and families, without exception; the support, information and choices which patients and service users, and their carers and families, will receive to make best use of these




	<p>The revised manual has therefore been drawn up to incorporate the recommendations contained within such guidance including the new guidelines published by NICE. It identifies the characteristics of service that are likely to have a significant impact on health outcomes. It is intended that those characteristics should help those involved in planning, commissioning, organising and providing cancer services to identify gaps in provision and check the appropriateness and quality of existing services. The measures provide a ready specification for the commissioning of cancer services within a given locality.</p> <p>Changes have also been made as a result of feedback from the use of measures in the manual published in 2004 and following the most recent independent evaluation of peer review published in December 2007.</p>	<p>reflect the principles; priorities and actions laid out in the End of Life Care Strategy published by the Department of Health in July 2008 and have been produced and refined following consultation and testing across a range of health and social care sites in England.</p>	<p>those with advanced disease, we want to support them to have as active and independent a life as possible. In short, we want to help these people to live with their cancer.</p> <p>Achieving the vision will require a personalised assessment and care plan for everyone and information and support to enable people to get back as normal a life as possible after cancer treatment. We will need to empower people to manage their condition base on their needs and preferences. It will require services which are responsive to individual needs and which ensure access to specialist care when needed. It will require coordination across primary and secondary care and across health and social care. Achieving the vision, will also require the routine use of patient reported outcome measures to monitor problems for cancer survivors as defined by them.</p>	<p>high quality services; the ways in which these services will be held to account for the outcomes they deliver through the NHS, social care and public health outcomes frameworks; the support which the Government will provide to assist these services to meet the outcomes for which they are accountable; and the work which the Government will lead with non-state sectors to help shape services that meet the needs of patients and service users. Outcomes strategies set out how the NHS, public health and social care services will contribute to the ambitions for progress agreed with the Secretary of State in each of the high-level outcomes frameworks: where only the NHS needs to be involved in improving outcomes in a particular area, the relevant outcomes strategy will be initiated and its development led by the NHS Commissioning Board; and where integrated action is required across any combination of the NHS, public health and social care services to improve outcomes in a particular area, the relevant outcomes strategy will be initiated and its development led by the Department of Health, in conjunction with Public Health England and the NHS commissioning Board as appropriate.</p>
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Policy document	Specialist palliative care measures, national end of life care programme	Cancer commissioning: Making the reforms work for patients	Improving outcomes - a strategy for cancer
<p>Policy documents having similar characteristics e.g. Importance of driving change</p>	<p>The National Council for Palliative Care (NCPC) is the umbrella charity for all those who are involved in providing, commissioning and using palliative care and hospice services in England, Wales & Northern Ireland. NCPC promotes the extension and improvement of palliative care services for all people with life threatening and life-limiting conditions. NCPC promotes palliative care in health and social care settings across all sectors to government, national and local policy makers.</p> <p>The National End of Life Care Programme works with the health and social care workforce across all sectors in England to improve end of life care for adults, supporting the implementation of the Department of Health's End of Life Care Strategy. The National End of Life Care Programme aims to: Promote high quality, person-centred care for all adults at the end of life in all care settings Enable more people nearing the end of life to choose where they live and die.</p>	<p>In January 2011, the Department of Health published its new strategy for cancer care – Improving Outcomes: a Strategy for Cancer. Andrew Lansley, Secretary of State for Health, subsequently announced on May 20th that the Cancer Networks would receive funding for 2012/13 and that, “beyond 2012/13, the NHS Commissioning Board (NHSCB) will support strengthened Cancer Networks”. The new reforms will move both national and regional specialised commissioning into the hands of the NHSCB, but what is yet to be determined is how the new changes will impact both the national and regional commissioning of specialised services in the treatment and diagnosis of rarer cancers. It is therefore unclear how the structure of specialised commissioning will be defined, and how this will affect outcomes for patients with rarer cancers, or the operation of the Cancer Drugs Fund. This project has sought to undertake a review of the specialised commissioning of cancer care with particular reference to the rarer cancers. It examines the role of cancer networks within this process and identifies important strengths and weaknesses in view of new commissioning arrangements.</p>	<p>This revised Manual of Cancer Services is an integral part of the NHS Cancer Plan, Cancer Reform Strategy and modernisation of cancer services. It will support quality assurance of cancer services and enable quality improvement.</p> <p>The National Cancer Peer Review Programme, which is led by the National Cancer Action Team and includes expert clinical and user representation, provides important information about the quality of cancer services across the country. Between 2004 and 2008 peer reviews of cancer services were carried out in each cancer network in England. Development of this Manual of Cancer Services 2008 and the continuation of a revised peer review process has been supported by the service and agreed by strategic health authorities following a review of all national programmes in 2007. An independent evaluation of the National Cancer Peer Review Programme also demonstrated strong support for the programme to continue, but recommended that the programme should be modified. A new process will therefore be implemented during 2008 but the measures contained within this manual will remain an integral part of the review process.</p>
















Issues and dates of the documents	June 2011	June 2012	December 2012
Content of the documents	<p>For the purposes of this guidance people are 'approaching the end of life' when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with: (a) advanced, progressive, incurable conditions (b) general frailty and co-existing conditions that mean they are expected to die within 12 months (c) existing conditions if they are at risk of dying from a sudden acute crisis in their condition (d) life-threatening acute conditions caused by sudden catastrophic events.</p> <p>A Working Definition of End of Life Care End of life care is care that: Helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support. Introduction: why act & early Adapted from Treatment and care towards the end of life: good practice in decision making, the General Medical Council 2010. Source: National Council for Palliative Care 2006 The End of Life Care Strategy 2008.</p>	<p>The purpose of this project was to review the way that Cancer Networks deal with rarer cancers and how various stakeholders think the new specialised commissioning structure will impact the treatment of rarer cancers, especially with respect to patient access to services and drugs, and value for money.</p>	<p>Raise awareness of the scope to prevent cancers, through lifestyle changes, and support people to make the necessary lifestyle changes – many of which will also have more immediate impact on incidence of other diseases, such as diabetes and cardiovascular disease</p> <p>Work to improve cancer survival rates, particularly through completing the age extension of the breast and bowel screening programmes, introducing flexible sigmoidoscopy bowel screening, tackling late diagnosis of symptomatic cancers and ensuring that all patients who can benefit have access to the best possible curative treatments</p> <p>Improve the quality of life of cancer survivors, acting on the information from the PROMs survey to develop the services they need and on the increasing evidence base about what works in supporting them to live as healthy a life as possible for as long as possible</p> <p>Improve patient experience through taking action on the issues identified as needing tackling in the latest results from the cancer patient experience survey. In the year ahead, while recognising the challenges associated with transition to the new NHS, we need to build on what is good from the past, and take the opportunities presented by the new architecture. There are risks associated with transition, but we must all act to ensure that they do not detract from our focus on improving cancer outcomes</p>












Appendix 20: Stages 1 to 2 data analysis – Health care professional interviews

HCP interviews stages 1 and 2	Code definitions	Sources	References	Colour code
Physiotherapist	Palliative cancer care physiotherapist within a palliative cancer care team	10	1418	
Difficult symptom	HCP descriptions of the types of symptoms which are difficult to manage and how they cope with this	9	196	
Mindset	The type of person that comes into palliative cancer care physiotherapist, as well as how SU copes psychologically	8	120	
Physiotherapists role	HCP understanding of what the palliative cancer care physiotherapist does in practice	10	240	
Rehabilitation	What the HCP understands rehabilitation to be in the context of palliative cancer care	9	281	
Symptoms	SU symptoms described by the HCP and how they might be managed	4	47	
Therapy Interventions	Any treatment either physical, psychological or spiritual delivered by the palliative cancer care physiotherapist	10	265	
Training	Education for the palliative cancer care physiotherapist, examples of continuing professional development and palliative cancer care physiotherapists educating others: Merged with CPD - 14/05/2013	7	262	
Quality of life	Quality of life of the service user as perceived by the HCP at the specialist palliative cancer care unit	10	270	
Post-physiotherapy	How the person's quality of life is perceived by the HCP after interventions by the palliative cancer care physiotherapist	10	180	
Pre- physiotherapy	How the person's quality of life is perceived by the HCP prior to the palliative cancer care physiotherapy intervention	10	79	
Service	Palliative cancer care service provision within a specialist palliative cancer care unit	10	2173	
Fusion of Boundaries	Where treatments overlap between professionals within the physiotherapy palliative cancer care service	10	143	
Communication	Between physiotherapists and other members of the palliative cancer care team including SU and their families	10	590	
Outcome Measures	Measurements of the physiotherapy palliative cancer care service	5	95	
Palliative Care Service	What the physiotherapy palliative cancer care service is currently providing: merged with	10	499	
















	expectations 14/05/13			
Service needs	What is lacking in the physiotherapy palliative cancer care service	8	358	
Staffing levels	Number of palliative cancer care physiotherapists	10	288	
Support	Support for the physiotherapist; support that the physiotherapist gives to others including HCP and SU	8	177	


Appendix 21: Stages 1 to 2 data analysis – service user interviews











SU interviews stage 1 and 2	Code definitions	Sources	References	Colour code
Communication	Service users' description of the communication between the palliative cancer care physiotherapists and other health care professionals	10	231	
Interacting	Participant's views of communicating with others	10	193	
Internet	Communication received around the internet	3	5	
Referral	Service users' description of being referred to other members of the team by the palliative cancer care physiotherapist	6	23	
Teaching	Teaching from the palliative cancer care physiotherapist to the service user	6	21	
Physiotherapy	Service users' description of the physiotherapy that they received	10	237	
Improvements	Service users' thoughts on what could be improved in the care that they have received from the palliative cancer care physiotherapists	6	20	
Physiotherapy Intervention	Service users' description of the interventions received from the palliative cancer care physiotherapist	10	165	
Previous Experiences	Service users' previous experiences of physiotherapy in general	6	50	
Physiotherapy Service	Service users' expectations of the palliative cancer care physiotherapy service	11	330	
Physiotherapy role	What the service users perceive to be the role of the palliative cancer care physiotherapist	3	10	
Post - physiotherapy	Service users' thoughts after attending the specialist palliative cancer care unit	11	252	
Pre-physiotherapy	Service users' thoughts before attending the specialist palliative care unit	9	71	
Quality of life	Service users' description of their quality of life	10	88	
Post-physiotherapy	Service users' description of their quality of life after palliative cancer care physiotherapy input	10	68	

Pre-Physiotherapy	Service users' description of their quality of life before palliative cancer care physiotherapy input	7	21	
Symptoms	Service users' description of their symptoms	10	535	
Bereavements	Areas of bereavement within the participant's life	4	19	
Coping Strategies	Service users' description of the ways they cope with their illness	8	53	
Difficult Symptom	Service users' description of the most difficult part of their illness that they have to cope with	9	100	
Fears and Anxieties	Topics that cause participants concern.	7	55	
Mindset	Service users' thoughts on their symptoms	10	164	
Past Hobbies	Description of activities that participants perceive they are no longer able to do.	3	25	
Past Jobs	Links back to the participant's jobs and previous life experiences	3	6	
Symptom Management	Service users' understanding of what help they may have and how they manage their symptoms themselves	9	82	
Types of Symptoms	Symptoms described by the service user	10	123	




Appendix 22: Stages 1 to 2 data analysis – observations (service users and physiotherapists)

Observations stages 1 and 2	Code description	Sources	References	Colour code
Communication	Observation of different types of communication that occurred between the service user / carer and the palliative cancer care physiotherapist	6	497	
Humorous	Observation of humorous exchanges between the palliative cancer care physiotherapist and the service user	2	15	
Non-Verbal Interactions	Non-verbal interactions observed between the palliative cancer care physiotherapist and the service user.	3	40	
Rapport	Rapport observed between the palliative cancer care physiotherapist and the service user	2	9	
Referrals	Observation of referrals to other members of the MDT by the palliative cancer care physiotherapist for the service user	1	5	
Social	Social interactions observed between the service user and the palliative cancer care physiotherapist	1	3	
Verbal Interactions	Verbal interactions observed between the palliative cancer care physiotherapist and the service user	3	49	
Environment	Description of the environment within which the palliative cancer care physiotherapist worked	6	58	
Atmosphere	The atmosphere that was captured during the observation of the palliative cancer care physiotherapist and the service user.	6	28	
Venue	The environment in which the palliative cancer care physiotherapist and the service user were observed	6	34	
Interventions	Observations of the types of interventions provided by the palliative cancer care physiotherapist to the service user	6	312	
Equipment	Equipment used or advised by the palliative cancer care physiotherapist to support the service user.	2	16	
Exercises	Observation of exercises given by the palliative cancer care physiotherapist to the service user	2	10	
Mobility	Observation of mobility intervention by the palliative cancer care physiotherapist to the service user	2	25	
Musculoskeletal	Observation of musculoskeletal assessments of the service user carried out by the palliative cancer care physiotherapist	1	21	












Objective Information	Observation of the objective information gathered by the palliative cancer care physiotherapist from the service user	2	32	
Outcome Measures	Observation of any outcome measures used by the palliative cancer care physiotherapist during the treatment intervention with the service user.	1	1	
Subjective Information	Observation of subjective information gathered by the palliative cancer care physiotherapist from the service user	2	25	
Treatment Modalities	Observation of treatment modalities used by the palliative cancer care physiotherapist to manage service users' symptoms	2	10	
Treatment Summary	Observation of treatment summaries supplied by the palliative cancer care physiotherapist to the service user	2	6	
Physiotherapist	Observations around the actions of the palliative cancer care physiotherapist	6	137	
Clinical Reasoning	Observation of the palliative cancer care physiotherapist using clinical reasoning in the assessment of the service user.	5	42	
Compliance	Observation of compliance to treatment being offered by the palliative cancer care physiotherapist to the service user.	5	21	
Consent	Observation of consent being gained by the palliative cancer care physiotherapist before and during treatment delivery.	4	6	
Experience	Observation of the palliative cancer care physiotherapists experience in treating the service user	6	32	
Patient - Therapy Relationship	Observation of patient / therapy relationship of the palliative cancer care physiotherapist and the service user during treatment delivery.	5	34	
Presentation	Observation of how the palliative cancer care physiotherapist presents to the service user.	5	10	
Verbal Reinforcement	Observation of verbal reinforcement being used by the palliative cancer care physiotherapist in the treatment of the service user.	6	18	
Reminiscence	Observations of service users musing over and recalling past history / life events	5	24	
Family	Observation of stories / memories around the service user's family divulged to the palliative cancer care physiotherapist during treatment delivery.	4	12	
Past Connections	Observation of service users connecting the past with the treatment provided by the palliative cancer care physiotherapist	3	12	
Service User	Observations around the service user during the delivery of the treatment by the palliative cancer care physiotherapist	6	104	
Emotions	Observation of service users' emotions during the palliative cancer care treatment delivery.	3	45	

Post-Quality of Life	Observation of positive experiences by the service user during the palliative cancer care physiotherapy treatment delivery to the service user	6	50	
Pre-Quality of Life	Difficult issues described during the observation by the service user prior to being seen by the palliative cancer care physiotherapist	4	8	
Symptoms	Observation of the types of symptoms the service user is experiencing	5	57	
Constipation	Observation of the symptom of constipation experienced by the service user	3	6	
Disabilities	Observation of disabilities experienced by the service user	5	15	
Dyspnoea	Observation of the symptom of breathlessness experienced by the service user	2	4	
Fatigue	Observation of the symptom of fatigue experienced by the service user	3	5	
Lymphoedema	Observation of the symptom of lymphoedema experienced by the service user	2	4	
Pain	Observation of the symptom of pain experienced by the service user	5	22	
Psychological	Observation of the psychological symptoms (e.g. anxiety, depression) experienced by the service user	4	4	









Appendix 23: Stages 1 to 2 data analysis – policy document collection




Policy document collection stages 1 and 2	Description	Sources	References	colour code
Allied Health Professionals	References made to allied health professionals within the policy documents. Includes AHP and professionals allied to medicine	8	132	
Best Practice	Best practice documented within the policy documents. Also includes good practice	12	217	
Cancer Care Service	Explores areas of development / improvement within the cancer care service, including recommendations and training needs.	13	1254	

Appendix 24: Stage 3 data analysis: health care professional interviews














HCP interviews stage 3	Code definition	Sources	References	Colour code
Physiotherapy	Key section identified from semi-structured interview schedule. Relates to three questions. See HCP Key themes document pdf in internals.	10	1894	
Death and Dying	Many of the symptoms described related to coping with death and dying. This was the most difficult part of the service user's illness that the HCP had to cope with.	10	225	
Patient Advocate	The complex communication and support offered by the palliative cancer care physiotherapists provided a sense of them being the patient's advocate.	10	611	
Physiotherapy Role	The interventions including physical, psychological assessments as well as the complex communication between HCP, SU and their families was seen as the main role of the palliative cancer care physiotherapist	10	744	
Sharing	One of the coping strategies for dealing with death and dying was the strong feeling of sharing through collaboration and support with peers.	9	314	
Physiotherapy Service	Key section identified from semi-structured interview schedule. Relates to four questions. See HCP Key themes document pdf in internals.	10	1422	
Evolving Service	Participants discuss at length the changes that the palliative cancer care physiotherapy service has gone through as well as the developments that have occurred.	10	851	
Service Issues	There is a strong sense from all HCPs that the palliative cancer care physiotherapy service requires more time and staff to maintain and improve the quality of the service delivery.	10	571	
Quality of Life	Key section identified from semi-structured interview schedule. Relates to three questions in total, however these were divided into quality of life pre-physiotherapy service (one question) and quality of life post-physiotherapy service (two questions). See HCP Key themes document pdf in internals.	10	306	
Supported	There is a strong sense that the HCPs perceived that the service user's felt supported after they had, had the palliative cancer care physiotherapy service provision.	10	199	
Vulnerable	There is a strong sense that the HCPs perceive the service users to be vulnerable prior to physiotherapy palliative cancer care service provision.	10	107	

Appendix 25: Stage 3 data analysis: service user interviews














SU interviews stage 3	Code definition	Sources	References	Colour code
Physiotherapy	Key section identified from semi-structured interview schedule. Relates to one question. See SU Key themes document pdf in internals.	10	237	
Confused	Participants had a very confused picture around physiotherapy, often confusing physiotherapists with other health care professionals looking after them. Most of the participants could describe physiotherapy that they had had in the past or had no idea of what to expect if they hadn't experienced physiotherapy at all.	10	109	
Physiotherapy Service	Key section identified from semi-structured interview schedule. Relates to four questions. See SU Key themes document pdf in internals.	11	330	
Connected	Participants describe how they feel connected through communication, both verbal and non-verbal including telephone connections and referrals to other health care professionals	6	28	
Enablement	Participants describe the types of interventions they have had from the palliative cancer care physiotherapists and how that has enabled them to do certain activities of daily living.	9	125	
Satisfied	The participants describe the palliative cancer care physiotherapy service in a positive manner in the majority of cases, with some comments on how to improve the current service provision	10	143	
Supported	Participants felt supported through communication both from the health care professionals as well as from their peers	11	386	
Quality of Life	Key section identified from semi-structured interview schedule. Relates to four questions in total, however these were divided into quality of life	10	88	

	pre-physiotherapy service (two questions) and quality of life post-physiotherapy service (two questions). See SU Key themes document pdf in internals.			
Bereavement	Participants describe the impact of their diagnosis on themselves and their families including their losses such as health, retirement, hobbies, loved ones, work and independence.	5	114	
Living	Participants' description of how they are living with their diagnosis, which includes their coping strategies and mind set.	10	224	
Restricted	Participants describe how their lives and activities of daily living have been restricted by their disabilities / symptoms, family situations and attitude to their diagnosis.	10	254	

Appendix 26: Stage 3 data analysis: observations (service users and physiotherapists)

Observations stage 3	Code descriptions	Sources	References	Colour code
Physiotherapy	Physiotherapists' experience and performance observed within the palliative cancer care environment	6	137	
Patient - Therapy Relationship	Observation of patient therapy relationship within the palliative cancer care environment	6	88	
Problem Solving	Observations of problem solving by the physiotherapist within the palliative cancer care environment	6	43	
Reinforcement	Observation of verbal reinforcement within the palliative cancer care environment	6	33	
Symptom Management	Observation of the skills used by the palliative cancer care physiotherapist for symptom management within the palliative cancer care environment	6	409	
Physiotherapy Service	Observation of the physiotherapy service delivered within the palliative cancer care environment	6	153	
Carers	Observation of carers within the palliative cancer care environment	5	51	
Environment	Observation of the palliative cancer care environment	6	56	
Humorous Banter	Observation of humorous banter within the palliative cancer care environment	5	25	
Professionalism	Observation of professionalism within the palliative cancer care service	6	21	
Quality of Life	Observation of quality of life within the palliative cancer care environment	6	135	
Emotions	Observation of emotions within the palliative cancer care environment	6	102	
Reminiscence	Observation of reminiscence within the palliative cancer care environment	5	33	

Appendix 27: Stage 3 data analysis: policy document collection

Policy documents stage 3	Code definitions	Sources	References	Colour code
Physiotherapy	Key section identified from policy documents. Relates to sampling decisions. See policy document Key themes pdf in internals.	13	784	
Interventions	Relates to assessments and rehabilitation within the palliative cancer care environment	11	155	
Outcome measures	Relates to care outcomes and outcome measures within the palliative cancer care environment	9	38	
Professional Bodies	Relates to professionalism and involvement of the professional bodies within the palliative cancer care environment	2	5	
Workforce Needs	Relates to training, education and competencies required to work effectively in the palliative cancer care environment	13	586	
Physiotherapy service	Key section identified from policy documents. Relates to sampling decisions. See policy document Key themes pdf in internals.	13	588	
Co-ordination	Relates to co-ordination of care within the palliative cancer care environment, including key people assigned to oversee this practice and includes communication and team work	13	204	
Evidence-Based Practice	Relates to audits and research within the palliative cancer care environment including best practice and pathways of care	13	123	
Patient-Centred	Relates to emphasis on patient / service user involvement within the palliative cancer care environment	2	5	
Uncertainty	Relates to fears and concerns around the speed of changes and current transition between cancer networks and commissioning groups within the palliative cancer care environment and the strategies put in place to allay those fears and concerns	13	256	
Quality of Life	Key section identified from policy documents. Relates to sampling decisions. See policy document Key themes pdf in internals.	4	39	
Empowerment	Relates to the ownership and management of the service users' needs and how that will be implemented into practice	2	12	
Well-Being	Relates to peer-support as well as health and well-being with promotion of a healthy lifestyle e.g. physical activity and appropriate diet	3	27	

Appendix 28: Stage 4: Cross-referencing – Health care professional interviews

Objective 2: To explore the beliefs, assumptions and perceptions of the role of physiotherapists in palliative cancer care from health care professionals (HCP) perspectives (semi-structured interviews)

Area 1: Physiotherapy

What do you understand about the role of physiotherapy in palliative cancer care?

What is the most difficult part of service users' illness that you have had to cope with?

Has any of the care offered by the palliative cancer care physiotherapy service helped you to manage this area of the service users' illness more successfully?

Physiotherapy role

Patient advocate

Death and dying

Sharing

Area 2: Physiotherapy service

How would you describe your expectations of the palliative cancer care physiotherapy service?

How would you describe the palliative cancer care physiotherapy that service users have received?

How would you describe the communication between the palliative cancer care physiotherapy service and other health care professionals you communicate with?

Describe what improvements you would make to the palliative cancer care physiotherapy service.

Evolving service

Service issues

Area 3: Quality of Life

How would you describe service users' quality of life before receiving interventions from the palliative cancer care physiotherapy service?

How would you describe the quality of life of service users after receiving interventions from the palliative cancer care physiotherapy service?

Describe what you feel has benefited service users by having palliative cancer care physiotherapy interventions?

Vulnerable

Supported

Appendix 29: Stage 4: Cross-referencing - Service user interviews

Objective 2: To explore the beliefs, assumptions and perceptions of the role of physiotherapists in palliative cancer care from service users (SU) perspectives (Semi-structured interviews)

Area 1: Physiotherapy

What were your expectations of the physiotherapy service before you arrived at the unit?

Confused

Area 2: Physiotherapy service

How would you describe your expectations of the physiotherapy service now?

How would you describe the physiotherapy you have received?

Describe what you feel has benefited you by having physiotherapy treatment?

How would you describe the communication between the physiotherapist and other health care professionals you are involved with?

Describe what improvements you would make to the care you have received by the physiotherapist.

Enablement

Supported

Connected

Satisfied

Area 3: Quality of life

How would you describe your quality of life before receiving physiotherapy?

What is the most difficult part of your illness to cope with?

Has any of the care offered by the physiotherapist helped you to manage this area of your illness more successfully?

How would you describe your quality of life since receiving physiotherapy?

Restricted

Bereavement

Living

Appendix 30: Stage 4: cross-referencing – service user and physiotherapist observations

Objective 3: To examine physiotherapists performance and behaviour in the palliative cancer care environment (observations)

Area 1: Physiotherapy

Patient-therapy relationship

Problem solving

Symptom management

Reinforcement

Observational Categories	Includes	Themes
Appearance	How the physiotherapist presents themselves to the service user	Professionalism
Verbal behaviour and interactions	Verbal interactions between the physiotherapist and the service user	Humorous banter Reminiscence
Physical behaviour and gestures	Non-verbal interactions between the physiotherapist and the service user	Emotions Patient-therapy relationship
Personal space	Proximity of the physiotherapist to the service user	Symptom management
Human traffic	People entering and leaving as well as spending time at the observation site	Carers Environment
Experience	How the physiotherapists use knowledge and skills within the observation site	Problem solving Reinforcement

Area 2: Physiotherapy service

Professionalism

Environment

Carers

Humorous banter

Area 3: Quality of Life

Reminiscence

Emotions

Appendix 31: Stage 4: Cross-referencing - policy document collection

Objective 1: To identify issues highlighted within palliative cancer care in relation to best practice recommendations (policy document collection)

Characteristics	Issues	Content	Categories
Drivers of change	Cancer Networks developments and changes	Accountability relationship between drivers of change	Uncertainty
	Commissioning services development	Process targets and outcome measures to track progress	Patient-centred
	Speed and scale of proposed changes	Total pathway of care to maximise resources	
	HCP awareness / comprehension of changes	Collective governance structure to promote collaborative decision making	
		Pathways developed from patients' perspective	
		Less self-assessment and more peer-review with pre-defined criteria	
		Needs of patients and their carers taken into account and involved in service evaluation	
		Views of patients and their carers to influence the development, delivery and evaluation of cancer services.	
		Patient becomes an active participant of the cancer team	
		Development of business cases for quality of care and patient experience	

		<p>Relevant experts from different provider organisations should contribute to the development of policies</p> <p>Development of referral guidelines for services offered, in accordance with any relevant Cancer Network guidelines.</p> <p>Audits, based on agreed policies, undertaken and the results used to inform service development.</p> <p>Develop/support implementation of a local unified policy for DNACPR. The South Central SHA to consider.</p>	
Survivorship, Supportive, Palliative and End of Life Care	Prevalence of cancer set to rise exponentially	All patients have the opportunity to benefit from affective new treatments	Empowerment
	Cancer is now a chronic disease	The need for supportive and palliative care of all patients facing a diagnosis of cancer and their families and carers	Co-ordination
	People are living longer through improved treatment regimens and as a consequence are living with more complex symptoms and disabilities	Palliative care and symptom control should be available at all stages of a patient's illness. Hospitals, primary care, social services and the voluntary sector should all be involved.	Well-being
	Promotion of healthy lifestyles remains a need	Introduction of designated cancer care co-ordinators	
	Communication across professional organisational boundaries is problematic	Appointment of a lead clinician to coordinate services for patients who will be closely involved in negotiating service agreements with purchasers.	
	Evaluative research is needed to test different strategies to facilitate co-ordination between hospital and	Information given to patients and carers about relevant local and national self-help and support	

home, and health and social care.

groups

Development of a service directory made available to HCPs, patients and carers.

Establish and support partnership groups involving patients, carers and local HCPs and their views taken into account when planning services.

Individual to lead on developing and sustaining patient involvement.

To discuss the needs of individual patients at multidisciplinary meetings; record the outcomes of these discussions and communicate them to the patient and carer (with the patient's permission); review the dynamic processes within the team and with other teams/services to maintain continuing effectiveness. Identification of other teams / services with which they interact most frequently and develop plans to promote co-ordinated care.

The outcome of consultations in which key information is discussed should be recorded in patients' notes and communicated to other professionals involved in their care. Patients should be offered a permanent record of important points relating to the consultation.

Develop and implement local systems to share information across providers, particularly out of hours services

Comprehensive and timely information transfer between teams/services about patient care and treatment plans should be in place.

Cancer service reforms and improving outcomes		Communication between cancer centres is vital.	
		Communicating significant news should be undertaken by a senior clinician who has received advanced level training and is assessed as being an effective communicator.	
		All staff should be able to respond appropriately to patients' and carers' questions in the first instance before referring to a senior colleague.	
		Specialist services and end of life care teams work more closely together to ensure continuity of care from the hospital into the community and provide equipment without undue delay.	
		Provide a holistic needs assessment for patients who are identified as dying, ensuring they are placed on an EoLC pathway such as the Liverpool Care Pathway	
		Ensure effective discharge planning and ensure access to fast track continuing healthcare where needed	
Cancer service reforms and improving outcomes	Research is required on supportive and palliative care	Promote physical activity as part of everyday life; Limit alcoholic drinks; advice on following the dietary recommendations for cancer prevention.	Professional bodies
	Empirical research is needed to map patients' motivations, expectations and experiences of care in a range of contexts, to	Guidance developed by professional bodies on the level of expertise and support required to manage the commoner cancers.	Workforce needs
		The Health Departments to work with professional bodies in developing the role of Primary Health Care Teams in the management of cancer	Outcome measures

identify different services and patterns of care received, and to identify ways to improve local service co-ordination.

There are staffing implications for all specialties and professions involved in cancer care.

Exploratory research is needed to determine the effectiveness of specific strategies for user involvement and to learn about the experience of users.

Research is needed to determine the most effective mechanisms for achieving user participation in the delivery of supportive and palliative care in different circumstances.

Research is needed to explore the role, components and outcomes of rehabilitation, including the contribution of AHPs.

Research is needed to determine what models of rehabilitation are most effective for different patient groups and how these are best integrated with other services.

Discussions should be held with appropriate professional bodies around workforce involved in cancer care.

Opportunity for HCPs and patients to develop knowledge and skills to foster confidence and underpin effective working relationships

Appointment of additional staff and the enhancement of knowledge and skills of existing staff. Front-line staff require enhanced training in the assessment of patients' problems, concerns and needs; in information giving; and in communication skills. Additional specialist staff will be needed in roles related to information delivery, psychological support, rehabilitation, palliative care and support for families and carers

HCPs to have access to education in the principles and importance of user involvement and how to act on user views.

To ensure education and development is available across the local workforce. Local hospices are likely to be key providers of local education and training and their role must be reflected in local plans and in their funding

To monitor outcomes of treatment and the implementation of changes in services.

Agree quality outcome markers for measuring provision of EoLC by different organisations and ensure those are written into local service specifications and contracts.

Identify staff who may benefit from training and should facilitate their participation in training and ongoing development. Individual practitioners should ensure they have the knowledge and skills required for the roles they undertake.

Interventions

Assessment of patients' individual needs is a critical first step in ensuring they receive the services they require.

Patients should be offered support to help them to assess their own needs so that the process becomes one of partnership between patients and professionals.

To develop assessment approaches/tools for use in routine practice by a range of HCPs

To develop common approaches to assessment, including the use of specific assessment tools linked with other domains such as continuing, social and intermediate care.

Assessments should encompass all aspects of supportive and palliative care, including the preferences of patients and carers with respect to: written and other forms of information; face-to-face communication; involvement in decision making; control of physical symptoms; psychological support; social support; spiritual support; rehabilitation; complementary therapies; self-

Interventions

Evidence based practice

management and peer support; family and carer support; bereavement support; involvement in the design and delivery of services.

A structured assessment must be undertaken at key points (around the time of diagnosis; commencement of treatment, completion of the primary treatment plan; disease recurrence; the point of recognition of incurability; the point at which dying is diagnosed; at any other time the patient requests it), in the patient pathway which is recorded, with mechanisms developed for sharing the data among the multidisciplinary team. There should be a locally agreed format in which findings can be recorded. Findings should be discussed at multidisciplinary team meetings

Following each assessment, potential interventions should be discussed with patients and carers and a mutually agreed action plan formulated.

Whenever possible and appropriate, family members and carers should be invited to accompany patients during clinical encounters and should be involved in discussions about treatment and care, in accordance with the patient's wishes.

Prompt referral to services should be agreed with patients following assessment.

Care should be evidence-based and delivered in accordance with guidelines, policies and care pathways agreed at Cancer Network level.

MDT should establish a system to ensure family

members and carers have regular opportunities to discuss particular concerns. This might be achieved by offering them an appointment with the 'key worker' at times acknowledged to be particularly challenging (diagnosis, end of treatment, recurrence, palliative care, time of death). encouraging sharing of fears and concerns

MDT should ensure that all family members and carers are offered information on a variety of topics, from a simple 'who's who' of professionals to more detailed accounts of cancer, its treatment and consequences and services available locally.

Ensure professionals know how to initiate conversations about advance care planning, end of life care, including DNACPR decisions, and that there are mechanisms to share the information with other services.

Area 1: Physiotherapy

Workforce needs
Professional bodies
Outcome measures
Interventions

Area 2: Physiotherapy service

Uncertainty
Patient – centred
Evidence based practice
Co-ordination

Area 3: Quality of Life

Empowerment
Well-being

Appendix 32: Stage 5: Mapping – Key area physiotherapy service

Research question	To what extent does palliative cancer care physiotherapy service provision meet the national standards of supportive and palliative cancer care best practice recommendations?			
Data sets	Service user interviews (Anchor)	Health care professional interviews	Observations	Policy documents
Objectives	2. To explore the beliefs, assumptions and perceptions of the role of the physiotherapists in palliative cancer care from service user perspectives	2. To explore the beliefs, assumptions and perceptions of the role of the physiotherapists in palliative cancer care from health care professional perspectives	3. To examine physiotherapists' experience and its possible connection with physiotherapy performance and behaviour in the palliative cancer care environment	1. To identify national standards of supportive and palliative cancer care best practice recommendations 4. To describe issues highlighted within palliative cancer care in relation to national standards
Marker	Semi-structured interview questions How would you describe the expectations of the physiotherapy service now? How would you describe the physiotherapy you have received? Describe what you feel has benefited you by having physiotherapy treatment How would you describe the communication between the physiotherapist and other health care professionals you are involved with? Describe what improvements you would make to the care you have received by the physiotherapist	Semi-structured interview questions How would you describe your expectations of the palliative cancer care physiotherapy service? How would you describe the palliative cancer care physiotherapy that service users have received? How would you describe the communication between the palliative cancer care physiotherapy service and other health care professionals you communicate with? Describe what improvements you would make to the palliative cancer care physiotherapy service	Categories Appearance. Verbal behaviour and interactions. Physical behaviour and gestures. Personal space. Human traffic and experience	Characteristics Drivers of change Cancer service reforms and improving outcomes Interventions
Key area	P H Y S I O T H E R A P Y S E R V I C E			
Categories	Enablement Supported Connected Satisfied	Evolving service Service issues	Professionalism Environment Carers Humorous banter	Uncertainty Patient-centred Evidence-based practice Co-ordination
Key points	1. Integrated MDT service 2. Instigating purposeful ability 3. Care pathways			
Overarching theme	Metamorphosis of cancer treatments nationally			
Key themes	Metamorphosis of physiotherapy service provision			
Sub themes	Outcome measures and commissioning: vulnerability; service user and healthcare professional confusion			

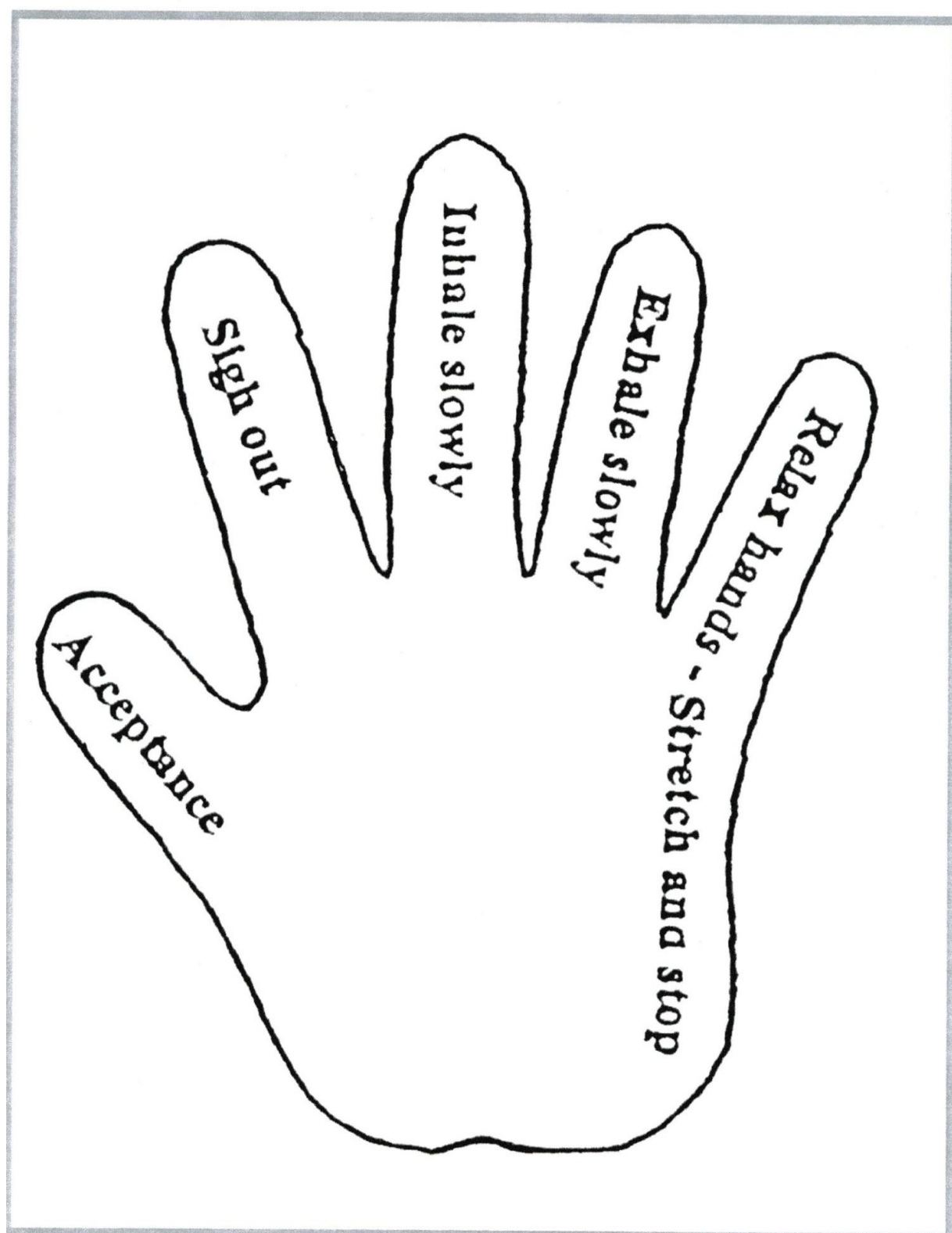
Appendix 33: Stage 5: Mapping – Key area physiotherapy profession

Research question	To what extent does palliative cancer care physiotherapy service provision meet the national standards of supportive and palliative cancer care best practice recommendations?			
Data sets	Service user interviews (Anchor)	Health care professional interviews	Observations	Policy document collection
Objectives	2. To explore the beliefs, assumptions and perceptions of the role of the physiotherapists in palliative cancer care from service user perspectives	2. To explore the beliefs, assumptions and perceptions of the role of the physiotherapists in palliative cancer care from health care professional perspectives	3. To examine physiotherapist's experience and its possible connection with physiotherapy performance and behaviour in the palliative cancer care environment	1. To identify national standards of supportive and palliative cancer care best practice recommendations 4. To describe issues highlighted within palliative cancer care in relation to national standards
Marker	Semi-structured interview question	Semi-structured interview questions	Categories	Characteristics
	What were your expectations of the physiotherapy service before you arrived at the unit?	What do you understand about the role of physiotherapy in palliative cancer care? What is the most difficult part of the service users' illness that you have had to cope with? Has any of the care offered by the palliative cancer care physiotherapy service helped you to manage this are of the service users' illness more successfully?	Appearance. Verbal behaviour and interactions. Physical behaviour and gestures. Personal space Human traffic and experience	Drivers of change Cancer service reforms and improving outcomes Interventions
Key area	P H Y S I O T H E R A P Y P R O F E S S I O N			
Categories	Confused	Physiotherapy role Patient advocate Death and dying Sharing	Patient-therapy relationship Problem solving Symptom management Reinforcement	Workforce needs Professional bodies Outcome measures Interventions
Key points	1. Therapeutic interventions 2. Complex communication 3. Professional adaptation			
Overarching theme	Metamorphosis of cancer treatments nationally			
Key themes	Metamorphosis of the physiotherapy profession			
Sub themes	Shift in mindset and treatment planning; integration of professional boundaries and physiotherapy skill development; emotional adjustment			

Appendix 34: Stage 5: Mapping – Key area Quality of Life

Research question	To what extent does palliative cancer care physiotherapy service provision meet the national standards of supportive and palliative cancer care best practice recommendations?			
Data sets	Service user interviews (Anchor)	Health care professional interviews	Observations	Policy documents
Objectives	2. To explore the beliefs, assumptions and perceptions of the role of the physiotherapists in palliative cancer care from service user perspectives	2. To explore the beliefs, assumptions and perceptions of the role of the physiotherapists in palliative cancer care from health care professional perspectives	3. To examine physiotherapist's experience and its possible connection with physiotherapy performance and behaviour in the palliative cancer care environment	1. To identify national standards of supportive and palliative cancer care best practice recommendations 4. To describe issues highlighted within palliative cancer care in relation to national standards
Marker	Semi-structured interview questions	Semi-structured interview questions	Categories	Characteristics
	How would you describe your quality of life before receiving physiotherapy? What is the most difficult part of your illness to cope with? Has any of the care offered by the physiotherapist helped you to manage this area of your illness more successfully?	How would you describe service users' quality of life before receiving interventions from the palliative cancer care physiotherapy service? How would you describe the quality of life of service users after receiving interventions from the palliative cancer care physiotherapy service? Describe what you feel has benefited service users by having palliative cancer care physiotherapy interventions?	Appearance Verbal behaviour and interactions Physical behaviour and gestures. Personal space. Human traffic and experience	Drivers of change Cancer service reforms and improving outcomes Interventions
Key area	Q U A L I T Y O F L I F E			
Categories	Restricted Bereavement Living	Vulnerable Supported	Reminiscence Emotions	Empowerment Well-being
Key points	1. Rehabilitation 2. Acquiescence 3. Complex conditions			
Overarching theme	Metamorphosis of cancer treatments nationally			
Key theme	Shift in mindset			
Sub themes	Emotional adjustment			

Appendix 35: Calming hand



(Adapted from anon)

Appendix 36: Practice development – provider recognition Standard Life



Standard Life Healthcare

Marshall Point
4 Richmond Gardens
Bournemouth
BH1 1JD

Tel: 0845 279 8877

Fax: 01202 552527

Mrs C Belchamber

Address
blanked out for
confidentiality

4 June 2009

Dear Mrs Belchamber

Provider Recognition

I am pleased to confirm that you have been added to our database as a provider of Physiotherapy.

Please note that we do not currently issue provider numbers, now that you are included on our database you simply need to quote the patients policy and claim numbers on your invoices.

Please ensure that any invoices are clearly marked 'invoice' and are sent to **Standard Life Healthcare, PO Box 28837, Edinburgh, EH15 1WP**. Please include all relevant treatment dates and corresponding amounts.

If you have any queries please do not hesitate to contact us on: **0845 602 8803**

Yours Sincerely

Miss Wendy Hudson
Contracts Advisor
Commercial Contracts

Pensions

Mortgages

Savings

Investments

Healthcare

Insurance

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Appendix 37: Practice development – provider recognition WPA



Provider Enquiries Telephone:
01823 625170
Provider Number:
920302870

PRIVATE AND CONFIDENTIAL

Mrs Caroline Anne Belchamber

Address
blanked out for
confidentiality

5 June 2009

Dear Mrs Belchamber

We have pleasure in confirming that your name has been entered onto our database so that we can pay benefit for your fees. Your provider number is given above and it is essential that this is quoted on all invoices submitted to WPA to ensure correct payment of your fees.

Payments will be made twice monthly on or around the 8th and 22nd of each month (dependent on the bank BACS run dates). The relevant remittance advice will be sent out by post within a couple of days thereafter. Should you wish to change any details in the future, please ensure that you quote your WPA Provider Number - indeed, for ease of identification, we strongly recommend that this is included in all documentation.

WPA has a large number of policies with a variety of benefits. We therefore recommend that your patients with WPA policies contact us prior to commencing treatment, to confirm what benefit is available to them.

The information you have given us, correspondence between us, and records of invoices submitted for your fees will be held on our database. It will be held in accordance with the Data Protection Act 1998 and will be used so that we can process claims for your fees, make payments and write to you and may be used for statistical analysis or to prevent fraudulent or improper claims. You can ask to see the information we hold about you. Please be aware that details of your provider entry may appear on our website. As you will appreciate, it is important that we maintain accurate and up to date records. It would help us, therefore, if you would inform this department of any change in your address or professional circumstances. We will not change your address or details unless you specifically ask us to do so. Please note, to protect your and our interests we may record telephone calls.

If you have any questions about your registration, please do not hesitate to contact the Provider Services Department and we will be happy to help.

Yours sincerely

Provider Affairs
providerservices@wpa.org.uk

www.wpa.org.uk You may be interested in using our interactive website - it's a user-friendly site, designed to give you access to a full range of WPA services - available 24 hours a day.



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Business Plan 2009

Physiotherapy Cancer Care

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Overview of private practice

Introduction

With the launch of the National Health Service (NHS) Cancer plan (DH 2000a) and the introduction of the National Institute of Clinical Excellence (NICE) guidelines healthcare professionals are becoming more aware of the gaps in service delivery. The NHS cancer plan states that annually 200,000 people are diagnosed with cancer. In England more than one in three people will develop cancer at some point in their lives. With improved treatments people with cancer are living longer (Hopkins and Tookman 2000) and the need for rehabilitation of this client group is increasing (David 1995). It has been recommended therefore that rehabilitation should become an integral part of care from diagnosis onwards (NCHSPCS August 2000). Rashleigh (1996) states that physiotherapists have a large preventative, educative and supportive role to play in the management of the person with cancer, as well as providing independent and complementary therapies for physical debility and pain. With this knowledge the Chartered Physiotherapist hopes to provide a vital gap in physiotherapy service delivery to this client group.

Physiotherapy Cancer Care

Physiotherapy Cancer Care is a unique private practice caring for people living with cancer. This is a start-up private physiotherapy practice looking for premises consisting of a treatment room and reception area within a quiet venue in A highly qualified Chartered Physiotherapist with sixteen years of experience in physiotherapy (of which six years was spent specialising in Oncology and Palliative care) will run the practice.

Chartered Physiotherapist's Biography

Since obtaining a Bsc (Hons) in Physiotherapy and becoming a registered, Chartered physiotherapist in 1993, the physiotherapist who will be running the private practice has gained experience working in a wide variety of settings. In 1996 she specialised in respiratory at Hospital NHS Foundation Trust and was an integral part of the adult cystic fibrosis team. Since September 2000 she has specialised her respiratory expertise further in the field of oncology and palliative care. During this time the Chartered Physiotherapist has successfully run a breathlessness clinic for primary and secondary lung cancer patients using the non-pharmacological approach. This expertise has been recognised and she has presented talks at University, Hospital NHS Foundation Trust, and County Hospital NHS Trust, Hospice and the Association of Chartered Society of Physiotherapists in Oncology and Palliative Care (ACPOPC) spring conference. The Cancer Network has recognised the Chartered Physiotherapist as a breathlessness physiotherapist specialist and she has subsequently been involved in the National Institute of Clinical Excellence (NICE) guidelines for lung cancer.

The Chartered Physiotherapist's work has also included covering a specialist palliative day care centre, which has been the focus of her interest in rehabilitation within the palliative care setting, leading to her Msc research undertaken on this topic and presented at the Chartered Society of Physiotherapy (CSP) congress in October 2003 and then at the United Kingdom Association of Cancer Registries (UKACR) in September 2008. This research was published in the September 2004 issue of the International Journal of Therapy and Rehabilitation. A further paper has been written for the peer-reviewed journal, Groupwork, which is due to be published shortly.

The Chartered Physiotherapist has also helped in the development of the physiotherapy service for oncology patients at Hospital NHS Foundation Trust from 2003 to 2006. During the period 2005 to 2006 the chartered physiotherapist carried out contract work (self-employed) as a specialist-training consultant for Rehab Plus. The latter involved writing and presenting oncology evidence-based courses for Occupational Therapists and Physiotherapists in various locations around the UK. Following on from this she was appointed as a

physiotherapy lecturer at University, completing her postgraduate certificate in Health and Social Care Education and is currently working towards her doctor of professional practice (DProf).

This private practice's key competitive advantage is the in-house knowledge base of the Chartered Physiotherapist in oncology and palliative care. There is also a gap in service delivery for people with cancer wishing to have further physiotherapy input on discharge from hospital. At present there seems to be a lack of competition from private practices in who do not specialise in treating people with cancer.

Product Description

Physiotherapy Cancer Care will be offering a unique service for people with cancer and will commence with the following treatments:

- Treatment to improve, maintain or manage the deterioration of exercise tolerance and muscle strength
- Treatment to maintain or improve joint range of movement and soft tissue flexibility
- Gait re-education to maximise independence in mobility and/or transfers
 - Adjuvant, non-pharmacological pain management, including the use of Transcutaneous Electrical Nerve Stimulation (TENS) to support pharmacological intervention in the management of nausea, vomiting and pain
 - Stress and anxiety management, for example, through relaxation and/or massage therapy
 - Advice and training on appropriate, safe and legal moving and handling techniques for the patient, carer or healthcare professionals working with the person with cancer
 - The non-pharmacological approach to aid the management and control of breathlessness in people with lung cancer
- Health Creation mentor service including the cancer lifeline kit

Marketing and Sales

To promote this new area of private physiotherapy practice a variety of advertising, canvassing and publicity will be used. The latter will comply with the CSP's rules of professional conduct which can be accessed on the society's website www.csporg.uk

The following is the marketing plan for Physiotherapy Cancer Care:

Organisation of Chartered Physiotherapists in Private Practice (OCPPP) website:

Becoming a member of OCPMP which Includes immediate entry on website www.physiofirst.org.uk. Which has a public site that incorporates a search facility 'Find a Physio' for the general public to help find a local member with a given specialty. Members can also request links to their own sites, which provides a free advertising opportunity.

Physiotherapy Cancer Care Website: Including photographs of the practice and the products that are available; Information of treatment times, cost and availability; The Chartered Physiotherapists qualifications and experience. This website will also have links to OCPMP, ACPOPC and Health Creations websites.

Association of Chartered Physiotherapist in Oncology and Palliative Care (ACPOPC)

website: This website was launched in October 2002 by the husband of the Chartered Physiotherapist running the practice who was the ACPOPC membership secretary for one year. An area is available on this website for advertising and is linked to the CSP website

Rehabfirst: All OCPMP members are able to receive referrals through an insurance industry known as rehabfirst. This was established in 2000 by OCPMP

General Practitioner: A letter will be sent out to local G.P.'s explaining the services available at Physiotherapy Cancer Care for people with cancer.

Yellow pages: Ability as an OCPPP member to advertise in the OCPPP corporate box.

Postcards: To advertise Physiotherapy Cancer Care postcards will be used. The front of the postcard will have an illustration of the conditions treated at the practice. On the reverse will be a description about the Chartered Physiotherapist who runs the practice, where to find the practice and how to contact the practice. An offer of a discount on treatments will be made available to anyone who comes to the practice accompanied with the postcard. Direct marketing will be used and postcards distributed as a mail shot to local residence.

Business cards: A business card will provide the name of the practice the logo and contact details. These can be handed out easily to existing clients who will hopefully use word of mouth to promote Physiotherapy Cancer Care.

Presentations: Providing talks to local professional groups working with people with cancer.

Measuring the response: A measurement will be made on how much income the referrals have generated which can be compared against the source of the referral and the cost of implementing that source. A relationship will then be made between the money spent and money generated as a result, which will provide information on return on Investment.

Development

A cautious approach will be taken initially working on a part-time basis and fitting in with the chartered physiotherapists current job and study time. At the outset this will allow one day a week for the practice to run. As the business picks up then a second day will be released from the current job. When the business is robust enough and the Dprof has been successfully completed the Chartered Physiotherapist will work entirely for Physiotherapy Cancer Care.

Initially the Chartered Physiotherapist will use the knowledge base that she already has but will then consider looking at courses specific to the Health Creator Mentorship service as well as acupuncture in Oncology and Palliative Care and the Buketo technique to add to the treatments offered at the practice.

As the Practice develops a receptionist/secretary maybe considered and in the long-term future a second physiotherapist.

Operations

The following information has been gathered from the CSP, which is the professional body for the Chartered Physiotherapist running the practice.

1. Thinking of private practice? – Information paper. Number PA7
2. Physiotherapists and Insurance – Information paper. Number PA 32
3. General Principles of Record keeping and Access to Health Records – Information paper. Number PA 47
4. Standards of Physiotherapy practice (CSP a, b, 2000)

Further information has been sought from:

1. The data protection act; <http://www.doh.gov.uk/dprhome.htm>
2. NHSE (1999) The protection and use of patient information – guidance from the Department of Health <http://www.doh.gov.uk/confiden/pguid3.htm>
3. The Office of the Data Protection Commissioner (2000) Subject Access and Health Records. Downloaded on 24/7/00 from <http://wood.ccta.gov.uk/dpr/dpdoc.nsf> - compliance advice

Treatments and Fees Protocol

- An indication of fees and the likely number and frequency of treatments will be stated to the client before the treatment program begins.
- Cash flow will be enhanced by taking payment from every client at the time of treatment when the practice first opens. This will then be reviewed.
- A cancellation charge of £10.00 will be considered.

Client's Records

All client records will be held on computer and will comply with the Data Protection Act 1998, with a procedure in place for clients to access their records. Software will be used that includes an audit trail that identifies any changes made to the text, as in a written record. The client's electronic records will regularly be saved on an encrypted memory stick and kept in a locked filing cabinet.

For identification and authentication the electronic system will not allow access to a user until the user has entered their user identity and password. The system will record all remote access requests including those for authorised system support and maintenance activities.

Client records will be retained in accordance with the CSP core standard 15 and Service and Service Standard 19 of the Physiotherapy Standards Pack (CSP 2000) which sets out the need to retain records in accordance with existing policies and current legislation.

On the advice of the CSP where client's records have been generated by computer, a hard copy will be printed off and signed each time a treatment is given. This practice will continue until case law allows for computer-generated records to be accepted in court.

Clients requesting access to their record will be entitled to:

1. Claim access to the record within a maximum of 21 days from the request. If an entry has not been made in the 40 days before the date of the application, then the time limit for granting access is extended to 40 days.
2. Receive an explanation of any terms that are 'not intelligible without explanation.'
3. Request corrections to any information considered inaccurate (i.e.: incorrect, misleading or incomplete). If the record holder declines to correct it, a note of the applicant's opinion must be included in the record (and copied to them).

A £10 fee will be charged for granting access to the client's records that are automatically processed (Subject Access and Health Records, 2000)

No fee will be charged if the access request is to view the record but not be supplied with a copy (Subject Access and Health Records, 2000)

Insurance

Professional Liability Insurance: This is provided by the CSP to all subscribing members to a limit of £5 million. The Chartered Physiotherapist running the practice is a fully subscribed member to date. Below is a summary of the insurance cover that the Chartered Physiotherapist running the practice would be entitled to:

Individual insurance (included as benefit of CSP membership)

Medical Protection Society – covered to £5 million (per individual) and in aggregate for Professional Liability

- Can top-up to £10 million = additional £75.00

St Paul International Business Insurance (optional benefit) - Covered to £5 million only, for Public and Product Liability

Medical Protection Society – covering malpractice up to £5 million

St Paul International - Covering Public and product Liability to £5 million

Premium based on turnover:-

Up to £100,000 = £380.00

Up to £250,000 = £410.00

Up to £750,000 = £490.00

Can top-up to £10 million for malpractice only with MPS = additional £110.00

Summary of the protocol for reporting of actual, or potential, claims under professional liability insurance

- Report claims or potential claims immediately
- Issue a simple acknowledgement letter to the claimant (or their representatives) confirming their correspondence has been passed to the CSP at 14 Bedford Row London WC1R 4ED for attention
- Provide the CSP with full documentation as soon as possible. Remember insurers have only 90 days to reach a decision on liability
- Identify all relevant documentation and let the CSP have copies within 7 days of the initial claim notification

The Physiotherapist running the practice will comply with the following:

- Professional responsibility and obligations will be maintained by the Chartered Physiotherapist running the practice and as a member of the CSP be bound by the Rules of Professional Conduct.
- Regular peer and professional support will be maintained through OCPPP (3,500 colleagues) and ACPOPC (400 colleagues)
- Participate in a mandatory scheme of Continuing Professional Development (CPD) with individuals expected by OCPPP to record a minimum of 25 hours annually or 50 hours of CPD over a two-year period.
- The CSP “Standards of Physiotherapy Practice”, which sets out national standards and covers everything from equipment and treatment, to privacy and communications with clients.
- Advice and information will be sought about rules, or any professional matter from the CSP Member Networks and Relations Function at the CSP
- Guidelines on good practice published by the OCPPP
- State registration through the Health Professions Council (HPC), which is mandatory for private practitioners. From 2004/5 ‘physiotherapist’ will be a protected title and can only be used by physiotherapists registered with the HPC
- As a registered Physiotherapist private medical insurance companies, such as BUPA and PPP, are more likely to pay out claims

Management

The Chartered Physiotherapist running the practice will manage Physiotherapy Cancer Care. This will include both clinical work and managerial work. Advice will be sought from Mr. Belchamber regarding, budgeting, website and general managerial matters. The website will be maintained and a security system put in place for confidentiality of the clients records by Mr. Belchamber who is a product development manager with 34 years of experience working with computer software. All correspondence, treatment plans, and information leaflets will be designed by the Chartered Physiotherapist running the practice who will act initially as the secretary for the practice. All documents will be printed at home on a high quality colour printer.

Financial Summary

The estimated start-up costs come to £..... with a small profit being made in the first year if full attendances for potential clinical times are achieved. Realistically the private practice will break even in the second year. The sales forecast is based on increasing knowledge of the private practice by healthcare professionals and by word of mouth.

Accounts: Accurate practice accounts will be maintained, and the advice of a qualified accountant will be sought when necessary.

VAT: State registered physiotherapists are exempt from VAT for the provision of physiotherapy treatment even if their turnover is in excess of the statutory limit. Furthermore registration with the Health Professional Council (HPC) grants exemption from VAT if turnover exceeds the statutory requirements for private practice premises to be licensed.

Income Tax: Tax relief will be claimed on the annual subscription to the CSP, the annual State Registration fee, ACPOPC subscription and the OCPPP subscription.

The following financial summary provides a basic overview of incomings and outgoings for the start-up of Physiotherapy Cancer Care. Sick leave and holiday leave has not been incorporated into the plan so this would need to be taken into account in the final total.

Year	2009 / 2010	2010 / 2011	2011 / 2012
Equipment costs	£500	£300	£300
Premises	£3,380	£3,380	£3,380
CSP Standards	£35	Nil	Nil
Annual membership fees	OCPPP £60 initial registration £137 annual subscription ACPOPC £20 annual subscription CSP £276.00 annual subscription State registration fee £108 annual subscription (HPC) ACPRC annual subscription £40	OCPPP £137 ACPOPC £20 CSP £276.00 annual subscription State registration fee £108 annual subscription (HPC) ACPRC annual subscription £40	OCPPP £137 ACPOPC £20 CSP £276.00 annual subscription State registration fee £108 annual subscription (HPC) ACPRC annual subscription £40
Stationery	£1000	£500	£500
Training	£1,500	£500	£500
Advertising	£400	£100	£100
Uniform	£60	£20	£20
Total outgoings	£	£	£
Treatments	3 treatments per week @ £35 per session = £ = £ per month = £ per annum	4 treatments per week @ £35 per session = £ = £ per month = £ per annum	5 treatments per week @ £35 per session = £ = £ per month = £ per annum
Total incomings	£	£	£
Total incoming minus total outgoing	£	£	£


Offering

Physiotherapy Cancer Care offers people with cancer a unique private physiotherapy service in the community providing specialist treatments, help and advice to the person with cancer, in a friendly and supportive environment.

Keys to success


1. The Chartered Physiotherapist running the practice must retain the clientele through professionalism and efficiency.
2. A continual flow of clients will be maximised by the websites and by word of mouth.
3. The Physiotherapy practice will succeed if the Chartered physiotherapist remains up to date with continuing professional development.
4. The Physiotherapy practice will succeed if the Chartered physiotherapist is able to balance her current work situation and the start-up of the physiotherapy practice.

Appendix 39: Practice development project - Flyer (front)




Physiotherapy Cancer Care


A unique physiotherapy service for people living with cancer




Group or individual treatments




Management of symptoms



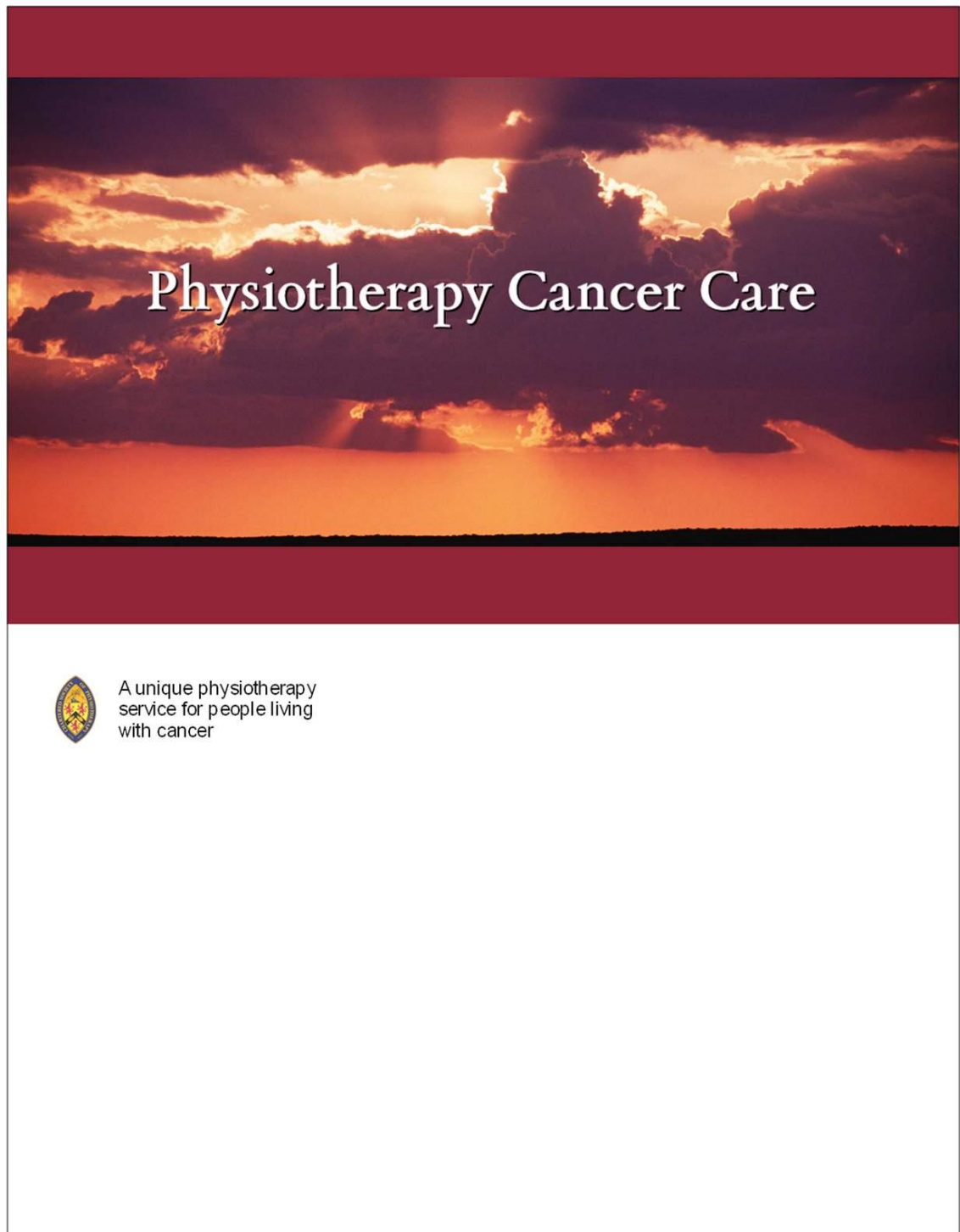
Presentations



Physiotherapy clinic or domiciliary visits



www.physiocancercare.co.uk
07730 431930



A unique physiotherapy
service for people living
with cancer

Appendix 40: Practice development project – Business card (front)



Practice development project – Business card (back)

An appointment card with a background image of a mountain range at sunset or sunrise. The card contains the following text and fields:

APPOINTMENT

FOR: _____

DATE: _____ TIME: _____

LOCATION: _____

IF YOU ARE UNABLE TO KEEP YOUR APPOINTMENT, PLEASE CONTACT US AS
SOON AS POSSIBLE.

Appendix 41: Practice development project – leaflet (front)

What Services can *Physiotherapy Cancer Care* offer?

- 1. Specialist advice and intervention**
- 2. Examination and assessment**
- 3. Treatment plans individually tailored to suit your needs**
- 4. Rehabilitation programmes designed within your capabilities to achieve your goals**
- 5. The non-pharmacological approaches to breathlessness, pain and nausea management**



Physiotherapy Cancer Care is a unique physiotherapy service providing care for people living with cancer. It is run by a highly qualified Chartered Physiotherapist with sixteen years of physiotherapy experience, of which six years has been spent specialising in Oncology and Palliative Care.

Physiotherapy Cancer Care aims to support and assist people who have physical problems experienced through cancer treatment. This latter has led to the need for rehabilitation, which is an integral part of your care from diagnosis onwards (The National Council for Hospice and Specialist Palliative Care Service 2000, NICE Guidelines on Supportive and Palliative Care 2004).

Physiotherapists have a large preventative, educative and supportive role to play in your management and can provide you with independent and complementary therapies for physical debility and pain (Rashleigh 1996). Therefore Physiotherapy Cancer Care provides a vital gap in the physiotherapy service delivery for people living with cancer.

Physiotherapy Cancer Care



Physiotherapy Cancer Care
Physiotherapy (Hons)
BSc (Hons) BSc

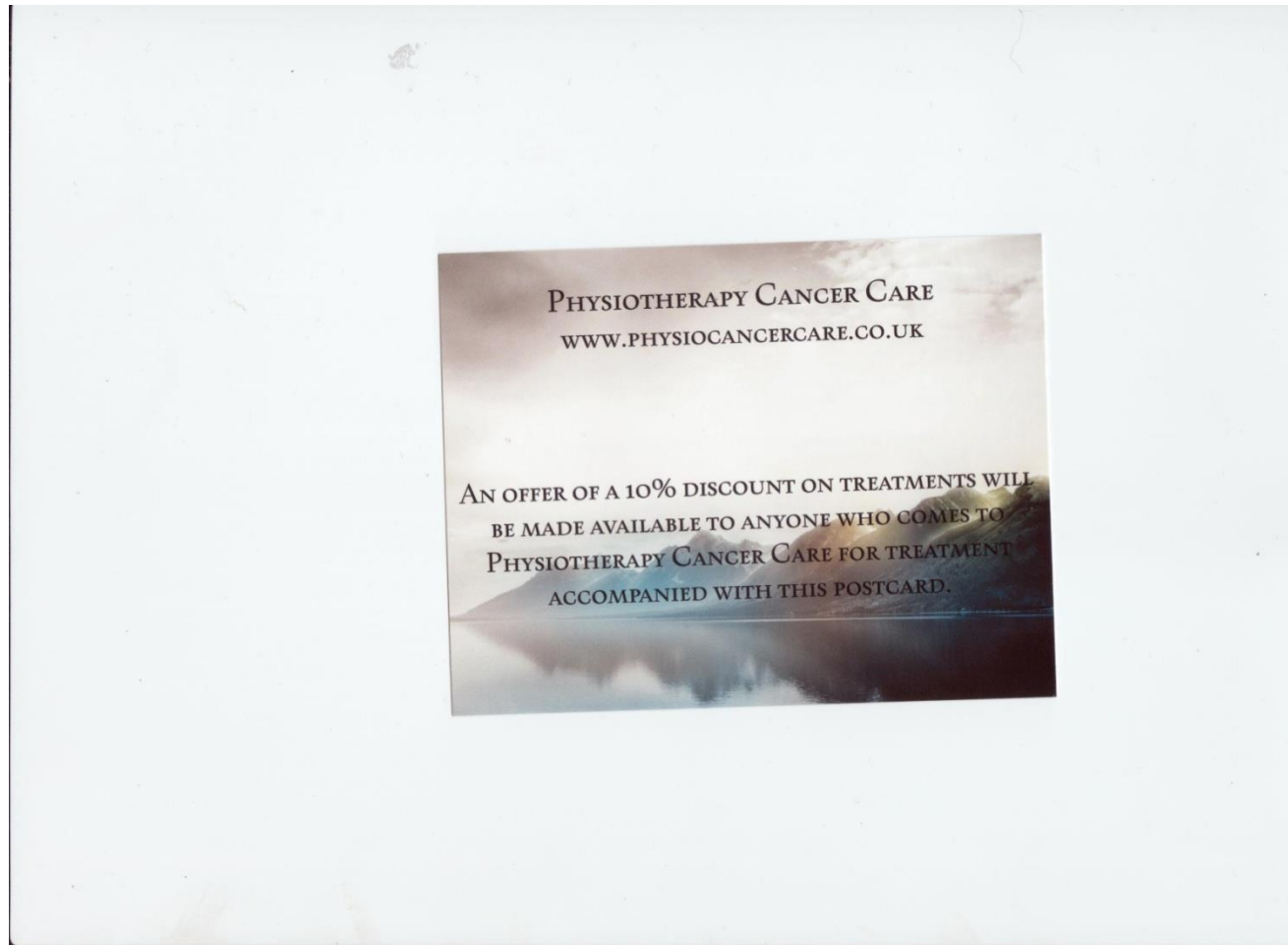
info@physiocancercare.co.uk
www.physiocancercare.co.uk
Tel No: 07730 431930

Caroline Belchamber
MSc, BSc (Hons), PGCE,
BTEC edexcel, HPC, SRP

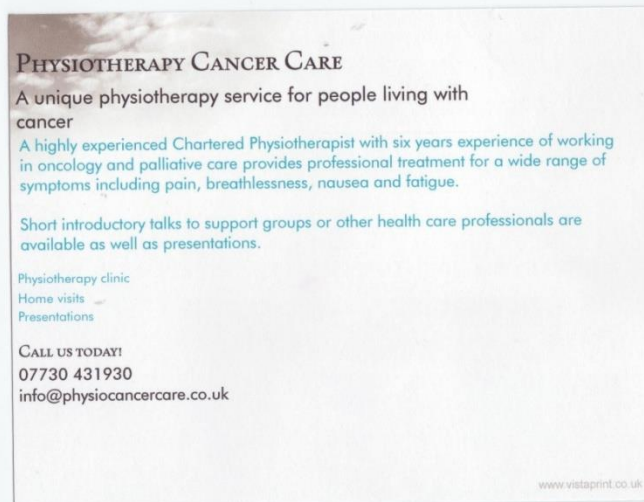
Practice development project – leaflet (back)

What are the benefits of physiotherapy?	What symptoms can be managed?	What treatments are available?
<p>There are a number of key benefits of being treated by a physiotherapist specialising in people living with cancer:</p> <ol style="list-style-type: none"> 1. Specialist knowledge, expertise and experience 2. Specialist skills to aid reduction of symptoms such as pain, fatigue, nausea and breathlessness 3. Advice and support to prevent any unnecessary discomfort or anxiety 4. Ability to tailor individual treatment plans to meet your needs 5. Education in self-management of your symptoms 6. Reduction of joint stiffness and deterioration of muscle strength through gentle exercises appropriate to your condition 7. Therapeutic soft tissue mobilisation 	<p>Breathlessness</p> <p>Pain</p> <p>Nausea</p> <p>Fatigue</p> <p>Decreased muscle strength</p> <p>Decreased joint mobility</p> <p>Decreased mobility</p> <p>Anxiety and loss of control</p>	<p>Transcutaneous Electrical Nerve Stimulation (TENS) to help manage pain and / or nausea</p> <p>The non-pharmacological approach to breathlessness</p> <p>Stretching and strengthening exercises</p> <p>Soft tissue mobilisation including massage</p> <p>Specific individualised exercise programmes</p> <p>Tailored rehabilitation including pre and post surgery</p> <p>Stress and anxiety management</p> <p>Moving and handling advice</p>

Appendix 42: Practice development project– promotional offer (front)



Practice development project - promotional offer (back)



PHYSIOTHERAPY CANCER CARE
A unique physiotherapy service for people living with cancer

A highly experienced Chartered Physiotherapist with six years experience of working in oncology and palliative care provides professional treatment for a wide range of symptoms including pain, breathlessness, nausea and fatigue.

Short introductory talks to support groups or other health care professionals are available as well as presentations.

Physiotherapy clinic
Home visits
Presentations

CALL US TODAY!
07730 431930
info@physiocancercare.co.uk

www.vistaprint.co.uk

Appendix 43: Practice development project - Licence agreement

Private
practice name
blanked out
for
confidentiality

**Chartered
Physiotherapists**

THE ASSOCIATION OF CHARTERED PHYSIOTHERAPISTS IN PRIVATE PRACTICE



Names blanked out for
confidentiality

Current room rental tariff. February 2009

We can offer accommodation at one of our rooms in 3 Springfield Road on the following terms.

Ad hoc basis

During the first three months we would only charge £10 per hour to help in the start up phase of your new business arrangement. Our reception would take a booking on a room if available and we would expect you to settle the fee at the end of that hour at our reception.

After the three month period we would charge £15 per hour for the use of a room on an ad hoc basis.

NB. We cannot guarantee the long term availability on a room with this arrangement.

We would expect you to keep us informed of any cancellations and reserve the right to deny bookings if late cancellations become recurrent.

Weekly reservation

An alternative option at either outset or after a three month period is to reserve and pay for a weekly designate half day or full day session. We would expect you to set up a standing order and pay a month in advance.

Full day is charged at £520 per calendar month

Half day is charged at £260 per calendar month

Full exclusive reservation

Another alternative which becomes available from time to time is exclusive reservation of a room on a monthly basis.

The charge is £650 per calendar month by standing order in advance.

Marketing

Included in that fee is the ability to display some of your marketing material in all of our three waiting rooms. We require it to be of a size that fits into the rotating stands. Other literature cannot be displayed.

Central Clinic and Administration:

Tel: Contact number
blanked out for
confidentiality

Private
practice name
blanked out
for
confidentiality

**Chartered
Physiotherapists**

IN THE ORGANISATION OF CHARTERED PHYSIOTHERAPISTS IN PRIVATE PRACTICE



Names blanked out for
confidentiality

License to occupy

We would expect you to sign a 'license to occupy' document and provide up to date
copies of your professional qualifications and your professional indemnity.

Central Clinic and Administration:

Tel:

Contact number
blanked out for
confidentiality

License to Occupy a Consulting Room at (private practice name)

Terms of Agreement

Between

Private practice name and address removed for confidentiality

And

Caroline Belchamber
(Address removed for confidentiality)

1. **Location**

(name of private practice and address removed for confidentiality).

2. **License**

The company will provide the Operator with a license for a period of six months from 1 July 2009 to 30th January 2010.

- **License Fee**

The Operator will pay a license fee of £10 per hour for the ad hoc use of a consulting room within (name of private practice and address removed for confidentiality).

- **Payment**

Payment is to be made on completion of each session based on the time used on a pro rata basis for any session over an hour. Payment by cash or card is acceptable.

- **Commencement Date**

1 July 2009

6. **Licence Renewal**

The renewal date for the Licence will be 6 months from opening and the licence fee will be reviewed on an upward only basis. The renewal fee will be no less than the average UK inflation rate for that year.

7. **Services Provided**

The company will provide the room and access areas to the room and the shared use of the waiting room. It will provide the room with heating, cleaning and utilities generally. There will also be trolley provided in the room for equipment. All other equipment and applications will need to be provided by the practitioner. Patients will be invoiced by the operator.

- **Insurance**

The Licensee will ensure that they have adequate personal and public liability insurance with a cover up to £5 million at all times. A copy of which is to be provided to (name of private practice)

9. **Signs and Notices**

The Licensee must not display any signs or notices without prior written consent of the Licensor.

The Licensee may only take up a maximum of two parking spaces at the (address removed for confidentiality) site at any one time.

Signed (For (name of private practice)
Physiotherapy)

Signed Date.....

Appendix 44: Practice development project – consultant letter template

Address and contact details
removed for confidentiality

Dr
BMI Healthcare
(address removed for confidentiality)

12th May 2009

Dear ,

Re: Telephone message Friday 8th May 2009

I am a Registered Chartered physiotherapist with sixteen years' experience of which six has been in Oncology and Palliative Care.

At the present time I am looking into setting up a unique physiotherapy service for people living with cancer, offering treatments in the comfort and security of their own homes. I am also considering providing a venue if people would prefer not to have a domiciliary visit.

I would like to know if you would be supportive of the above? I will be happy to meet with you if you would like to know more about the service and treatments which could be offered to your patients and to discuss the feasibility of such a venture. I would really value your thoughts.

Kind Regards

Caroline Belchamber MSc (CPD) Health, BSc (Hons), PGCE, BTECH (edexcel), MCSP, SRP

Appendix 45: Practice development project – Consultant response

Name blanked out for confidentiality

Consultant in Clinical Oncology

Consultant's hospital address
and contact details blanked out
for confidentiality

Cancer centre address
and contact details
blanked out for
confidentiality

21st May 2009

Mrs Caroline Belchamber

Address blanked
out for
confidentiality

Dear Caroline

Thank you for your recent letter in respect of setting up a physiotherapy service for patients living with cancer. I remember you well from your days when you helped us on [redacted] and are more than happy to support you in this venture and would be happy to refer patients to you as appropriate.

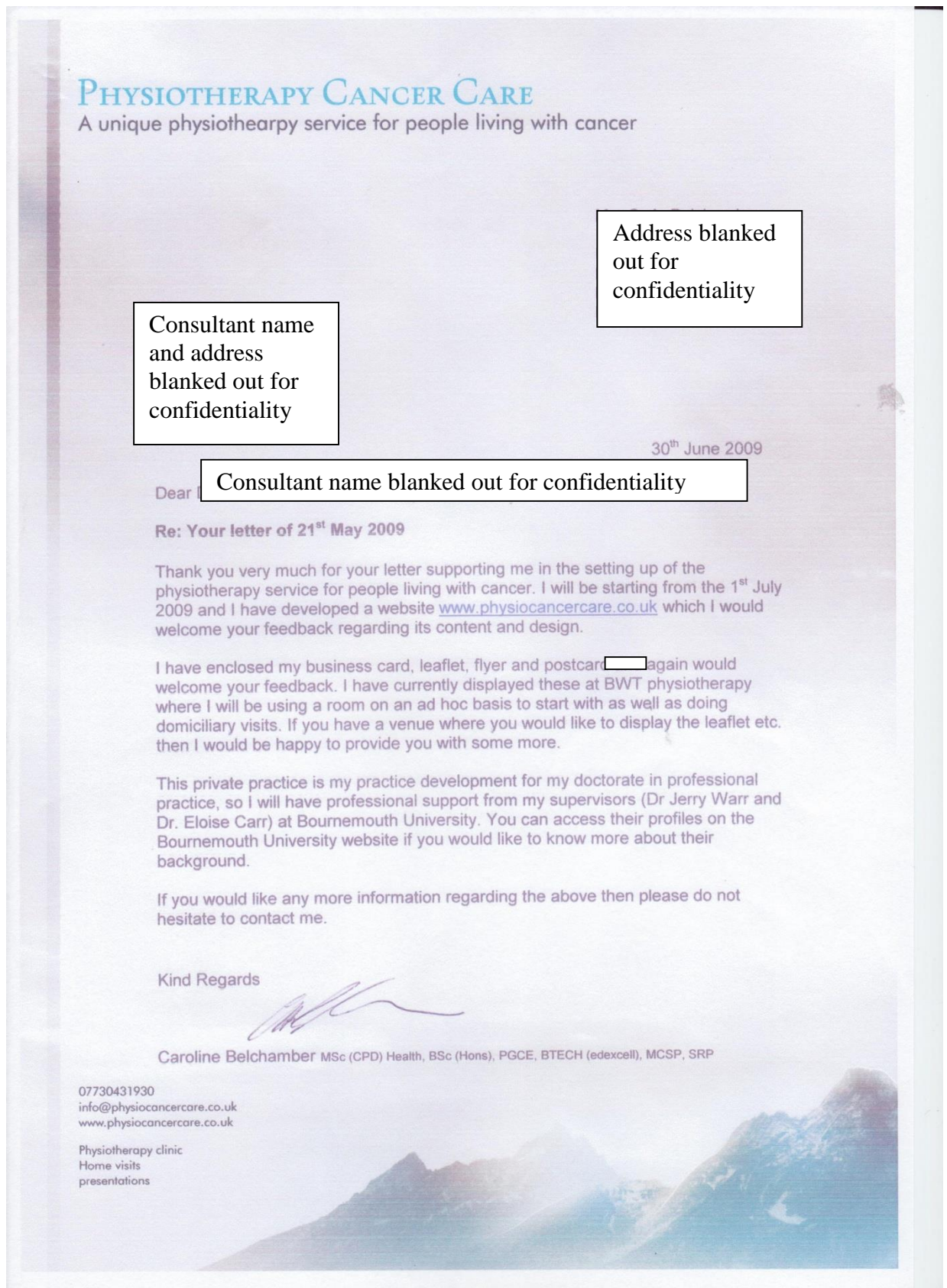
Kind regards

Yours sincerely

Consultant name blanked out for confidentiality

Consultant in Clinical Oncology and Radiotherapy

Appendix 46: Practice development project – further correspondence to consultant



Appendix 47: BUPA brief

Brief for Caroline Belchamber:

General advice on the important factors and points we should take into account when developing our proposition and service model for this palliative rehabilitation service.

General insight to how a palliative rehabilitation service fits into an end-of-life care pathway – from your understanding of the service specification, how would this service fit in with MDT meetings in primary/secondary care?

Share expertise with regards to the types of physiotherapy interventions and treatments which we may have to deliver, given the patient mix in (area removed for confidentiality) below:

Cause of death	27. Percentage of deaths from respiratory deaths (underlying cause)	340	14.3%	13.8	11.2
	28. Percentage of deaths from respiratory deaths (mentions)	831	35.0%	34.2	28.9
	29. Percentage of deaths from cancer (underlying cause)	653	27.5%	27.7	23.1
	30. Percentage of deaths from cardiovascular disease (underlying cause)	681	28.6%	29.6	25.3
	31. Percentage of deaths from liver disease (mentions)	113	4.8%	3.8	2.7
	32. Percentage of deaths from renal disease (mentions)	144	6.1%	5.8	3.6
	33. Percentage of deaths from Alzheimers, dementia & senility (mentions)	429	18.0%	17.3	7.9

Advise on the structure and content of a typical palliative physiotherapy assessment

Advise on the types of physiotherapy interventions that may be suitable in a group setting, as opposed to on a 1-2-1 (physio to client) basis.

Advise on the type of work that may be undertaken by a Rehabilitation Support Worker (as identified in the service specification.) How much responsibility do they have and what types of interventions could they deliver?

Share knowledge about how the role of a palliative physiotherapist would have to link in with other allied health professionals (i.e. occupational therapists, dietitians etc.)

Look over and comment on our proposed service model put forward to facilitate the service specification which has been devised by (name removed for confidentiality) CCG.

Appendix 48: Examples of multi-dimensional outcome measures in palliative cancer care

Outcome measure	Number of items	Completion time	Additional comments
Palliative care Outcome Scale (POS) ⁵	10 items on physical symptoms, emotional, psychological and spiritual needs, provision of information and support 1 open question on main problems	mean time 6.9 min (patients) and 5.7 min (staff); repeated assessments of patients and staff mean time < 4 min ⁵	scores from 0 ('no effect') to 4 ('overwhelming'); patient, staff and carer version; widely used palliative care measure freely available after registration
POS-S Symptom list	10 symptoms 2 questions about the symptom that affected the patient the most and that has improved the most	few minutes	scores from 0 ('no effect') to 4 ('overwhelming'); additional symptom versions available for other conditions (POS-S MS, POS-S renal); freely available after registration
Distress Thermometer ⁹	overall distress score 20 symptoms, 5 items on practical problems, 4 on family problems, 5 on emotional problems, 2 on spiritual concerns	median length of time 5 min, with 75% taking no more than 10 min ¹⁰	distress score 0-10; other items yes/no
Edmonton Symptom Assessment Scale (ESAS) ⁶	9 symptoms and 1 "other problem"	approximately 5 min ¹¹	each symptom with NRS 0-10 developed to measure the most commonly experienced symptoms in cancer patients; freely available
Memorial Symptom Assessment Scale (MSAS) ¹²	28 physical and 4 psychological symptoms	20-60 min, ¹³ short form < 5 min	measuring presence, frequency, severity and distress of symptoms; short form version available (MSAS-SF); only presence and distress of symptoms; developed for cancer patients but also used in other conditions
Hospital Anxiety and Depression Scale (HADS) ⁷	14 items (7 depression, 7 anxiety)	2-6 min ¹⁴	developed to assess depression and anxiety for people with physical illness; not freely available
EORTC QLQ-C30 ¹⁵	5 functional scales (physical, role, emotional, social, and cognitive), 3 symptom scales (fatigue, nausea/vomiting and pain), a global health status/ QoL scale and six single items (dyspnoea, insomnia, appetite loss, constipation, diarrhoea, and financial difficulties)	first assessment 12 min (SD 7.5 min), second assessment 11 min (SD 6.5 min) ¹⁵	not freely available, widely used in cancer research; modular supplement available for a range of malignancies (lung, breast, gastric, brain etc.)
EORTC QLQ-C15-PAL ¹⁶	pain, physical function (3 items), emotional function (2 items), fatigue (2 items), QoL (1 item), symptoms (6 items)	< 20 min ¹⁷	not freely available, shortened version of the EORTC QLQ-C30 for palliative care patients

(Bausewein et al. 2011)

Appendix 49: Practice development project – Lone working policy

Policy for the protection of lone workers in Physiotherapy Cancer Care

Title:	Physiotherapy Cancer Care Manager
Version:	1
Description:	<p>The following to be carried out when going on domiciliary visits:</p> <ul style="list-style-type: none"> a) Notify husband of intention to attend a domiciliary visit b) Provide domiciliary address and contact details in confidence c) Provide time of visit and intended length of time at the venue d) Contact husband on leaving for domiciliary visit and notify of any changes e) Contact husband on return from domiciliary visit f) Carry a charged mobile g) Carry an alarm in case of emergencies
Purpose:	To maintain safety and security when carrying out domiciliary visits
Author:	Caroline Belchamber
Date ratified:	January 2009
Ratified by:	Caroline Belchamber
Date issued:	January 2009
Review date:	January 2010
Cross reference with:	<p>NHS security management service: Developing a policy for the protection of lone workers: NHS: CFSMS 2009 – version 2.</p> <p>CSP information paper: health and safety No. 7 Personal safety for Lone workers. 2009</p>
ID reference number:	REF/DOM/V1
Signed by:	Caroline Belchamber

Appendix 50: Practice development project – Access to medical records policy and procedure

Document Number	2009/V1
Document Title	Access to health records policy and procedure
Author	Caroline Belchamber
Author's job title	Physiotherapy Cancer Care Manager
Ratified date	January 2009
Review date	January 2010
Owner	Caroline Belchamber
Owner job title	Physiotherapy manager

1. Background

1.1 The access to Health Records Policy and Procedure for Physiotherapy Cancer Care complies with the Data Protection Act (1998).

1.2 The Act provides a right of access to living individuals in respect of all personal data both manual and electronic, of which they are the subject

1.3 The access to Health Records Act (1990) remains in force to govern access by personal representatives of deceased patients to a deceased's medical records.

2. Roles and Responsibilities

2.1 Physiotherapy Cancer Care is responsible for ensuring that all valid access requests are managed in accordance with the Act.

2.2 Physiotherapy Cancer care's manager will ensure that all access requests are in accordance with the Act and this policy and procedure

2.3 Physiotherapy Cancer Care's manager has executive responsibility for ensuring compliance with arrangements made under the Act.

2.4 Physiotherapy Cancer Care's manager is responsible for setting the required disclosure fee in line with the Data Protection Act

3. Definitions under the Data Protection Act (1998)

3.1 Accessible record – "Any health record which consists of information relating to the physical or mental health or condition of an individual made by or on behalf of a health professional in connection with the care of that individual." Health records fall under the Act irrespective of the date upon which the record was made.

4. Exemptions

4.1 A request can be refused if Physiotherapy Cancer Care is not supplied with the fee as prescribed under the Act and reasonable information as to the identity of the applicant

4.2 If disclosing the personal data would reveal information regarding a third party (e.g. a relative or information provided by another identified person), unless that person has consented to the disclosure, (or it is reasonable to comply with the request without that consent), this information can be withheld

5. Consent by a health professional

5.1 Before deciding whether any of the exemptions in section 4 apply, if and when Physiotherapy Cancer Care takes on additional staff the health professional responsible for the clinical care of the patient will be consulted prior to disclosure

6. Responding to access requests

6.1 A request for access must be made in writing; no reason for the request needs to be given. Subject to any applicable exemption, the applicant will be given a copy of the information and an explanation of any abbreviations or medical terminology given. Physiotherapy Cancer Care will not charge for the explanation, but will charge a fee for the application and copying charges

6.2 Regulation on subject access fees states that a maximum fee of £50 can be charged for access to medical records

6.3 Physiotherapy Cancer Care is entitled to satisfy itself that the applicant is either the patient or, if the applicant is applying on behalf of the patient, that the person has been authorised to do so

6.4 The obligation to provide a copy of the medical records may be waived if it is not possible to supply a copy or to do so would involve disproportionate effort (e.g. medical records have been destroyed after legal timeframe)

6.5 The Act does not provide an express right to directly inspect medical records, although it is permitted with the agreement of the patient and Physiotherapy Cancer Care. It remains the Department of Health's policy that such requests should be accommodated subject to the exemptions listed in section 4

6.6 Requests for access will be responded to promptly and no later than 40 days after the receipt of a completed and signed application form and fee. In exceptional circumstances, if compliance is not possible within this period, the applicant will be advised accordingly

6.7 Where an access request has previously been complied with, the Act permits data controllers not to respond to a subsequent identical or similar request unless a reasonable interval has elapsed since the previous compliance. There is no definition of “reasonable interval” but regard will be given to the nature of the data and how often it is added to. The reason for the request (s) will also be considered

7. Rights of ratification

7.1 Where an applicant considers that information contained in their medical records is inaccurate, they may apply for a correction to be made. If the health professional is satisfied that the information is inaccurate, i.e. incorrect, misleading or incomplete the medical records may be corrected. If the health professional is not satisfied that the applicant’s concerns are justified, a note of the applicant’s comments will be appended in the part of the medical record to which the comments relate. Whether or not the medical record is corrected. The health professional will supply the applicant with a copy of the correction / appended note, without charge. Care will be taken not to obliterate information significant to the future care and treatment of the patient

7.2 If Physiotherapy Cancer Care’s attempt to rectify the medical records and resolve the concerns is not accepted, the patient may apply to the court, for an order or to the Data Protection Commissioner for an enforcement notice. Either of which may require that the inaccurate data and any expression of opinion based on it is rectified, blocked, erased or destroyed

7.3 However, where the data is inaccurate but accurately records information given by the data subject or another person, the Court of the Commissioner may instead order that the medical record be supplemented by a statement of the true facts as approved by the Court/Commissioner

8. Procedure for access to health records general information

8.1 All formal applications for access to medical records must be made in writing to the manager of Physiotherapy Cancer Care

8.2 Under the Data Protection Act 1998 Physiotherapy Cancer Care is required to provide access within 40 days of receipt of a completed and signed application form and the appropriate fee. Therefore if Physiotherapy Cancer Care takes on health professionals in the future they will be given 10 days to review the medical records and give their consent or to indicate if any part of the medical record is exempt from access (see section 4)

9. Requests for access by the patient

9.1 Upon receipt of a telephone / e-mail enquiry or letter from the patient requesting access to their medical records, an access to medical records form and letter explaining the procedure will be sent to the patient

9.2 When the completed and signed access to medical records form is returned it will be securely filed by Physiotherapy Cancer Care once it has been carefully checked to ensure the identity of the applicant. An acknowledgement letter will then be sent to the applicant

9.3 The medical records will be disclosed within 40 days of receipt of a completed application form and fee, however, if the patient has been treated or their medical records updated during the 40 days immediately preceding the application the expectation is that a response will be made within 21 days

9.4 If copies of the full set of medical records have been requested a copy of the medical notes will be sent to the patient with a covering letter and the date recorded by Physiotherapy Cancer care

9.5 If only part of the medical records have been requested the appropriate sections will be sent to the patient with a covering letter and the date recorded by Physiotherapy Cancer Care

10. Third party requests for access to health records

This procedure only applies where there is no litigation intended against Physiotherapy Cancer Care

10.1 Third party requests can be received from firms of solicitors, the Criminal Injury Compensation Authority (CICA) and independent health professionals requesting the medical records for medical reports. Requests should be accompanied by the patient's consent for disclosure of their medical records. If there is no consent, the solicitors will be contacted and asked to provide authorisation. Physiotherapy Cancer Care will be unable to release any medical records until in receipt of the patient's written consent. Checks will be undertaken to determine whether litigation against Physiotherapy Cancer Care is being contemplated

10.2 The procedure for patient's request in section 9 will be followed

11. Invoicing

11.1 Under the Data Protection Act the maximum fee that can be charge for each disclosure is £50. Physiotherapy Cancer Care will request a minimum charge of £10 to cover costs

Signature of Assessor: Caroline Belchamber

Date: January 2009

Appendix 51: Contract with local hospice

Contract between Physiotherapy Cancer Care and (local hospice) for period of paid attachment

1. Post Title: Breathlessness clinic manager

2. Parties:

This is a paid contract between Caroline Belchamber, manager of Physiotherapy Cancer Care, (address removed) and (name removed), Chief Executive, (address of hospice removed)

3. Duration:

The contract is for the duration of 52 weeks between 1st January 2010 and 31st December 2010

4. Purpose of the contract:

To manage and run the breathlessness clinic with own case load. Management will include training a key worker and attending the breathlessness sub-group for the (County) Cancer Network as well as any other key meetings regarding the practice development of the breathlessness clinic. Attending meetings held out of the contract time will require the negotiation of time and pay. This includes any additional paper work such as audits, which need to be compiled for the future development of the breathlessness clinic

5. Hours of work:

5.1 The hours to be worked under the contract will be agreed between Caroline Belchamber, manager of Physiotherapy Cancer Care and (name removed), Chief executive of (local hospice) and the board of trustees

5.2 A probationary period of four hours a week is proposed on a Thursday for six months and then if both parties are in favour increasing the number of hours through re-negotiation

6. Remuneration:

6.1 Physiotherapy Cancer Care is a private practice offering its services to (local hospice's) breathlessness clinic and will invoice (local hospice) on a monthly basis in arrears for the agreed work carried out as outlined in clause 4

6.2 Fees are in line with advice from the CSP and from historic data collected by the private practice special interest group, PhysioFirst, www.physiofirst.org.uk of which Caroline Belchamber is a member.

6.3 A fee of £.. per hour will be charged for the running and management of the Breathlessness clinic at (local hospice). This will amount to £... a month (calculated on a four week month)

6.4 Fees will be reviewed on an annual basis

7. Holidays:

Annual leave will run from the 1st September to 31st August in line with Bournemouth University of 18 days pro-rata with one-week closure at Christmas. Caroline Belchamber will take annual leave unpaid from (local hospice) in-line with the annual leave negotiated with Bournemouth University.

8. Sickness:

In the event of accident, illness or other incapacity preventing the proper performance of Caroline Belchamber's duties, (local hospice) will not be required to pay Caroline Belchamber during this time

9. Reporting:

Caroline Belchamber will be responsible for Physiotherapy Cancer Care and the running of the breathlessness clinic. Caroline Belchamber will report breathlessness clinic activities regularly to (the chief executive) and disseminate any relevant information to the rest of the (local hospice) team members

10. The contract:

10.1 The contract does not confer the status of an employee of (local hospice) upon Caroline Belchamber. It is a condition of the contract, because, Caroline Belchamber will be working on (local hospice) premises, that she will maintain certain standards of conduct expected of any contract post holder. These standards include but are limited to those standards set out in (local hospice) policy as well as Caroline Belchamber's registering body (Health Professions Council, HPC) and professional body (Chartered Society of Physiotherapy CSP) as well as Caroline's specialist interest group (the Association of Chartered Physiotherapists in Oncology and Palliative, ACPOPC) care outlined on the Physiotherapy Cancer Care website: www.physiocancercare.co.uk and the ACPOPC website: www.acpopc.org

10.2 Under the terms of the contract Caroline Belchamber will be entitled to payment as outlined and agreed with (the chief executive) and the board of trustees at (local hospice). For the avoidance of doubt, the contract is a contract appointment and does not signify any obligation for Caroline Belchamber to continue working at (local hospice) after the agreed period

10.3 This contract status applies only to the period of attachment as described above and implies no offer of permanent employment

11. Indemnity:

Physiotherapy Cancer Care is covered by professional liability insurance through Caroline Belchamber's professional body, the CSP. The latter provides £5 million as a fully subscribed member, which will cover the physiotherapeutic management by Caroline Belchamber of people with breathlessness at (local hospice)

12. Confidentiality:

12.1 Caroline Belchamber will at all times both during and after termination of this contract keep secret and not use any information obtained during the term of this contract which is confidential, including in particular;

12.1.1 the identity of any patient / client, including those of (local hospice) partner organisations and details of their medical records and / or treatment including any other confidential information relating to them

12.1.2 any personal information regarding employees of (local hospice) including any other confidential information relating to it and

12.1.3 any information regarding (local hospice's) business or financial affairs which is not available in the public domain

12.2 (Chief executive) and the board of trustees will at all times both during and after termination of the this contract keep secret and not use any information obtained during the term of this contract which is confidential, including in particular;

12.2.1 any personal information regarding the manager of Physiotherapy Cancer Care including any other confidential information relating to it and

12.2.2 any information regarding Physiotherapy Cancer Care's business or financial affairs which is not available in the public domain

13. Data protection:

Caroline Belchamber will comply with the provisions of the Data Protection Act 1998 in line Physiotherapy Cancer Care Data Protection Policy (see 'client's records' on the website www.physiocancercare.co.uk menu bar) and with (local hospice's) Data Protection Policy

During Caroline Belchambers period of attachment she will honour the terms of the Data Protection Acts as follows:

The 1998 Act establishes a set of principles, which users of personal information will comply. It imposes a new duty to "process" information fairly and lawfully ~ "process has a wider definition, which covers obtaining, holding, recording information and any other operation including disclosure of information.

It is the responsibility of Caroline Belchamber to ensure that all computerised / manual personal information relating to patients or other members of staff to which she has access in the course of attachment is regarded as STRICTLY CONFIDENTIAL.

14. Conflict of interest:

Caroline Belchamber will keep (chief executive) aware on an ongoing basis of any conflict or potential conflict of interest, which may arise during the period of the contract. If Caroline Belchamber is in doubt if a conflict of interest exists or may exist, she will inform (Chief Executive) and discuss until a suitable arrangement can be agreed.

15. Medical Fitness:

Caroline Belchamber has had all immunisations required as a registered, practicing Chartered Physiotherapist. Documentation regarding the latter was passed by (local hospital) Occupational Health Department in October 2008.

16. Professional Registration:

Caroline Belchamber holds the appropriate HPC professional registration. Verification of this can be found by accessing the Physiotherapy Cancer Care Website www.physiocancercare.co.uk and clicking on 'resources' on the menu bar and then accessing 'Check here to find out if your healthcare professional is registered' or alternatively accessing HPC website using the link below: <http://www.hpcheck.org/lisa/online/register/MicrositeSearchInitial.jsp>

17. Personal Property:

During the course of this contract Physiotherapy Cancer Care will not accept any responsibility in respect of theft, loss or damage to personal property or any vehicles parked on (local hospices) premises.

Any keys or other items, which may be issued to Caroline Belchamber by (local hospice) will remain the property of (local hospice) and will be returned on the termination of this contract.

Any equipment brought in from Physiotherapy Cancer Care to (local hospice) will remain the property of Physiotherapy Cancer Care and will be returned on the termination of this contract.

Caroline Belchamber will hold the right to wear the Physiotherapy Cancer Care uniform whilst working at (local hospice).

Any marketing of Physiotherapy Cancer Care will be discussed in advance with (Chief Executive) and a decision made with the board of trustees.

18. Termination of the contract:

This contract may be terminated by:

18.1 Either party upon service of one week's notice. If (local hospice) terminates this contract a copy of the termination letter should be sent to Caroline Belchamber, Physiotherapy Cancer Care, (address removed)

18.2 Caroline Belchamber at any time. This is most likely to occur if (local hospice) fails to observe the terms of this contract

18.3 This contract will automatically cease upon expiry of the period in clause 5

Signed on behalf of Physiotherapy Cancer Care

Signature:..... Date:.....

Print Full Name:..... Position:.....

I acknowledge receipt of this document and have read and understood and agreed to the terms listed.

Signed by the contract holder:

Signature:.....

Date:.....

Print Full Name:.....

Appendix 52: Student volunteer protocol

Student Volunteer protocol for Bournemouth University (BU) Physiotherapy (PT) and Occupational Therapy (OT) students at (local hospice)

Introduction

Aim: To provide BU PT and OT students with the opportunity to interact with health care professionals (HCP) and service users (SU) within a proactive and developing hospice environment.

Objectives:

1. To develop communication skills with both HCP and SU (verbal, non-verbal, written and using information technology)
2. To develop competencies around basic treatment skills with overview from the staff at (local hospice)

Recruitment

Notification of the volunteer opportunity at (local hospice) for OT and PT students will be available on the electronic notice board 'MyBU' under the Continuing Professional Development (CPD) unit 'CPD made e-asy' for all level of PT and OT students to access (level C – year 1; Level I – year 2; Level H – year 3) If students are interested in applying they are requested to contact Caroline Belchamber via e-mail: caroline@belchamber.net stating what the student feels they could bring to the hospice and what service they might like to be involved in . Once their interest has been acknowledge with the statement of what the student could offer to the hospice, application forms will be provided. The forms will need to be completed with two references and submitted to the volunteer co-ordinator at (local hospice). The student will then be required to have an interview and enhanced CRB check once the hospice has received satisfactory references to allow (local hospice) to make an informed decision as to whether the potential student volunteer is suitable to carry out the student volunteer role.

Induction process

Mandatory training (manual handling; CPR; Infection control; Breakaway; safeguarding children; Fire safety) required for placement during the students BSc (Hons) program will be monitored and kept up to date by the university. Fire safety specific to (local hospice) will be addressed at induction. Any other additional mandatory training required by the hospice will be organised and delivered through (local hospice).

Student volunteers will be given the opportunity to orientate themselves to (local hospice's) service provision by observing the following:

- a) Senior physiotherapist / respiratory nurse assessing and treating SU in the breathlessness clinic
- b) Senior physiotherapist / nursing staff assessing / treating patients in day care / home visits

- c) Lymphoedema sister in the lymphoedema clinic
- d) Fund raising and administration support networks

Confidentiality / consent agreement

OT and PT student volunteers will follow the (HPC) 'Confidentiality – guidance for registrants' document, which can be accessed at: <http://www.hpc-uk.org/publications/brochures/index.asp?id=164>

Consent will be gained from SU at (local hospice) before any interaction with the student volunteers occurs

Professional standards

Student OT and PT volunteers will adhere to the Health Professional Council's HPC standards of proficiency and standards of conduct performance and ethics. This will include their own professional body standards of conduct and ethics: CSP for PT students and BAOT / COT for OT students. These can be accessed at:

HPC

<http://www.hpc-uk.org/aboutregistration/standards/standardsofproficiency/>

<http://www.hpc-uk.org/aboutregistration/standards/standardsofconductperformanceandethics/>

Chartered Society of Physiotherapy (CSP)

<http://www.csp.org.uk/publications/core-standards-physiotherapy-practice>

<http://www.csp.org.uk/professional-union/professionalism/csp-expectations-members/professional-rules>

<http://csplis.csp.org.uk/olibcgi?infile=details.glu&luid=34416>

British Association of Occupational Therapists and College of Occupational Therapists

<http://www.cot.co.uk/publication/books-z-listing/professional-standards-occupational-therapy-practice>

<http://www.cot.co.uk/standards-ethics/standards-ethics>

Special interest groups

OT and PT Student volunteers will be encouraged to become student members of the special interest groups, such as the Association of Chartered Society of Physiotherapy in Oncology and Palliative Care (ACPOPC), which can be accessed at: <http://acpopc.csp.org.uk/>

Or equivalent for OT students:

<http://www.cot.co.uk/people-structure/special-interest-groups-sigs>

Outcome measures

(Local hospice) will audit and monitor the student volunteer's role using the 'Student Volunteer Impact Appraisal Form' (Appendix 1) to ascertain the suitability of their continued role within (local hospice). At any point that (local hospice) feels the student volunteer is at risk to the vulnerable patient group attending (local hospice) or themselves, then they will be given a verbal warning followed by dismissal if the issues is not rectified satisfactorily within a stated time limit.

Student Volunteer's Role

The following tasks will be available at varying times for the volunteer students to undertake on an independent basis. Individual allocation of the tasks will be by the discretion of the nominated staff overseeing the student volunteer, who will explain in full what is required and the timeline for the task to be completed. Tasks will be allocated in relation to the level of skill and competence that the individual volunteer student is able to undertake autonomously.

2. Communication

- a) To talk to SU (patients and carers) pre and or post assessments / treatments (e.g. breathlessness clinic; lymphoedema clinic; Fatigue, Anxiety and breathlessness (FAB) group)
- b) To go through leaflets as and when appropriate to respond to questions within the volunteer student's own competencies, but to recognise limitations and refer more challenging questions to the appropriate HCP at (local hospice)
- c) To explain / demonstrate and re-enforce knowledge of individual and group exercise regimens
- d) To design and develop group and individual exercises using Physio Tools software package
- e) To develop information files (e.g. gathering together hard copies of key documents for easy access for student volunteers / work experience observations) for the different services available at (local hospice)
- f) To develop leaflets (in accordance with the (local hospice) regulations) about the (local hospice) services for the wider HCP and SU

3. Treatment input

- a) To support SU with relaxation techniques, individually or in a group
- b) To provide SU (patients / carers) with relaxation massages
- c) To assist in the running of the rehabilitation services (e.g. FAB; Pulmonary Rehabilitation; Art therapy)

Reference: Fisher, P. J. and Cole, K. M., 1993. *Leadership and Management of Volunteer Programs*. San Francisco, CA: Jossey-Bass Publishers, Inc.

Appendix 1: Student volunteer Impact appraisal form

Measuring the difference OT and PT student volunteers make within the (local hospice) organisation

Complete the need / service column and return to (name) within thirty days of being assigned the task. At the beginning of the task, list each need to be addressed / service to be provided in the space below. If your task has more than three needs to be addressed, request additional forms from (name). On a three monthly basis (based on the start date of the task assigned) and / or at the end of your involvement with the task / service user (SU), complete the Impact appraisal column. (Name) staff will send you a new form after you have submitted a completed form, if your involvement with the task / SU will continue.

Circle either 1 or 2 if this form is being completed for:

1. Three-month review
2. To close task

Name: _____

Date: _____

Student Volunteer: _____

Skills (OT or PT): _____

Task: _____

Area (e.g. day hospice; breathlessness clinic; lymphoedema clinic):

Student volunteer ID code: _____ (staff use only for audit)

Assigned to: _____

NEED / SERVICE

1. SU Need: Volunteer Task:

IMPACT APPRAISAL

Rate the impact you had on the SU:

	Very successful
	Fairly successful
	Uncertain (explain)
	Not too successful
	Unsuccessful

Comments on your task:

Comment on the service you provided:

List the approximate number of hours you worked with LMH per month:

Month	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec
Hours												