Sanctuary versus Business Culture: Perspectives of service users and professional staff towards service user involvement at a UK hospice

A thesis submitted for the degree of Doctor of Philosophy

By

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ABSTRACT

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AIM - To explore the perspectives of service users and professional staff towards service user involvement within the context of a changing cultural environment at a UK hospice.

METHOD – Case study and thematic analysis including interviews with 16 staff including the CEO and 6 service users at a UK hospice.

FINDINGS – Three overarching themes were identified: involvement and disempowerment in decision-making; belonging and alienation in a period of organisational change; struggle to maintain wellbeing and identity in a changing culture.

A key finding is that service users receiving care from the hospice wanted their voices to be heard, valued and respected for their personal care and issues affecting the hospice. Service users did not consider it a burden to be asked for their views. They felt disempowered by a consultation process about organisational changes that appeared not to take their views on board. There is a need to consider whether a reliance on surveys for involving service users is sufficient or can become tokenistic.

External social-political-economic pressures plus increasing privatisation of public services could influence the way that hospices operate in future. This could involve moving from a sanctuary to a business culture and potentially towards managerialism by adopting a regulatory rather than rights-based approach with an emphasis on increasing reach, measuring numbers and hitting targets. Service users being viewed as consumers with a focus on reablement/rehabilitation activities and less on psychosocial support could also serve to push hospices to start behaving more like hospitals.

CONCLUSION – More qualitative research is needed to ensure the voices of service users living with a life-limiting illness are heard. The contributions they make towards co-production of services and research should also be heard and influence practice and policy. Service users should also be more involved in education and training of staff.

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CHAPTER ONE: INTRODUCTION

1.1 Aims and rationale for the study

The aim of this thesis is to explore the perspectives of staff and service users on service user involvement in palliative care within a changing organisational environment at an independent hospice in the UK by means of a case study and thematic analysis.

This chapter presents the personal, social, economic and political context and the rationale that led to my research into service user involvement in palliative care. I also explore the terminology that surrounds this topic. For the purpose of my study, service user refers to a person receiving palliative care.

The number of relevant studies identified during the literature review that were related to the focus of this thesis suggested that perspectives on service user involvement in palliative care held by service users and professionals is under-researched (Payne et al., 2005; Payne et al., 2008). It was however a realistic expectation that service users and professionals would hold distinct views on service user involvement in palliative care and was therefore a legitimate topic for exploring further.

An independent hospice agreed to facilitate my research for data collection purposes and this activity took place from 2013 to 2016. During this time, the hospice underwent significant organisational changes. An understanding of service user involvement from the perspectives of service users and staff participants was not possible without also looking at the reasons for and impact of these organisational changes.

The organisational changes also needed to be seen in the context of external socio-economic-political pressures that Third Sector organisations, such as charities and including independent hospices, were facing (Haslam, Theodosopoulos and Tsitsianis, 2014). The external pressures and organisational changes at the hospice combined to add to the complex levels of findings that emerged from the data. A decision was taken to use a case study approach for this study because of its ability to enable deep understanding of a single or small number of cases in their real world contexts allied with other complexities related to the case (Yin, 2012). Case study data are also likely to emerge from a variety of sources.

The active voice is used in this thesis as my personal background and experience played a significant part in providing the catalyst for pursuing the topic of this research and my professional and voluntary experiences have helped inform my knowledge and theorising. These experiences prompted a need for me to be transparent and explicit in this thesis about my own position in the research and the need for reflexive self-awareness to run through it. Peshkin (1988) suggested that a researcher should engage with their own subjectivity and the different 'I's within them. Addington-Hall et al (2007) described reflexivity as an on-going activity that requires exploration of the self, values and biases during data collection and through all the processes used. Addington-Hall et al (2007) also viewed the explorations of the self as being crucial when observing people's distress as a researcher.

The section on reflexivity in this chapter indicates how my own voice is handled separately from the data gathering, analysis and theorising activities carried out on the topic of this thesis (Peshkin, 1988; Webb, 1992; Gough, Thomas and Oliver, 2012). As Finlay (2008) pointed out, in order to demonstrate that a study is trustworthy and credible then sufficient evidence needs to be provided or a case made that is firmly rooted in theory. My study is firmly rooted in the approach to theorising described by Finlay (2008).

On a practical level, quotes from research literature appear in this thesis in bold indented type with the named author(s); quotes from participants appear in the same manner in Chapter Five: Findings.

The next section of this chapter describes my own experience as a family carer for both my parents and the influence it had on the choice of research topic for this thesis.

1.2 Personal, professional and voluntary experience

1.2.1 Family background and experience

I was a family caregiver for my parents between the years 1998 – 2008 – my father had motor neurone disease and my mother had dementia following a stroke. The lack of involvement and influence that my parents and family members felt able to exert upon health and social care professionals in numerous health settings for their care towards the end of both their lives, whether at home, in a care home and hospital, was very noticeable. There was an absence of the words 'palliative care' or 'end of life care' being spoken by health and social care professionals in those three settings. The experience led to the writing and publishing of a family case study called 'The Findlay Report' (Findlay et al., 2006). The report contains a description of events on a day-to-day basis as well as recommendations for helping to improve experiences generally for people at the end of their lives. In 2017, I commissioned a professional playwright, Brian Daniels, to write a play based on 'The Findlay Report.' I collaborated with the playwright over a period of eight months to develop the script. The play is called 'Fighting For Life' and it had its premiere performance in London in January 2018 and has been performed at various locations across the UK during the year with more to come in 2019. Each performance is followed by a question and answer session involving a chaired expert panel including me that enables audience members ranging from healthcare, social care and palliative care professionals to academics, family carers and people living with various conditions to make contributions and ask questions about the issues raised in the play. I have also devised and written a website for the play ('Fighting For Life', 2018).

The next section looks briefly at my professional background as it pertains to the topic of my study.

1.2.2 Professional and knowledge background

I have an MSc in Politics from Strathclyde University and worked in a senior position for The Labour Party at national level in Westminster for just over four years while they were in government which involved liaising with government ministers, MPs, Prime Minister's office and special advisors. I have a certificate in management studies from the Open University. I also worked in a managerial role for 11 years with the Confederation of Health Service Employees (COHSE) and then with UNISON, the public service union that was created following the merger of three unions including COHSE. The years working in the trade union movement provided useful background knowledge and an appreciation of many of the issues and perspectives of health professionals working in a variety of settings. I was able to draw on this experience during the data collection activity and analysis for the topic of this thesis taking account of issues around subjectivity and reflexivity as described further in this chapter.

While taking account of my own personal, professional and knowledge backgrounds in my research it was also important to recognise the significance of potential pre-understandings that I may bring to it. I adopted the approach of Finlay (2008) who described the process of a researcher maintaining openness to the world while reflexively controlling any pre-understandings. She refers to this kind of process as being akin to a dance.

> Caught up in the dance, researchers must wage a continuous, iterative struggle to become aware of, and then manage, pre-understandings and habitualities that inevitably linger. Persistence will reward the researcher with special, if fleeting, moments of disclosure in which the phenomenon reveals something of itself in a fresh way**.** (Finlay, 2008, p.1).

As part of my dance, I constantly questioned myself about potential biases I may have in my thinking or perhaps falling in to old habitual ways of thinking. Regular meetings with my supervisors through the whole process of my study enabled any potential pre-understandings to be identified and discussed. Another important part of my experience and where I also needed to be aware of any potential pre-understandings concerns my involvement with palliative care service user groups. My involvement with such groups is discussed in the next section.

1.2.3 Involvement with palliative care service user groups

Following the experience with my parents, I joined a number of service user groups operating with different charitable organisations - Marie Curie, the National Council for Palliative Care and the Cicely Saunders Institute - that work in palliative and end of life care covering practical care, research and policy. I have spoken at numerous national health and social care conferences, seminars and training workshops over the last 12 years about my personal experience as a family caregiver including speaking from the main stage at a European Association of Palliative Care (EAPC) conference called ‘Palliative Care 2020’ held in Brussels in 2014. I have also spoken at numerous All Party Parliamentary Group meetings held in Parliament on Hospice and Palliative Care and on Motor Neurone Disease.

My involvement in the service user groups mentioned above enabled me to meet and talk about my experiences as a family caregiver with other family caregivers and with people living with terminal illnesses as well as discuss issues around palliative care with health and social care professionals. Such discussions also enabled me to listen to and appreciate other points of view and to broaden and challenge my own thoughts and perspectives and understandings about palliative care and the involvement of service users.

My research for this study has enabled me to challenge and doubt aspects of my own agenda that may have arisen from my personal experience and experience of being a member of service user groups in palliative care. My experience of service user groups attached to third sector research and practice organisations indicates that they are almost wholly made up of bereaved relatives who may have been caregivers rather than people who are living with a terminal illness so the bereaved caregiver voice predominates. The service user group at the hospice involved in my study also comprises mainly bereaved or current caregivers. A search of the literature for studies about the influence and difference between the caregiver’s voice and service user voice in service user groups in palliative care, whether aligned with large or small organisations, has proved to be sparse (Bradburn and Maher, 2005; Black, 2008). There have been studies carried out on service user groups in mental health, for example (Wallcraft and Bryant, 2003; Sweeney and Wallcraft, 2010) and of disabled people. Such groups have tended to be in existence for longer than service user groups in palliative care and have developed over time, including the formation of groups initiated and led by service users themselves such as INVOLVE UK and Shaping our Lives (Beresford, 2013). It may also be the case that people living with cancer have had more opportunity to take part in service user groups in palliative care than people with non-malignant conditions (Cotterell, 2006).

The subject of caregiver and service user involvement in service user groups in palliative care is discussed further in Chapter Two: Literature Review of this thesis. The perspectives of both caregivers and service users on palliative care and end of life care are important and can add greatly to knowledge. I feel it is also important that caregivers do not become a kind of proxy for service users in providing answers to research questions perhaps because caregivers appear easier to identify and involve for instance. I therefore targeted the perspectives of service users receiving palliative care directly for the purposes of my study.

The next section looks at terminology and definitions concerning the words palliative care, end of life care, service user, service user involvement and service user involvement in palliative care and explains the approach I adopted for my research.

1.3 Terminology and meanings

1.3.1 Palliative care and end of life care

The literature review highlighted that there were differences ascribed to the meanings and usage of the words palliative care and end of life care. In a scoping study on service user involvement in palliative care, Payne et al., (2005) discovered that definitions of the words ‘palliative care’ were poorly understood and not agreed. The review indicated that debates have continued and attempts made since the 1990s to find an agreed definition for ‘palliative care’ (Payne et al., 2008; NICE., 2004).

The World Health Organisation (WHO) offered a definition of palliative care as follows:

> Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (World Health Organisation, 2004).

Although the definition above from WHO provided a focus for the approach of palliative care it did not give any indication at what point it would be appropriate to start providing such care and nor did it provide an agreed template that other organisations could follow. In 2014, the Worldwide Palliative Care Alliance (WPCA) sought to provide further explanation and clarification:

> First, palliative care is needed in chronic as well as life-threatening/limiting-conditions; Second, there is no time or prognostic limit on the delivery of palliative care; Third, the Global Atlas describes the need for palliative care at all levels of care; Fourth, palliative care is not limited to any one care setting. Palliative care is provided wherever a person's care takes place, whether this is the patient's own home, a care facility, hospice in-patient unit, hospital, or outpatient or day care service. (Connor and Bermedo, 2014, p.7-8).

This explanation and clarification provided by the WPCA in 2014 did not necessarily filter through to other organisations working in the area of palliative care. The words 'palliative care' and 'end of life care' could sometimes be conflated and used interchangeably which could potentially add to confusion (Marie Curie, 2016; NHS Choices, 2016).

If there is confusion about the meanings of the words 'palliative care' and 'end of life care' and when such care starts then this could also potentially cause confusion with perspectives on service user involvement in palliative care. This confused situation is potentially further conflated by differences in meanings and understanding surrounding the words ‘service user’ and ‘service user involvement’.

For my research, I adopted the meaning of the words ‘palliative care’ as put forward by the Worldwide Palliative Care Alliance in 2014 in the quotation above. Specifically that there is no time limit for a person to receive palliative care and that it can be provided in any setting.

1.3.2 Service user

The words ‘service user’ were also shown to be contentious in the literature with differences of opinion about who was included within the term. Those potentially included could range from only those people directly receiving palliative care or end of life care services to people receiving such care plus their caregivers that could therefore include family or significant others (Branfield and Beresford, 2006; Wright et al., 2006; Bradshaw, 2008; Beresford, 2008; Rose, Fleischman and Schofield, 2010). Beresford (2005) criticized the term ‘service user’ because it could imply people had only passive roles in their own care when they may actually wish to play an active part in their care.

For my research the words ‘service user’ refer to a person directly receiving palliative care from a hospice. This enabled perspectives of service users and staff at the hospice to be gathered and analysed to help theorisation about service user involvement in relation to palliative care.

1.3.3 Service user involvement

Attaching the word ‘involvement’ to the end of the words ‘service user’ was a term that developed mainly in health and social care circles (Antoniou, 2010; Beresford, 2010; Beresford et al., 2012). The literature search indicated gaps and a lack of understanding about the general meaning of the words ‘service user involvement’ (Evans et al., 2003).

Payne et al (2008) also discovered a lack of agreement between professionals and service users about what service user involvement meant. Understanding of whom the words ‘service user’ referred to was confused by the variety of other terms used in the literature to describe them, for example, patient, consumer and client (Beresford, 2005; Deber et al., 2005). The words ‘service user’ and the other terms being used to describe them also appeared in the literature in conjunction with other terms for involvement such as participation, partnership, engagement and co-production (Realpe and Wallace, 2010; NHS England, 2013; NICE, 2016; Scottish Health Council, 2016). It appears that researchers tended to decide for themselves what terms they preferred to use and defined the meanings they ascribed to them in papers and articles about their particular studies.

Service user involvement could refer to people’s individual involvement in decisions about their day-to-day support, but it could also mean people coming together to work in a collective way to provoke change or for mutual support and enabling them to put forward their own experiences and opinions (Branfield and Beresford, 2006). Butcher (2010) provided a definition of service user involvement in cancer care. The author suggested it meant the active involvement of patients and carers in the planning, commissioning, delivery and evaluation of cancer services. Butcher (2010) also talked about empowerment of service users and contested the notion that in the NHS empowerment only meant involving service users in decisions about their own treatment and care and suggested that this was not the same as empowerment in terms of service user involvement. NICE (2004) guidance on the meaning of service user involvement in cancer care also described the empowerment of people who use the services in order to influence care on a broader scale.

INVOLVE (2012) attempted to distinguish between the terms involvement, participation and engagement. They suggested that involvement meant members of the public being involved in research projects and research organisations for identifying research priorities as well as being members of an advisory or steering group; participation meant where people completed a survey or took part in a focus group and then engagement was where information and knowledge about research was disseminated through the media, for example, and via open days at a research centre, Another service user organisation called Shaping Our Lives believed that involvement should mean service users setting the agenda (Beresford, 2012) with disabled groups advocating for involvement to be rights-based (Beresford, 2011).

1.3.3.1 Ladders of involvement

An early attempt to classify service user involvement was put forward by Arnstein (1969) in a 'ladder of citizen participation' (see Figure 1 below). The ladder displays different kinds of activities in the form of eight rungs that could lead to three types of involvement: nonparticipation, tokenism or citizen power. 'Manipulation' and 'therapy' are the lowest rungs of the ladder where the power holders educate or cure, then moving up to 'informing,' 'consultation' and 'placation' in the next three rungs of the ladder, then 'partnership,' 'delegated power' and 'citizen control' taking up the top three rungs with 'citizen control' at the top where service users had powers of decision-making.

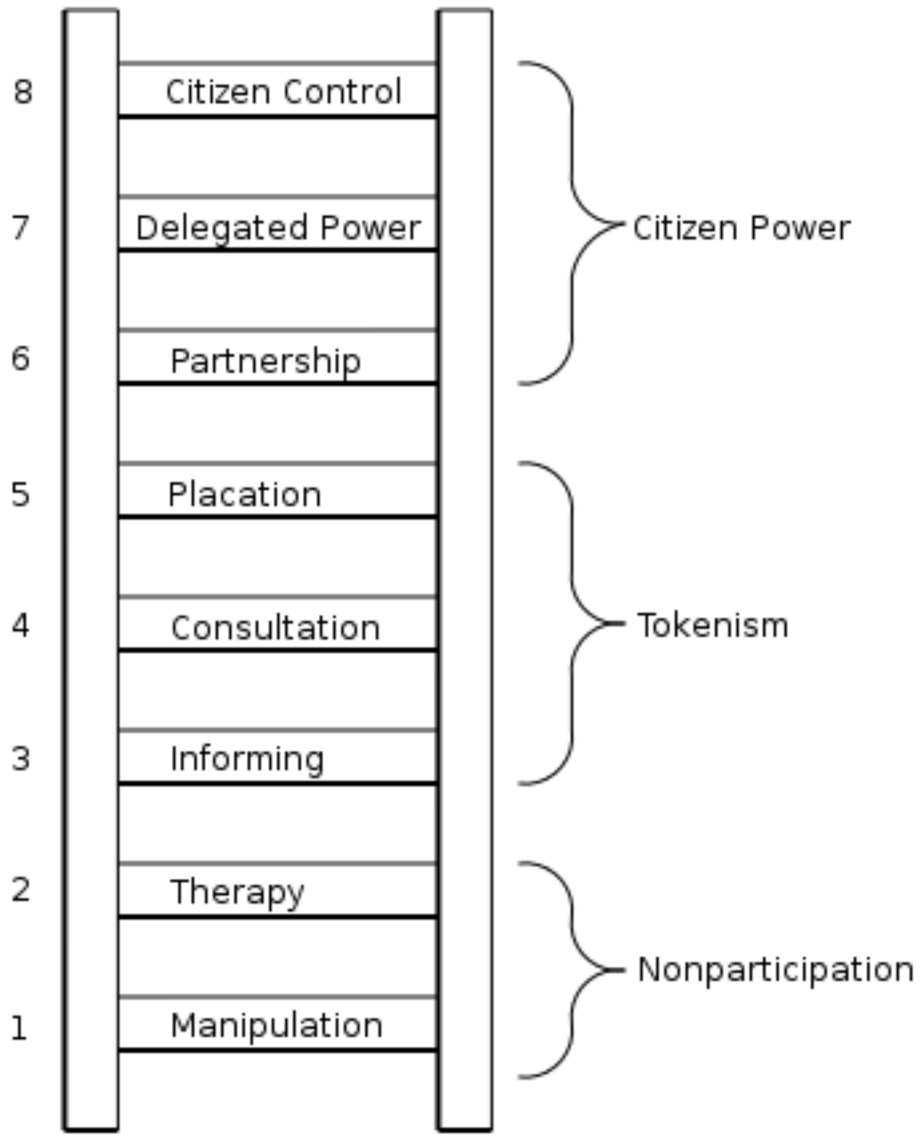


Diagram 1.1: Arnstein's Ladder of Citizen Participation

The ladder devised by Arnstein has been subsequently used and adapted by researchers over the years since 1969 when it first appeared (Forbat, Hubbard and Kearney, 2009; Tritter, 2009). Although Arnstein's ladder implied a hierarchy of involvement it was not overtly presented as the case and the literature showed there were criticisms about its inability to demonstrate any relationship between different levels of the ladder or that a variety of involvement activities could potentially be taking place at the same time (Tritter, 2009).

Hanley et al (2004) produced an amended version of Arnstein's ladder and identified consultation (lowest level) where people are asked for their views that may or may not influence decisions; collaboration (middle level) that involves on-going partnerships with the public and people using services; and user-controlled (highest level) where power and decision-making lay with service users rather than with professionals (Hanley et al., 2004).

There was no indication in Arnstein's ladder or subsequent ladders about how power relationships within and between the different levels worked in practice. For instance, what levers would need to be pulled to enable a move from one level of the ladder to a higher level or, indeed, if there were any levers that could prompt a downward movement on the ladder. Tritter (2009) argued the case for a mesh or network of involvement as being more useful to capture the myriad possibilities around activities associated with service user involvement. The author identified that service user involvement was different in countries that adopted a rights based approach rather than a regulatory approach. Tritter (2009) also considered that the development of healthcare markets led to situations where global organisations such as the World Trade Organisation could exert influence directly or indirectly on the regulation and policy making surrounding healthcare systems.

In spite of the possible limitations identified by researchers such as Tritter and McCallum (2006) since Arnstein's Ladder appeared in 1969, I believe it provided a useful criterion for helping to assess service user involvement. I used Arnstein's Ladder as a guide for helping to identify and analyse service user involvement in palliative care at the hospice. In doing this, I understood that I needed to be aware of the potential for further levels of complexity towards such involvement that may not fit into this particular ladder that were also important to identify. This awareness included the possibility of snakes as Tritter and McCallum (2006) referred to them. Snakes occur in the view of these authors view where there are missing rungs in Arnstein's Ladder that they considered limited it as a tool for enabling an increase in service user involvement particularly in healthcare circles. They also considered that Arnstein's Ladder could lead to the majority voice being the only voice that was being heard or had influence.

The amended versions of Arnstein's Ladder that I discovered in the literature focused mainly on service user involvement in healthcare. I did not discover an amended version of it for service user involvement in palliative care. The usefulness or otherwise of devising such a ladder is discussed further in Chapter Six: Discussion of this thesis.

1.3.4 Complex meanings of service user involvement in palliative care

There appears to have been a greater acceptance for people living with cancer rather than with other life-limiting conditions to have involvement in their own care, including palliative care, and also involvement in decision and policy-making as it affected that care at an individual level and on a wider scale (Butcher, 2010; Cotterell, 2006).

The complexities of people living with terminal illnesses had been studied by Rhodes and Small (2000) who discovered that even though individuals may have the same disease, their experiences and approach to how they dealt with it and talked about it was very individual. Potential differences between the person with the illness and their carer were also pointed out by Rhodes and Small (2000) as was the importance of illness narratives and how people with a terminal illness could transform that experience into a story about their lives and by so doing, potentially speak for others in that situation. Problems could also arise between a model of healthcare based on public participation where policy-making concentrates on needs assessment across populations as a whole that is akin to a marketing model, rather than an approach based on the direct involvement of service users themselves in decisions about their care (Rhodes and Small, 2000).

> The patient as consumer remains the compliant object of the service delivery system, in contrast to the patient as decision-maker user, who takes the role of subject. It is the transition of the patient from passive object to active subject of care which is at the heart of patient empowerment. (Rhodes and Small, 2000, p.20).

The literature around research on health issues generally as well as in palliative care indicated that very little had been written by service users themselves (Payne et al., 2005; Sargeant et al., 2007;). Articles and research studies by health and social care professionals would be peer reviewed before being published and therefore their views were more likely to dominate and have influence (Payne et al., 2005). This aspect is explored further in Chapter Two of this thesis.

Being a “compliant object of the service delivery system” or “patient as decision-maker user” mentioned in the quotation above by Rhodes and Small (2000) are factors related to the focus of my study and are discussed more fully in Chapters Two and Six of this thesis.

The next section looks at the hospice involved in my research as a brief history in order to help contextualise this study and assist with theorising about the influence of organisational changes on service user involvement that took place at the hospice during the period of my data collection.

1.4 Hospice - brief history

1.4.1 Establishment of hospices

The word ‘hospice’ is a derivative of the Latin word ‘hopses’ that means host and guest and implied a mutual caring between provider and receiver (Allen, 2002). The author traced the roots of hospice back to medieval times when buildings offering personal and compassionate care were provided along the routes that religious pilgrims would travel on their way to the Holy Lands (Allen, 2002).

Dame Cicely Saunders, a former social worker and qualified medical doctor, is generally acknowledged as the founder of the modern hospice movement (Lutz, 2011; Clark, 2015; Clark, 2016) and established St Christopher’s Hospice in south-east London in 1967 (BMJ, 2005; Shotter, 2006; Baines, 2011; Clark, 2014; Cicely Saunders International, 2016).

> Her (Cicely Saunders) contribution was to define a new field of care that focussed on the last stages of life, particularly when associated with progressive diseases such as cancer or neurological conditions. This came to be known as “palliative care,” an extra layer of support for adults, children, families and communities designed to prevent and relieve pain and suffering when death is impending, and in bereavement. (Clark, 2015).

Clark (2015) said that part of this work necessitated a challenge to the orthodoxy of medicine towards death with its taboos by opening up practical, political and philosophical spaces for the care of people who were dying. The author also noted how Saunders challenged the professional distancing from patients that was prevalent up to the 1950s and determined to replace it with a more human form of engagement.

> You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die. (Dame Cicely Saunders, 1918-2005).

Kubler-Ross (1969) had been a prominent and influential researcher with her seminal book “On Death and Dying” that involved over 500 interviews with dying patients. As well as identifying five stages through which many terminally people progressed, Kubler-Ross also made a plea for homecare and not treatment in an institutional setting and that service users should be able to take part in decisions that affected their lives. Kubler-Ross also made the observation while testifying at national hearings in a US Senate Special Committee on Aging that society had a tendency to try to be death - denying where both the dying and old were isolated. She believed this was to enable others not to be reminded of their own mortality (Kubler-Ross, 1972).

1.4.2 Sanctuary versus business approach to hospice care

1.4.2.1 Sanctuary approach

A sanctuary implies a place of refuge or of protection away from others. The notion of hospices providing a safe space appeared to form the basis for the founding of St Christopher's Hospice in 1967 by Dame Cicely Saunders. She wished to provide a home environment for those with life limiting illnesses that could help alleviate pain and prepare people for death (St Christopher's Hospice, 2017).

> We can create and proclaim sanctuary for people in the process of caring for them. The word sanctuary elicits something quite soulful, if not archetypal, from deep within…What better way to live out one's life than to feel beloved and enfolded? What better place to be than in sanctuary! (McDowell, 2007, p.31).

The quote above appears to focus on the individual needing care perhaps even evoking a spiritual approach to care towards the end of a person's life, and the hospice being the place that could provide that kind of care. Dame Cicely Saunders also envisaged hospice providing a "safe and secure environment" (King's College, London, 2015) that would concentrate on quality of life with a focus on pain management leading up to the death of a person.

The influence that an approach to service provision can have on the enablement of service user involvement and the type of user involvement that is pursued has been identified by a number of researchers mentioned previously (Rhodes and Small, 2000; Beresford and Andrews, 2012). It therefore follows that the type of service provision approach or model used by a hospice could influence the type of service user involvement that is pursued.

As mentioned earlier in this chapter, the culture of healthcare generally seems to be changing with a shift towards marketisation and people being viewed as consumers of care. This shift may also be found in other areas of care such as hospice care. The hospice involved in my study underwent significant organisational and cultural changes during the course of my fieldwork. The levers that prompted these organisational changes and the impact they had are discussed more fully in Chapter Six: Discussion of this thesis. A brief overview is provided next of what I refer to as a business approach towards the provision of hospice care.

1.4.2.2 Business approach

Cultures of care appear to be changing across healthcare generally that also appears to be influencing hospice care. A publication from Hospice UK details a strategy for transforming hospice care in the UK from 2017 – 2022. Part of this transformation includes a commitment to widening access to hospice care to all communities and extending it to a range of settings "beyond the walls of hospices" (Hospice UK, 2017). The publication does not explain how a hospice should change or what model it could adopt, business or otherwise, in order to meet these strategic aims. However, it does provide a number of indicators as to what success could look like. For instance, finding new and diverse income streams; launching innovative models of care that could be replicated and scaled up; better quality data sets produced based on population needs and using new technological methods to support caregivers. The emphasis in the strategy report appears to be on service provision; scaling up of hospice care services and making the hospice sector more resilient for the future. In this scenario, the service user appears to be viewed as a passive recipient of palliative or end of life care rather than an active participant.

A precise definition of a business model is not straightforward according to Zott, Amit and Massa (2011). These authors discovered over 1,700 articles in peer-reviewed journals published since 1995 around the concept of business models generally in any field and did not discover a common or widely accepted language to describe these models. A number of authors referred to a business approach as a series of assumptions and hypotheses (Magretta, 2002; Osterwalder, 2013) or strategies (Drucker, 1994) that should be tested and refined over time.

In spite of the lack of an agreed and precise definition of a business model, for the purposes of my study I incline towards a general description where an organisation or company produces or provides goods or services that are bought by consumers. This could lead organisations to be in competition with each other on prices charged for instance and initiatives to increase their market share over and above those of their competitors and so lead to an increase in their profits and/or share price. These profits could then be invested back into the organisation or paid to shareholders as dividends or a combination of both.

Whether a business model approach as described in the paragraph above could operate in the context of a hospice is not a subject that is apparent in the literature on hospices. Haslam, Theodosopoulos and Tsitsianis (2014) provided some clues to this possibility while researching the financial accounting processes followed by hospices in the UK generally. The authors discovered that hospice financial accounting information was fragmented and scattered within academic and practitioner texts that implied such information was not uniform or coherent across all hospices. In reviewing the findings from their search, Haslam, Theodosopoulos and Tsitsianis (2014) discovered that the hospice accounting model was changing from a more traditional one where voluntary donations are put towards care to a more complex model involving many more stakeholder interactions. The unpredictable and local nature of voluntary donations had, according to Haslam, Theodosopoulos and Tsitsianis (2014), led to a fragmented hospice service that they concluded had contributed to the lack of a national plan for the provision of palliative care in the UK.

Haslam, Theodosopoulos and Tsitsianis (2014) also identified that funding constraints had heralded a change in government policy towards the Third Sector indicated by a move to try and integrate the voluntary sector within the provision of national healthcare.

If healthcare generally in the UK is moving away from the principle of being a public service that is free at the point of use and parts of the system become progressively privatised, then it is also possible to foresee that for-profit organisations and businesses will see healthcare in the UK as a potential lucrative market for them to move into. This kind of shift has already been taking place over a number of years such as with the Private Finance Initiative (PFI) for example. PFI involves a private company building an NHS hospital and then leasing it back to the NHS. The Centre for Health and Public Interest (CHPI) conducted a search using accounting records provided by the Treasury and Companies House covering the years 2010 – 2015 and concluded in a report published in 2017 that those companies that had run PFI contracts had made pre-tax profits of £831 million (CHPI 2017). The report also discovered that nearly £1billion of taxpayers' funds will go to PFI companies as pre-tax profits and that only eight companies "own or have equity stakes in 92% of all the companies holding contracts with the NHS meaning there is very little competition between the companies bidding to build and run NHS PFI hospices" (CHPI 2017, p.4). Whether a similar PFI move could be introduced for building more hospices in the UK is worth consideration although there may be more lessons to be learnt from the development of hospices in the USA that is explored below.

As Haslam, Theodosopoulos and Tsitsianis (2014) discovered, the funding models of independent UK hospices are becoming more complex with many more stakeholders involved. Such funding changes could also lead to an even further fragmented hospice service as each independent hospice decided on its own approach to deal with its changing funding circumstances and also make the possibility of a national plan for the provision of palliative care in the UK recede even further.

The approach that Dame Cicely Saunders adopted towards the provision of hospice care had an impact across the world (Clark, 2015) including in the USA. For-profit insurance-based hospice care had grown substantially in the USA since the first hospice was established there in 1974 making them more like businesses and therefore likely to adopt more business-like management techniques (Smith and Himmel, 2013; Whoriskey and Keating, 2014). Smith and Himmel (2013) and Whoriskey and Keating (2014) considered that the insurance-based approach to hospice care in the USA could potentially be adopted by some hospices in the UK. A deeper analysis of the literature on the approach and operation of hospices in the USA and the ways it helped to interpret some of the findings in my study are included in Chapter Seven of this thesis.

The traditional hospice movement as espoused by Dame Cicely Saunders does not seem to fit comfortably within a business model or approach and yet such an approach has been developed considerably within the NHS. The manner in which changes in hospice care are handled has implications for service users and staff. Whether following the lead of changes in the NHS or those implied in the indicators provided by the Hospice UK (2017) strategy publication mentioned earlier, the manner of the changes also hold implications for service user involvement.

The next section looks at the socio-political-economic context of hospices in the UK that is discussed in more depth in Chapter Six: Discussion of this thesis as relevant to understanding the findings. This is followed by a brief description of the case study approach towards the UK independent hospice involved in my research and then an outline of the organisational changes that took place there that occurred during the period of my data collection.

1.4.3 Socio-political-economic context of hospices in the UK

The UK independent hospice that was involved in and facilitated the research for this thesis is one of around 220 such hospices currently operating in the United Kingdom. The traditional financial model for independent hospices involves receiving a percentage of regular funding from government bodies that covers up to around a quarter of the costs with the main funding stream involving voluntary donations and contributions (Hospice UK). This means that hospices have to engage in fundraising activities in order to meet the total operational and resource costs of the services they are providing (Hospice UK)

Viewing a hospice as a business appears to be driving a change in financial or fundraising behaviour from the more traditional model of donations being used for care to a more complex model involving many more stakeholder interactions (Haslam, Theodosopoulos and Tsitsianis, 2014). Hospices provide around 80 per cent of palliative care services in the UK (Hospice UK) and with claims on such services likely to increase in the UK in the future, the fragmented nature of the service is potentially a further barrier to the provision of an effective national palliative care plan (Haslam, Theodosopoulos and Tsitsianis, 2014)

1.4.4 The case study hospice

This section is included at this point in order to help contextualise my research before moving on to the literature review.

Three different types of case study have been identified: intrinsic case study – concentration on a single case with no attempt to generalise or build theories; instrumental case study – where a case is examined to provide insights into an issue where the main focus is elsewhere; collective case study – a number of cases are investigated to explore a general phenomenon (Stake, 2000)

Using the definitions mentioned in the above paragraph, the case study of the hospice involved in my research follows an instrumental case study form. The organisational changes that have taken place at the hospice are investigated in order to enable further theorisation about the focus of my research on service user involvement at the hospice as well as enable more general theorisation about potential implications for hospices in the UK. The possibility of various practices from a single case study being generalisable in particular institutional settings, even if not practised in similar ways across different settings, can be considered with caution. The case study approach is also used mainly in qualitative research when it becomes difficult to control all the variables that might be of interest to a researcher (Silverman, 2010).

> The case study's unique strength is its ability to deal with a full variety of evidence, including documents, artefacts, interviews and observations. (Merriam, 1988, p.4).

Background information about the hospice involved in my research was drawn from public records posted on-line by the hospice, and from the hospice's own website.

1.4.4.1 Organisation and governance

The UK independent hospice involved in my study was established on its current site in southern England in the 1980s.

A Board of Trustees provides governance through the hospice committee structure and board members were elected from the membership of the company with one third standing down or for re-election after a three-year term of office that included the Chair who could not serve more than two consecutive terms of office (information from hospice website, Companies House, Charity Commission).

At the time of writing, around 2,000 service users annually were receiving care services from the hospice provided by over 300 staff full-time and part-time staff plus over 1,000 volunteers. About one third of the hospice's income came via government grants with the remainder coming from donations and fundraising activities. This kind of funding approach appears to be the general position for most independent hospices in the UK (Hospice UK, 2017).

1.4.4.2 Organisational changes 2013 - 2016

The reasons why decisions were made by the hospice management to instigate organisational changes at the hospice emerged from a variety of sources. My relationship with the hospice that agreed to support this study began in 2011 and carried on through the years to 2016. During the years 2013 – 2016 particularly I made frequent visits to the hospice premises to carry out interviews with service users and staff and also to have informal conversations with staff during those visits. This enabled me to gain a deeper understanding of the hospice and how it operated.

As a result of the data emerging from service user and staff participants concerning the organisational changes at the hospice, I carried out a search for information about the hospice organisation itself. I conducted a brief thematic analysis using information provided in the hospice's annual reports and accounts each year from 2011 to 2016. A search was also carried out for information on the website of Companies House with a further information search about the hospice carried out online.

The interviews for this study were conducted with different service users and staff participants before and after the organisational changes were being implemented at the hospice. Interviews with staff involved a diverse range of participants from across the hospice and at all levels of the managerial structure. There was a palpable desire to talk about the effects the changes were having from the perspectives of the service user participants and from a number of staff participants. It was therefore not possible to analyse the data and theorise about the topic of the thesis without also exploring the organisational changes at the hospice. An analysis of the findings that emerged from participants and their perspectives on the organisational changes at the hospice are detailed in Chapter Five of this thesis.

The wish to make organisational changes at the hospice coincided with the appointment of a new hospice CEO and a new Chairman of the Board of Hospice Trustees. There were also staff redundancies, changes to job descriptions and an increase in staff numbers in what might be termed as backroom departments. This included an increase in staff numbers and expansion of the remit of certain departments for acting both internally and externally to the hospice and also expansion of marketing and fundraising functions of the hospice. There were also significant changes in arrangements for use of the hospice day centre by service users and the role of staff at the day centre. These findings emerged during interviews with participants and the impact that these changes had on them is discussed in Chapter Five of this thesis.

1.5 Managerialism and organisational culture

According to Klikauer (2013), managerialism is not a modern management method or an institutional model but rather it is an ideology that has transcended into society. The author contends that although the word managerialism is widely used there is little information to be found on its theoretical basis. The author also contends that over the years, managerialism has come to see itself as the expression of a special group, that is, management that entrenches itself within an organisation and basically takes over all decision-making. Managerialisation lies at the gateway between management and society, according to Klikauer (2013), where changes in management and at work have helped to engineer changes in society.

An exploration of the literature on theories of management and organisational behaviour indicated that there were numerous theories that have been developed over many years (Handy, 1981; Drucker, 1992; Enteman, 1993; Drucker, 1999; Anheier, 2000; Kirkpatrick, 2006). Handy is still regarded as an influential thinker on cultural and structural theories in businesses and in non-profit organisations and he identified four organisational cultures: power, role, task and person. In a power culture, Handy (1981) considered that people needed to be politically minded and willing to take risks; a role culture would be preferred by people that liked security and predictability; a task culture meant a manager being flexible and ready to be judged by results; in a person culture the individual was the central point and any structure or organisation would exist only for assisting the individuals within it. Handy (1981) also claimed that there could be different cultures operating within the same organisation.

Drucker (1992) was another influential theorist on organisational behaviour and management. He identified a tendency to assume that management in organisations implied business management and he claimed that non-profit organisations had shied away from making use of management tools for that reason. At the time of writing his book, Drucker (1992) concluded that there had not been a great deal of material written on leadership and management up to that time that was specifically aimed at non-profit organisations. The role of the board in a non-profit organisation, for example, was different to a business as was the relationship with volunteers at a non-profit organisation and the need for such activities as generating income through fund-raising along with managing the sometimes intense commitment of staff working at a non-profit organisation (Drucker, 1992).

It is reasonable to expect that staff working for a hospice had a degree of intense commitment due to the nature of the type of care that they were providing to people living with a terminal illness. Feelings of stress amongst staff working in hospices due to the nature of the work could be expected to be quite high but as Vachon (1995) discovered, stress could also be caused when support, involvement in work and decision-making and workload are not provided for staff. This gives an indication that the type of service provision and management approach could potentially have an effect on involvement of staff in an organisation such as a hospice, as some of my findings indicated, as well as have an effect on service user involvement.

The applicability of management theories and practices described in this section to the management, culture and practices of an independent hospice was not clear from the literature. Operating and managing a hospice as a business appeared to be an under-researched topic.

It was not the aim of this study to formulate a potential management or business model or theory appropriate to independent hospices. The aim was to use the findings generated from the data about the organisational changes that had taken place at the hospice involved in the study, theorise about why the changes had been introduced and the potential impact on service user involvement in palliative care.

I felt it is worth considering the responses of independent hospices to external reverberations that are beyond their ability to control but nevertheless, have to respond to in order to survive. These reverberations could be caused when neoliberalism, concerned primarily with politics and economics that shows itself in government policies pursued by different political parties when in government, combines with managerialism that is concerned mainly with corporations and management that then both flow out and start to influence society. There appears to be no set formula as to how an independent hospice should respond to such challenges but the hospice involved in my study may have decided on a particular approach to deal with it. This aspect is discussed in more detail in Chapter Seven of this thesis.

1.6 Reflexivity

Addington-Hall et al (2007) explored reflexivity in the research process. These authors studied research methods used in palliative care and pointed out the importance of critical reflection and engagement in the research process. They also emphasised the need for the researcher to include an exploration of themselves and their own biases and values when carrying out data collection and also the environment within which the research was taking place.

In the introduction to this thesis, I described my personal experience of being a family carer for my parents; also my professional experience and my experience of working with a number of palliative care service user groups. As well as being aware of and using all this experience, it also meant exploring my own subjectivity while engaged in the process of this research particularly with regard to decisions during the process of data collection and interpretation. Peshkin (1988) talked about researchers engaging with their own subjectivity and also engaging with the different "I's" within themselves while the research was actively in progress rather than engaging retrospectively once the research process had finished.

> By monitoring myself, I can create an illuminating, empowering personal statement that attunes me to where self and subject are intertwined. I do not thereby exorcise my subjectivity. I do, rather, enable myself to manage it – to preclude it from being unwittingly burdensome – as I progress through collecting, analysing and writing up my data. (Peshkin, 1988, p. 20).

Peshkin was studying aspects of education but his use of the "I" in research has been adopted by researchers in other topic areas (Savage, 2007; Bradbury-Jones et al., 2010). Bradbury-Jones et al (2010) concluded that Peshkin's "I's" could help nurses gain deeper self-understanding including of their own emotions that would help enhance their therapeutic activities.

I have used Peshkin's "I's" approach through my data collection and analysis of the topic of this thesis. In order to enhance rigour and to help avoid proselytising my own views and opinions in this thesis, a number of clearly presented reflexive extracts that focus on the research topic appear through the thesis at appropriate points. These reflexive extracts also help to add further possible dimensions to the interpretation of the data.

Utilising Peshkin's "I's" plus reflexivity enabled the lived experience of participants in this research, service users and staff, to be explored that helped to generate rich data and add further dimensions to the findings, analysis and theorisation in relation to the topic of this thesis. An awareness of the organisational changes taking place at the hospice and being alert to the various leads and issues that were emerging from the data enabled further complexities to be explored. The reflexive extracts that appear in various parts of this thesis also include extracts from my reflexive PhD journal. The intention is to elucidate how all my approaches and understandings were relevant to and impacted on my research

1.7 Chapter conclusion

This chapter has summarised the original intention of the research topic of this thesis and how it developed and also summarised the need for flexibility in the methodology adopted. It has presented the economic, political, social and managerial context for the study and my personal and professional context as the researcher. It has also presented the context for the case study and clarified the meanings of service user involvement, palliative care and end of life care.

My approach to this thesis is to move between personal/reflective and evidence/theorising (Finlay 2002) and to clearly indicate when these particular features are being put forward. The aim is to show how models of service provision adopted by a hospice can influence the role and experience of service user involvement.

The next chapter, Chapter Two, puts forward a review of the literature related to the topic of this study on service user involvement in palliative care and indicates how the views of service users and staff in hospice settings have rarely been elicited.

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

This study is concerned with exploring the perspectives and understandings of service users receiving palliative care and of staff providing that care in a UK hospice towards service user involvement in palliative care.

This chapter sets out a review of key literature in this topic area and is an opportunity to evaluate concepts and findings that form the academic basis of my study. This chapter also identifies previous evidence and gaps to justify the rationale for conducting my study.

The first part of this chapter describes the approach taken towards the literature search strategy. Quality Assessment Prompts (Dixon-Wood et al 2006) were used in the inclusion and exclusion process. Further details about the search strategy including a table are presented below.

A critical review of three main themes that emerged from the key literature identified from the search is included in this chapter. These themes are: 1) Power and control, that involves potential tensions between service users and professional staff providing palliative care around decision-making. It also involves potential tensions between professional staff working in different areas of healthcare and palliative care such as between staff working in clinical services, for example, and those working in general nursing; 2) The importance of relationships in palliative care, including between service users receiving palliative care and family carers and with healthcare professionals; 3) Debates around who should be viewed as having a role in service user involvement in palliative care. For example, a number of the key studies concluded that family carers should be viewed as an intrinsic part of involvement with other studies highlighting the problems that can emerge if family are involved.

2.1.1 Approach to the literature search process

The literature search covers the years 1995 – 2018 and involved conducting a methodical review that included elements of a scoping review. Arksey and O'Malley (2005) identified four types of scoping review: 1) to map fields of study; 2) to determine the value of conducting a full systematic review; 3) to summarise and disseminate research findings; 4) to identify research gaps in the literature. The authors also state that a scoping review approach enables a researcher to be flexible in use of search terms and identification of appropriate studies in an iterative and reflexive way in contrast to systematic reviews.

This approach enabled academic and other studies and articles to be extracted from electronic databases, reference lists, key journals and the grey literature covering conferences, studies produced by relevant organisations and my own networks that were relevant to my study. (Hart, 2009; Silverman, 2010; Booth, Papaioannou and Sutton, 2012). I also used Quality Assessment Prompts devised by Dixon-Woods et al (2004) and Arnstein's Ladder of Citizen Participation (1969) for full text assessments to add rigour to the final selections for critical review.

Searches of the literature on other subject areas were conducted later in the study process. This activity was prompted by findings that emerged from the data and included business/management studies and theories as well as management approaches in health, social care, education and other public services. It was useful to identify this additional literature in order to enhance theorisation from the findings and is discussed in Chapter Six.

2.2 Searching the literature

The literature search indicated that most research into service user involvement in healthcare took place from the mid 1990s and gained some momentum over the following years. There was a concomitant increase in the amount of research being carried out into service user involvement in palliative care from this time although it was still considered to be an under-researched area (Payne et al, 2005). Based on this finding, the search for studies relevant to the topic of my study therefore started from 1995.

2.2.1 Databases and searches

The databases used in the search for the years 1995 - 2018 were CINAHL, SCOPUS, PsycInfo and ACADEMIC SEARCH COMPLETE (ASC). An initial search of the literature using specific key words appropriate to my study uncovered a limited number of studies. I decided that relevance to the topic of my research was a more important determinant for inclusion than the methodology that may have been used in a particular study. This meant using search methods associated with a scoping review as put forward by Arksey and O'Malley (2005) described earlier in this chapter.

The different more probing strategy involved using combinations of key words and searching databases in a methodical way for each combination of words. It also involved hand searches of journals, relevant conference reports and searches using the names of authors who have conducted research into service user involvement in palliative care. This search strategy and the results that emerged are described below.

As the search process continued, the strategy I adopted was to concentrate on those databases where most results were emerging and to use filter searches where it was felt appropriate (see Table 2.1 below).

2.2.1.1 Keywords

Search 1:
"service users" AND "involvement" AND "palliative care"

Search 2:
"patient" AND "involvement" AND "palliative care"

Search 3:
"service user involvement" AND "palliative care" with 'abstracts' ticked

Search 4:
"service user" AND "participation" AND "palliative care"

Search 5:
"professionals" AND "involvement" AND "palliative care"

Search 6:
“service user” AND “involvement” AND “hospice”

Search 7:
“patient” AND “involvement” AND “hospice”

Search 8:
“patient involvement” AND “hospice care”

Table 2.1: Databases searched with results 1995 - 2018

KEY: * indicates not searched on that combination of keywords

	CINAHL	**SCOPUS**	**PSYCINFO**	**ASC**
Searches				
1	13	52	10	20
2	181 (filter search from 534 hits)	37 (filter search from 1,182 hits)	149 (filter search from 415 hits)	*
3	8	*	*	*
4	10	5	7	*
5	75 (filter search from 187 hits)	22 (filter search from 322 hits)	98 (filter search from 258 hits)	*
6	3	*	15	*
7	74 (filter search from 186 hits)	*	*	*
8	3 (filter search from 23 hits)	6 (filter search from 21 hits)	7 (filter search from 73 hits)	29
TOTALS	**367**	**122**	**286**	**49**

OVERALL TOTAL: 824

2.2.2.2 Search of the grey literature

This wider exploration involved searching the grey literature such as conference reports plus academic papers and reports produced by governmental bodies and independent think tanks as well as by Third Sector and voluntary organisations operating in the UK, rest of Europe and worldwide.

Examples of the wider sources that were searched included:

- Joseph Rowntree Foundation; Shaping Our Lives; INVONET; National Council for Palliative Care; Dying Matters; Marie Curie; Hospice UK; Cicely Saunders Institute; SCIE Online; Social Care Online; Intute Health and Life Sciences; Intute Social Welfare; European Association of Palliative Care; websites of end of life care studies departments at academic institutions;
I conducted searches using authors' surnames as keywords that included: Beresford, P; Brearley, S; Carr, S; Cotterell, P; Forbat, L; Payne, S; Sargeant, A; Small, N.

Reports and articles that emerged after title and full text sifting from searching the grey literature: Cotterell (2006 - thesis); Croft, Chowns and Beresford (2012 - report); Daykin et al (2010), also Payne et al (2008), that was an executive summary of the 2005 scoping study.

A total number of 824 studies emerged using the key words search process described at the start of this section. These were then reduced to 74 by title and abstract sifting. The sifting process was based on a short formula put forward by Dixon-Woods et al (2004) as follows:
WHO: adult (aged 18 and over) service users receiving palliative care and professionals/staff providing palliative care;
WHAT: service user involvement in health/palliative care /hospice care
HOW: Perspectives/understandings of service user involvement generally and in relation to health/palliative care service provision.

2.2.2.3 Quality Assessment Prompts

A full text sifting of the 74 studies involved use of Quality Assessment Prompts (QAP) formulated by Dixon-Woods et al (2004) that included the following questions for appraising a research study:

- **Are the aims and objectives of the research clearly stated?**
- **Is the research design clearly specified and appropriate for the aims and objectives of the research**
- **Do the researchers provide a clear account of the process by which their findings were reproduced?**

- **Do the researchers display enough data to support their interpretations and conclusions?**
- **Is the method of analysis appropriate and adequately explicated?**

(Dixon-Woods et al, 2004, p. 224).

Following the full-text sifting, 28 studies and reports were identified for critical review (Appendix 4). There is debate in the literature generally about the appropriateness of checklists for assessing qualitative research. The authors state that whatever tool is used, the ultimate assessment of a research study is down to the judgment of the individual reviewer.

I stated earlier in this chapter that relevance to the topic of my research was more important as a determinant for inclusion or exclusion of a study rather than the methodology. Exploring perspectives and understandings fits more naturally with a qualitative approach (Silverman, 2010; Denzin and Lincoln, 2012). As Curry, Nembhard and Bradley (2009) point out, qualitative research is exploratory in nature and uses discussions and observations, for example, to help generate insights and enable understanding of complex social processes from the point of view of the study participants. Quantitative research often seeks to statistically test hypotheses and may be carried out in randomised or non-randomised experimental and natural settings to generate numerical data. A mixed methods approach to research uses both qualitative and quantitative approaches to research that can enhance insights gained from both methods (Curry, Nembhard and Bradley, 2009). I included studies for critiquing that used qualitative, quantitative and mixed methods approaches and also included systematic reviews where I considered that they helped illuminate the subject of my study.

The next section in this chapter provides a critical review of the 28 studies that emerged from the literature search and sifting processes.

2.3 Critical review of the key literature (1)

The areas covered by the 28 studies include health, NHS, social care and palliative care. The methods used include qualitative (21); quantitative (1);

mixed methods (1); scoping review (1) and systematic review (4). Data collection was carried out by interviews with service users/patients (7); with patients and professionals/staff (5); with patients and family (2); with patients, family and professionals (2) and with professionals and families (2).

2.3.1 Recruitment of participants and ethical considerations

In the 18 studies where interviews were conducted and focus groups organised, participants were identified and approached using a variety of recruitment methods. Approaches to patients were carried out primarily through the services and judgment of professionals that could have led to bias in selection. There is a preponderance of patients with cancer involved in the studies that may be due to those with non-malignant conditions being more difficult to identify or limited opportunities to put themselves forward. The existence of cancer networks involving patients meant that potential participants for research studies could be more readily identified and approached. Also, professionals may judge that a particular service user was too unwell to be a participant and should not be disturbed without necessarily seeking the view of that service user before reaching such an assessment.

The studies all took account of the ethical dimension of involving service users receiving palliative care as participants in their research through informed consent. Ethical considerations can bring forward complex issues that need to be negotiated and may have an impact on the numbers and abilities of service users to become participants, particularly in the context of life-limiting illnesses and palliative care. Ethical considerations when conducting research in palliative care are discussed in more detail in Chapter Three of this thesis.

The scoping review conducted by Payne et al (2005) emerged as a key study by providing a guide into the literature on service user involvement in palliative care prior to 2005. It covers the methods that were adopted for accessing the views of service users as well as the views of family carers, advocacy groups, researchers, practitioners and policy makers on this subject. This review is briefly critiqued in the next section.

2.3.2 Critique of 2005 Scoping Review

The scoping study was conducted over one year in three phases: phases one and two ran concurrently and involved a review of the literature and the methods used and the gathering of views of key informants to identify a sample of people who have expertise about user involvement in palliative care. Phase three comprised a consensus building meeting that involved service users, carers, professionals and ‘experts’ identified during phase two during which the participants were invited to comment on the preliminary findings including their strengths and weaknesses to help shape the eventual findings of the scoping study.

The literature search of academic databases, the internet and grey literature identified 2,046 hits with 507 studies selected to be reviewed that were ultimately reduced to 53 papers. Data was extracted by bibliometric analysis and annotated bibliography followed by a synthesis. Critical appraisal methods developed by Hawker et al (2002) for analysis of literature on evaluative and mixed methods research were used.

The findings of the scoping review showed that within the search criteria, palliative care formed the second highest proportion of literature on service user involvement. The authors discovered that this mainly involved descriptive accounts or accounts drawn from particular contexts as well as project reports but very few papers on research or case studies. Their analysis also showed that 96 per cent of the extracted literature was written by professionals with four per cent written independently by service users alone or in conjunction with professionals. Although service users and professionals appeared keen to share their experiences of user involvement, the scoping review discovered very little evidence about the effectiveness of such involvement for patients or professionals and no clear reasons as to why organisations would implement service user involvement except to comply with government directives.

Primary data were collected through semi-structured interviews conducted via telephone and face-to-face along with site visits: (patients = 19), carers (carers = 12), volunteers (n=2), professionals (n=13), ‘experts’ (n=4), project team (n=8) making a total of 54 participants. The interviews were transcribed verbatim and analysed using thematic analysis with field notes from site visits also analysed.

How to get service users involved not only in discussions about palliative care but also in a position where they had a measurable influence was identified as a problem area. Some of the service users participants in this review expressed the view that they felt empowered by being involved in discussions with health and other professionals about their own care or as a carer and could see some demonstrable changes at their local level as a result of their input which in turn kept them motivated. However, in the observation of service user involvement processes during the field work site visits, a lack of motivation to devolve power to service users or to adapt organisational structures to enable their genuine involvement was revealed.

The scoping study also revealed that while there had been increased consultation with service users, it was often accompanied by unrealistic expectations that service users could turn their experiences into practical suggestions without assistance or training. Those participants who had attended and contributed to service user involvement groups or forums felt that they were a good method of getting their views across and for contributing to service development. There was inequity noted by some participants who, because they had conditions other than cancer, could not access specialist palliative care services and therefore did not have the option of participating in service user involvement activities.

Four main issues could be identified from the 2005 scoping study: that there are gaps in understanding and analysis of palliative care from the perspectives of service users; that professional accounts of user involvement dominate what is known about palliative care and therefore about service user involvement within that context; that further examination is needed around the concept of service user involvement and how it relates to palliative care and, that there are examples of good practice where a link can be made between service user involvement and enhanced services yet there is little by way of rigorous evaluation.

The critique of key literature that emerged during my own literature search also considers whether the four main issues identified by the 2005 Payne et al scoping review mentioned above have been addressed in subsequent studies.

2.4 Critical review of the key literature (2)

This section provides a critical review of the other 27 key studies (Appendix 4): Aspinal et al (2005); Beresford and Branfield (2006); Boelk and Kramer (2012); Carter et al (2004); Cotterell (2006); Cotterell et al (2011); Croft, Chowns and Beresford (2012); Daykin et al (2010); Etkind et al (2018); Evans et al (2003); Forbat, Hubbard and Kearney (2009); Francois et al (2017); Fredriksson, Eriksson and Tritter (2018); Fudge, Wolfe and McKevitt (2008); Gauthier and Swigart (2003); Haarsma et al (2015); Johnston and Smith (2006); Karnilowicz (2011); Kars et al (2016); Lee, Kristjanson and Williams (2009); McCormick and Conley (1995); Mockford et al (2012); Ocloo and Matthews (2016); Palumbo (2015); Richardson, MacLeod and Kent (2010); Sargeant et al (2007); Woods, Beaver and Luker (2000).

The majority of the studies in this critical review were qualitative that seemed appropriate to the topics that were being researched allowing for in-depth analysis of personal experiences. The study by Gauthier and Swigart (2003), for example, provided a valuable in-depth look into the lives of service users living with a life-limiting illness and the complexities of decision-making that surround them. Based on the findings, the authors put forward a model of decision-making for service users who were moving towards the end of their lives. The four systematic reviews covering healthcare services have been included as I considered they offered insights into the topic of my research. These insights include relationships between patients and family carers and patients and professionals and their possible influence on preferences and involvement of those receiving care (Kars et al, 2016; Etkind et al, 2018).

Potential barriers to service user involvement in healthcare are also highlighted including balance of power (Mockford et al, 2012; Palumbo, 2015).

Payne et al (2005) discovered that there were very few research studies that explored service user involvement in palliative care as a topic of itself or provided an evaluation of it. Rather, the focus is generally on descriptive accounts of the process of establishing and practising such involvement. There was also a lack of involvement of service users themselves in the design, implementation and evaluation of research into palliative care. Cotterell et al (2011) addressed this point in their study where service users with cancer were involved in all aspects of the research activities and this is explored in this review.

2.4.1 Theme 1 – Power and control

The words ‘power’ and ‘control’ appeared in a number of the key studies. Balance of power issues related to service user involvement were identified between patients and staff in a number of studies (Carter et al, 2004; Gauthier and Swigart, 2003; Haarsma et al, 2015; Karnilowicz, 2011; Lee et al, 2009; Richardson, Macleod and Kent, 2010). These studies highlighted particular tensions in decision-making between patients and professional staff around the provision of personal palliative care. For example, if staff made decisions on behalf of service users without consulting them first then this led to feelings of disempowerment. Power and control issues could also occur between patients and family carers (Beresford and Branfield, 2006; Etkind et al., 2018), between family carers and professionals (Francois et al, 2017) and between professions (Daykin et al, 2010).

The ability of patients and/or family members to be involved in the provision of care or influence decision-making and policy generally may rely on the ethos of the organisation that they may be engaged with. For example, Karnilowicz (2011) identified that the power differential between patients and staff was particularly evident in healthcare. Croft, Chowns and Beresford (2012) collected data from 29 hospices as part of their study and found that most hospices considered that they had always put the patient at the centre of their activities as part of their original ethos. And yet the authors also identified significant contradictions towards service user involvement with an emphasis on the process rather than outcomes. The studies by Karnilowicz (2011) and Croft, Chowns and Beresford (2012) indicate that there may be different approaches and attitudes towards service user involvement depending on the type of organisation, for example, whether a hospital or a hospice.

Arnstein (1969) devised the Ladder of Citizen Participation that provides a model of involvement and has been described in Chapter One and is briefly reviewed here. One of the strong themes that Arnstein put forward about citizen participation generally covers the issue of power and control, where it lies and how it affects participation:

> Participation without redistribution of power is an empty and frustrating process for the powerless. It allows the power holders to claim that all sides were considered, but makes it possible for only some of those sides to benefit. (Arnstein, 1969, p. 2).

Arnstein (1969) also claims that the situation described in the quotation above helps to maintain the status quo by enabling the powerful to claim that all sides were considered when in fact only some of those sides would benefit. The author goes on to say that citizens may be able to voice their opinions and be heard by the powerful but lack the ability to ensure those opinions are acted upon. Arnstein admits that the ladder is a simplification but claims it does help to illustrate that there are different levels of citizen participation. Another interesting point the author makes is that neither the powerless nor powerful can be viewed as homogeneous entities but claims that the powerless do appear to perceive the powerful as representing a permanent and immovable system with those deemed to have the power regarding others as “those people” (Arnstein, 1969, p.3) irrespective of any differences between them whether class, for instance, or perhaps even gender. The author also claims it is possible for citizens to move up and down between the different rungs and for there to be blurring of the boundaries between the rungs.

Daily decision-making and empowerment experienced by people with life-limiting illnesses was explored by Richardson, MacLeod and Kent (2010) using a phenomenological hermeneutic approach (Max van Manen, 2014). This approach enabled the authors to study the lived experience of patients attending an outpatient clinic of a community hospice in New Zealand and to examine and reveal meanings buried within the words used by participants. There were 14 participants receiving palliative care who were each interviewed face-to-face and analysis involved reflection and total immersion in the text to help identify themes coupled with analysis and constant reflection of issues related to power and control inequities in nursing practices. Three themes were identified from the data: 1) "lived space chaos" (Richardson, MacLeod and Kent, 2010, p.132) as the participants were living in a chaotic and complex period of their lives that started straight after diagnosis and prompted mixed feelings such as anger, disbelief and powerlessness; 2) contracting worlds where aspects of normality in the lives of the participants began to shrink not only in their social lives but also physically as their bodies changed due to their conditions and moved away from what they had regarded as their former selves; 3) capitulation, that came about when participants eventually realised their lives were coming to an end and the closer they got to death the more submissive they became. The authors discovered that there is a tendency for people with life limiting illnesses to be seen generally as a homogeneous group where all of them behave in the same manner and the care approach that is adopted can be a "one size fits all model which can leave the person and their family members feeling disenfranchised, frustrated and not listened to" (Richardson, MacLeod and Kent, 2010, p.130). The authors attested that people with life limiting illnesses being able to make decisions for themselves, however mundane they may seem to others, was important for their sense of empowerment and autonomy.

Richardson, MacLeod and Kent (2010) attested that it is difficult to deconstruct an individual's feelings and behaviours to different aspects of the decision-making process during the period after diagnosis. The authors therefore saw empowerment of service users with a life limiting illness as an important element especially in the final phase of their lives to enable them to make decisions for themselves. Staff providing care to people with a life limiting illness can start to make value judgments about the care and begin to make decisions on their behalf because they perceive a person to be too vulnerable, for instance, or too sick to make decisions for themselves. This led the authors to advise health staff to be aware and mindful of the level of control that they could exert.

Kars et al (2016) identified fear of burdening vulnerable service users as an important reason for gatekeeping in palliative care research by professionals working in hospice and homecare settings coupled with a protective attitude. While asserting that health professionals should become partners in care with patients, the authors also believed it important for more research to be conducted around empowerment in order to understand how it could work.

An auto-ethnographic approach adopted in a study by Karnilowicz (2011) enabled the author to use personal experience to explore psychological ownership and identity related to prostate cancer and chronic illness. The author identified that the power differential seemed to be particularly evident in the health industry and that analysis of disease and illness would benefit from the perspectives of the less powerful, that is, through a patient’s lived experience of their illness. Service user involvement and empowerment could be “undermined by the seduction of health-discourse so that the patient ends up wanting what the system wants them to want” (Richardson, MacLeod and Kent, 2010, p. 135).

Gauthier and Swigart (2003) wished to explore their own understandings of the reality and perspectives of the lives of people who had a life limiting illness. These authors used a constructivist paradigm with grounded theory in order to construct a tentative model of the process of decision-making surrounding aspects of care for patients in two hospices. The authors talked about how decisions are made and how, in line with the findings of Richardson, MacLeod and Kent (2010), the apparent mundanities of those decisions held great significance for a person's autonomy as they moved towards the end of their lives.

Gauthier and Swigart (2003) identified the complexities of decision-making in a hospice context and that these complexities involved past as well as current experiences. Three major concepts were identified from the data: 1) realisation and then acceptance that the end of life was near; 2) living and making decisions on a day-to-day basis that adapted and changed according to the progression of the condition that included increasing physical dependence as an important factor and, 3) dealing with the unpredictability of a life limiting illness. The authors considered that the third concept was the most important and called it "embodied responding" (Gauthier and Swigart, 2003, p.126). It referred to all the elements that make up a whole person such as physical, psychosocial and spiritual and that all these elements influence decision-making generally and at an individual level. The authors stated that physical symptoms, pain and a deteriorating physical condition all influenced decision-making and that increased physical dependence had an influence on when and how decisions were made. Several of the participants were reported as saying in this study that their particular condition had been well-managed by the hospice but that their spiritual, emotional and family aspects, for example, of their illnesses had not been accommodated. The authors concluded that decision-making affecting service users at the end of life involved a complex process of interactive events and the perception of control over decision-making between service users and staff needed further exploration.

The studies by Gauthier and Swigart (2003) and Richardson, MacLeod and Kent (2010) indicate the importance that service users with life-limiting illnesses attach to all aspects of their lives after diagnosis, not only the medical or clinical aspects. It could be contended therefore that the approach towards service user involvement for palliative care may need to be approached and handled differently towards such involvement in general healthcare.

The power relationships between professions and between staff is another aspect of control identified by Daykin et al (2010) that could potentially add barriers for service user involvement in palliative care. In this study, the authors attempted to identify key principles for the development of user involvement through the perspectives of service users and professionals in one cancer network. This study used the Delphi Technique involving 357 individual stakeholders and collaboration between the NHS, two universities and two voluntary sector organisations.

The Delphi Technique involves presenting a series of questionnaires to informed individuals on a particular issue, data is then analysed and a new questionnaire developed on the basis of results obtained in the first questionnaire (Keeney, Hasson and McKenna, 2000). These new questionnaires are then sent back to the original participants to enable them to reconsider their initial thoughts and opinions. The key principles in the Daykin et al (2010) study were identified through analysis of 120 priority statements that were then ranked. One main conclusion from this study was that consensus development is key to understanding professional attitudes to service user involvement and that power dynamics between professions and between professionals and service users affects the approach adopted towards service user involvement.

Although the study by Daykin et al (2010) covered a large number of participants in one cancer network, the method they employed to gather data through a series of questionnaires and statistical analysis of priority statements, did not enable in-depth probing of any of the responses from service users or staff. The study also only involved service users with cancer who were members of a network as participants and so its findings and conclusions could not necessarily be wholly extended to encompass service users with all life-limiting illnesses. Some of the service users may have felt confident about taking part in such studies and could express themselves well through the written word whereas other service users may not be so adept at writing and so their views could be lost. The value of this study may lie in providing data for further in-depth exploration using a qualitative approach that involves semi-structured interviews, for example.

Aspinal et al (2006) concluded that there were differences between patients, relatives and staff on what was important to measure at the end of life. The study involved 10 focus groups with 75 participants (10 patients, 35 professionals and 30 bereaved relatives). Recruitment of bereaved relatives and patients was carried out with voluntary organisations, hospices and hospital palliative care teams and staff were recruited from hospital palliative care services and a palliative care research unit.

The authors used a modified nominal group technique that enables ideas and thoughts to emerge from group participants through the posing of a single question and is intended to be non-hierarchical to enable equal weight to be applied to all the views put forward. The authors noted that there was a dearth of literature on the perspectives of service users as to what was important to measure at the end of life, an observation that concurred at that time with the scoping study of Payne et al (2005). They also considered that there is a particular problem in palliative care as the words ‘service user’ when used in this context can refer not only to patients but also to their families or close friends and neighbours. Terminology around palliative care and understandings around the words ‘service user’ were discussed in Chapter One.

Aspinal et al (2006) identified 14 themes from the Nominal Group Technique that were then given rankings and seven of these emerged as the most important.: ’symptom management’; “‘dignity’; ‘quality of life’; ‘relationships’; ‘preparation’; ‘co-ordination and continuity’; and ‘choice and control’” (Aspinal et al, 2006, p. 400). There were differences identified by cross-comparison between professional groups and patient groups. For example, professional groups had ‘symptom control’ as their first priority whereas patient groups had ‘preparation’ and ‘co-ordination and continuity’ as their priorities. Possible reasons that the authors put forward for service users not having symptom control at the top of their priority list was that professionals may have had a bio-medical approach to the subject and also service users may well have had their symptoms under control at the time of the group study and so it was not an issue for them. Palumbo (2015) identified that professional hostility towards co-production in healthcare enabled a bio-medical approach to continue.

The quotation “knowledge is power” is attributed to Sir Frances Bacon in 1597 and is a concept that Haarsma et al (2015) appeared to identify with from their study. The authors conducted 18 in-depth interviews and three focus groups involving 16 patient representatives and 12 staff in six palliative care networks in the Netherlands. Quality of care and dissemination of information were identified as having the greatest impact on involvement by enabling citizen control and partnership in palliative care. However, the authors also identified tensions between the patient representatives and staff in relation to operational and strategic involvement. Beresford and Branfield (2006) identified the need for networking and knowledge sharing among service users and service user organisations as important enablers for influencing policy.

The studies reviewed in this section under Theme 1 provide an indication of the complexities that exist around decision-making for service users with a life limiting illness (Gauthier and Swigart, 2003; Aspinal et al., 2005; Richardson, MacLeod and Kent, 2010). The studies also indicate the extent of the role of power and control around service user involvement including in palliative care (Arnstein, 1969; Daykin et al., 2010; Richardson, Macleod and Kent, 2010). Arnstein (1969) expressed this aspect in terms of the relationship between the powerful (professionals) and the powerless (service users). Richardson, MacLeod and Kent (2010) developed this theme when they mentioned empowerment of service users and intimated how such empowerment could potentially be manipulated by the dominance of health discourse. Payne et al (2005) discovered that health was the dominant voice in literature around service user involvement in palliative care that could also serve to help embed the dominant health discourse in palliative care. If complexities in decision-making surrounding service users with life-limiting illnesses were added to these assertions then the possibility of the health discourse prompting service users to want what the system tells them to want in palliative care would appear to be quite strong. Formal power structures in a working environment emphasise the role of the professional and can act as barriers to effective service user involvement whereas a more open and interactive process could enhance patient control and power in decision-making (Carter et al, 2004). Such scenarios have implications for service user involvement in palliative care.

2.4.2 Theme 2 – Relationships in palliative care

Relationships, influences and tensions involving patients and staff, patients and family, family and professionals and between professions towards service user involvement are highlighted in a number of the key studies.

In a systematic review, Etkind et al (2018) explored the care preferences of older people with advanced illness in a hospital and community care setting and the role of family in that process. The authors discovered that the family is particularly important as an influence on care preferences that are then further influenced by a complex interaction of family, illness and other care factors. Trusting care relationships were found to influence care preferences of the older people and the wish to avoid being a burden. Concerns about other family members and not upsetting them unduly seemed to be prominent among the older people in the study. The authors found that the presence and support of the family had a strong influence that may supersede the personal wishes of the older person. The authors referred to this as a trade-off. While acknowledging the importance of family involvement in discussions about care preferences, the authors also highlighted the role of staff and clinicians in providing support to families and the patient while enabling the care preferences of the patient to be achieved. This was felt to be especially important where there was conflict between the views of a patient and their family. Beresford and Branfield (2006) highlighted the risk of marginalising the views of patients or service users by including family members in decisions and called for a more explicit and inclusive approach otherwise there could be a risk of bias by omission.

Johnston and Smith (2006) conducted a phenomenological study exploring the perceptions of 22 patients with life-limiting illnesses and 22 palliative care nurses towards palliative nursing care in two acute hospitals and two hospices in Scotland. The nurse-patient relationship in palliative care was seen as important and valuable in the context of palliative care with an emphasis on good communications skills. The authors discovered that those with life-limiting illnesses also expressed a desire to keep their independence and remain in control. Both patients and palliative nurses expressed agreement that interpersonal skills on the part of the nurses were very important along with kindness and compassion. The patients in this study also noted the difference between the hospice and hospital environments where they had been receiving care. The patients attributed importance to the “atmosphere, safety and sanctuary of the hospice environment” (Johnston and Smith, 2006, p. 706) as well as viewing it as a place of security and hope.

McCormick and Conley (1995), Woods et al (2000) and Lee et al (2009) explored perspectives on decision-making from the perspectives of patients with life-limiting illnesses. Lee et al (2009) identified a main issue experienced by palliative care patients in their study as lack of involvement in decision-making. The type of relationship they had with staff was believed by patients to hold significance for the amount of involvement they had in decision-making. The relationships were determined by the culture and environment as well as the manner of the staff member. The authors point to difficulties that staff may have when, for example, patients make decisions that differ from their advice, even if autonomy is accepted. The risk of paternalism was seen as a risk for palliative care patients due to fluctuations in their conditions that can impact on their autonomy and ability to make decisions. A distance between patients and staff developed when staff did not engage with a patient and came to be viewed as aloof and disinterested in the person and only concerned with the disease and/or professional protocols. The authors concluded that the behaviour of staff and the culture of an organisation can be vital to engendering relationships that can then enable patient involvement in decisions.

McCormick and Conley (1995) also highlighted how sensitive patients can be to non-verbal language of staff engaged in their care and how lack of appropriate or direct communication between staff and patient can lead to problems. The authors cite the example of a patient learning that his prognosis was grim and he was expected to die soon from his daughter and was upset that such news had been shared with her before it was shared with him. The notion of enabling an individual to integrate the way that they die into their lifestyle was put forward by these authors and that the agenda of each person near the end of life will be unique.

Woods, Beaver and Luker (2000) identified what they referred to as the moral complexity of family involvement in palliative care. This involves the complexity surrounding the role of family members and their relationships with professionals or staff. The author identified a concern among staff around professional boundaries and the ethics of confidentiality and best interest. In this study, 15 patients, 10 family carers and 19 bereaved family carers were interviewed all involving a cancer diagnosis apart from one patient with a non-malignant condition. The aloofness of professional staff at the hospital where patients attended was identified and mirrored the findings of the study by Lee et al (2009). The approach of caring and kindness of certain health staff was mentioned by some participants and the hospital was seen to exert a lot of control over a patient even in the final stages of illness. Woods, Beaver and Luker (2000) also provide examples of how family can act as protectors of a patient so they do not hear bad news from anywhere. For example, when gathering data for their study, one woman gave permission for researchers to approach her husband on the condition that his stomach cancer was referred to as an ulcer. The issue about information and who holds and controls it mentioned earlier in this chapter also emerged in this study. The tendency of professionals to control information was seen as a way of demarcating between ‘professional’ and ‘lay’ or family carer. The lack of information for family carers meant they had worries about whether they were providing effective care. Information about a particular condition was seen to be useful as opposed to details about prognosis as a way of maintaining positivity and hope. All these aspects highlight the complexities around people with a life-limiting illness. Woods, Beaver and Luker (2000) also highlight the problem of an ethical framework that has a focus on individual patient autonomy in the context of a family or lay carer being just as significant.

Palumbo (2015) conducted a systematic review exploring service co-production and value co-creation to health services and provided a challenge to the traditional bio-medical model of care. The author maintains that co-production of health care services implies creating partnerships between patients and staff that can lead to greater freedom of choice and enable patients to become members of care teams. This situation could then lead to increased patient satisfaction, better service innovation and cost savings.

Cotterell et al (2011) also explored relationships between cancer service users and professionals. Problems described by service users included the attitudes of professionals towards certain cancer treatments. For instance, professionals would talk explicitly about cancer treatments at meetings with service users present that caused service users to become upset and that proved to be challenging situations for the service users to deal with as well as challenging for the professionals to deal with. There was also the perception identified by some participants that their needs or wishes were peripheral to activities in the eyes of the professionals causing service users to feel undervalued. It could be inferred from the study findings that the joint cancer groups involving professionals and cancer service users provided a learning environment for both groups. As well as providing challenging situations, the group working could potentially provide positive opportunities. For instance, the groups could provide an environment for any problems or issues to be discussed and so help to improve communication and understanding between professionals and the cancer service users. Cotterell et al (2011) acknowledged this learning potential but also called for greater networking between different groups in cancer and palliative care in order to help strengthen the groups’ positions and enhance learning opportunities.

2.4.3 Theme 3 – Debates around who is involved in service user involvement in palliative care

Forbat, Hubbard and Kearney (2009) looked into the range of models of involvement and explored what they termed "the muddle of conceptualisation of involvement" (Forbat, Hubbard and Kearney, 2009, p. 2547) and how this can lead to difficulties for professionals, patients and managers in implementing policies in this area. The authors identified four models of involvement that they derived from the literature that are defined by who is involved and what they are doing by being involved. The first model sees service users as consumers who purchase or choose services that is driven by free market economics; the second model sees the patient as a citizen who develops a preference for services in relation to others and with regard to the public good that is driven by social democracy; the third model sees the patient as a partner in care and is different from the first two models in that it concerns an individual's involvement in their own care. Underpinning the second and third models of involvement is the experiential knowledge that service users bring and have a unique perspective to bear when considering care services. This is a similar finding to Cotterell (2006). The fourth model concerns service user involvement in research. The different approaches to involvement initiatives leads the authors to contend that the agenda for involvement is broad and can be confusing. The most common method of service user involvement mentioned by professionals in the study was the use of patient satisfaction surveys. This was troubling to the authors for its lack of connection with involvement as such surveys tended to be tightly prescribed offering only formulaic ways of answering rather than allowing for in-depth responses that could be further probed. Such surveys also do not show any indication of partnership working between service users and professionals.

Interviews with the CEOs of the five health boards in the Forbat, Hubbard and Kearney (2009) study revealed that they believed they were actively involved in involvement work and gave examples of holding large public meetings and having random individual conversations. The authors considered that the CEOs in the main saw service user involvement as a way to manage public expectations around health service delivery, for example, rather than with individual patients. This approach taken by the CEOs was seen by the authors as not connecting with the four models of involvement that they had identified and considered it did not even reach the first rung on Arnstein's ladder. The authors concluded that this approach to service user involvement indicated a connection with free market economics and viewing the patient as a consumer.

It would seem, at first sight, that patient satisfaction surveys could be placed on the fourth rung of Arnstein's ladder (1969), that is, consultation as they appear to show that people are being consulted. But it could be argued they could also be placed on the lowest rung, that is, manipulation as the surveys could be used to give an appearance of consultation but are actually nothing of the sort. Whether such surveys are placed at the lowest rung or the fourth rung on Arnstein's ladder, they are still at the level of manipulation and tokenism and therefore indicate that these surveys have dubious relevance to service user involvement.

Sargeant et al (2007) focussed on exploring the motivations for service users and professionals to be engaged in service user involvement activities in palliative care. The authors describe service user involvement as **"**the way in which people are involved in making suggestions and taking decisions about how different services are run and developed"**,** (Sargeant et al., 2007, p.127). Using an interpretive and participatory approach, participants were identified through a user group attached to a third sector organisation, a snowball technique and the UK Hospice Information Directory. All participants were already involved in service user involvement activities and 51 semi-structured telephone and face-to-face interviews were carried out with service users, palliative care professionals and academic experts who had a background in service user involvement in palliative care. Also, four service user involvement programmes were observed and field notes made. Interview transcriptions and field notes were entered on the QSR NVIVO database and thematically analysed and were then followed by consultation meetings involving 48 service users and professionals to discuss the preliminary findings (17 patients; 12 carers; two volunteers; 13 palliative care professionals; four academics and others who had already contributed to the data). It included service users with advanced conditions in cancer, heart disease, respiratory disease and neurological diseases and with three service users also having learning disabilities. Data from these meetings were added to the database and contributed to the findings.

It was interesting to note that Sargeant et al (2007) regarded as a failing the lack of informal caregivers, who would be primarily family members, in research generally about service user involvement in palliative care. The authors regarded carers as playing a significant role particularly for service users with chronic conditions. They also saw a reliance on articulate patients in much of the literature on user involvement coupled with the lack of the informal carers' voices as problems and indicative of wider problems in conceptualising and implementing service user involvement. For these reasons, service users, informal carers and professionals were interviewed for their study.

Sargeant et al (2007) presented their findings from participants in two parts covering motivations and barriers for service users and motivations and barriers for professionals. For service users, motivations included the feeling of being empowered through being involved; attending user group meetings enhanced feelings of self-worth and the feeling they were valued for their skills and knowledge. An important driving factor was the opportunity to contribute to improvement in services. Barriers for service users included tokenism and dominance of a professional agenda, for instance, service user involvement meetings being arranged at the convenience of the palliative care service rather than the needs of the service users. This could mean meetings being held on weekdays during office hours that might prevent service users and carers who were working from taking part. There were also views expressed about the lack of diversity within service user groups so making them unrepresentative of the wider community and feelings of being an unpaid worker involving huge time commitments and workloads that could cause problems for service users with progressive illnesses.

Motivations for professional staff included personal and professional values; a desire to empower patients and carers; the initial driver came from external service directives to implement user involvement especially Clinical Governance Directives. Barriers for staff included that it was time-consuming; the perception that engaging with palliative care patients was too difficult and that patients had better things to do with their lives in the time they had left; organisational barriers and lack of leadership, for instance, relying on satisfaction surveys or only inviting a token service user to meetings and feelings of being threatened and viewing such activities as an add-on to their current roles.

A significant finding of the Sargeant et al (2007) study was that service user involvement in palliative care in a number of organisations is initiated and sustained by a few motivated individuals whether service users or staff and that as soon as they depart then the initiative struggles to continue. The study also states that the participants in their research were already contributing to service user involvement activities and therefore could potentially represent a biased group. The authors identified a need to seek to involve participants in research on service user involvement who have declined to contribute to other service user involvement activities.

The study by Sargeant et al (2007) poses questions about the criteria used for including and excluding participants and if there is such a thing as the ‘right kind of patient’ for taking part in service user involvement activities. The authors contended that there might be service users who are articulate, have access to technology, socially skilled, available during the day and English-speaking who may be over-represented in involvement activities. They also identified service users who attempt to take part but become disillusioned because they feel their views were not being taken into account. The voices of those service users with more experience may also be continually heard above everyone else because they have potentially become professionalised or have developed careers in service user involvement.

Boelk and Kramer (2012) attempted to advance the theory of family conflict at end of life by exploring the perceptions of 37 professionals through focus groups and 15 family carers through in-depth interviews that were experiencing conflict in the context of a non-profit hospice. The authors identified long-standing family issues, family dynamics and problems that can surface and possibly be exacerbated when faced by life-limiting illness. Boelk and Kramer (2012) also concluded that professional training and the hospice system may underestimate the complexities of some family situations including cruelties that may have taken place and the depth of dysfunction that can then influence the quality of care at the end of life. The notion of autonomy for people with a life-limiting illness and the ability to have control of their decision-making is complex. Boelk and Kramer (2012) consider that professionals are mistaken if they think that merely by working with a family to provide compassionate and quality care then a patient will die well.

It is reasonable to point out that it is not possible for carers to understand what it is like to be living with a life limiting illness. It could be said that it is not possible for any individual living with a life limiting illness to be able to say what other people with life limiting illnesses would be experiencing. Rhodes and Small (2000) identified the situation where individuals may have the same diseases but would experience and deal with those diseases in different ways. Richardson, MacLeod and Kent (2010) maintained that one size does not fit all in care of people with a life limiting illness. Cotterell (2006) also recognised that people living with a life limiting illness do not readily form themselves into groups that then try to influence issues that affect them or tackle inequalities. In a cross-sectional study involving respondents in England and Sweden, Fredriksson, Eriksson and Tritter (2018) considered that health systems needed to integrate an effective approach to Patient Public Involvement in individual treatment decisions and in shaping local health and social care priorities. The authors also considered that more work is needed to understand the desire to be involved and actually being involved.

A number of the studies included in this critique mention that their research was mainly exploring service user involvement from the point of view of people living with cancer and have therefore purposely recruited service users with cancer to take part. It is worth exploring this aspect and reflecting on the influence that such involvement could exert on the meaning and approaches towards service user involvement in palliative care.

2.4.3.1 Cancer service users

From my reading of the literature generally, a large proportion of research participants in studies about service user involvement in palliative care are people living with cancer. A number of studies (Forbat, Hubbard and Kearney, 2009; Daykin et al., 2010; Richardson, MacLeod and Kent, 2010; Cotterell et al., 2011) specifically mention that they wished to recruit service user participants who had cancer and sometimes recruited from cancer networks.

Cotterell (2006) explored the experience and needs of people mainly living with cancer but also other conditions. There were 25 service user participants involving nine face-to-face interviews, participant observation of service users in a hospice day centre and three service user group discussions. The author also established a Service User Research Advisory Group (SURAG) that included service users living with a life limiting illness and was attached to a palliative care organisation in the third sector. As well as helping to recruit participants for the research, members of the SURAG also developed the research questions, conducted interviews and facilitated focus groups and took part in data analysis and theme identifying sessions as well as being involved in drawing up the final themes.

There were 7 themes identified in Cotterell’s study: diagnosis (of a life-limiting illness); fear; anger/ frustration; grief (for a past life that has irrevocably changed following the diagnosis); relationships (that have changed with spouse, family members, friends); difference/individuality; independent/ dependent (being dependent on others such as family and professionals, for instance, as the life-limiting illness progresses and potential tensions with trying to maintain some independence).

> It was clear that for participants with non-cancer conditions, experiences of services were very different locally to those with a

> cancer diagnosis. Palliative care, mainly provided by a hospice and available to people with cancer, was reported on favourably but in contrast experience of other providers of care and support was patchy in quality. From these areas favourable comments were normally reserved for some individual professionals, day centres, or support groups. Palliative care was not commented on explicitly by participants with non-cancer conditions as they were either not aware of palliative care or not in receipt of it. (Cotterell 2006, p. 325-6).

Cotterell (2006) also commented on the way that service user participants with non-cancer conditions expressed feelings of being marginalised not only in their living conditions but also with the lack of support they felt they received and difficulties they faced in getting recognition of their needs that would then be acted on. Service user participants in this study who had cancer placed value on their ability to access hospice day centre facilities that were not necessarily available or known about by service users with non-cancer conditions.

The study by Cotterell (2006) also discovered that service users being able to maintain independence, keep control and have choice while living with a life limiting illness were viewed as key requirements. Choice also meant service users having an involvement in decisions on issues that affected them, feeling empowered in everyday life and being able to control the environment around them in terms of within relationships and the range of services and support that they needed

It can be inferred from the Cotterell (2006) findings that there is a potential inequality between service users living with cancer and those service users living with non-cancer conditions in terms of access to palliative care services. It could also be inferred from the findings that service users with cancer may have a stronger and more influential voice when it comes to service user involvement in palliative care as they have access to more facilities such as hospice day centres.

An interesting facet of the Cotterell (2006) study was the emotional aspect of the findings that emerged that the author considered was due to the involvement of service users as researchers and as members of the SURAG. The author considered that this enabled the findings from this study to be firmly embedded in the concerns of service users themselves.

The findings of a study by Cotterell et al (2011) build on the points that emerged from Cotterell’s 2006 study. It also indicates that service user involvement can lead to enhanced life opportunities for active service users with cancer. The focus of the interpretive and participatory qualitative research by Cotterell et al (2011) was to explore the impact of involvement on the lives of service users affected by cancer. There were 64 participants from across the UK who were already engaged in involvement activities in cancer services, palliative care and research. The data gathering involved eight focus groups involving service user group members plus nine face-to-face interviews with service users involved at local, national and regional levels.

The authors provided a definition of service user involvement in cancer care as follows:

> Activities undertaken by service users with a view to informing or influencing services, policy, planning and/or research based on their experience of being affected by cancer. (Cotterell et al, 2011, p. 161).

The Cotterell et al (2011) study also reflects on legislation that was current at the time of the research in 2010 and mentions the terms of the National Health Service (NHS) Act, 2006. This Act put a statutory requirement on NHS organisations to strategically embed service user/patient involvement in all their activities. This legislation has been superseded by further legislation covering the NHS as described in the introduction to this paper and includes the Health and Social Care Act 2012 that does not reiterate the importance of service user involvement in health care or palliative care nor was it included in subsequent amendments.

As mentioned earlier in this chapter, Payne et al (2005) considered that a top-down approach was not necessarily the answer to enabling effective service user involvement. However, Cotterell et al (2011) considered that the creation of formal structures in cancer care and the creation of the Cancer Partnership Project provided a framework that included financing for partnership working between professionals and service users and for influencing local cancer service development. It could be inferred that such partnership working in cancer services and the influence that this situation could exert on cancer care service provision could spread more broadly and also exert an influence on palliative care service provision generally. It could also potentially provide cancer service users with an influential presence in palliative care service provision and in policy-making in this area.

Further to the points mentioned above, Cotterell et al (2011) also mentioned the Department of Health's Cancer Reform Strategy (2007) that asserted the importance of service user involvement and that it was an essential component of cancer commissioning and delivery of services. It could be said therefore that legislation covering cancer care demonstrates how a top-down approach can sometimes be effective in enabling service user involvement in service provision. This legislative approach to service user involvement covering people living with other life limiting conditions and for palliative care service provision generally has not been evident in legislation following 2007.

Other findings by Cotterell et al (2011) included identifying three main themes for service user involvement in cancer care: expectations and motivations; positive impacts of involvement and, challenging impacts of involvement.

The authors reported that a number of service users became involved because of a bad experience with their own cancer care and they wanted to improve things for others. Other service users or people they knew had received very good care and they wanted to give something back while others expressed a desire to become involved in order to change things for the better. Expectations for some service users about what they could achieve at the start of their involvement were very limited and cautious and others experienced disappointment that their involvement did not appear to help change very much. For those participating in this research and receiving palliative care, their involvement in the cancer groups was seen as helping them deal with feelings of hopelessness. The involvement in cancer groups also seemed to offer service users a sense of belonging, of being able to contribute and helped to relieve feelings of isolation, depression and loneliness.

It could be argued that the issues discussed in this section suggest there is an opportunity and potential for learning from the way that cancer networks have emerged and developed over the last 10 to 15 years or so. This knowledge could potentially be used as a basis for enabling the development of service user groups and service user involvement in palliative care including those service users with non-cancer conditions. It should be noted however that service users with life-limiting illnesses other than cancer are not likely to have life-limiting illness networks that they could join in the same way that they are available for those with cancer.

It was unusual among the literature to find a research study such as Cotterell et al (2011) that involved service users living with life-limiting illnesses as members of the research team. The literature indicates there is an increasing awareness of the need to include service users in research activities around palliative and end of life care and also health subjects. The emphasis of that involvement, however, appears in the main to be as participants rather than formulating or leading a particular research project. On Arnstein's ladder (1969), the Cotterell et al (2011) study appeared to have moved into the top three rungs of the ladder labelled as 'Citizen Power.' My study is not concerned with exploring service user involvement in palliative care research. But when exploring literature on this subject and studies make claims of service user involvement in their research it would be useful to discern who is in control of the research project and who influences the ultimate conclusions in order to test the veracity of the claims.

There is also the possibility that the views and experiences of service users involved in cancer networks could have a disproportionate effect on service user involvement in palliative care. As discussed earlier in this section, differences in the experiences and expectations of service users with cancer and those with non-cancer conditions, particularly towards palliative care and what such care could offer, emerged in the findings of the study by Cotterell (2006). Whether cancer care groups and networks have continued to have substantial influence on service provision and policy making in palliative care in the years following the study by Cotterell et al (2011) could be the subject of other research.

Croft, Chowns and Beresford (2012) conducted a national survey of palliative care social workers in the UK and made a plea for moving beyond the rhetoric about service user involvement. They wished a start would be made in challenging the reality and extent to which service users are actually involved across a whole range of activities. The survey elicited responses from 20% of the specialist palliative care social workers contacted in 42 settings operating in the NHS and voluntary sector including 29 hospices across the UK. The authors discovered that service user involvement was mainly at a consultative level and in practice meant contributing to leaflets and offering feedback through such methods as questionnaires or informal discussions. It was not possible to assess from the survey how much notice was taken of feedback generated by service users by the organisations involved. Just under half of the respondents to the survey mentioned the existence of a service user group as being evidence of the development of service user involvement. The scope of involvement was found to be limited with very little occurring in education, planning or research for instance. The need for commitment of senior staff towards service user involvement was recognised but staff faced difficulties in achieving it due to heavy workloads and cutbacks even though it was acknowledged that such involvement had benefits. This also indicates how external forces such as funding cuts in public services can potentially have an impact on the ability of service user involvement to be implemented effectively in hospices and in other public and charitable service organisations.

2.5 Summary

To recap, three main themes emerged from the critique of studies in Appendix 4. These are: power and control**,** relationships in palliative care and debates around who is involved in service user involvement.

I provided an in-depth review of the Payne et al (2005) scoping review and while it did not make claims to be exhaustive, it had a broad search strategy that took in service user involvement from other areas including health, maternity care and psychiatry, for instance as well as collection of primary data. The studies included in the critique explored aspects of service user involvement in palliative care using various methodological approaches and participants included service users (patients), professionals (staff) and family carers plus four systematic reviews.

Many of the studies pointed out the complexities of people’s lives when they have a life limiting illness. These complexities can affect the personal perspectives of a service user about who they are, for instance, and what they regard as normalcy in their lives as they deal with the changes that their bodies are undergoing. Further complexities emerge as people around the service user with a life limiting illness can start to assume different roles that can affect family dynamics, for instance, if a family member becomes a carer (Sargeant et al., 2010). Whether family carers should be involved or not in studies about service user involvement in palliative care or health care or in other areas is open to debate. It would partly depend on the focus and aims of the research. The inclusion of family members in research who may also be carers occurred in a number of studies (Boelk and Kramer, 2012; Etkind et al, 2018; Evans et al, 2003; Francois et al, 2017; Lee et al, 2009). Other studies considered it important to only explore the views and perspectives of service users/patients in their studies (Beresford and Branfield, 2006; Carter et al, 2004; Cotterell, 2006; Cotterell et al, 2011; Etkind et al, 2018; Gauthier and Swigart, 2003; Karnilowicz 2011; Lee et al, 2009; McCormick and Conley, 1995; Richardson, MacLeod and Kent, 2010; Woods, Beaver and Luker, 2000).

Arnstein (1969) was concerned about the relationship between the powerless and the powerful in relation to citizen participation and concluded that any participation without redistributing power was a frustration for those who were powerless. Arnstein also recognised that the powerless appeared to view the powerful as representing a permanent and immovable system. Service users being seduced into “wanting what the system wants them to want” (Richardson, MacLeod and Kent, 2010, p.135) can further compound the situation. An article published in 2007 on Public Patient Involvement in the NHS concurs with the findings of Payne et al (2005). The article talks about the “proliferation of involvement sometimes at the expense of genuine influence” (Brearley, 2007, p. 227). The article goes on to identify four problems around involvement in the NHS that hinder rather than enable influence and accountability: victims and perpetrators (patient representatives feeling marginalised and powerless operating within structures devised by others; organisations feeling threatened by any proactive activities initiated by service users); involving everyone but listening to no-one plus involvement at the expense of accountability and asks where is the national voice. Brearley refers to the NHS Centre for Involvement in the 2007 article that no longer exists. She also mentions National Voices that does still exist but she questioned whether as a national voice for the voluntary sector in policy making it could be a national voice for patients and citizens at the same time. Whether there are any national voices operating on behalf of service users in the NHS is one aspect of involvement, but the issues about influence when service users get involved in NHS structures is a subject area for research that is probably still needed. The same could be said about involvement in palliative care but any national voices or local voices acting on behalf of patients, apart from those attached to voluntary and charitable organisations, appear to be thin on the ground.

Daykin et al (2010) identified power dynamics between service users and professionals but also identified power dynamics between different professions and between different professionals in health all of which could influence the approach adopted towards service user involvement. Aspinal et al (2006) expounded on the importance of co-ordination and continuity of care between different care services for evaluating care towards the end of life and the authors considered it should be included in future research in this area.

The future of service user involvement in healthcare and where power and control resided was a subject commented on by Rhodes and Small (2000). These authors identified two possible approaches towards service users in the health system: either a service user could be regarded as a consumer and so remain a passive object of service provision or a service user could be regarded as someone who was involved in decision-making. The conditions for empowering service users in healthcare, therefore, could only happen if service users moved on from passivity to being active subjects..

Further to this, the use of terminology to describe service users in healthcare and palliative care, judging from literature published around 2008/9 onwards, has seen an increase in use in academic studies and legislation of the words consumer and/or client. This increase might imply there is an actual or preferred desire among policy makers, for instance, for service users to remain as passive consumers of health and/or palliative care services rather than be empowered.

The relationships theme highlighted the importance of the relationship between professionals/staff and service users in palliative care (Haarsma et al, 2015; Sargeant et al, 2007). If any tensions were identified, these could be contributory factors for building barriers to effective service user involvement. Better communication between service users and professionals in palliative care to enable effective relationships between these two groups was identified as an issue (Cotterell 2006; Evans et al, 2003; Johnston and Smith, 2006; Sergeant et al 2007). Relationships between patients and their family carers were also seen as important in healthcare and palliative care especially where there are any conflicts between them. Aspinal et al (2006) highlighted differences between professionals/staff, patients and family towards what is important to them at the end of life. Family dynamics, conflict and dysfunction were seen as contributing influences on quality of care at the end of life (Boelk and Kramer, 2012). In this kind of scenario, the relationship between the service user/patient and professionals/staff would be important for helping to resolve any issues. A further problem to this situation could be if any power dynamics were being played out between service users and professionals/staff (Daykin et al, 2010) or complexities in decision-making between service users/patients and professionals/staff (Gauthier and Swigart, 2003). The need for professionals/staff to create a psychosocial cultural environment best suited to enabling a positive self-identity for service users/patients and for the relationship between the two groups to be collaborative and empowering was considered important by Karnilowicz, 2011.

The third theme covered debates around who is involved in service user involvement in palliative care and complements aspects that emerged in the first two themes. A notable aspect that emerged from the literature concerned the number of studies that involved predominantly service users with cancer as participants. No studies emerged from the literature that explored the influence of cancer groups, non-cancer groups or other groups on healthcare, palliative care or service user involvement in palliative care and so could provide the background to topics for further research.

2.6 Chapter conclusion

In the introduction to this chapter, I described the focus of my study as being concerned with exploring the perspectives and understandings of service users receiving palliative care and of staff providing that care towards service user involvement in palliative care. This chapter has provided a review of the literature in this topic area and provided an opportunity to explore concepts, issues and debates that form the academic basis of my study.

Sargeant et al (2007) regarded the participation of family carers in their study as very important and contended that carers should be routinely involved in palliative care research. Aspinal et al (2006) identified differences between staff, patients and family carers in their study as to what their priorities were at the end of life and Boelk and Kramer (2012) identified how family complexity and conflict can emerge when a family member is moving towards the end of life. I considered that while exploring complexities around family carers and their relationships with a service user/patient with a life-limiting illness or with professionals/staff is important for studies researching palliative care towards the end of life, this was not a focus for my research and could potentially obscure the findings. I therefore decided that service users/patients and staff would be the focus for part of my data collection activities.

I believe that including an exploration of the context within which service user involvement is being carried out can enhance findings and theorisation around service user involvement in palliative care. The way that such involvement is described in policy and the literature will position “patients as consumers, citizens, partners and co-researchers depending on context and ideological drivers” (Forbat, Hubbard and Kearney, 2009, p. 2549)**.** I did not uncover any studies in the literature that used a case study approach at a hospice that also included an exploration of the internal operation and management of the hospice and its culture or external pressures that could have impacted on decision-making such as financial considerations. There may have been valid reasons for this. For example, ethical considerations or unwillingness of hospices to take part in such studies or researchers may have considered it was not relevant for their particular study.

In times of financial constraints and cuts in public services in the UK coupled with increases in the population and the increasing longevity of people with life-limiting illnesses, it is conceivable that the charitable and the private sector may become more important in providing palliative care services in the future. There are implications in such a move for service user involvement generally in all services as well as palliative care. It is conceivable, for instance, that cancer charities that Murray and Sheikh (2008) identified as being influential because of their support of many hospices and cancer outreach programmes could become more influential in driving the palliative care agenda and service user involvement in a time of austerity.

The aim of my research is to consider whether service user involvement is known about or understood by service users and staff and whether variations in perspectives between them can cause misunderstandings or tensions over the care provided and whether any lack of clarity has consequences for palliative care service provision. This service provision could mean on an individual basis where service users have an opportunity to influence their own palliative care or it could mean a situation where service users have input into and influence on local service provision and on wider policy and decision-making in palliative care.

I therefore decided that it was important to use an appropriate method for my study in order to explore all the complexities that surround service user involvement in palliative care. I considered that a single case study approach would be appropriate to enable theorisation from the findings to be placed in context. Reflexivity would also allow for sensitivity on my part as the researcher during the data collection process and for the drawing out of potentially hidden meanings behind the data collected. A description of the methods used in my study is provided in Chapter Four.

2.6.1 Research question

Finally, based on my findings in this literature review, my research question is as follows:

What are the perspectives of professional staff and service users towards service user involvement in palliative care within the context of organisational and cultural change in a UK independent hospice?

The next chapter provides an analysis of methodological approaches in research.

CHAPTER THREE: METHODOLOGY

3.1 Introduction

This chapter presents my reasons for choosing a qualitative approach for my study and explores a range of qualitative approaches in order to provide a rationale most suited to answering my research question.

This chapter in particular presents a rationale for using case study in more detail with reference to the points mentioned in Chapter One. I consider the strengths and weaknesses of this approach and its appropriateness for my study.

3.2 Philosophical underpinnings of my research

Silverman (2010) provides a useful definition of methodology and what it constitutes:

> A *methodology* refers to the choices we make about cases to study, methods of data gathering, forms of data analysis etc in planning and executing a research study. So our methodology defines how one will go about studying any phenomenon. In social research, methodologies may be defined very broadly (e.g. qualitative or quantitative) or more narrowly (e.g. grounded theory or conversation analysis). Like theories, methodologies cannot be true or false, only more or less useful. (Silverman, 2010, p. 110).

This section sets out my methodological journey and explains how I decided on the approach that would be appropriate for addressing my research question.

Qualitative research is concerned with the way the world is understood by people and how their lives, behaviour and interactions express this understanding. It also concerns their perspectives about their own worlds and the meanings expressed for instance, via personal narratives and the use of language (Creswell, 2003; Schwandt, 2007; Silverman, 2010; Denzin and

Lincoln, 2011). Qualitative methodologies comprise many methods and practices and cross several disciplines; as such, they can mean “many things to many people” (Denzin and Lincoln, 2005a, p.10). In deciding which research approaches that might be appropriate to address my research question and understand perspectives and experiences of service user involvement in palliative care, I took account of the view that:

> Qualitative research does not veer towards one single methodological practice, is difficult to define clearly and has no theory or paradigm that is distinctly its own. (Denzin and Lincoln, 2005a, p. 6-7).

Denzin and Lincoln are regarded as key authorities on qualitative research and they view qualitative researchers as philosophers “guided by highly abstract principles” (Denzin and Lincoln, 2011, p.12). They also state that these principles include beliefs about ontology, that is, the nature of human beings and the nature of reality and epistemology, that is, the relationship between the researcher and what is known and how knowledge is gleaned about the world and the relationship between “the inquirer and the known” (Denzin and Lincoln, 2011, p.12) and methodology. The authors propose that these beliefs shape the path that the qualitative researcher takes, influences how the researcher views the world and how they act on those views.

3.3 Paradigms in qualitative research

Epistemology, ontology and methodology in qualitative research all are bound within a paradigm (Kuhn, 1962; Silverman, 2010; Denzin and Lincoln, 2011). The main interpretive paradigms that shape qualitative research include **positivism** that had its origins in quantitative research and is a philosophical system where every rationally justifiable assertion can be scientifically verified or is capable of logical or mathematical proof (Denzin and Lincoln, 2011; Jupp, 2006). A **post-positivist** approach questions the possibility of objectivity recognising that the knowledge and values of the researcher can influence what is observed, it requires context, contains the belief that context-free experimental design is not sufficient and wishes to seek new meanings (Denzin and Lincoln, 2011). A **constructivist-interpretive** approach assumes that individuals construct their own realities providing multiple interpretations (Denzin and Lincoln, 2011) while **critical theory** suggests that knowledge is not value-free and bias should be indicated (Denzin and Lincoln, 2011). The rationalist, structuralist viewpoint of an objectified reality is questioned under a **feminist post-structuralism** approach and where relationships between language, subjectivity and power-relations are explored as they impact upon gender in particular (Spender, 1980; Lather, 1992; Lather, 2006; Denzin and Lincoln, 2011).

Philosophical ideas and approaches underpinning qualitative research have developed over time and continue to evolve. Consequently, opinions and views on definitions and concepts within the different paradigms vary. Indeed, Guba and Lincoln (1994) contend that qualitative and quantitative methods can be used with any research paradigm.

> Questions of method are secondary to questions of paradigm, which we define as the basic belief system or worldview that guides the investigator, not only in choices of method but in ontologically and epistemologically fundamental ways. (Guba and Lincoln, 1994, p. 105).

The authors of the quotation above admit that they have a particular commitment to constructivism and therefore their analysis of paradigms should be viewed with that fact in mind. It is the choice of paradigm that “sets down the intent, motivation and expectations for a piece of research” (Mackenzie and Knipe, 2006, p.193).

A bibliometric analysis into methodologies used in palliative care research conducted by Payne et al (2008) and covering the years 1997 – 2006 discovered that there was a diversity of epistemological and theoretical frameworks with no single paradigm emerging. The authors considered that this diversity of approaches could help enrich what is understood about dying. Addington-Hall et al (2007) also considered that palliative care research required a multi-disciplinary approach that draws on an array of research methodologies and should include researchers from different professional and academic backgrounds carrying out the studies. In this respect, my academic background is in politics and my professional background is in communications covering journalism, editing, devising and managing social campaigns for example while working in the business, public and voluntary sectors in the UK. This does not mean that the findings and theorisation of my research will be more or less useful than any other research conducted on service user involvement in palliative care but it has the potential to further enrich understanding as mentioned by Payne et al (2008).

Pressure for service user involvement in palliative care research is identified by Beresford et al (2007) who name two key sources for this pressure: service user movements especially the disabled movement and “mainstream research, government and the service system” (Beresford et al 2007 p35). The authors contend that the pressure from service user movements has encouraged new approaches that place emphasis on equal relationships between research, researchers and participants and also linked with rights and demands of service users as opposed to research being concerned with developing new knowledge.

Beresford et al (2007) also considered palliative care to be slow in developing service user involvement in policy-making compared to other areas in health. The authors make the point that there appears to be a feeling among health professionals that patients receiving healthcare are routinely involved in their care because of commitments to listen to patients and act on their wishes. However, “offering a voice is not the same as accessing people’s own voices” (Beresford et al, 2007, p. 32) and the authors believe that while palliative care may contain a desire to provide holistic care, it has tended to be medically led. The authors point to what they describe as a “significantly pessimistic strand in academic/research discussions of user involvement in palliative care” (Beresford et al, 2007) that was apparent at the time they were writing. There does not appear to have been much further research into this topic area from 2007 to the present day that has emerged from searches of the literature. In order to access people’s own wishes that Beresford et al (2007) considered has been lacking in palliative care research, it is necessary to select a methodological approach that will enable such access to be realised.

Accessing the voices and perspectives of people receiving and providing palliative care as part of the case study approach forms a major part of my research in order to provide answers to my research question. Addressing service user involvement in palliative care from the perspectives and understandings of service users and staff potentially involves issues that could be unrelated to care or service delivery (Pollard and Evans, 2013).

3.3.1 Positivist and post-positivist

As mentioned previously, positivist and post-positivist research have most commonly been aligned with quantitative methods of data collection and analysis. Post-positivism can be aligned in some sense with the constructivist paradigm and post-positivists tend to see the world as ambiguous, variable and multiple in its realities - "what might be the truth for one person or cultural group may not be the "truth" for another" (O’Leary, 2004, p.6). This theory also suggests that “post-positivism is intuitive and holistic, inductive and exploratory with findings that are qualitative in nature” (O’Leary, 2004, p.6-7). I did not feel that either of these approaches would enable me to fully address my research question. Discovering the perspectives and understandings of service users receiving palliative care towards service user involvement is an important part of my research and that requires accessing the views of service users as mentioned earlier in this chapter by Beresford et al (2007).

3.3.2 Constructivist-interpretive

Proponents of the constructivist-interpretive approach aim to understand the complex world of lived experience from the point of view of those who are living it. The constructivist-interpretivist researcher tends to rely upon the "participants' views of the situation being studied" (Creswell, 2003 p8) and recognises the impact on the research of their own background and experiences. Constructivists do not generally begin with a theory (as with post-positivists) rather they "generate or inductively develop a theory or pattern of meanings" (Creswell, 2003, p. 9) throughout the research process.

The constructivist researcher is most likely to rely on qualitative data collection methods and analysis or a combination of both qualitative and quantitative methods (mixed methods).

Interpretive and constructivist approaches featured in a number of the studies reviewed in Chapter Two (Gauthier and Swigart, 2003; Aspinal et al., 2006; Cotterell 2006; Sargeant et al., 2007; Forbat, Hubbard and Kearney, 2009; Daykin et al., 2010; Richardson, MacLeod and Kent, 2010; Cotterell et al 2011). In order to answer my research question I feel it is important to explore the views of service users as individuals who could help shape my research rather than solely having a passive role. I am interested in exploring the complexities of the service user experience as it relates to service user involvement in palliative care but not the service users' lived experience of dying. A constructivist approach could offer insights into the topic of my study but I feel it does not provide the means to explore in-depth the reasons why, for example, decisions taken by professionals can affect service user involvement but service users may have no real involvement in making those decisions. For example, there may be external factors outside of the control of service users, staff or management in organisations but which affect the way that the organisations develop. These factors can include social-political-economic influences such as austerity measures in the UK over the last 10 years that were introduced by the government as its way of dealing with the UK's deficit. The austerity measures included cuts in grants, for example, that were available to the charitable sector that also impacted hospices that was discussed in Chapter One of this thesis. Although independent charitable hospices generally raise around two-thirds of their necessary funding, the government provided around a third of funding through grants. Hospices had to consider acting in order to deal with a potential shortfall in their budgets due to governmental decisions and would therefore have influenced decision-making by hospice managements as regards their priorities and future organisational structures. Such decisions by hospice managements may not include involvement of service users in those decisions even though the decisions would have an impact on service users. A constructivist approach to my research, therefore, may provide some answers to my research question but I consider that it did not enable enough consideration of the context or the potential of external influences to impact on service user involvement in palliative care.

3.3.3 Phenomenology and hermeneutics

The constructivist-interpretive approach grew out of phenomenology and hermeneutics. Phenomenology arose from Germany before the First World War and was developed initially by Edmund Husserl (Kockelmans, 1994). Husserl wanted to explore the structure of human consciousness and the way it works based on an assumption that the world we live in is created by consciousness. He believed that this process requires reflection and does not proceed from collecting large amounts of data and generating a general theory from that data as in a scientific approach.

Phenomenology is used to help illuminate the specific and identify phenomena through how they are perceived by actors in a situation and is an approach used to emphasise personal perspectives and interpretation (Rasmussen, 2010; Belousov, 2016). The word phenomenology can refer to "a research method, a philosophy and an approach" (Dowling, 2004, p.31).

Hermeneutics assumes that people experience the world through language providing understanding and knowledge and was developed by Martin Heidegger (Dowling, 2004, p.31). Husserl focused on the nature of knowledge (epistemology) while Heidegger concentrated on the nature of existence (ontology). Hermeneutics guided by Heidegger is sometimes referred to as "interpretive phenomenology" (Dowling, 2004, p.31). A second approach, hermeneutic phenomenology was developed by Gadamer (Greatrex-White 2008; Fagerberg and Norberg, 2009) and a third approach, developed by the Dutch School involved the combination of descriptive and interpretive phenomenology (Dowling, 2004).

Phenomenology and hermeneutics featured in the study by Richardson, MacLeod and Kent (2010) that was reviewed in Chapter Two of this thesis. This approach enabled the authors to delve into the lived experiences of service users attending an outpatient clinic at a single hospice and to become immersed in their daily lives. The authors produced theories from the data collected about the feelings of disbelief and powerlessness felt by service user participants that were associated with having life-limiting illnesses. The authors seemed to imply that power, in their view, needed to be given to service users by staff but did not then delve into the possible reasons that may prevent staff from doing so. For example, the hospice management or code of conduct may guide the behavior and professional approach of staff as may other professional standards of conduct. The study by Richardson, MacLeod and Kent (2010) also assumed that staff and service users could become partners in care by a change in attitude on their parts rather than needing any input from the hospice itself. The ability to delve into the lived experiences of service users with life-limiting illnesses can provide rich data for enhancing knowledge and for theorising about palliative care generally. But what this approach seemed to lack for the purposes of my study was its inability to allow for delving into the organisational structure of the hospice to examine why the circumstances had developed in the way that they had. I considered that in order to enact the changes the authors were espousing required more information than could be provided by service users and staff alone and needed context.

3.3.4 Grounded theory

Glaser and Strauss (1967) are generally acknowledged in the literature as the founders of grounded theory.

> Grounded theory is a qualitative strategy of inquiry in which the researcher derives a general, abstract theory of process, action, or interaction grounded in the views of participants in a study. (Cresswell, 2009, p.13 and 229).

This description indicates differences between grounded theory and Husserl's phenomenological hermeneutic approach described earlier in this section. Glaser and Strauss believed that the discovery of theory from data "provides us with relevant predictions, explanations, interpretations and applications" (Glaser and Strauss, 1967 p1). The authors believed that they had "ensured the close correspondence of our theory to the realities of terminal care" (Glaser and Strauss, 1967, p. 240) and also believed that the categories they assigned to the data, such as: "death expectations, nothing more to do, lingering and social loss designate general properties of dying patients that unquestionably are vividly sensitizing or meaningful to hospital personnel" (Glaser and Strauss, 1967, p. 240/241).

Over the years following publication of their 1967 work, it has been claimed that Glaser generally remained true to classic grounded theory while Strauss, in conjunction with Corbin, reformulated and developed the classic approach (Heath and Cowley, 2004; Strauss and Corbin, 1998; Corbin and Strauss, 2008).

> The procedures of grounded theory are designed to develop a well-integrated set of concepts that provide a thorough theoretical explanation of social phenomena under study. A grounded theory should explain as well as describe. (Corbin and Strauss, 1990, p. 5).

Charmaz (2014) considers that grounded theory is an iterative method that provides systematic but also flexible ways for gathering and analysing qualitative data and for constructing theories from that data. The author posited the view that a grounded theory approach enables the researcher to interact with their data by moving back and forth between data collection and data analysis. Each of these activities helps to inform and develop the other and by so doing enables the researcher to enhance the abstract level of the analysis (Denzin and Lincoln, 2011).

Charmaz has also written about the "chronically ill" (Charmaz, 1983, p.168) as she phrased it and the loss of self. She lamented the medical approach to the issue of pain and considered that it missed out other experiences that a person could be going through. These other experiences related to people affected by long-term ill health experiencing a wider loss of self that could include leading restricted lives, social isolation as well as a feeling of being a burden to others.

Charmaz (2008) also considered that a social constructionist approach enabled what she referred to as the ‘what,’ ‘how’ and ‘why’ questions to be addressed. She contends that ‘what’ and ‘how’ questions deal with what people construct and how the social construction process develops but she also considered that on their own these two questions do not answer the why question. Charmaz believed that linking grounded theory with constructionism enabled the researcher to ask questions about why some things were happening while maintaining a perspective on the complexity of social life.

Gauthier and Swigart (2003) used constructivist grounded theory in their study that was reviewed in Chapter Two of this thesis. The emphasis in this study was on the lived experience of the participants and it provided some useful insights. For example, the authors discovered that no matter what may appear to be the mundanities of decision-making, when a service user was coming towards the end of their lives those decisions were important to them and they regarded it as important that they actively took them rather than someone else doing so on their behalf.

A constructionist grounded theory was worth consideration as an approach for my own study. However, I was not convinced about the potential of this approach to enable exploration of all the ‘why’ questions (Charmaz, 2008) particularly those related to the context and the impact that context could have on service user involvement.

The topic of my research concerns service user involvement in palliative care and perspectives on such involvement from service users receiving palliative care and staff providing palliative care at a UK independent hospice. Therefore, as a qualitative study it would necessitate delving into the understandings and perspectives of the lived experience of these service users in order to glean their understandings and uncover new findings. The paradigms and approaches described in this section all had the potential to be appropriate for my study. The problem I had with them was the omission of context. So a further consideration was to elicit an approach that could enable context to form part of my study and be an aid to theorising. This led me to reflect on the potential of case study to enable this and is discussed in the next section.

3.4 Case study

According to Yin (2012), case study research enables an in-depth understanding of a single or small number of cases that are set in real-world contexts. He also suggests that this kind of research assumes that exploring the context and other complex conditions related to the case(s) are integral to understanding the case(s) and aims at analytical rather than empirical generalisation. Hammersley and Gomm (2009) point out that case study refers to research that explores a few cases, often only one, but in great depth and that where a case study is concerned with developing theoretical ideas then it is likely to be detailed and open-ended. The authors also point out that some commentators view case study as more than a method but rather as a research paradigm of itself.

Methodological issues have arisen around the purpose and nature of case study and have been open to debate. As Hammersley, Gomm and Foster (2009) point out, these debates cover the generalisability of this approach; causal or narrative analysis where causal processes operating in the real world can be analysed; the theory around it involving either a case being a unique pattern of parts that can only be understood as a whole or include an explanation of what is happening in a case in terms of its wider societal context, although there is a general assumption that case study always includes the wider context in some degree; authenticity and authority where case study can potentially capture the uniqueness of a person, situation or group and be represented in an authentic way rather than necessarily be generalisable to a wider population. Eisenhardt (1989) stated that any theories derived from case study research can be idiosyncratic in a single case study approach and therefore it is not always possible to generalise the theories that emerge. Yin (2012) argues that the aim of a case study in qualitative research is to provide analytical rather than statistical generalisations and the intention is to generate and extend concepts.

I was drawn to case study as an approach for my research because of its ability to capture the uniqueness of a situation and include the wider societal context. I believed these to be important aspects in relation to the hospice involved in my study. As mentioned previously, my research was not focused on perspectives about coming towards the end of life and the care provided but rather on service user involvement in palliative care. I considered that the wider context including the operation and management of the hospice would have an influence on its approaches to such involvement. I also considered that external socio-political-economic factors would influence decisions taken by the hospice management that could also, potentially, impact on its approaches to service user involvement.

A range of perspectives involving service users, staff and the CEO at the hospice on service user involvement are integral components of the case study design used in my research. I took the decision not to include family carers in my study after consideration of the findings elicited by a number of studies on their role in the care process that were critiqued in Chapter Two. The possibility for family conflict and tensions (Boelk and Kramer, 2012) plus balance of power and control issues (Gauthier and Swigart, 2003; Carter et al, 2004; Beresford and Branfield, 2006; Lee et al, 2009; Richardson, Macleod and Kent, 2010; Karnilowicz, 2011; Haarsma et al., 2015) that could occur between a family carer, with the family member receiving care and with professional staff could potentially move my research away from its core focus. Further, in a systematic review, Etkind et al (2018) discovered that the presence and support of the family had a strong influence that may supersede the personal wishes of an older person.

I believed that using thematic analysis of the interview data enabled themes to be identified that enhanced the potential for generalisability and transferability of the findings. The combination of service user and staff perspectives and identification of internal and external factors enabled me to pose questions and discuss possible future implications for my topic area that are presented in Chapters Six and Seven.

3.4.1 Case study design

A framework for designing case studies involving three steps is suggested by Yin (2012). The author suggests that the first step is to define the case that could be a person or an organisation or an event among others where the case and its context may overlap but where the case would serve as the main unit of research. A second step is to consider whether the case study will involve one or multiple cases and the third step is to consider whether to use theory to assist with developing the research question, for instance or to help with defining the most appropriate data to be gathered. Yin (2012) also acknowledges that the case study method is still evolving and needs new contributions to improve its design and implementation and that this presents a challenge for those pursuing a case study approach.

Walshe et al (2004) consider that there are situations in palliative care research where case study is an appropriate approach for exploring complex situations, also when the context of a study is important and when the design needs to be flexible.

> Using case study strategies rigorously and appropriately can contribute to knowledge in a way which is sensitive to the complex, context-dependent and multi-professional nature of palliative care. (Walshe et al., 2004, p. 677).

Walsh et al (2012) discovered that evaluations in palliative care research are difficult due to five factors: 1) services can be variable and have different components; 2) the deterioration of service users involved in palliative care research can cause problems with retention or follow-up; 3) finding a comparator group can be challenging; 4) quantitative experimental approaches do not provide information on the relationship between cause and effect, and 5) case studies can potentially focus on one aspect of a complex system rather than exploring the relationships between all the aspects that were involved (Walshe, 2011).

Collis and Hussey (2014) present two types of approaches to carrying out a single case study: an exploratory approach where there is little or no theory or a lack of knowledge, and an opportunist approach where an opportunity has arisen due to the researcher having access to an organisation or person. The authors state that although an opportunist approach may be limited to a few aspects of an organisation's modus operandi, the results can still be illuminating. The hospice involved in my study underwent significant organisational and cultural changes during the course of my fieldwork. In order to understand the impact of these changes and their influence on service user involvement I felt that studying the modus operandi of the hospice and the organisational changes would provide further useful answers to my research question.

3.4.2 Benefits and limitations of case study methodology

A case study is a strategy that seeks to understand the dynamics that are at play in complex settings and, as previously mentioned, can involve single or multiple settings (Eisenhardt, 1989; Hammersley, Gomm and Foster, 2009; Collis and Hussey, 2014; Yin, 2012). A case study approach can also use different levels of analysis within a single study (Eisenhardt, 1989; Yin, 2012). The strengths that a case study approach brings include the likelihood of generating “novel theory” (Eisenhardt, 1989, p. 546) and “creative insight often arises through the juxtaposition of contradictory or paradoxical evidence” (Eisenhardt, 1989 p. 547). Eisenhardt (1989) notes that the theories arising from case study research are likely to be empirically valid as from the very start of a research project, researchers need to answer to the data and the evidence generated. Donmoyer (2009) notes three advantages of case studies: first, the ability to go to places where others might not be able to access; second, enable others to view the world through the researcher's eyes and perhaps see things that might otherwise be missed as well as add to theoretical understanding with nuance and subtlety and third, decrease defensiveness - “the vicarious experience provided by case studies might be preferable to direct experience: vicarious experience is less likely to produce defensiveness and resistance to learning” (Donmoyer, 2009, p. 22). This author also maintained that schema theory played a role in the generalisability of case studies. Schema Theory is used in psychology and cognitive sciences to describe a pattern of thought and behavior that identifies categories of information and the relationship between them. A schema theory approach to generalisability sees the purpose of research “to expand the range of interpretations available to the research consumer” (Donmoyer, 2009, p. 19).

Eisenhardt (1989) also notes that a limitation of a case study approach is the amount of rich data that can be generated. Trying to include too much can lead to overly complex analysis with the end result lacking in focus. In quantitative research, the researcher may use quantitative methods such as regression analysis for instance, in order to help assess the most important relationships between variables (Draper and Smith, 1998). Qualitative research, however, may include a large volume of data that cannot be reduced in such a straightforward manner. Sale, Lohfeld and Brazil (2002) discuss the qualitative-quantitative debate in the context of using both these approaches for mixed-methods research in healthcare and describe the differences in approach as well as the impact they have on research findings. For example, the authors considered that a quantitative researcher would use a factory record as being indicative of what actually occurs in the workplace, whereas a qualitative researcher might see it as just one of the ways that people in a factory view their work environment. Another example the authors used was surgical waiting lists. For a quantitative researcher, the list is like a “bus queue” (Sale, Lohfeld and Brazil, 2002, p.47) where people are moved around the list or taken off it based on the urgency of the surgery. For a qualitative researcher, understanding the meaning of the list would involve determining how the list was organised and managed by the people that created it. I was mindful therefore when selecting a single case study approach for my research that exploring official public records and other documentation around the hospice was one aspect for providing answers to my research question. But more than this, it would enable analysis of the motivations of those who were shaping the organisational changes at the hospice.

Walshe (2011) discusses the benefits and limitations of case study design and evaluation in palliative care research. A limitation the author identified includes the possibility of difficulties in generalising from the findings due to bias or subjectivity, but they considered that a rigorous approach including a clear audit trail of information could enhance the case study method. Another limitation is the potential unwillingness of organisations to participate in case study research perhaps due to ethical concerns, for example a potential breach of confidentiality.

It is useful at this point to briefly look at a study by Payne et al (2007) where the authors reviewed three case studies that were conducted in end of life care and assess whether the methodological approaches adopted by these studies might be appropriate for my research.

Payne et al (2007) examined case study research methods in three studies on end of life care. Study 1 (Payne et al., 2007) was concerned with exploring the extent to which community hospitals were involved in providing palliative and end of life care to older people with cancer and non-malignant diseases. Study 2 (Field et al., 2006) examined the purpose and delivery of adult bereavement support services by hospices to older people and the views of those who did or did not use those services. Study 3 (Rolls and Payne, 2004) examined the nature of childhood bereavement services in the UK and why people used them and the benefits they derived from doing so. The case study designs in all three studies were based on the process model of Yin (2003) and each study sought to examine the dynamic nature of the services they were exploring and “how they fitted within their organisational, social and cultural contexts” (Payne et al., 2007, p.240)

Payne et al (2007) claim that case studies offer a rigorous and systematic approach and are useful additions to the qualitative “toolbox of evaluative methods” (Payne et al., 2007, p.242). The authors state that case study methods can enable “complex and multi-faceted processes to be understood in context” (Payne et al., 2007, p.242) as also proclaimed by Walshe et al (2004). They claim this approach also enabled the investigation of how different service models can arise in certain situations which I regard as particularly useful if a case study is being conducted with an organisation that undergoes significant organisational changes at the same time that a piece of research is being conducted as with my study. There is an opportunity with a case study approach to identify where changes are being made, the reasons for those changes and the potential impact they make by examining and comparing organisational documentation, for instance, over time.

Payne et al (2007) point out the difficulties that can emerge while conducting case study research in palliative care. These need to be borne in mind by researchers in this area and are relevant to my own study. For instance, because analysis may be based on only one or two cases then ethical considerations such as confidentiality and anonymity in the presentation of findings need to be paramount. Lawton (2000) faced this situation when conducting an ethnographic study while working for six months in one hospice. Nonetheless, she managed to write up the findings without it being possible to identify the hospice that was being studied. Payne et al (2007) point out the important role of the researcher and the need for reflexivity in the analysis and interpretation of the findings. I would suggest these are also important for fulfilling ethical requirements of confidentiality when presenting the findings.

The conclusions provided by the three studies mentioned in this section and the review of them by Payne et al (2007) provided some useful pointers for my study. The review authors conclude that case study methods could be empowering for participants due to placing value on their experiences and how their work contributes to an organisation but could also be challenging by revealing conflicts and tensions. A case study approach therefore offered one way for prompting new evidence and enabling theories to emerge on the topic of my research that had not been apparent in the literature.

What I feel is lacking in the studies mentioned in the Payne et al (2007) review is that the terms of reference they used for providing context appeared to only cover the participants within the context of a hospice, for example, or across hospices but not the context within which the hospices themselves operated. For example, the external social-political-economic contexts that the hospices operated in and that may have had an impact on the extent to which the hospices were able to provide services to service users or have enough resources to recruit or maintain necessary staffing levels. There is also the question of management style within the hospices and the kind of culture that was engendered as a result. I feel that these aspects of context are important as without giving them consideration, I believe only a partial story can emerge. There also seemed to be an unquestioning and implicit feeling within the three studies and the review paper by Payne et al (2007) that hospices naturally always carried out best practice. I proposed that looking at context more widely particularly in regard to hospices was important for my study at a time of fluctuating political and economic dynamics in the UK within which hospices have to function and which could provide some new findings and theorising on the topic of my study. I believed that the impact of UK governmental policies such as austerity measures on the financing of health and social care that includes palliative and end of life care and hospices and the ability of service users to be involved are considerations that needed to be included within the scope of my research. Hospices do not operate in isolation from their external contexts.

3.4.3 Case study and service user involvement in palliative care

During the literature search for my study, there was an absence of case study approaches for research into hospice care or a hospice’s role in facilitating or controlling service user involvement in palliative care. One exception is the ethnographic study by Lawton (2000) mentioned earlier in this chapter. Lawton described the personal emotional impact that spending time in a hospice had, including processing the deaths of service users whom she had got to know over the six months of the research as well as such things as the visible signs of physical decay in people along with lethargy and despondency of service users. Lawton (2000) recognised the importance of the hospice day centre in the lives of service users who attended it and its role in helping them to deal with loneliness and isolation. She identified tensions between staff, service users and the management at the hospice and noticed how the management could appear distant and removed from the daily experiences of service users. For example, the management did not understand or appear to want to find out the role that the hospice day centre played in the changed lives of service users as a result of them having life limiting illnesses. I found this aspect of Lawton's study relevant to my own study. A case study approach would enable delving into some of the documentation around the hospice involved in my study and indicate how it is organised and decisions made and by so doing, potentially contribute some answers to my research question.

3.4.4 Approach to data analysis

Charlesworth et al (2016) explored transformational change in health and social care systems and applied thematic analysis to evidence they had collected from four case studies and then presented their results in narrative form. The authors note that health organisations are complex adaptive systems and that trying to change them "creates unexpected dynamics and changes elsewhere" (Charlesworth et al., 2016 p.166).

In my study, I have triangulated data with case study and two types of participants. The hospice itself is part of a complex health and care system in the UK. The organisational changes that were introduced in the course of my data collection were unexpected not only by me but also by those working with and receiving care from the hospice. Charlesworth et al (2016) also alluded to changes in dynamics between staff and service users and within these two groups while change is in progress. I therefore considered it was important to use methodological and analytical tools that were appropriate for a qualitative study that would also enable me to delve into the levels of complexity that were emerging during my data collection.

3.4.5 Thematic Analysis

Braun and Clarke (2014) acknowledged that although thematic analysis was being more widely used it was only just beginning to get proper recognition as a useful analysis tool for qualitative research. They state that it is a way of identifying and analysing patterns in qualitative data and works with research topics exploring people's experiences and understandings as well as with large or small sets of data. The authors put forward six phases of thematic analysis: familiarisation with the data; coding; identifying themes; reviewing themes; naming themes; writing up (Braun and Clarke, 2014).

This flexibility of thematic analysis enables its use in conjunction with other methods (Charlesworth et al., 2016; Ritchie, Tolson and Danson, 2017). Thematic analysis was also used with other methods in a number of studies as detailed in Appendix 4. These approaches involved the use of thematic analysis with case studies, grounded theory, narrative analysis, content analysis, constructivism and phenomenology in a variety of combinations.

I referred to Braun and Clarke (2006), Gillham (2009) and Braun and Clarke (2014) for guidance for the thematic analysis of my data. Ultimately, it is in the hands of the researcher to interpret the coding method that is applied to the data. Braun and Clarke (2006) also stated that by not adhering to a theory of language or a particular framework, thematic analysis can be used as part of an on-going reflexive process by the researcher.

3.5 Trustworthiness

I followed the criteria for trustworthiness in my research put forward by Lincoln and Guba (1985) involving credibility (having confidence in the 'truth' of the findings; transferability (that the findings can be applicable in other contexts); dependability (consistent findings that could be repeated) and confirmability (findings shaped by participants and awareness of potential researcher bias).

I established credibility by visiting the hospice involved in my study on numerous occasions over a four- year period. The main reason for my visits was to interview participants that were conducted primarily on the hospice premises. I interviewed staff working in different areas at the hospice at all levels of seniority. This helped in developing a deeper understanding of the hospice and in analysing the effect of the organisational changes that were being enacted especially on service user involvement. This prolonged engagement with the hospice also enabled me to engage in informal conversations with staff and volunteers that helped me to formulate a wider overview of the hospice and how it operated including thoughts around the organisational changes that were taking place. Observing the physical environment and how it was changing also added to credibility. This included, for example, two or three members of staff working in offices previously used by one staff member on the main hospice site plus the moving of non-medical departments to another office building away from the main site.

I used triangulation involving multiple sources of data in order to enhance understanding, dependability and confirmability. This included data gleaned from service users, staff, hospice CEO and public records. Interviewing the hospice CEO a few months after interviewing service user and staff participants enabled me to raise some of the points and issues that emerged from the data and helped in further establishing credibility and dependability of the issues.

Using a case study approach at a single UK hospice over a number of years enabled me to provide thick description (Geertz, 1973) so making the data useful for studies by other researchers. It is feasible to assume that other hospices in the UK may be facing similar financial constraints. They may be contemplating significant organisational changes in order to try and deal with these constraints and ensure their financial sustainability into the future. It is reasonable to conclude that the data and findings that emerged from this research could be transferable to other UK hospices particularly if they also are considering a move towards a more managerialist and/or hospital/NHS approach to hospice care.

The research process and themes that emerged from the data were robustly discussed in regular meetings with my PhD supervisors over the course of my study. These meetings enabled a disentangling of any occasions when it was thought my own attitudes, for example, might have been influencing evaluation and critiquing of the data that may have caused bias. Remembering Peshkin’s ‘I’s as described in Chapter One, I used reflexivity to counter this possibility that then also led to deeper understanding of the data and the complexities that were emerging. These processes aided the confirmability of my research.

3.6 Chapter conclusion

In this chapter, I have provided an explanation of the philosophical underpinnings of my study. My research is concerned with understanding service user involvement in palliative care at a UK hopsice using a case study approach incorporating the perspectives of service users and staff and public records

The epistemological and ontological approaches to my study are not to provide one reality or truth about service user involvement in palliative care. Qualitative approaches for research into issues around palliative care are increasingly being regarded as appropriate and the need espoused by some researchers such as Addington-Hall et al (2007) for more flexibility in methodology are important considerations. The unexpected organisational changes at the hospice already mentioned meant that I needed to show subtlety and respond to them and my choice of methodology was a reaction to that.

The use of reflexivity in qualitative research and the need to acknowledge the role of the researcher are important components for a critical research project (Altheide and Johnson, 2011). The influence the researcher has on research processes and awareness that in an interview situation, “power dynamics are at play” (Adams, 2010, p.2) are also important considerations. So the need for rigour and intuition on behalf of the researcher (Pezalla, Pettigrew and Miller-Day, 2012) while interacting in the research process is also important in providing validity/credibility to the research findings (Jootun, McGhee and Marland, 2009). Reflexivity is presented in more detail in the next chapter.

One purpose of my study is to add to theorisation and knowledge about understandings around service user involvement and service provision in palliative care. I believe that by using a single-case study and interpretivist approach with thematic analysis and reflexivity enables me to delve into the lived experiences and understandings of service user and staff participants. It also enables me to consider the extent to which institutional and managerial practices and power relationships in a hospice that is operating within a changing social-political-economic context can have an impact on perspectives and understandings of service user involvement in palliative care.

I believe a case study approach is flexible enough to capture nuanced understandings of service user involvement in a complex and changing cultural setting in a UK hospice. My study will therefore help to fill a gap in research about perspectives and the impact that context can play on this topic and, as Donmoyer (2009) posited, expand the range of interpretations.

The next chapter provides a detailed explanation of the methods used in my study for data collection.

CHAPTER FOUR: METHODS

4.1 Introduction

This chapter provides an explanation of the research methods that I adopted for data collection for my study. It also describes the participants in the study including inclusion and exclusion criteria and the approach for data analysis. Attention is also given to reflexivity and credibility, confidentiality and ethical considerations.

4.2 Qualitative research

As discussed in Chapter Three, qualitative research is concerned with the way the world is understood by people and how their lives, behaviour and interactions express this understanding. This includes their perspectives about their own worlds and the meanings expressed. Denzin and Lincoln (2005a) describe how qualitative research does not veer towards one methodological approach and has numerous paradigms. Denzin and Lincoln (2011) also state that beliefs about ontology and epistemology and the relationship between those enquiring and what is known help to shape the path that a qualitative researcher takes.

I adopted a post-positivist paradigm for my study that recognises a researcher can influence what is observed and requires context. The role of reflexivity in my study is significant.

I considered that case study and thematic analysis were appropriate ways of gathering and analysing data in order to provide answers to my research question. I presented the reasons for choosing case study in Chapter Three. Case study enables an in-depth understanding and exploration of the context in which an organisation is operating (Yin, 2012). In my study, understanding the context of the hospice was vital for providing clues as to why and how the hospice as an organisation was changing and the impact this had on the views and understandings of participants. Case study supported by triangulation of data sources that included service users, staff and the hospice CEO plus public records provided a means to strengthen my strategic approach during the fieldwork activities for my study and my approach to data analysis. This approach also enabled an in-depth exploration of layers of evidence from the data as the analysis proceeded.

For gathering data from participants in my study I used semi-structured interviews with service users receiving palliative care and staff providing palliative care at the hospice. Interviews are generally regarded as an important tool in qualitative research for the purpose of gathering data (Fossey et al., 2002; Gillham, 2009; Adams, 2010). Addington-Hall et al (2007) regard qualitative methods as being the most useful and frequent methods used in palliative care research.

> Qualitative research questions focus chiefly on three areas: language as a means to explore processes of communication and patterns of interaction within particular social groups; description and interpretation of subjective meanings attributed to situations and actions; and theory-building through discovering patterns and connections in qualitative data. (Fossey et al., 2002, p.723).

In exploring the perceptions of a vulnerable group such as service users who are receiving palliative care, it is important to use a method that is open and flexible and that meets ethical standards required in such circumstances. Thematic analysis enabled the identification of themes from the interview data.

4.2.1 Semi-structured interviews

Gillham (2009) suggests that the semi-structured interviews could be regarded as the most important method in qualitative research due to its flexibility while also providing structure. Flexibility within this interview approach enables further probing by the researcher of issues that arise while the interview is in progress as well as allowing for participants to speak freely at times without being stopped. This could mean participants may deviate from the topic at hand but then the researcher can gently veer them back towards the structured questions at an appropriate moment. The probing questions from the researcher can then open up the interviews. I was keen that the participants interviewed in my research felt able to speak freely while at the same time, I would keep a list of questions to hand as an aid to help ensure the desired areas were covered as well as enabling the interviews to be completed within the agreed timeframe. When analysing the data following an interview it may be that any unexpected responses that appeared to be far off the topic at the time could actually provide useful information for follow-up questions with future participants.

Gillham (2009) suggests that the costs associated with semi-structured interviews can be high because of the level of analysis and interpretation that the data gathered requires. I do not necessarily regard this as a negative aspect of semi-structured interviewing particularly when researching palliative care. While recognising the potential complexities involved, analysis of the layers of meanings that emerge from the interviews can add significantly to theorising.

Other interviewing approaches in qualitative research include structured and unstructured interviews. Structured questions can still enable a participant to offer their own experiences during an interview but Addington-Hall et al (2007) considered it was perhaps not flexible enough for palliative care research that involved service users living with a terminal illness as participants. Unstructured interviews are totally open-ended and enable participants to tell their story with minimal prompts (Addington-Hall et al., 2007). This method may be more appropriate if also including observation of a situation or the study is being conducted over a long period of time. There was a particular focus to my research and I felt a flexible structure involving semi-structured interviews was the most appropriate method to use.

4.3 Ethical considerations

4.3.1 Involving people with life-limiting illnesses in research

Ethical considerations around involving service users receiving palliative care as participants in research is always a factor that has to be heeded from the start and throughout the data gathering process (Gysels, Shipman and Higginson, 2008). These considerations involve providing appropriate and full information to any service user participants so they can give informed consent. Service users receiving palliative care can experience a range of “physical, psychological, social and spiritual (or existential) distress” (Addington-Hall et al., 2007, p.4). This means that “beneficence” (Addington-Hall et al., 2007, p.28) is needed, a principle that involves furthering the wellbeing of others and to do no harm while weighing risks and benefits during any actions.

In the literature, service users receiving palliative care appeared to be regarded as a vulnerable group that could potentially be used as a reason for not involving them in research. However, Addington-Hall et al (2007) question whether all service users with a life-limiting illness should automatically be regarded as inherently vulnerable and consider that this is open to debate. At the time that Addington-Hall et al (2007) were writing, they noted that vulnerability appeared to be a subject of contention. The authors also noted that at that time, a small amount of literature was starting to emerge that sought the views of service users with life-limiting illnesses on why they were taking part in research. Beaver, Luker and Woods (2013) also looked into this topic and concluded that wanting to help others in a similar situation and being able to tell their own stories were potential benefits for service users in this position. Beaver, Luker and Woods (2013) also concluded however that it might not be possible to find out definitively whether there are benefits or potential harm to service users. The notion that service users receiving palliative care might take a positive or negative attitude to participating in research was interesting to note for my own study.

It was necessary to be aware that any enquiry into experiences of palliative and end of life care has the potential to be distressing for those taking part. It was important that the wishes of service users were respected and each service user fully understood that not wanting to take part did not compromise their care in any way whatsoever – it was entirely voluntary on their part. This fact was included very clearly in the information pack about my research that was given to service users who had been identified as possible participants. There is also the role of the researcher to consider in this and their potential influence in the process of the research as Addington-Hall et al (2007) point out. Researchers may also at times feel distressed at the responses given by participants.

It is important to respect the right of any participant who becomes distressed during an interview to take a break or withdraw from the interview process. My research focuses on aspects of service user involvement in palliative care rather than requiring participants to provide deep reflections on their personal feelings associated with death and dying. Service users may however welcome the opportunity to express their views and experiences in this more sensitive area and a semi-structured interview approach allows for this to happen. There is still a need to be very sensitive to the possible needs of interview participants, especially with service users who have a life-limiting illness. Specific guidance on this was sought from the hospice involved in my study as well as advice and guidance provided by other ethical bodies.

In my research, a service user participant would be informed prior to an interview starting that if they become ill or upset during the interview and wished to be referred to a member of hospice staff then this could be arranged. It was explained that if a service user participant expressed a wish to have a friend/supporter present during the interview then I would explain as sensitively as possible that the research was seeking their own personal views on the subject at hand and that the aim was to have a setting where they felt able to express themselves freely. If the participant still wished to have someone else present than this would be respected and logged and account taken of it in the analysis. None of the service user participants in my study requested to have anyone else present during the interviews.

As well as understanding the potential needs of the participants in my research during the interviewing sessions, it was also necessary to obtain official ethical approval from various bodies. This firstly involved submitting a paper about my study to the hospice ethics committee. I attended a meeting of that committee with my PhD supervisor in 2011 and verbal approval was given, followed by written approval. The Brunel University Ethics Committee was next to grant approval and wrote: “the committee would wish to commend the high quality of your application” (August 2011). The hospice had requested that I gain NHS approvals as well because many of their service users were referred to them via GPs and hospitals, for example. NHS approvals were sought in 2012 through IRAS from the appropriate local Research Ethics Committee (REC) that gave its approval in March 2013. The appropriate Research and Development Unit then gave its approval in May 2013. The ethical approvals process took over 12 months to complete that included both NHS bodies losing my application at various stages and provided quite a challenge. There was a requirement at that time for ethical approvals to be in place before interviewing of staff or service users could commence (see Appendix 2).

4.3.2 Confidentiality

Participants were given options about when to schedule the interviews and in the case of service users, where to carry out the interviews that was most convenient for them. The majority of interviews were conducted in private meeting rooms either on the hospice premises or in the hospice day centre building. One interview with a member of staff was conducted in an off-site office building owned by the hospice and two interviews with service users were conducted by telephone.

I transcribed the audiotapes of interviews and names and details of the interviewees will not be publicly disclosed. The tapes will be stored securely at Brunel University for 10 years as per the University guidelines.

Any interim reports published during the research process, at the end of the process or in the final thesis include anonymous quotations from the data collected. Staff are only referred to by generic rather than specific job descriptions such as nurse, counsellor, therapist or human resources for example. I sought guidance on maintaining confidentiality in written work involving a hospice by referring to Lawton (2000) who was a participant observer at an NHS hospice where she conducted an ethnographic study of the process of dying. She managed to maintain the anonymity of the hospice and participants throughout her written material. In my analysis, service users are referred to by pseudonyms in order to respect confidentiality.

4.4 Procedures

4.4.1 Initial visits to the hospice and ethical approvals

The National Council of Palliative Care (NCPC) recommended that I approach the particular hospice that became involved in my study. They were aware that the hospice was very active in palliative care research and therefore likely to be supportive. I established contact with a member of staff in the Education Centre at the hospice who then arranged for me to visit. I first went there in 2011 and discussed my study with the CEO and then showed me round the hospice site. The CEO was very supportive and agreed in principle that they would facilitate access for me in order to identify and interview participants at the hospice. This support was contingent on getting necessary ethical approvals as described earlier in this chapter. It was agreed that the staff member in the Education Centre that I had initially communicated with would continue as my main point of contact with the hospice for the duration of the fieldwork.

One suggestion that emerged from my discussions with the hospice CEO on my initial visit was for me attend focus group meetings involving service users that had been started at the hospice day centre. The purpose of attending would be to explain my research to the focus groups, hand out information about my study and then the group members could decide whether they would like to be individual participants. There was also a hospice service user group that used to meet on the hospice site that comprised mainly current or former caregivers. While awaiting for the outcome of the ethical approvals process, I attended a meeting of this user group in order to explain my research and discover if they could offer help in identifying potential participants particularly service users at the hospice. It became clear from this meeting that the group members did not interact with the hospice service users and informed me that they did not seek Criminal Records Bureau checks (now called Disclosure and Barring Service checks) to enable its members to interact on an individual basis. Their knowledge about and liaison with service users receiving care from the hospice seemed to be quite limited. As a result of attending this meeting, I decided to include questions about awareness of the hospice service user group and its role on my list of questions to ask participants in my study.

The possibility of attending staff meetings at the hospice was also raised in my discussions with the hospice CEO. There were full staff meetings held at least two or three times a year and the CEO felt they would be very helpful for recruitment of participants. A range of staff covering various roles at the hospice usually attended these meetings and so I would be able to speak about my research and reach many staff in one place.

It was at the point when I had received ethical approvals from all appropriate bodies and was ready to recruit participants that I discovered that organisational changes were taking place at the hospice that proved to be significant for my study. These changes included the appointment of a new hospice CEO, the ending of the service user focus groups at the day centre and the ending of full staff meetings. I therefore had to rethink my initial plans and take a different approach for recruiting participants due to the changing circumstances. My contact at the hospice remained in place and I was able to discuss with her possible approaches for identifying participants. Payne et al (2007) highlighted the importance of finding a regular contact on research sites and this importance was proven in my study.

The identification of potential participants was achieved through a number of methods. Firstly, staff identified and approached individual service users and passed on the information pack about my study. Secondly, posters that I had produced were pinned on appropriate notice boards around the hospice buildings including the day centre. One version was targeted at staff and another version targeted at service users (see Appendix 1).

4.4.2 Interviews

I identified early themes as they emerged from the interviews and used them as a basis for formulating further questions while thinking analytically about the data through the whole interview process. I also talked with and sought suggestions from members of the service user group at the UK National Council for Palliative Care to help inform interview questions and their thoughts on what they considered might be useful angles to consider.

4.4.2.1 Preliminary interviews

While waiting for the formal ethical approvals process to be completed, the hospice agreed that I could carry out two preliminary interviews in order to test my questions. These preliminary interviews involved a nurse/educator and a former caregiver of someone who had died at the hospice. The hospice wished to wait until full ethical approvals had been granted before I started to interview service users/patients. Both of these preliminary interviews took place in a meeting room at the hospice's on-site day centre. The intention was to help in assessing their understanding of the information provided and about the research project itself. It was also to check with them whether the questions were clear; that they understood what they were being asked and whether any amendments might be needed to them or the content of the written materials.

These preliminary interviews also enabled me to practice and consider my own interview technique and other aspects. For example, I assessed the meeting room environments and whether there was enough space between myself and the participant to avoid invading personal space on either side; whether it was possible for a wheelchair to get through the door and be maneouvred by the service user once inside a particular meeting room; whether there were staff nearby (not in the same room) who could be called in quickly if a service user fell ill during the interview and requested assistance; whether the rooms were hot or cold or temperate; and to make sure water and glasses were available for myself and the participant. Prior to each interview starting I tested my handheld tape machine by asking each participant to say a few words into it and also assessed where to best position it depending on the pitch of a participant’s voice. In short, to practice setting the scene prior to each interview and to take account of all aspects of the interview arena and environment in terms of comfort and accessibility. I mentioned to each participant before the start that the interview would last for up to an hour and if during that time, they started to feel unwell or did not wish to answer a particular question or wanted to stop the interview completely, then they should say so and we would either move on to the next question or end the interview as they wished. Neither of the participants asked for the interview to be stopped nor was any request for any intervention by another health professional during the interviews.

After each of these two preliminary interviews I asked each participant for feedback and they responded that the questions were understandable and they felt able to offer responses and to speak openly. I also asked if they found the room environment comfortable and if it enabled them to feel calm and at ease during the interviews. The meeting room where both these interviews were conducted was quite small and there was perhaps not enough space between the participants and myself. I considered that for subsequent interviews, I would request a larger meeting room if possible on the hospice premises and this was provided. Both participants also said that they had read and understood the information that I had provided about my research and did not request any clarifications.

4.4.2.2 Useful information from the preliminary interviews

I discovered in both of the preliminary interviews that the questions and structure served two purposes: they allowed the participants to talk freely about their thoughts and experiences and enabled a good flow of conversation to develop during the interviews. I discussed the interviews with my supervisors about the reactions of the two participants as well as my own thoughts on whether the questions and the order seemed to help or hinder the flow of the interviews.

It was agreed that the questions did not require any significant changes at this point for future interviews while staying mindful of maintaining an iterative and reflexive approach as the interview activity progressed. Such an approach would aid possible revisions to questions being asked in response to issues that may emerge during each of the interviews.

The questions presented in the next section were initially asked of the two participants taking part in the preliminary interviews and then used in subsequent interviews.

4.4.2.3 Questions for service user participants

A number of introductory questions were asked at the start of each interview in order to start building a rapport and also to help the participant feel comfortable with speaking out loud and being audio-recorded. These questions included, for example, asking when they first had contact with the hospice and how long they had been receiving care from the hospice.

The order of the questions as they appear below was used as a guide to ensure that all were covered during the interview. The order they were asked depended on the responses given by the participant who might, while answering one question also provide answers to other questions in the list and therefore these did not need asking again. This did not preclude asking probing questions on particular aspects as the interview progressed.

These introductory questions led into the main interview questions that were as follows:

1. Have you ever heard people talking about service user involvement at the hospice or generally?
2. What do the words ‘service user involvement’ mean to you?
3. How do you get involved in your own day-to-day care? Do you have any examples? Do you feel you were consulted and listened to?
4. In addition to any personal influence you may have had in the care that you receive, have you had any experience of or taken part in any service user involvement activities at the hospice – or in any other field? If yes, what do you think were the benefits and limitations of it?

5. What are your perceptions and understandings of service user involvement generally and as it may apply in palliative care?
6. Are you aware of any service user involvement activities at the hospice and have you had any involvement with them? If yes, in what way? If no, what do you think has stopped you?
7. Have you ever discussed service user involvement with others including service users and staff?
8. Can you think of and describe any benefits of service user involvement at the hospice?
9. Did you expect to receive information about service user involvement after your referral to the hospice? How else are you encouraged to get involved in your care?
10. Are you aware of any formal requirements of service user involvement in palliative care? Formal requirements covers the hospice's philosophy, for instance, or contained within legislation such as Acts of Parliament and guidance from the Department of Health on service user involvement in palliative care.
11. What would you like your involvement in your own palliative care to look like?
12. Is there anything you would like to add about your reflections and perceptions on service user involvement in palliative care? Do you think it could make a difference to palliative care?

4.4.2.4 Questions for staff participants

As with the service user pilot interview, a number of introductory questions were also made to the staff participant. These questions included, for example, asking about their role at the hospice and how long they had been working there. These introductory questions led into the main interview questions as follows and again, not necessarily in this same order and also involving probing questions:

1. What do the words 'service user involvement' mean to you?
2. How do you perceive patients getting involved in or influencing their care? What do you see as the benefits and limitations of patients' involvement in decisions and practices related to their own care?

3. Have you had any experience of or taken part in any service user involvement activities in any field? If yes, what do you think were the benefits and limitations of it?
4. What are your perceptions and understandings of service user involvement in palliative care?
5. Have you ever discussed service user involvement with others including service users and staff?
6. Are you aware of any service user involvement activities at the hospice and do you have a role in them?
7. Do you feel able to involve service users in their palliative care?
8. Are you aware of anything that has changed at the hospice as a result of service user involvement?
9. Are you aware of any formal requirements of service user involvement in palliative care? By formal requirements is meant the conditions that may be contained within the hospice's charter; in the code of conduct for your own profession or through legislation ie Acts of Parliament and guidance from the Department of Health on service user involvement in palliative care.
10. Do you have any ideas on what would be a 'good' model for service user involvement in palliative care?

    Is there anything you would like to add about your reflections and perceptions on service user involvement in palliative care? Do you think it could make a difference to palliative care?

4.5 The interview process

There was direct communication between each participant and me in order to agree a date, time and location for the interview. I discussed the availability of suitable rooms with my hospice contact where interviews could be conducted in private. I was able to make use of a large room at the hospice day centre that I booked in advance through the receptionist. I used meeting rooms in the hospice education centre building, situated on the main hospice site that I booked in advance through the education centre receptionist.

All interviews lasted for around an hour. There were instances where participants wished to continue speaking for longer than the hour. When this happened I checked with each participant during this extra time to ensure they were able to continue or wished to stop.

4.5.1 Interview context

I was also sensitive and aware of the possibility that a service user participant in particular may get upset or start to feel unwell during an interview. They may then either want to stop and carry on after a short break or want to stop for the day and arrange another time or not want to carry on with the interview at all. Information provided to potential participants at least a week before any interviews took place stressed that they could call a halt at any time and rearrange it or not as they wished. None of the participants expressed a wish to stop or said they felt too unwell to carry on during the course of the interviews. One service user participant had agreed to be interviewed in a room at the day centre but on arrival at the hospice I discovered that he had become unwell that morning and had been taken home. He had requested if the interview could be rearranged and it was carried out successfully the following week. This particular service user was keen to have the opportunity to talk about the organisational changes at the hospice and how he felt they had affected him. He had experience of care provided by the hospice and had used the day centre prior to the changes being implemented and so was significant for my study.

Two service user participants were interviewed via telephone while they were in their own homes and the discussions were recorded via the phone speaker. Both of these interviews lasted for around an hour each.

The main tranche of interviews with staff participants at the hospice took place during 2013-15 and in early 2016 and interviews with service user participants mainly took place during 2015. During data collection I was able to continuously review the data as the interviews progressed, refine questions and re-evaluate findings as they emerged. For example, there were instances where a number of staff participants described changes in their roles and job descriptions at the hospice that had happened as part of the organisational changes. I probed further during the interviews after hearing such responses that also prompted me to frame potential questions for subsequent interviews with staff participants about their roles. This aspect among other issues that emerged from staff and service user participants are detailed in Chapter Five.

Decisions about the inclusion and exclusion criteria for participants in my study are detailed in the next section.

4.5.2 Inclusion and exclusion criteria

I decided that the total number of participants to be recruited for the research interviews involving staff and service users would number up to 40. I considered that this number would provide enough flexibility during the process of gathering and analysing data for including an optimum number of interviews. The point in the process when saturation may be reached would become apparent during the process of data analysis. Although I also considered what Malterud, Siersma and Guassora (2015) referred to as information power in qualitative research where they contended that the more relevant information that a sample holds then the lower the number of participants that would be required.

The inclusion criteria for service users was as follows:

a) adults of 18 years and over
b) aim for gender balance but accept there may be challenges in attaining such a balance due to factors outlined in this chapter when conducting research involving people living with life limiting illnesses
c) aware of their condition and that they are receiving palliative care
d) able to speak and comprehend English.

The inclusion criteria for staff was as follows:

a) adults of 18 years and over
b) aim for gender balance if possible but accept proportionality

c) to include a cross-section of staff as participants across disciplines covering clinical, non-clinical, therapists, managers, paid and unpaid (volunteer) staff
d) working at the hospice for at least a month and so having time to settle into their role and become familiar with the hospice itself.

In discussions with the previous CEO and my contact at the hospice, I considered that the majority of service user participants would come from those attending the hospice day centre that was located on the same site as the main hospice. There was a possibility of including service users in the in-patient unit although opportunities for this were reliant on staff identifying and approaching them. There was also the possibility of identifying service users receiving care from the hospice while living elsewhere such as in a care home for example. There was an opportunity to interview a service user in a care home but after arranging a date and time to visit the interview was called off the night before. This was due to what a member of staff said was a significant deterioration in the health of the service user.

4.5.3 Research information materials for participants

I prepared a letter of invitation for service users (Appendix 1) and staff (Appendix 1) and compiled a research information pack for each group that contained the letter plus information about my research (Appendix 1) and an expression of interest form (Appendix 1) that had my contact details on it to fill in and return to me. This approach was intended to ensure confidentiality so that even if a member of staff had handed the information pack to a service user, for example, the staff member would not be aware if the service user had filled it in and returned it to me. If a service user agreed to be interviewed, then a consent form (Appendix 1) would be provided at the time of the interview and signed by both just before commencement of the interview.

I designed and produced two posters (Appendix 1) to help promote my research and aid recruitment that would be displayed on noticeboards around the hospice aimed. One poster was aimed at service users and another aimed at members of staff. Staff working on the reception desks in the day centre and in the main hospice agreed to take receipt of closed envelopes containing completed expression of interest forms. They kept them in a sealed box and then hand the envelopes to me during my visits to the hospice. This was to enable potential participants who did not have access to email, telephone or who were not physically able to post back a form, to take part if they so wished. As well as including posters about my research on noticeboards, my hospice contact passed on information to individual staff members who would then contact me directly. I also attended an in-patient nurses work meeting at the hospice that was arranged by my contact and involved around six nurses. I was able to talk to them about my research and handed information to them at that meeting so they could contact me directly if they wished to take part.

The identification of staff members for approaching to take part in my research proved to be less challenging than identifying service users. This was due mainly to my hospice contact and staff members approaching other staff on my behalf. The posters on staff noticeboards helped raise awareness of my study around the hospice generally. My contact told me that in her experience, staff looked regularly at noticeboards particularly if something new had been pinned up.

The discontinuation of the service user forums and changes in attendance arrangements at the hospice day centre meant I could not speak to service users in groups. I had to rely on members of staff to approach service users individually on my behalf. The posters may possibly have helped to raise awareness of my study among service users at the day centre. In reality, it was the day centre nurses handing out information to service users that generated their interest. Staff then enabled service users to act on their interest by providing them with the information about my study so they could get in touch with me to express interest about becoming a participant.

4.5.4 Participant sample

A total of 22 participants were interviewed for my study. This involved 16 paid hospice staff, including the staff member who took part in the preliminary interview, two unpaid hospice staff (volunteers) and the hospice CEO. Six service users were interviewed including the family caregiver who took part in the preliminary interview.

Using case study and thematic analysis for collection and analysis of the interview data enabled flexibility around decisions on the direction to take in future interviews. This also helped to inform further questions to explore with future interviewees. For example, I was concerned to include staff members in roles at all levels of the hospice hierarchy. A decision about which staff to aim for next was taken after one or two staff participant interviews had been completed and an initial analysis had been performed.

I first identified and held the first tranche of interviews with staff at the hospice. I felt this would provide an opportunity for me to explore their perspectives on the hospice itself, how it operated and their roles as well as on their perspectives on service user involvement. I also felt it would enable early themes to be identified that could help inform further interviews with other staff participants and also with service user participants.

4.5.4.1 Hospice staff and unpaid staff (volunteers)

Staff participants in my study operated at different levels in the organisational structure. I considered that this could provide a range of understandings and perspectives for analysis. The emphasis in the literature seemed to be primarily concerned with exploring the perspectives of clinical staff towards service user involvement as described in Chapter Two. By clinical staff, I refer to those providing physical medical care to service users such as nurses, medical doctors and medical consultants. There were other staff that had direct contact with service users such as counselling and homeopathic services for example. I did not uncover any studies in the literature that had involved exploring the views or understandings of staff in hospices that had no direct contact with service users even though they were working in the arena of palliative care. This could include those working in administrative fields such as personnel, human resources or Information Technology (IT) for example. I interviewed staff fulfilling such roles at the hospice in my study. This provided further perspectives on the organisational changes as well as on service user involvement. In taking this approach, I believed that interesting perspectives would emerge around service user involvement as well as on the organisational changes at the hospice.

I took the opportunity to also conduct interviews with two unpaid hospice support staff otherwise known as volunteers. One of the volunteers was a ward helper in the in-patient unit and another volunteer performed reception work at the hospice and was also an unpaid ambassador who attended external events and gave presentations about the hospice. There were over 1,000 volunteers at the hospice fulfilling a variety of roles such as tending the garden; providing lifts for service users from their homes to appointments at the hospice and fundraising activities. It was not my intention at the start of my study to include hospice volunteers as participants. However, I considered it useful to include them as volunteers fulfilled a considerable number of unpaid roles at the hospice. They would likely have perspectives on the organisational changes and how these impacted on them and their roles and relationships at the hospice.

4.5.4.2 Service users

As mentioned earlier in this chapter, I carried out interviews with hospice staff first in order to help provide me with an overview of their perspectives on service user involvement and about the organisational changes at the hospice. I have also described in this chapter the reasons why identifying service user participants proved challenging.

Of the six service users that were interviewed, four of them had been visiting the hospice day centre for a year or more prior to the changes coming into effect. The data gathered from them provided before and after perspectives around the change in culture at the hospice. I attempted to identify other service users during 2014/15 who had started receiving care from the hospice after the organisational changes had been in place for a year or so. It was mentioned to me by a day centre nurse that changes in arrangements for service users attending the hospice day centre meant that it was proving difficult for the nurses to spend time talking with service users and therefore to establish relationships with them. Most service users had started to attend the centre for booked-in-advance appointments with specific staff for specific purposes rather than dropping in on any days during the week as was the case with the previous day centre arrangements. Service users would leave straight after their appointments were over leaving no time for socialising with staff or other service users. The number of staff working in the day centre had also been reduced over the previous year that added to time limitations for those staff still in place. These changing circumstances served to make it difficult therefore for staff to identify potential service user participants. As the literature shows, there is also potential for staff such as nurses in palliative care, to categorise service users as vulnerable and therefore in need of protection from anything they may perceive as a potential burden (Addington-Hall et al., 2007). Deterioration in the condition of a service user was discovered by Stone et al (2013) to be a fairly common reason given by staff as a reason for preventing a palliative care service user from taking part in a research project. The authors referred to this as gatekeeping.

In the findings of interviews with service user participants that are included in Chapter Five, I also include some details about their personal situations that they mentioned during the interviews. Analysis of this data helped to shed light on the topic of my study.

Due to the findings that were emerging from my data with service users and staff, I considered it would be very useful to interview the hospice CEO in order to aid my theorising. I left around six months following the last of my participant interviews to give time for further analysis and reflection before securing an interview with the CEO in early 2016. The interview lasted for nearly two hours and enabled me to explore the CEO's understandings and perspectives on service user involvement as well as on the organisational changes that had taken place at the hospice over the previous two and a half years. During the interview I was also able to put forward some of the issues that had emerged from the interviews with staff and service users. The CEO was a key informant in my study and analysis of the interview data enabled validation of early findings as well as extending the findings.

4.6 Thematic Analysis of the interview data

As suggested by Braun and Clarke (2006), I familiarised myself with the data by listening to the tapes of the interviews shortly after having conducted them and then writing initial transcripts by hand to help with the immersion process. In the handwritten transcripts, I highlighted substantive words and statements that were emerging that could add substance to my enquiry (Gillham, 2009). This highlighting process also helped to identify initial aspects of the data that may prove to be relevant in providing answers to my research question and potentially included as direct quotations in my thesis. I also made my own notes covering my reflective thoughts that arose as I listened to the tapes as well as highlighting areas for possibly informing questions in future participant interviews.

Following this initial process, I immersed myself further in the data by transcribing each of the interviews on to a computer. This process involved a combination of listening to the tapes, referring to my handwritten transcripts and then referring backwards and forwards to the taped versions as necessary to help ensure accuracy. I then compared the typed transcripts with my handwritten versions and attached different coloured labels (or codes) to the issues and points that emerged. This approach to the data enabled me to immerse myself further within it.

Reflecting on the data collected, I felt that the views being expressed would have a significant bearing on identification of the themes. I also felt that there might be some underlying issues not mentioned that could then form the basis of questions in further interviews. I also attempted to pick up on a particular tone of voice coming through from participants in their responses to certain questions. For example, if a participant seemed irritated or hesitant when responding or went quiet that could hint there were perhaps further layers of issues that were not being voiced.

Substantive statements and issues that emerged from my data are shown in the table in Appendix 3 covering service users and are included in Chapter Five.

I identified patterns of meaning in the data as the collection and immersion process continued that could lead to themes. I then gathered relevant patterns of data together and placed them under a general named theme. As the data collecting, immersion and analysis processes continued, I reviewed the themes to decide whether they seemed to be still relevant or needed amending or were no longer appropriate.

I constructed three overarching themes that were defined and given titles ensuring that each theme told a story and reflected the essence of the content of each theme. I was aware that this is a recursive process through the different stages (Braun and Clarke, 2006).

As well as reflecting on the content of the data that I collected, I was also aware of the need to reflect upon my own subjectivity and pre-understandings. This reflexivity on my part was necessary due to my own personal experience of caring for my parents towards the end of their lives as described in Chapter One. I was very mindful during the interviews that although I was encouraging the participant to speak and was asking probing questions, I should not appear to be agreeing or not agreeing with what they said or offering any form of words they might like to use. I was also aware of the need to keep any thoughts that I might have to myself and not verbalise them during any of the interviews. I felt it important to also be mindful of and manage my subjectivity when in the process of analysing the data and identifying patterns and themes.

The write-up involved the interlinking of the analysis and data extracts and placing of this analysis in context with existing literature and is presented in Chapter Five.

The description of the data analysis process in my study in this section has focused on that collected from participant interviews.

4.7 Public records

I visited the hospice setting numerous times over a period of years starting from 2011 and, as also previously mentioned, significant organisational changes were taking place at the hospice during the period of my fieldwork. A number of these changes included the appointment of new personnel at senior level and a significant change in arrangements for the use of the hospice day centre.

I conducted a search into information and documentation about the hospice, its operation and management. This included the hospice website looking for information about personnel, for example, the role of the board and the activities of the official hospice service user group. I also used search engines to look for information about the hospice that may have been taken off the website as being out of date but that still existed on-line and might be relevant. I discovered and analysed the hospice's report and accounts covering a number of years available as open access on the Internet. I also searched records lodged with other relevant national bodies covering the charitable sector in the UK and further searches of websites of local newspapers that covered the area where the hospice was based. A participant had mentioned during the interview that local newspapers had covered aspects of the organisational changes taking place at the hospice. I was interested to find out what was being said and consider if it was relevant for my study.

4.7 Reflexivity

I mentioned reflexivity at the start of this chapter and also discussed it in Chapter One. I highlighted the views of Addington-Hall et al (2007) about the need for a researcher to be aware of themselves and their own biases and values when carrying out qualitative research as well as the need for continuous critical engagement including of the environment within which the research is taking place. This of itself can also be considered as data. I also referred to the "I's" described by Peshkin (1988) where the author believes that the subjectivity of a researcher can be managed through self-awareness and reflexivity during all of the data gathering process, analysis and writing-up. I was very mindful of this advice throughout the whole of my data collection and analysis process including the writing up. Finlay and Gough (2003) talk about how qualitative researchers are concerned with unravelling how their own stories interweave with experiences in the field.

As part of a reflexive approach, I have included details of my own caring experiences in this thesis. I have also included a description of my experiences as a member of a number of service user groups in palliative care, in order that they are openly declared as part of a transparent approach to my study. As well as these declarations, I also needed to be aware of the potential emotional effects on me as the researcher when listening to the responses of service user participants in particular during the interviews as well as staff participants. Addington-Hall et al (2007) understood this aspect of palliative care research and suggested that an iterative process in research supervision "provides an arena where biases, values, prior knowledge and emotional pain can be examined and understood" (Addington-Hall et al., 2007, p.167). My own self-awareness and connections with service user groups and experts in the field was strongly augmented by regular discussions with my research supervisors. I had regular supervision meetings throughout the whole of my research project so there was constant review and discussions in relation to the collection and analysis of the data and the findings. I considered that this approach also helped to enhance the credibility of my research.

> Focusing on the process of investigation and communicating that process, the problems and solutions encountered in accessing, collecting, analysing, and interpreting data – to the best of our ability – is quite consistent with analytic realism or the general notion that the social world is an interpreted one. (Denzin and Lincoln, 2011, p.593).

4.8 Chapter conclusion

This chapter has described the methods that I used to carry out my data collection and analysis. The issues and overarching themes arising from my data plus relevant information that emerged about the hospice from my searches of documents posted on the internet into its operation and management over a number of years enabled me to build a picture of the period of change at the hospice. The combination of a qualitative approach using case study and thematic analysis of the data enabled me to delve into levels of complexity that could aid theorising and help provide some answers to my research question.

Theorising about the impact of significant organisational and structural changes on organisations including hospices and the potential influence such changes can have on perspectives on service user involvement in palliative care is included in Chapter Seven.

The next chapter describes in detail the findings from the data collected from interviews with service users, staff, volunteers, CEO and public records.

CHAPTER FIVE: FINDINGS

5.1 Introduction

In taking a case study approach that was described in Chapter Four, I was able to explore a single case in its natural setting using a variety of methods to gain in-depth knowledge (Gomm, Hammersley and Foster, 2009; Yin, 2012; Collis and Hussey, 2014). A case study highlights the importance of context and for enabling an understanding of the dynamics that might be present in a single setting particularly in relation to management behaviour. A range of perspectives and understandings has been incorporated into my study including those of service users/patients and professional staff as well as drawing on public records published on-line about the hospice. The reasons for not including the views of family caregivers as part of my data collection activities have been put forward in Chapter Two. Therefore, references to service users in this and subsequent chapters mean those directly receiving palliative care from the hospice.

The findings from analysis of the data are presented in this chapter in three sections. The first section includes findings from interviews with service user participants receiving care from the hospice; the second section covers staff participants working at the hospice and the third section covers findings from public records and an interview with the hospice CEO about the hospice and its organisation. A key finding from the data indicated that organisational changes taking place at the hospice during the period of data gathering had an impact on service users and staff participants that had implications for understandings about service user involvement. This finding prompted a decision to interview the hospice CEO and to seek further information about the hospice's operation openly available on the Internet. This triangulation of data added to the trustworthiness of my findings in conjunction with reflexivity that added to dependability and reliability as discussed in Chapter Four.

Quotations from participants are included in this chapter with pseudonyms used for service users and staff roles indicated by general job titles to help ensure confidentiality (Appendix 3). I put forward some personal reflections within the text itself and at the end of the chapter.

5.2. Findings from service user participants

Through thematic analysis, I identified three overarching themes: Involvement and disempowerment in decisions at the hospice relating to organisational change and service user involvement; belonging and alienation relating to the day centre and hospice community and, maintaining and losing a sense of wellbeing and identity within the changing hospice setting.

Each of these themes presents a particular tension between contradictory or similar experiences. Most of the participants expressed both positive and negative experiences and feelings about service user involvement and how they engaged with the hospice. These experiences and perspectives appeared to have been heavily influenced by the organisational changes that were occurring at the time, particularly those affecting the hospice day centre that all of them attended. A number of the comments made by service users during the interviews were very strong and direct. Three of the service user participants in particular, who had been visiting the hospice over a number of years, focused their angst about the new organisational arrangements at the hospice CEO. This is perhaps not surprising as, for them, the CEO represented the face of the hospice senior management and was the person who conducted consultation meetings that they attended and whom they had talks with during the change process. The CEO represented a visible change that was occurring in the hospice culture and was regarded by service users as responsible for introducing the new arrangements. It was necessary therefore to carefully explore the underlying meanings behind the data collected from service user participants and indications it might provide to aid understanding of the levels of complexity including the impact of a managerialist approach. As already mentioned at the start of this section, it also led to a decision to seek an interview with the CEO to further explore the issues that were arising from service user participants.

Part of the organisational changes taking place at the hospice involved the introduction of new formal arrangements for enabling service users to attend either of the two hospice day centres. These new arrangements were introduced in 2014 and had been in full operation from around six months before I started to conduct my interviews with the service user participants. These new arrangements consisted of two parts: one part required service users to choose in advance as to which weekday they wanted to attend the day centre and once chosen, they were then required to attend on that chosen day every week; the second part involved the introduction of an 8 weeks on, 8 weeks off programme meaning the service users could attend the day centre(s) on one weekday for 8 weeks and then not be able to visit again for 8 weeks. This represented a significant change to previous arrangements where service users had more autonomy in choosing which days to attend the day centre and for deciding the activities they would pursue that would then be facilitated by day centre staff.

The contradictions and tensions are analysed in this chapter and are reflected in each of the overarching themes that are described next.

5.2.1 Overarching themes - summary

1) Involvement and disempowerment in decisions at the hospice relating to organisational change and service user involvement.

While participants had been given the opportunity to contribute to consultations on planned organisational changes, they felt disempowered when their views appeared to be ignored by management and seemed to make little difference to the plans. Service users that had been attending the day centre prior to the changes being introduced expressed feelings of involvement during that earlier time and then disempowerment through and beyond the change process. One service user who had started attending after the changes had been implemented also expressed feelings of disempowerment in decision-making about activities that could be pursued at the day centre.

2) Belonging and alienation relating to the day centre and hospice community.

A sense of belonging to a hospice community was valued but was perceived as becoming eroded by a new, rigid structure of management and with changes in the arrangements implemented at the day centre. A previously close connectedness between individual service users and staff at the day centre appeared to have become fragmented and service users reported increasing feelings of alienation and isolation especially those that lived alone.

3) Maintaining and losing a sense of wellbeing and identity within the changing hospice setting.

Involvement in activities facilitated by the hospice and interacting with other service users and staff supported participants’ sense of wellbeing and sense of themselves as worthwhile rather than being reduced to an illness. The fear that this might be lost due to the organisational changes at the hospice caused worry and frustration.

The three overarching themes filter through the data in an intertwined manner as participants could appear to experience disempowerment, alienation and loss of identity, for example, through one sentence. For the sake of clarity and understanding, each of the themes is explored separately.

5.2.2 Theme 1: Involvement and disempowerment in decisions at the hospice relating to organisational change and service user involvement.

I identified feelings of anger in the data with service user participants that took part in the consultation process at the hospice around the proposed organisational changes and felt that their views appeared to have been ignored by the hospice management that included the CEO. This was felt especially by three participants called Bob, Polly and Milly who had each been attending the hospice day centre prior to the organisational changes being enacted and therefore had experience of the previous arrangements. Although Bob was in constant pain throughout the interview (he was wearing a syringe driver for pain management), he said he did not want to re-arrange it or take a break during it because he felt so strongly about what was happening at the hospice and said he was very keen to talk about it.

Bob, Polly and Milly described a number of consultation activities at the hospice. For example, they had taken part in questionnaires and/or attended meetings organised by the hospice that were seeking their views on the changes. They had also attended consultation meetings with hospice management including the CEO. The participants all said they strongly expressed their views and the concerns they had but that they subsequently felt their views were ignored and this engendered feelings of disempowerment among them.

> We were asked last year when they [senior management and CEO] changed over [pause] we were asked how we felt. We done questionnaires which were a total waste of time 'cos I feel they didn't [pause] the comments that we passed on as patients were not used [pause] the questions we asked were gone round rather than answered. (Bob).

These comments above by Bob indicated an initial belief that as he had taken part in consultation activities about the organisational changes then his views would be taken into account by management. He then expressed dissatisfaction and annoyance that his contribution and those of other service users appeared to have been discounted by management without further explanation. Bob also described another consultation meeting he took part in to discuss the changes.

> We had this meeting with the governors here and we were told it would alter and we had no choice. It means that being disabled, I don't have a choice, I don't have a say, I have to take whatever comes along. I'm grateful I can get up here otherwise I'd be stuck at home all day but I'm not frightened to say what I think. I think they

> need more staff here …this day centre has gone downhill tremendously. (Bob).

Bob's further feelings of resentment come through in this quotation above as does his perception that in being disabled he therefore did not "have a choice" about the proposed changes. Bob said "I'm not frightened to say what I think" that suggested he may have felt slightly intimidated by the change process at the hospice but would still seek to challenge what was happening for however long he had left. Whether he perceived that there might be consequences from speaking up was not clear. Bob's choice of words suggested anger at the management although not at the nurses who provided him with direct care. Taking into consideration that Bob had a life-limiting illness, there would have been a time limit on how long he could keep challenging the hospice, a situation of which he was well aware.

> People have the wrong impression of hospice; they think they come here to have end of life care but it's not only that. I've been fighting my disease for 2 years and know I'm at the end of this but I don't know how long I have to last after that. (Bob).

Polly had taken part in the hospice consultation activities and also felt that her views had been ignored and her questions left unanswered leaving her to conclude that decisions had already been taken. Milly was very direct in expressing her views about changes in arrangements at the hospice day centre and the resentment she felt at not being listened to especially after having had a relationship with the hospice for some years beforehand. It appeared that Milly and other service users felt some kind of proprietary hold over the day centre because of the relationship they had built with the hospice due to their activities conducted through it over time. They had also built relationships with individual members of staff, sometimes over a number of years, and they feared such relationships were being diluted.

The comments quoted above from Bob, Polly and Milly show that they experienced feelings of profound disempowerment after taking part in the formal consultation activities at the hospice that then helped to ferment an undercurrent of resentment and anger. The feelings expressed and quotations mentioned in this section potentially indicated that the hospice management was taking a top-down approach to decision-making about the organisational changes even while hosting consultation activities involving all groups that would be affected by them. Evidence for such a top-down approach is explored in section three of this chapter.

Stanley had also been attending the hospice day centre prior to the changes and seemed to think that the day centre was not performing too well after the changes had been introduced.

> There were 6 people there, last time, 4 people before, been like that for last 12 months. They have seats for 10/12 people and the level of service must be expensive in relation to the number of people taking advantage. (Stanley).

Stanley thought that those attending the day centre regularly on the days when he went were, like him, probably aged 80 or over with some disability both physically and vocally. He considered he had progressed further along his illness trajectory than others in his day centre group that had the same illness.

> Very difficult not to be critical or sounding cynical – I'm so very grateful for the assistance, the care, the interest shown by the staff to people such as me, but, we have so little in ourselves to offer. I don't know how many groups there are [at the day centre] for different illnesses but this must be one of the worst groups because everybody is virtually on the way out - not frightened of death but frightened of the circumstances, the pain, the anguish, the amount of time it takes, where they'll be – very difficult to take when you're that person – that's my biggest emotion. (Stanley).

From Stanley’s comments above it became apparent that the changed arrangements at the hospice day centre did not feature strongly in his thoughts as with other participants. Also from his comments it appeared that although he welcomed the opportunity for interactions with other service users, he did not regard visits to the day centre as providing opportunities for different forms of socialising with them. This might well be because he was further along in his illness trajectory than the other service user participants although Bob also felt he was close to the end. Stanley’s thoughts indicate that a wish for involvement or ability to do so could diminish due to illness progression particularly in the late stages or perceived late stages.

David started using the hospice day centre after the changes had been made and so had no experience of taking part in the consultation activities.

> We’re actually going through a bit of flux at the moment, trying to find where it should be, this day centre, for people or service users, and what criteria it should take. It had an old system which apparently collapsed when I wasn’t involved at all and I can’t comment about it, but I came in when the new system was up and running. (David).

David stated in the quotation above that he perceived or maybe had been told that the old system at the day centre had “collapsed.” He may have picked up this word from other service users that had been attending the day centre prior to the organisational changes coming in. He may also have heard strong feelings being expressed by other service users such as Bob, Polly and Milly for instance. David also picked up the sense that maybe there had been something wrong with the previous arrangements for using the day centre and therefore needed to be changed. Bob, Polly and Milly had strongly expressed a wish for the old arrangements to be reinstated. But David also had views from his slightly different perspective about how the hospice should be deciding what happened at the day centre and how service users should be involved:

> If we knew what they [hospice management] wanted then maybe we could be a bit clearer as to what we want. Sometimes I may say to [name of staff member] or one of the other staff or volunteers, I wish we had so and so. Now that should then be moved on from the service worker to say well, look, someone mentioned this, let's start batting the ball about and see where we get to. It should do [work like this] but I'm not sure it does do. (David).

David had started attending the day centre after the changes had been implemented and displayed a willingness to try and work within and get involved in the arrangements there rather than trying to get the previous regime reinstated. However, any requests David made to staff or volunteers did not appear to achieve very much. He had picked up that there was perhaps a dearth of communication and information flowing between service users and hospice management to enable new activity ideas to be considered that is highlighted in the quotation above.

The perspectives of Bob, Polly and Milly were influenced by their bridging of two different timeframes that is, before and after the changes at the day centre were implemented. The anger and distress they expressed showed how they believed that, for them, the consultation process had been a sham and felt their views had been ignored. Whether the hospice management or CEO deliberately set out to ignore the points that they and other service users may have put forward is not clear. On the one hand, it could be argued that the changes at the day centre would have caused concern among some service users however the process had been handled. On the other hand, the consultation methods used by the hospice management for involving service users and the lack of feedback to those that took part suggests an element of tokenism in the approach.

5.2.3 Theme 2: Belonging and alienation relating to the day centre and hospice community.

To recap, attendance for service users at both hospice day centres prior to the organisational changes being implemented was possible on any working day of the week, every week. This was changed to an 8 weeks on, 8 weeks off programme that was described earlier in this chapter.

> When we filled these forms in we were told that it would be done this way and unfortunately (staff member) has done it the way (they) wanted to do it and (they have) cut all these staff out. He [The CEO]'s come along like the big boss and said we want more people to come in – okay, they've now got a Monday and Wednesday group…and you have to make yourself available on Monday or Wednesday. We were told if we didn't like those two days we couldn't come, so what do you do? That's not increasing the amount of people here, that's cutting down the days. I used to come up here twice a week, Wednesday and Thursday, now I've got to do everything in one day and there are limits as to what you can do in 5/6 hours. (Bob).

It is clear in the quotation above that Bob held the CEO as the face of senior management responsible for the introduction of the new attendance regime at the day centre. Bob observed that not only had nurse numbers been cut but the impact of the changes also cut opportunities for service users to attend the day centre and meant less time for them to take part in activities when they were there. Polly had developed a sense of belonging during the time that she had been attending the hospice day centre but the changes had affected that sense.

Bob, Polly and Milly appeared to see the day centre as a vital part of their lives that not only helped them deal with the fact they had life-limiting illnesses but also facilitated the opportunity to pursue worthwhile and enjoyable lives with others aside from receiving clinical care. Stanley had also been visiting the day centre before the change in arrangements but support from his family seemed more important to him possibly because he considered he was at a late stage in his illness. It seems from David's comments that his visits to the day centre provided a welcome distraction not only from his illness but also from feelings of isolation and regret at home compounded by his wife living in a care home some distance away and whom he could no longer visit. Milly lived alone, and although the number of visits she could make to the day centre had been reduced she still regarded it as a vital activity in her life even though the changes provoked feelings of resentment.

> On a Monday, we used to have a group and we would talk about things. Now, it's put down in black and white and you obey like a little kid. Makes me very angry. I didn't obey when I was a little kid, don't expect me to now I'm a big one… We're not in charge, we're not in a position to do anything. (Milly).

Milly's perception was that she was being treated like a child and, as a result, she started to feel disempowered by and alienated from the hospice, Bob expressed concerns about the numbers of staff at the hospice day centre.

> They've cut down the staff. It used to be on a 1 or 2 to 1 basis and now they've cut that down because of budget cuts or whatever it is. In my position I think they should have 2 nurses on because if you get someone ill, because we're all on basic palliative care and coming here for various other reasons to help us progress and deal with dying [pause] they've brought the staff down to a level now where you've got 1 main nurse and then you've got the helpers which are not able to administer anything should anything happen. There's at least 13 people or so in a room and 1 nurse for 13 people is stretching it a little bit. If my driver goes off [syringe driver for pain medication] and there's only one nurse there, it could be a life and death situation. They shouldn't put the staff they've got here now in that position. (Bob).

The cuts in numbers of qualified staff (nurses) at the day centre could have influenced the kind of activities that Bob chose to take part in. For instance, only those activities where the one nurse on duty was near at hand. The cuts in numbers of qualified staff may not actually have presented a "life and death situation" for Bob but his use of these words indicated a real fear in his mind that it could potentially do so. His concern about not putting "staff they've got here now in that position" suggests a previous collaborative or mutual caring relationship between those receiving care at the hospice and those providing it that he felt had been diminished by the changes.

The changes in attendance arrangements at the day centre provided few if any opportunities for service users to gather together informally and decide on socialising activities, for example, in ways that were possible prior to the changes. As well as prompting feelings of alienation and isolation, the inability of service users to meet together informally could also limit their opportunities to discuss with each other about the changes taking place at the hospice. It is reasonable to conclude therefore that the organisational changes had diminished opportunities for service user involvement at the hospice other than those prescribed by management such as satisfaction surveys that could potentially also be labelled as tokenistic exercises.

Opportunities for service users to take part in activities organised by other organisations in the area during their 8 weeks away from the hospice day centre seemed very limited if they existed at all. A sense of deep-seated resentment about this situation comes through from Milly who stopped going to the hospice day centre altogether for a while but eventually felt that because there were no other alternatives, she would start attending it again under the new arrangements.

> That to me is so stupid. If you're dying for 8 weeks, you're going to be dying for the next. No disrespect, but you are. I refused to go back but I've deteriorated so I've gone back. It's the only place I could think of that would get me out of here for a day. I'm here [home] 7 days a week. Before the changes, there was a Monday, Tuesday, Wednesday and Thursday club and you could go in and do art – there were some gentlemen there that loved the art classes, they stopped going ages ago. There is no atmosphere, no jollity. (Milly).

For those service users affected in this way, it could also serve to enhance their feelings of vulnerability due to their life-limiting illnesses as well as the sense that as they were near death they did not matter and had no option but to accept what was available. These are quite drastic feelings for service users receiving care from a hospice to hold and it appeared that even though a number of them expressed them very strongly during the consultation activities they still felt ignored.

As the face of senior management, the CEO appeared to be a lightning rod for a lot of the criticism that was coming through the data. The findings helped prompt my decision to seek an interview with the CEO to delve further into the reasons for the organisational changes, into the issues arising from service user participants and the potential impact on service user involvement. The findings from this interview are presented in section three of this chapter.

In order for service user involvement to be effective, it is important that those who are invited to get involved and take part, such as through a consultation process, for example, feel that they have had some influence on decision-making as a result. Milly said that she believed that staff views on the changes had also been ignored by management. It could be inferred therefore that the lack of meaningful involvement in the organisational changes at the hospice, poor lines of communication and feelings of alienation were experiences shared by both service users and some members of staff.

Bob, Polly and Milly had established a great sense of belonging at the day centre that had been enhanced by developing friendships over a number of years with other service users and staff that helped to make them feel like they were part of a community. They described how these feelings had been thrown into disarray, as they perceived it, by the organisational changes. This seemed to have affected their sense of wellbeing and identity as well as their ability to see themselves as people whose lives and opinions still mattered. These aspects provide the focus for the next theme.

5.2.4 Theme 3: Maintaining and losing a sense of wellbeing and identity within the changing hospice setting.

Prior to the changes in arrangements at the day centre, service users had a say in activities they would get involved in on a particular day, even planning days out with other service users in a spontaneous way. These activities included organising Christmas parties, holding raffles to raise money to pay for a minibus to go on lunch outings, for instance and to visit the seaside. As well as this kind of engagement helping to promote a strong sense of belonging in service users, it could also provide a means for them to maintain connections with the outside world. Polly felt that “people coming in now don’t know ‘cos they weren’t here before to see what it was like before.”

The ability of service users to decide collectively what activities to pursue prior to the changes helped provoke a sense of control and shared purpose that could also have helped enhance their feelings of wellbeing and identity. These feelings appear to have been tested by the manner in which organisational changes at the hospice had been introduced. For example, Polly felt that a new waiting list system and the provision of smaller rooms for service users wanting to attend art classes at the day centre had been a deliberate move in order to discourage attendance. Having to wait for a vacancy to appear in a club membership, for example, might be considered acceptable in general circumstances, but there are very different ramifications for a person with a life limiting illness having to wait in line. For example, they may die before a vacancy appears (and also means someone else may well have died and created that vacancy) or their illness may have progressed to a point where it was not possible for them to attend.

> [We were stuck] in a dingy old room where the volunteers have to walk half a mile to the kitchen to get the dinners – in the old room, the kitchen was there. It’s really made us uncomfortable, it’s claustrophobic, has one door, small windows opening out on to noisy machinery, it’s horrible. We said we didn’t want changes but it was already cut and dried. (Milly).

Being made to feel “uncomfortable” and so possibly unwelcome at the day centre represents quite a cultural shift in the approach of the hospice prior to the organisational changes. The cultural shift as regards day centre use was further displayed by attempts to change its purpose.

> (The CEO) wants to change the big room into a café for outside people But (they) won’t get people in there – it’s at the edge of town and we’ve got more cafes in town than anything else. The garden’s been left to wrack and ruin – I wish I had the energy, I’d do it. (Milly).

A sense of disempowerment, increasing alienation, of not being listened to and a diminishing of feelings of wellbeing and identity come through in Milly’s two quotations above. She further revealed how vulnerable she felt in having a deteriorating life-limiting illness by not having the energy to tidy up the garden herself.

David started attending the day centre after the changes had been implemented and noticed a lack of or very limited response from management to suggestions from service users about activities at the day centre. For example, David wanted a book club set up for service users at the day centre.

> [The hospice management] asked us if we [the hospice] get it [book club] up and running, would you be interested? Yes! Then you wait and wait and suddenly it crashes. They [hospice management] said they did not have enough people to use it. What’s enough? 1, 2, 5, 10? If they’re looking at half a dozen then maybe they should look at their remit of what the book club is actually about. It’s hard enough getting a book club going in the normal sense, some people think I ain’t gonna waste me time on books when I got a month to live or even 6 months to live whatever. What makes a good forum? Maybe they [hospice] were expecting there was gonna be a drove of avid readers comin’ at them, I don’t think so, the wrong establishment for that. (David).

David's experience indicated a top down approach to decision-making at the hospice without any explanation or feedback attached to it. This experience also further revealed that a focus on individual service user wishes at the hospice did not seem to fit with a systems level approach to change that was more concerned with distribution of resources. Although a refusal to set up a book club may have appeared a fairly minor issue, when allied with the waiting list system mentioned by Polly earlier then a possible pattern of chipping away at facilitating the wishes of individual service user wishes starts to emerge. Reflecting on this, fairly quick decision-making and communication of decisions was important to enable service users to live fully in the here and now as they did not know how much longer they may have left. Whether hospice management had actually considered this aspect was not clear at this point in data collection.

Social participation opportunities at the day centre were important for service users who started attending prior to and after the changes in arrangements. David for example said, "mine is more social coming here" although he admitted it was not always welcome looking at other people and reflecting on his own mortality. But the day provided somewhere for him to go even if only one day a week and if this opportunity was not there "no, that'd be the end of the story, like."

Stanley also noticed deterioration in other service users when visiting the day centre and felt quite a strong obligation to appear smiling and strong in front of them.

> Two others in my group have the same condition as myself, not as bad as me, and I know they're weighing me up every time I see them because they know they're progressing to my level. Level 2 with oxygen, I'm level 6 with oxygen. That tells you something about how sick a person might be. I feel a moral obligation to be more cheerful with the group than what I am really feeling. Very difficult sometimes not to be flippant; very conscious that I have a responsibility to make

> light of any sort of involuntary noise that I might make in their presence, no matter how much pain it was causing. (Stanley).

When asked if appearing more cheerful than he was actually feeling was a positive or negative experience for him, Stanley was not able to give an answer, he just expressed the view that he felt a duty to do it. This potentially indicated that Stanley retained a strong sense of his own identity and worth aligned with a sense of responsibility in relation to other people who had the same life-limiting illness as he did but were at earlier stages in the trajectory of the illness.

As the findings under this theme indicate, there was resentment and anger felt by service users at the organisational changes as well as the way that decisions were subsequently taken that affected them. There was also a sense of resigned acceptance and along with the lack of any other options in their local area meant they felt they had no choice but to continue attending the day centre under the new arrangements. Decisions about requests from service users that were lodged through formal channels appeared to be made behind closed doors by management and then handed down or just fizzled out with no feedback.

The three themes presented in this section indicate the tensions that service user participants were experiencing during and after the organisational changes. Four participants felt disempowered and ignored by management in decision-making at the hospice that affected their feelings of self-worth and identity. The depth and strength of feelings are indicated in the quotations presented in this section.

5.3 Service user findings summary

Three overarching themes have been presented and discussed so far in this findings chapter covering the data gathered from service user participants. Each of these themes show a particular tension between contradictory or similar experiences and reflect experiences before and after organisational changes at the hospice. The data indicated that those receiving care at the hospice have needs as patients but also as people aside from their life-limiting illnesses. This included a very strong need felt by service user participants to have opportunities to talk about their situations, have their voices heard and their concerns acknowledged and acted on one way or another.

Bob, Polly and Milly bridged two different approaches to the operation of the hospice day centre both before and after the changes. They indicated that they felt a certain amount of involvement albeit warily from taking part in the consultation activities. Only after the views and concerns they had expressed were either not addressed or were ignored did they start to feel disempowered by the exercise. David also experienced difficulty when getting involved in a formal consultation process about setting up a book club. He discovered that his views seemed to be discounted because he was in a minority. There was a similar thread of hierarchical decision-making running through the management approach to consultation activities that was apparent from the experiences of Bob, Polly, Milly and David irrespective of when they had started attending the day centre.

A sense of belonging and development of friendships between service users and with staff had helped to generate a sense of community at the hospice. The data show that such feelings were thrown into disarray by the organisational changes and prompted feelings of alienation as well as affecting a sense of wellbeing and self-identity among service user participants. The opportunity for socialising and social participation was seen as important factors for service users at this stage in their lives. The organisational changes did not allow for spontaneity in decision-making on their part or for willingly or easily facilitating their chosen activities.

Service user involvement at the hospice appeared to move to a more tokenistic approach. This tokenism was indicated by the consultation activities conducted at the hospice based heavily on patient satisfaction surveys with a few face-to-face meetings. The impression from service users was that they felt the management had already taken decisions before the consultation process began. On reflection, the perceived lack of feedback or responsiveness from management could be a sign that they welcomed some views more than others and possibly tried to exclude those that were perhaps too critical or challenging of the proposals.

> It would be nice if people would just listen – we may be dying but we're not dead yet. (Milly).

The next section in this chapter explores findings from data involving staff participants at the hospice.

5.4 Findings from staff participants

The organisational changes that took place at the hospice from 2013 onwards included the assignment of new job descriptions to existing staff members; new staff being recruited and a reduction in the numbers of qualified clinical staff working at the day centre. The roles of staff participants are included in Appendix 3.

Through thematic analysis of the data, I identified three overarching themes: Understandings of service user involvement and potential barriers in a changing organisational environment; Involvement and disempowerment in changing staff roles at the hospice and Belonging and alienation relating to roles and working relationships at the hospice and the impact on service user involvement.

5.4.1 Overarching themes - summary

1) Understandings of service user involvement and potential barriers in a changing organisational environment.

Different understandings of the nature, extent and limits of service user involvement at the hospice emerged from the data. These understandings appeared to differ depending on the role that a staff member fulfilled at the hospice. A sense emerged that the hospice could be moving towards a more clinical or hospital-style approach in the care it provided. Nurse participants that worked at the day centre were used to regular and direct contact with service users and they sensed that barriers to this were starting to appear.

These barriers included increased workloads caused by reductions in qualified nurse numbers especially at the day centre that meant less time to spend with individual service users. This had an impact on the ability of nurses to facilitate service user involvement activities that they had previously provided at the day centre and described by service user participants prior to the changes being introduced.

2) Involvement and disempowerment in changing staff roles at the hospice

This theme mirrors the theme identified from the service user participant data in that staff also felt a sense of tension between their own involvement and disempowerment due to the organisational changes. Staff participants had an opportunity to take part in consultation activities conducted by the management but a number of them felt that management had already taken decisions outside of the consultation. This included decisions on changes to specific roles and job descriptions. Any possible impact that the organisational changes might have on staff previously engaged in facilitating service user involvement activities did not emerge from the data.

3) Belonging and alienation relating to roles and working relationships at the hospice and the impact on service user involvement.

The sense of belonging encapsulated the apparent need of staff participants to feel part of the hospice community. The fact that longstanding staff had been made redundant appeared to be a relatively rare phenomenon at the hospice prior to 2013 and seemed to prompt feelings of insecurity among staff as well as among service users. Data from service user participants indicated that staff members were discussing their reservations about the changes with service users in private. It could be argued that such conversations were as a result of relationships and trust between staff and service users that had been built over time. These conversations also potentially indicated that staff felt they had limited outlets at the hospice in which to express their real views.

The three themes reflect the impact of the organisational changes on staff participants at the hospice. A critical assessment of the influence that the changes had on staff perspectives and understandings around service user involvement became quite complex. The changes in arrangements at the day centre had a big impact on the ability of current staff to continue facilitating social participation and involvement activities for service users in the ways they had been doing prior to the changes.

The three overarching themes filter through the data in an intertwined manner and are explored separately in the following sections.

5.4.2 Theme 1: Understandings of service user involvement and potential barriers in a changing organisational environment.

Understandings of the words ‘service user’ and ‘service user involvement’ varied between staff participants and seemed to depend on the roles they had at the hospice. A number of participants referred to the annual patient survey or audit that had been conducted at the hospice over a number of years as an example of service user involvement. An in-patient nurse, for example, believed that such an audit “gives people at the bottom, if you like, the power to influence things and improve things.” Unpacking this comment revealed a number of assumptions. For example, a belief that an audit empowers people that take part in it and that the comments that come through will be acknowledged and acted on even though there might be no particular evidence to show that this is the case. The comment also implies that the in-patient nurse believed decision-making was correctly in the hands of those at the top with others given their chance to contribute once a year.

A nurse manager believed that the words ‘service user’ was a term that referred to patients and also relatives, carers and friends and those using day centre and community services. The nurse manager also described service user involvement as the way that people are able to have a say in the way their care is provided. She was aware of the service user group at the hospice and believed that it provided a formal means of involvement. She perceived there was also an informal way of achieving involvement through the use of individual care plans where service users would be involved in writing the information contained in them.

The quotations mentioned above seemed to imply that the two nurse participants viewed service user involvement on a broader scale as an activity that happened elsewhere such as through the hospice service user group for example. Otherwise, such involvement seemed to be viewed as an individual activity that happened solely around the provision of care services. Other staff had different understandings of the words service user and who was covered by it.

> A service user would be someone who uses our services. First patients and families and then other organisations that we interact with, that we supply a service to whether that be education, support to GP practices and improve their awareness of palliative care. (Personnel Manager).

The quotation above revealed a much broader view of who a service user might be that included a belief that some staff would fall under the term. The personnel manager expressed a similar view to the two nurse participants quoted above that service user involvement was achieved through individual care plans. An educator at the hospice regarded external staff receiving training at the hospice, including students, as service users because they were using services provided by the hospice. The idea that staff could be regarded as service users was put forward by two staff that did not have direct contact with service users (that is, patients) at the hospice as part of their roles. It could be inferred that having a more outward facing role that involved interactions with external individuals and organisations could potentially blur the meaning of 'service user' as well as the meaning of 'service user involvement.' This line of understanding implies that service user involvement could potentially be seen by some staff as an activity that can occur among professional staff thus adding to complexity of understandings.

Staff participants were asked about the service user group at the hospice. The in-patient nurse did not appear to be aware of it, even though she had worked at the hospice for 12 years, or what it did. With her role in the in-patient unit, there was more understanding in her responses of the potential for informal and individual participation or involvement of service users in their own care rather than their ability or necessity to influence decisions on a wider scale.

A counsellor participant had previous personal experience of being a member of a service user group. The counsellor was aware of the hospice service user group and was aware that it had some influence on decisions concerning the day centre during the organisational changes. The counsellor seemed to believe that the service user group was quite powerful although perceived that the caregiving voice in the group might be stronger than the service user (patient) voice. He also thought that by providing the means for a collective voice, the service user group was stronger than individuals in trying to influence decisions.

> Day services were going through a huge change. Service users used to come for the whole day for therapies, meals, social things. But the hospice was moving away from that and said it was ditching the groups. There was a big uproar and so they kept the existing groups…The service user group [at the hospice] had a lot of meetings about it. The collective voice made them [service users] heard. (Counseller).

The opportunity for service users to meet together and discuss issues among themselves as well as fill in surveys was felt by one nurse to be a worthwhile exercise that could provide useful feedback.

> I do wonder sometimes about the tick box exercises of surveys and the limitations of people putting their handwritten thing that they hand in and how much that limits the honesty that might be expressed there, you know. [There are] formal periodic opportunities for service users to feedback on the quality of care and experience of the hospice, but I'd also like to see regular focus groups as well - that sort of forum felt to be genuinely neutrally held [before the organisational changes] and I think it's a good way of people feeding back. (Day Centre Nurse).

The quotation above hinted at a desire for a move back to some arrangements for service user involvement in the form of focus groups that the hospice was operating prior to the organisational changes being implemented. Socialising was an important part of involvement too in the day centre nurse’s estimation.

> Social context is very important, a place where people can share, they can forget, they can be themselves, they can feel listened to, there’s a whole lot of benefits that come from creating a social context that spills into the other areas - don’t divide up these artificial ways. To my mind it’s core and very important anyway. (Day Centre Nurse).

The importance of a social context enabled service users from this nurse’s perspective to feel comfortable and feel as though they were being listened to that “spills into the other areas.” This view contrasts with the views expressed in earlier quotations in this section when social context was not mentioned in relation to service user involvement and was perceived as only being about provision of care services.

> Staff can sometimes be too parental in their approach towards patients. Some patients were really frightened about the prospect of being in a hospice and so talking with them about what care they would want and planning for what happens when the symptoms get worse was considered a step too far. It puts professionals off, we like to think we can be sensitive to a patient when they have been given a diagnosis and don’t want to overload them with anything else. (Nurse).

The quotation above indicated a potential barrier for staff when trying to initiate conversations with service users about the kind of care they wanted and how much they wanted to be involved in decisions about it. But it also indicated that perhaps personal fears and perspectives of staff could act as barriers to attempting such discussions indicating a desire not to want to risk upsetting service users. There was general acknowledgement from participants that individual service users could have involvement in decisions about their own care, on admission and through patient surveys and audits, although some caveats to that involvement were put forward as described above.

The service user group at the hospice has been mentioned earlier in this section. There was an implication that service user involvement at the hospice was potentially made stronger by the presence of family and friends advocating on behalf of service users.

> It [service user group] has lots of influence. For example, transport services - people were going to have to find their own way [to the hospice day centre] and now it's been kept the same as before. There weren't going to be any kind of drop-in sessions for big groups and that changed. The service user group fed into hospice decision-making, for example, the trustees who have joint meetings with the service user group. The service user group has become more powerful than when I first joined [the hospice]. Done a lot on recruitment; more carers on it who lost someone; about 25% of people [on it] are receiving care but not right at the end of the journey-hard to catch. (Nurse).

The above quotation seems to imply that family members whether current or previous carers for a service user at the hospice acted as advocates for service users through the service user group especially during the organisational changes. It was interesting to reflect that when service user participants were asked during the interviews whether they were aware of the hospice service user group, they all responded that they did not know about it or what it did.

Following a discussion with the chair of the hospice service user group prior to my data gathering activities, I noted in my PhD journal that the chair had told me they did not speak to service users about the organisational changes and did not seek to get security clearance for members of the group to do so. On the one hand, this could potentially imply there was a potential disconnect between this group and service users at the hospice generally especially those using the day centre. On the other hand, it could also imply that informal channels of communication were being used from service users via family carers to the group that they then acted on. It became apparent that service users with cancer and their families had a strong voice at the hospice via the service user group. The counsellor believed that a local cancer network was very influential with their contacts to health professionals in the area. The implications of such influence are discussed more fully in Chapter Six.

Senior management participants appeared to have knowledge about the hospice service user group and the activities it engaged in.

> The service user group has influenced the content of advanced care plan forms and these are now being used countywide, not just at the hospice. It took two years for the care plan forms to be devised with the user group pushing strongly for it to be a patient-held document. Also when the hospice management are thinking about strategic matters, the opinion of the hospice service user group would be sought. (Senior Educator).

The quotation above from a senior educator at the hospice presents wider knowledge of the work of the hospice service user group compared to other staff participants. This is due to the fact that the educator attends senior management meetings and would be privy to information being fed into such meetings. The educator expressed a view that a representative from the service user group should attend senior management team meetings to take part in decision-making that did not happen at that time. The reasons why this did not happen did not emerge from the data. It could be implied that hospice management did not see a role for the group being involved in decision-making around staffing or wider hospice issues. Even with a hospice service user group presence on various committees, it could not necessarily be construed as evidence of effective service user involvement at the hospice. Such a presence could mean one person attempting to act as a conduit for a whole community of service users and caregivers but actually only perhaps being representative of particular sections of that community. Service user participants were not aware of the user group's existence and their views could therefore be missed.

5.4.3 Theme 2: Involvement and disempowerment in changing staff roles at the hospice

As with the service user participants, some staff participants appeared to have an initial expectation that if they took part in the consultation activities at the hospice then their views could potentially have an influence on decisions around the organisational changes. As with the service users, for some staff this expectation was short-lived.

> There was a 'consultation period,' there were several factors presented at the beginning of that consultation period that seem to have been decided already [and] the extent of the changes surprised me [it seemed to be] management behind closed doors talking about the changes. (Day Centre Nurse).

The words 'consultation period' in the quotation above have single quotation marks around them to show there was an indication of irony in the tone of voice in which this comment was made. A sense of resentment permeated this quotation about decisions being taken in secret considering the extent of the changes taking place. The Day Centre Nurse also sensed that service users experienced similar reactions to the consultation activities at the hospice.

> Some of the things were, eventually did shift, but I know that there were with some service users, a dissatisfaction and anger in the fact at how some of the changes seem to have been decided on without earlier consultation. It could have been presented: these are the issues we face nationally, what are the possible solutions we can come up with as a collective, but that didn't happen. To my mind that would have made the process a whole lot smoother and would have made things a lot less stressful for service users and would have been more representative of those service users and have an opportunity to be represented properly at the beginning. (Day Centre Nurse).

The quotation above indicates awareness that some of the decisions taken early on by management outside of the consultation process had to be altered. It could also be inferred from this quotation that there was a desire for staff and service users at the hospice to be viewed as a community that could have provided potential solutions in a collective way.

An on-line staff satisfaction survey was operated by the hospice but it was not clear whether this method was available to both staff and volunteers, was used widely or had any tangible effect on the hospice.

> The organisation has grown massively, particularly recently and there are always things going on that we don't know about. I would like to have a lot more feedback but I'm not sure how honest people are in feedback; have questionnaires for people who want to feedback and they cover all areas. It would help our growth and understanding to have much more contact with patients and families but it's practicalities, isn't it? (In-patient Nurse).

Part of the practicalities mentioned in the quotation above also seem to relate to changes in roles and job descriptions due to the organisational changes that had an impact on a number of staff participants and affected their previous ability to interact more closely with service users.

> I do feel, in the last few years, there has been less time to do psychological care, the chatting, but then we've had different roles step in as well [such as] family support that had been more ward based so it's been taken away from our role and added to another role. (In-patient Nurse).

A "homely environment" was how the in-patient nurse described the culture at the hospice prior to the organisational changes with staff wearing polo shirts and carpet on the floors. Her perception was that the hospice was becoming more clinical in its approach and the homely atmosphere was declining. The nurse regarded this as a "shame" but believed it to be necessary because of “legislation, particularly on infections” and believed that “sometimes it’s a compromise.”

A flexible and less formal approach within the hospice prior to the organisational changes being introduced, appeared to enable an element of control for service users that was then diminished fuelling feelings of resentment. For staff it seemed to be a question of adapting and carrying on as required with the organisational changes whether or not they agreed with them or felt any resentment. It also appeared that informal methods of communication between certain staff such as nurses and service users at the day centre continued to a certain extent during and after the organisational changes and indicated a potential desire for such interactions to continue from both sides.

The data showed therefore that staff appeared to have differing perspectives on the role and influence of service user involvement at the hospice. These perspectives seemed to rely to some extent on the particular roles the staff fulfilled. For instance, the in-patient nurse seemed to accept that service user involvement was very much a formal and management level pursuit and that service user views could influence decisions through patient satisfaction surveys for instance. Perspectives on the effectiveness of formal methods of consultation and their potential for enabling those taking part to affect decision-making seemed to be influenced by a notion that if there was a visible presence of these activities, such as people filling in forms and surveys, then it must automatically mean they will have some sort of influence. However, as mentioned previously in this chapter, the use of formal methods of consultation can be tokenistic and used as a way of giving an appearance of involvement and influence but in fact do not do this.

The problems mentioned by the counsellor that followed initial changes to arrangements at the hospice day centre indicated that formal methods of consultation had not enabled individual service user voices to be heard. However, collective action via the hospice service user group appeared to the counsellor to have influenced management and led to amendments to previous decisions in order to try and allay service user concerns. The counsellor also mentioned the fact that the local cancer network that operated in the local area was particularly strong and in his view had an influential voice at the local hospital among health professionals that worked there. The possibility that service user involvement and its effectiveness and influence might be connected to particular conditions, such as cancer, are discussed in further detail in Chapter Six.

The use of consultation activities at the hospice perhaps provides an example of management trying to give the impression of empowering service users and staff by appearing to involve them in decisions about the changes. At the same time however, management kept hold of the reins of ultimate decision-making by controlling the limits of that empowerment. Management plans for the day centre were altered only when service users acted collectively outside the consultation activities via the hospice service user group to protest about some of the changes. This kind of recourse was not available to staff.

Reflecting on the organisational changes at the hospice, such an experience could potentially incline the management to try and embed the hospice service user group more tightly into the overall system and structure. By doing this, the management could then potentially monitor and control the group more tightly and hope to avoid any further problems in the future. This aspect is discussed further in Chapter Six.

5.4.4 Theme 3: Belonging and alienation relating to roles and working relationships at the hospice and the impact on service user involvement.

As mentioned at the start of this section, the sense of belonging encapsulated the apparent need of staff participants to feel part of the hospice community that emerged from the data of those staff that had been at the hospice for a number of years prior to the organisational changes. This community sense was enabled, for example, by the holding of regular hospice-wide staff meetings covering all roles that also allowed for social interactions across different disciplines. The sense of alienation started to arise in 2013 when the hospice-wide staff meetings were discontinued.

Along with role changes, there was a perception that there had been an increase in the number of staff at the hospice but uncertainty about the areas where any new staff had been appointed.

> Been through a big period of change throughout the hospice…and it's been quite hard for people, bucking against change; not particularly happy with things. I'm now managing staff who I had previously been working alongside [and it has been] quite difficult. (Clinical Nurse Manager).

The feeling behind this quotation above indicated an attitude towards change that might be the perspective of anyone in many working environments that had been promoted from the shop floor, as it were, into a management role that involved supervising others who had previously been colleagues at the same level. It also indicated awareness that other staff were finding the changes difficult and possibly fostered a sense of resentment as a result. The clinical nurse manager seemed to feel that this promotion could have added further to feelings of discontent that potentially could be an alienating force between her and other staff.

An indication of where new staff were being appointed is highlighted by the moving of a number of departments originally based at the main hospice site to other offices a few miles away. The departments that were moved included marketing, finance, IT and personnel that did not have direct interaction with service users. These departmental moves could lead to the perception that work carried out at the main hospice site was to be confined to providing clinical services. The moves could also potentially engender feelings of alienation between different members of staff depending on the site they worked at as well as a further chipping away of a sense of community among all those working at the hospice.

> We have moved from an on-site in-house team where we see and speak face-to-face with a lot of individuals from different disciplines to one where now, off-site, it is more structured. People have become

> less visual to us but I think we have become more strategic in the things that we do with the end user in mind, not losing sight of what we're here for and what we do and work for. It's about what can our team add to the bottom line to create more funds to provide clinical services. We constantly think of how we can do things better to improve the reputation of the hospice and improve the work and lives of our employees. (Personnel Manager).

The quotation above appears to indicate that a slicing away of particular functions helped to enable a more structured and therefore potentially more effective approach to the particular work area. It is interesting that the personnel manager mentioned funding towards clinical services as a primary aim rather than going towards socialising activities for example and the importance of reputational activities. But having distance was not all positive.

> A slight negative for me is because I'm slightly detached from the nucleus [of the hospice] and the patients within it. Not because I see patients often but sometimes I feel I could be a support service for any organisation because we are remote. I'm quite lucky because I do come in and out of [the main hospice site] quite regularly but some members don't, so you lose the visual attachment to the patients, if you like, and engagement with other members of staff. (Personnel Manager).

The personnel manager regarded himself as lucky in being able to regularly visit the main hospice site that enabled him to keep hold of a visual sense of the organisation as well as some links with other staff. The comment that the offsite departments could be a support service for any organisation could further indicate a potential softening of the ties that previously bound the hospice together as a community operating on one site.

I took the opportunity to interview two hospice volunteers during my fieldwork. Although unpaid, they seemed to have important and varied roles. These roles included gardening; nurse helpers; ward helpers; complementary therapists; kitchen helpers; hairdressers and drivers. Many of these roles meant interacting with service users and staff at the hospice. Indeed, service user participants mentioned that they formed friendships with those volunteers that provided them with regular car lifts to the day centre and, after being driven home, service users would invite volunteers into their homes for a cup of tea. With the organisational changes, this kind of invitation to tea was discouraged for reasons that were not particularly apparent to service users or volunteers. This represented a further potential strand in the story of disconnect, disempowerment and alienation from the hospice felt by the different participant groups.

The numbers of volunteers at the hospice may have increased since the start of the organisational changes and one volunteer participant conjectured whether this could mean a management intention to replace staff with volunteers. There were well over 1,000 volunteers at the hospice at the start of 2016.

> The hospice could not function without volunteers and I'm not sure if the volunteer centre is managed as well as it could be. The bulk of people here are not paid so they should put more resources in. There is training for volunteers and they are accredited so they should be treated better particularly if they are giving up time and money and if they're not supported, they get angry. A lot of volunteers are professionals in their own rights – charities could not survive without them…take them out now and everything would grind to a halt in this hospice. (Volunteer 1).

The quotation above indicated a perception that the hospice was potentially moving towards a different model of care involving more volunteers taking on what could be referred to as supportive roles. This could lead to paid staff focusing on the direct contact roles with service users possibly with an emphasis on the clinical side of care.

> I sense a pressure towards medicalisation of palliative care. There are some external vibes in terms of the complexity of treatments that are available to people now that’s all good and well but I have felt at times that it is squeezing the psychosocial softer qualities that we bring that, to my mind, are equally and sometimes more important. (Day Centre Nurse).

The quotation above provides a hint of possible tension with the perception that emphasis is moving towards a clinical or medicalised approach to care at the hospice that could potentially bring its own problems.

> There’s a lot of arrogance in the orthodox medical profession unfortunately and that gives a very narrow view of healthcare to the detriment of people receiving that healthcare. There should be a healthy and holistic approach to it with patients having an awareness and having control of their own health. (Complementary Therapist).

The complementary therapist did not necessarily view the organisational changes at the hospice as a problem. She seemed to welcome an increase in interaction with nurses at the hospice but did seem to be aware of some hostility towards her role from what she referred to as orthodox medical professionals. It could be inferred that there was some tension between different areas of expertise that staff were fulfilling at the hospice as the organisational changes came in and new staff were being appointed. It did not necessarily mean they acted as forces of alienation although this seemed to depend on where the new appointees were based either at the main hospice site or at the offices off-site.

Formal preparation of staff at the hospice for the impending organisational changes appeared to have been limited but the effects of the changes did have some positive results for one staff participant.

> No formal training to deal with changes but do have reflective sessions where we sit with some of the counsellors from the hospice and talk about things that have happened on the ward and reflect, support each

> other. It’s very beneficial. Everyone feels better supported than previously and that they are listened to. When these happen, the floor is covered with bank staff so whereas it used to be where 1 or 2 staff were able to go and the rest would be rushing around the floor, don’t have this anymore, all staff go, it’s mandatory really. (Clinical Nurse Manager).

This particular change mentioned above appeared to be welcome when compared to how reflective sessions had been handled previously before the organisational changes were introduced. The effect on service users of having bank staff provide their care while these reflective sessions took place was not mentioned. It could be inferred that the reflective sessions helped to encourage a greater sense of support and belonging but perhaps more of a professional belonging rather than a sense of belonging to a wider hospice community.

The findings under this theme indicate that the moving away of certain departments from the main hospice site to another site a few miles away could potentially signal a split in the hospice community that could add to feelings of alienation. The change in operation of the day centre caused some staff to feel they had less time to engage in interactions with service users than they had been able to previously, outside of providing necessary medical care or to facilitate activities on behalf of service users.

5.5 Staff findings summary

Three main themes have been presented in this section and a key point that emerged from the data includes a general belief among staff that service user involvement is primarily concerned with care provision and services. This was the case irrespective of whether staff participants believed the term covered not only patients or families but also GPs or external staff groups who came into contact with the hospice for training purposes for example.

There was a general view among staff that service user involvement was not an activity that could or should enable service users to have broader influence over decision-making at the hospice. This view seemed to depend on the particular role of a member of staff. For example, the day centre nurse, counsellor and senior educator viewed service user involvement as covering broader decision-making and involvement activities at the hospice. The in-patient nurse considered it was all handled in the main through annual patient surveys that gave service users “a little bit of power.” The amount of social interactions possible with service users appears to account for some of this difference.

There was a general awareness that the hospice had a service user group but not much knowledge about what it did. The senior educator who was also a member of senior management decision-making bodies at the hospice was aware of it from a hierarchical perspective, that is, due to a service user group representative attending some senior management meetings and also being a trustee of the hospice. The counsellor was also aware of this group but for a different reason. He had seen the impact it had acting as the focal point for channelling collective objections to initial changes in arrangements at the day centre. However, reflecting on this view, it seemed that this group might only have provided a collective voice for those that were members or had connections with members of the group rather than for service users across the hospice.

The data and main themes indicate there were some shared tensions felt by staff and service users. These tensions were in relation to concerns and worries towards the organisational changes taking place at the hospice and the potential impact they could have on relationships and work practices. For example, for the day centre nurse it meant having less time to spend talking with service users and only having time to administer to their physical and clinical needs. The data also show that a lack of time to talk with staff and reductions in numbers of qualified staff at the day centre was also noticed and regretted by service users who felt they were losing important connections.

5.6. Public records, hospice CEO and managerialism

Analysis of data from interviews with service user and staff participants indicated that the hospice could be introducing a business or managerialist approach to its operation. New appointments at a senior level including a new CEO occurred at the same time as the organisational changes were being introduced. I felt this situation warranted further exploration particularly in regard to possible influence on service user involvement at the hospice.

Further data were therefore generated from two sources, firstly, written public sources about the hospice that involved a search, analysis and comparison of online hospice accounts and provided clues about the changes in the organisational and managerial approaches at the hospice during the years of my study, and secondly, the new hospice CEO who took up the post just prior to the organisational changes being implemented. I felt it was important to understand the new organisational objectives, the reasoning behind the changes and whether the implications for service user involvement had been considered.

A review held by the hospice that took place before the start of my fieldwork was, according to the data, intended to identify the kinds of risks that the hospice could face, the potential impact of such risks and ways to mitigate the impact. A big part of the reasons for this review included the belief that the role of hospices was changing and there needed to be a considered response to such changes to ensure the hospice could sustain its position into the future. Decisions around the reorganisation appeared to be taken for the purposes of sustaining and developing the financial health of the hospice as well as broadening its reach and were significant factors to emerge from the data. The cost of operating an independent hospice will vary of course, depending on its size and reach but, generally speaking, it necessitates a hospice raising millions of pounds annually.

The data generated from the CEO indicated an intention for the hospice to move towards a more business-like approach in its relationships with external bodies. This intention appeared to be partly driven by the wish for hospice care to be seen as a concept rather than a building that could provide a holistic approach to care and then drive such a philosophy across the wider health and social care system. Part of this thinking on the part of the CEO appeared to be the recognition that although the care being provided by the hospice was reaching certain people, there was still an unmet need and there was a desire to address this unmet need. Reaching out across the health and social care system included establishing links and working collaboratively with NHS bodies such as Clinical Commissioning Groups, for example, as well as with local GP and community health services. This kind of approach also included dealings with other UK hospices by forming partnerships for certain activities such as procurement. During interview, the hospice CEO considered that the voluntary sector, unlike the public sector, could use a range of tactics to help deliver change and deliver improved outcomes. There was also a belief that this could be achieved on a larger scale than one hospice organisation and more broadly than palliative care by using “sometimes quite commercially-driven approaches with a sense of clear values and a clear sense of mission around, you know, improving health and care” (hospice CEO). The CEO also held the view that hospices had traditionally focused on fairly specialist needs but by turning them into something that was much more fundamental to a system then the principles of what hospices do could be scaleable and deliverable to more people.

The words “delivery of services” that appeared in the data are often used to describe how health and social care systems provide care for people. It implies a perspective that service users play a passive role and yet their ability to play an active role in their own care with a degree of involvement in decision-making around it emerged as an important element of care in findings from a number of staff participants at the hospice particularly the nurses. The ability to have some control over their activities at the day centre was also cited by service user participants as being an important factor for them in helping to maintain independence and feelings of identity that were explored earlier in this chapter. So there was a potential tension between ambitions for scaling up the activities and reach of the hospice while running the risk of potentially alienating service users and possibly staff particularly while the operational and structural changes were taking place.

The changes included an internal reorganisation of the hospice structure that involved separation of activities at management level. For example, a governance committee comprising senior managers from across the hospice was established to oversee risk management at a corporate level while clinical tasks were to be overseen by a clinical committee made up of trustees and staff. A representative of the hospice service user group was a member of the clinical committee and attended meetings but was not a member of the governance committee at the time. This hinted that there may have been a management view that the service user group should be concerned with clinical and general care issues at the hospice rather than being involved in major decisions affecting the hospice overall. This points towards a managerialist approach that had implications for service user involvement at the hospice. This approach is further indicated by the terminology used in the public records to describe the approach of the hospice in developing external partnerships such as, for instance, “maximising efficient spending” and “open data and trends to assist hospices maximising value for money” (Hospice Report and Accounts). This type of language would not be out of place in a private sector business.

Another hint of increasing managerialism at the hospice was indicated by the moving of a number of departments, such as marketing, finance, fundraising and personnel, to another location with care, clinical and nursing services remaining at the main hospice site. The departments that were moved, according to the data, would be following a more business-like approach in their work. While there may be very good reasons for any organisation changing the physical location and practices of particular departments, it could potentially lead to problems with communication and co-ordination across the whole organisation. While there were formal methods of decision-making through the management committees, the departmental location moves could reduce the opportunities for informal lines of communication between management and staff to sort out potential problems, for example, or for offering encouragement and support. Cornell and Nwoka (2015) suggest that a systems level approach to management relies on an organisation being seen as a system that has integrated parts that need to be co-ordinated to promote efficiency. Any inefficiency in communication and co-ordination between staff and management could potentially have an effect on communications with service users and on service user involvement

The public records showed an increase in the number of volunteers at the hospice over the years of my fieldwork. A possible reason for this could be a stronger focus on fundraising activities for enabling the hospice to sustain itself into the future. Figures indicating a year-on-year increase in bed occupancy at the hospice featured in the data along with an increase in throughput of service users, increased capacity at the day centre and another increase in visits to people living in the community that needed palliative care. On the one hand, it could be considered that these are welcome developments, as they appeared to show more service users in the locality were receiving palliative care. The CEO implied that the services must be good as the annual patient surveys regularly showed a very high satisfaction rate among service users, for example, as high as 95 per cent rating it good or excellent. On the other hand, there was no information provided in written reports about the quality of the care being provided or the experiences or involvement of service users receiving care or using other hospice services. It can be concluded that the hospice reports and accounts strongly indicate that significant organisational change was taking place at the hospice that involved a move towards a corporate, business-like and managerialist approach in its governance.

The organisational changes at the hospice could be viewed on the one hand as positive actions that had been taken in order to ensure the survival of the hospice and could lead to an extension of its services. On the other hand, it could be said that these kind of systemic changes could turn a hospice into another sort of organisation completely.

The interview with the CEO followed the same structure as with other participants. The aim was to understand the CEO's perspectives on service user involvement in palliative care and at the hospice and also on the organisational changes. The CEO was aware that I had interviewed service user and staff participants from across the hospice prior to this interview. This meant that I was able to ask questions about the issues that had emerged from the data collected previously.

Two key themes emerged from the data gathered from the interview with the CEO. Firstly, there were implications of a managerialist approach being adopted towards organisational changes at the hospice. This was also indicated in the public records where the remit of a new CEO was described as being to deliver organisational change. Secondly, service user involvement at the hospice being increasingly framed as consumer engagement with a focus on rehabilitation. The terminology used during the interview indicated very strongly that the CEO regarded service users receiving care at the hospice as consumers, a term perhaps more usually associated with those wishing to buy good and services.

The background of the CEO is relevant to mention here as it adds to the idea of the kind of significant organisational change being desired by the hospice. The CEO had management and commissioning experience in the NHS and other public sector organisations and indicated a whole systems and population-level interest in service delivery. The voluntary sector was perceived as offering more flexibility and autonomy in affecting change.

> There’s been big cultural differences and practical differences, I think, working in the public sector than in the voluntary sector. I sort of think of it (voluntary sector) as the best of both worlds – actually making stuff happen, delivering change, delivering better outcomes is easier in the voluntary sector ‘cos you can use a range of tactics and techniques to do that, but you’re applying all of those sometimes quite commercially-driven approaches with a sense of clear values and a clear sense of mission around, you know, improving health and care. (CEO).

Delivering change was therefore a crucial aspect of the CEOs remit and potentially doing so in a “commercially-driven” way as mentioned in the quotation above. It could be claimed that the CEO being regarded by at least three service user participants as a lightening rod for criticism of the organisational changes was understandable to a certain extent, in their minds at least. The CEO had not been involved in the original decision taken by the hospice to undergo significant changes but had been appointed to deliver them and therefore represented the internal face of those changes to service users.

The CEO also talked about opportunities for improving outcomes on a larger scale than one hospice organisation and more broadly than palliative care.

> I don’t think hospices are anywhere near commercial enough in their thinking to be perfectly honest, um, I think they’re quite cosy and quite protective and precious about how they approach delivering their care and their services. I think rather than just perhaps focusing on being a niche provider of superb care to a lucky few, actually thinking about how do you drive a philosophy of care across the wider health and social care system. I think that’s an entirely different challenge that, for me, is much more engaging and exciting and the possibilities of getting that right in the context of demographic change, and seeing how far you can take hospice care and making it something quite different and much more fundamental to a system, I think that is really interesting. (CEO).

A sense of enthusiasm and energy emerges from the quotation above in trying to create transformation in hospice care that could enable it to lead change and drive a philosophy of care across the wider health and social care system. The CEO also believed that hospices are generally quite small in the scheme of things and focused on fairly specialist needs whereas they should be willing to grow substantially and get much more involved in service delivery and form more partnerships with other organisations. The words “delivery” and “deliverable to” used in the data from the CEO are often used in health and social care systems. It implies a perspective that service users play a passive role and yet their ability to play an active role in their own care with a degree of involvement in decision-making around it emerged as an important element of care in the findings from a number of staff participants at the hospice particularly nurses. The ability to have some control over their activities at the hospice day centre was also cited by service user participants as being an important factor in helping them to maintain a certain amount of independence and feelings of identity that were explored earlier in this chapter. So a potential tension emerging between ambitions for scaling up the activities and reach of the hospice while running a risk of alienating current service users and possibly staff.

The CEO had views on the long-term future of the hospice and hospices in the UK generally and the implications for long-term planning.

> In 10 years, undoubtedly, we will be a much bigger organisation when you look at demands for our services - not just growing demand for hospice care as it's currently configured, I think it's that combined with the fact when you look at the overall economic environment and public expenditure, the gaps in NHS and local authority social care etc are only going to get bigger. I think we'll have a much more mixed model of delivery, some of it will be paid for, some of it won't be paid for, some of it will be state funded, some will be voluntary funded, personal budgets. (CEO).

Such a move on funding, as described in the quotation above, could enable hospice services to reach more people and with growing populations and increasing demand then this could be a good thing. It could also lead the way to the potential development of a consumer-type model of care. This is not to imply that such an approach would necessarily be a bad thing as the use of personal budgets, for example, could potentially empower individual service users that could then help to drive more personalised and flexible care. The CEO also considered that such an approach to funding could provide a way of addressing any funding gap as it could open the way for people to top up and that a consumer-led model of hospice care could better meet hospice funding challenges of the future. Reflecting on this, however, it occurred to me that a mixed model of delivery could also potentially introduce different levels of care between those who could afford to pay for extras themselves and those who were not able to.

The experience of hospices in the past, as the CEO pointed out, was that they could rely on a core amount of funding through a grant from the local authority or the local NHS. Such grants are now open to competition and the grants are becoming contracts with some hospices losing out and ending up in sub-contracting arrangements sometimes with other for-profit providers. So it could be argued that a competitive funding environment is already underway and hospices need to respond effectively in order to sustain their futures. Whether hospices are currently competing with each other for funding contracts is not clear and perhaps this is a topic for further research and, if it is occurring, an exploration of the implications.

The issue of funding and competition could provoke a move towards hospices in the UK taking a similar approach to hospices in the USA whether they were wanting to or not, but doing so in order to survive. The insurance-based system of hospices in the USA is briefly described in Chapter One of this thesis and points out that a large proportion of them are for-profit. Such an outcome would have an impact on what could be called a more traditional hospice culture. It would also have an impact on relationships between staff in different disciplines; between staff and management; between staff and service users and between service users and the hospice. There would also be fundamental implications for service user involvement in palliative care generally and in hospices if service users were to be regarded as consumers provided by an insurance system of payment.

The findings from four service user participants in this study that had been visiting the day centre on a regular basis for some time before the changes were introduced indicated that there was upset and disappointment with the process. From their perspectives, they felt their views had not carried any weight and had been ignored by management. There was recognition by the CEO of the difficulties that the organisational changes may have caused for current service users.

> With some of the changes we put in place around some of our service models where we did talk to service users a lot before we made the changes, we did a lot of workshops, we did a lot of face-to-face meetings and things, but despite doing all of that, it created a huge anxiety for our current service users. I think what they were fundamentally struggling with was, they didn't disagree with anything we were doing in terms of our plans for the future, what they had a problem with was what we were doing with them currently was a core part of their, you know, their ethos and changing something that affected them personally, here and now, when their prognosis might be quite short or where there is a lot of uncertainty in how they're feeling about things anyway. (CEO).

Following on from the quotation above, using hindsight to reflect on the changes and how they were handled, there was recognition from the CEO that perhaps some of them should have been approached in a lower key way and on a more informal basis rather than heralding them as big changes coming in all at once. It was felt that such an informal approach might have helped to assuage some of the anxiety felt by some current service users. Learning from this experience, the CEO commented that any future developments or improvements in current services would be achieved in a much lower key way.

What emerged from the data is that service user involvement using a managerialist approach may mean having to take account of the views and input of other ,s some of whom may carry more influence than the views of service users/patients. These stakeholders, for instance, could include hospice volunteers, people living in the community that are asked for their views on what the hospice is doing and perhaps other local care organisations that may have sub-contracting arrangements with the hospice. It could be argued that this would seem to further position service users/patients as consumers. Beresford (2016) contends that the neoliberal model advanced by government for cutting back public welfare systems and privatising public services advances the approach of seeing service users as consumers who pay for services. This author also talks about the difficulties of trying to fit a consumerist model of care on to service users that have life-limiting illnesses. It could be argued that viewing service users/patients as consumers in a hospice context may require the invention of a different kind of managerialist approach, perhaps a hybrid model that seeks to maintain the traditional hospice movement ethos while borrowing business approaches for certain aspects of the hospice's functions such as those concerned with generating income, for instance. These issues are discussed more fully in Chapter Seven of this thesis.

As described earlier in this chapter, the change in arrangements at the hospice day centre caused consternation among four of the service users interviewed in this study. This change involved a move to a 8 weeks off, 8 weeks on standardised arrangement at the day centre. During the 8 weeks on, service users would be able to visit the day centre for the day rather than for attending an appointment; during the 8 weeks off, they could only visit to attend appointments. Previously, service users could visit the day centre on any weekday and stay for the day. The new arrangements involved service users choosing from a menu of options and making appointments for attending the day centre to carry them out. If all service users are choosing from the same menu it would help make the delivery of care more efficient and effective. What it would not allow for is spontaneity on behalf of service users about what they would like to be doing at any given moment or much flexibility as regards their changing and unpredictable life-limiting illnesses.

Another possible consequence of individual personalisation of care involving choosing from a menu of services is the hindering of opportunities for social interaction between service users that the data shows was an important aspect of their visits to the hospice. Relationships that had developed between service users and staff at the hospice, sometimes over months or even years were also affected by the changes. Service user participants, such as Milly, seemed to be left feeling bereft at the sudden disappearance of staff due to reorganisation that they had got to know over a few years of visiting the hospice and played a part in their coping mechanism. A challenge for management at the hospice and the CEO, therefore, was to try and realise the desire to scale up coverage of the hospice's services while maintaining responsiveness to service users making use of those services. This challenge for management also involved trying to add value for an individual service user at the hospice while managing the expectations of other individual service users according to the resources available at any one time. It would already be a challenge to manage expectations of service users with a life-limiting illness because of the unpredictable nature of their conditions. A too rigid system of providing care and services could unwittingly cause further anxiety for a service user.

The data shows that service user engagement underwent changes at the hospice during the reorganisation. For instance, a package called "I want great care" was introduced by the CEO, that collects data from individual organisations and enables benchmarks to be set and then compared with other similar organisations. Reports from this package are fed into the hospice management system and comparisons drawn from other reports and information gathered from other sources to help inform future decisions around the quality and care that is being provided. Other reports could include those compiled from patient satisfaction surveys, for example, conducted at the hospice. Other activities aimed at engagement that emerged from the data included using Patient-Led Assessments of the Care Environment (PLACE), also introduced by the CEO, that is used generally in the health service. These assessments can involve cleaning audits, for example, and formal processes that draws feedback from service users/patients about their feelings on the environment and their experiences with it. The CEO took this further to ask service users about their experiences of care at the hospice. The PLACE assessment tool focuses on the collection of quantitative data that can be statistically analysed with data posted on-line from other organisations using the same tool (NHS Digital, 2017).

Although a PLACE survey may enable more opinions to be gathered, it is not an activity that could be regarded as facilitating service user involvement. Patient satisfaction surveys or audits and evaluation exercises “tend not to be valued by service users and can discourage more effective involvement” (Beresford, 2016, p. 266). There appeared to be numerous opportunities along the process for the hospice management to interpret responses as well as on decisions about priorities. This could also provide opportunities for management to either not acknowledge or even decide to ignore individual or “unwanted voices” (Beresford, 2013, p. 8; Ocloo and Matthews, 2016, p. 3). The CEO was very enthusiastic in describing the changes at the hospice and was careful to emphasise that the care side of the hospice was very important too. I considered that this indicated a genuine intention to maintain the original principles of the hospice movement while approaching the provision of its services in a different way in order to ensure financial survival.

It could be argued that a move towards a more prescribed method of feedback could have implications for service user involvement at the hospice. For example, it eliminated the possibility of service users coming together as a collective with other service users to discuss the issues. Prior to the organisational changes, service user focus groups were in operation at the hospice that offered a way for individuals to express their views in a safe environment with others in a similar situation. These views could then be fed into hospice decision-making processes with service users exercising control over any messages to be passed on to management. The focus groups were discontinued after the organisational changes were introduced. It could be concluded, therefore, that prescribed and formal feedback processes can be disempowering for service users while providing a facade of involvement. Such processes also hint at the change of approach by the hospice management in viewing service users as consumers.

A service user group had been operating at the hospice for a number of years. At the time of starting my fieldwork, the group did not appear to have a great deal of involvement or interaction with service users at the hospice and comprised mainly current or ex-carers of family members that had received care from the hospice. It was quite difficult in the data to assess the group's relationship with the hospice management and with individual service users and the criteria or process used for appointing individuals to sit on it. Service user participants said they had no knowledge of this group or what it did. Management however used the group as a sounding board for testing ideas and sharing plans. Towards the end of my data gathering activities, there were signs of a move towards involving members of the service user group, along with individual hospice trustees, in identifying and interviewing service users at the hospice that were willing to be interviewed in-depth for gaining feedback. A final summary report would be fed into the management team but, as mentioned earlier in this section, such a report would be competing with reports from other sources and management would still have the final say. If the group predominantly comprised carers and ex-carers then it would be reasonable to conclude the caregiver perspective could be uppermost in any reports going to management as opposed to perspectives from individual service users receiving care. Perspectives from these two groups on the same issues can be very different. So what can seem a straightforward and comprehensive approach to service user engagement to an outside observer can actually contain levels of complexity and caveats that can affect the final conclusions.

Along with the changes to more formalised attendance arrangements at the day centre, there were also changes made to the centre's purpose. The focus was turned towards reablement that was also seen as an integral part of scaling up services. Reablement is intended to encourage service users to develop confidence and skills to carry on with activities themselves outside of the hospice environs and enable them to continue living well and independently at home (Samuel, 2017). It is also intended as a short and intensive service aimed at people who have just returned home from hospital, for example, or are frail or recovering from illness or injury. It is not my intention to delve deeply into the positives or negatives of reablement in relation to palliative or hospice care but it could be seen as a good approach for enabling service users to practice self-care and live more confidently when at home. The Social Care Institute for Excellence has produced an online guide on reablement aimed at health professionals (SCIE, 2018). But there are some important caveats for its application in palliative care. For example, a reduction in on-going support is one intention behind it and yet service users with life-limiting illnesses need continuous and flexible support to the end of their lives. As Milly indicated, she is not ill for the 8 weeks when she is allowed to attend the day centre and then well for the following 8 weeks when she is not allowed to attend for a day. The CEO did not mention spiritual or social participation as important aspects of palliative care but such activities could also be viewed as playing a big role in reablement.

5.7 Chapter conclusion

Analysis of all the data collected for my study indicated that significant organisational changes had taken place at the hospice during the course of my fieldwork. The changes also heralded a change in management approach and culture at the hospice. The themes that emerged indicate that a change in management style can create an environment that provides challenges for effective service user involvement.

Very strong opinions were expressed in the quotations presented in this chapter from three service user participants in particular and that they felt disempowered by the change process as well as alienated from the hospice community and felt they needed to fight to hold on to a sense of identity and worth. A number of staff participants regretted the move away from a community environment that they felt had been present before the changes and considered that the hospice was moving towards a more clinical and hospital-style approach with an emphasis on physical care. Staff participants had also intimated that they had felt disempowered during the consultation process and by the implementation of the organisational changes that had affected their relationships with individual service users.

Analysis of the public records indicates that, in order to more effectively meet potential challenges in the future, there was a desire by the hospice management to change the direction of the hospice and introduce organisational changes and hopefully, therefore, secure the continued existence of the hospice. This desire included the wish to broaden the scope of the hospice and enable a wider distribution of its services to reach more people especially during a time of population increase. This involved the appointment of new personnel at senior level including a new CEO to oversee the changes. The CEO was very enthusiastic about introducing and seeing through the significant changes at the hospice as well as trying to influence the health and social care sectors more broadly. The CEO admitted to underestimating the possibility of resistance to the breadth and scope of the proposed changes particularly those affecting current service users at the day centre and the anxiety it would cause. A lower key, informal approach may have been better rather than announcing big changes were coming. The CEO considered this had been a learning point causing a move towards an informal approach when developing other proposed changes.

Challenges that hospices could potentially face in the future were considered by the CEO to include having to compete with the private sector for funding and contracts that is already happening in the healthcare sector generally. The CEO also considered the possibility of individuals having to pay something towards their own healthcare whether through insurance policies, for instance, private budgets or other personal means that could have an impact on palliative and hospice care.

The future of care and how it will be paid for is an issue that other organisations are delving into and coming to similar conclusions as the CEO. For example, The King’s Fund (2017) noted that the NHS funding model via taxation was coming under such pressure that it raised questions about its sustainability. The Fund described the ways that other European countries pay for healthcare either through taxation or by private health insurance or social health insurance. All the funding models incorporated some form of service user charging in the funding mix.
https://www.kingsfund.org.uk/publications/how-health-care-is-funded

The data showed an understanding that the introduction of a paid-for relationship between a hospice and an individual could affect that relationship and provoke different expectations. For example, in a customer/consumer-provider scenario that has already appeared in some parts of healthcare, people may have access to information about other providers and can compare them through benchmarking reports, for instance, and seek alternatives. So elements of a competitive market and a consumer-led model could potentially find its way into hospice care although it was considered by the CEO that this scenario could be years away. However, the CEO also felt that exploring every avenue of bringing in money for hospices should be explored including fee-paying that could then be put back into the hospice ensuring free care was also available for those that needed it. A gap between expectation and reality "is possibly opening up and we'll have to manage that really carefully, and there will be some difficult trade-offs between those that are paying and those that are not paying 'cos without one, you might not be able to do the other" (CEO).

The data also shows that providing care on an individual basis in a hospice during a time of significant organisational change, whatever those changes may comprise, can be problematic. The move towards widening the distribution of hospice resources and viewing service users as consumers receiving services could prompt a shift of focus from responding to service users as individuals. This situation, allied with a greater emphasis on a clinical/hospital and rehabilitative/reablement approach to care could carry further implications for future relationships between service users, hospice, staff, volunteers and management and therefore, for effective service user involvement. As Richardson, MacLeod and Kent (2010) also highlighted, the dominance and attraction of health discourse can lead to service users or patients wanting what the system wants them to want.

Another facet of taking a business or managerialist approach is to view all resources as potential assets that could be used to gain a competitive edge. For example, the services of those working in Information Technology at the hospice to the NHS as well as to other hospices although any help for those with the same ethos may be provided for free. There was also the possibility of sharing human resource services with other independent hospices in the locality along with GPs and other outside providers paying for training programmes provided by the hospice.

The implications emerging from the data around service user involvement at the hospice leant towards viewing it in the future as a patient engagement process or consultation and feedback process via various methods such as written surveys and consultation events such as meetings. The emphasis appeared to be on reablement as a big part of this engagement process with the intention of enabling service users using the day centre to continue with activities such as exercising when they went home with the aim of adding to their quality of life. While this might be something that service users at the hospice may welcome, there was a sense that service users were gradually being disempowered. But the move towards using on-line surveys was also viewed by senior management as a means for enabling individual service user voices at the hospice to come through and not having sole reliance on those views coming through the hospice service user group.

The themes and issues that have been presented in this chapter form the basis for discussion and theorising that is presented next in Chapter Six following some personal reflections.

5.8 Personal reflections

I had met and talked with senior staff at the hospice in my study prior to the organisational changes being introduced from 2013 onwards that included a vision for the future of the hospice. The general atmosphere at the hospice at that time seemed very relaxed and I was informally introduced to staff while being shown around the main site.

The initial impressions that I had of the hospice altered at the time my fieldwork started in earnest in 2014. I noted in my journal, for instance, that more staff had been fitted perhaps three into an office space previously meant for one. Also, staff that I met informally mentioned their concerns about the future of the hospice and I learnt that a number of long-serving members of staff had left. I became very aware of needing to guard against making assumptions at this point about the changes and also when interviewing and analysing data. It was important to exercise rigour in managing the data collection and analysis in order to minimise any potential bias.

As I had personal experience of caring for both my parents at the end of their lives, I was also aware of the need to avoid imposing my own feelings on the accounts that interviewees put forward. I used reflexivity to become aware of my own sensitivities and to try and guard against making assumptions that everyone has the same experiences. For example, some of the accounts from service user participants were very strongly worded. While it would have been tempting to be sucked into their perspectives, I attempted to stand back from them while not diminishing their concerns. The emotion that came through from service user participants was palpable and I was aware of the need to stay detached but not aloof. Maintaining rigour involved regularly standing aside from any personal emotional impact of what was being said during data collection and during the analysis.

The unexpected organisational changes at the hospice in my study presented new challenges that provided more levels of complexity than I was expecting. I therefore had to adapt to the changing circumstances in order to identify participants and conduct interviews as well as effectively identify themes and theorise about the findings while maintaining a focus on providing answers to my research question. The organisational changes at the hospice proved to be intimately bound up with this process.

CHAPTER SIX: DISCUSSION

6.1 Introduction

The research question for this qualitative study is:

What are the perspectives of professional staff and service users towards service user involvement in palliative care within the context of organisational and cultural change in a UK independent hospice?

My own position as a layperson pursuing this study enables me to provide a unique perspective on the topic of my research. The different ‘I’s (Peshkin, 1988) that I bring to the study cover my personal and professional life and my voluntary work as a member of palliative care service user groups with a number of UK third sector organisations. These ‘I’s account for the active voice used in the writing of this thesis.

This chapter presents a discussion on service user involvement including the tensions that emerged in the data as the hospice involved in my study underwent significant organisational changes during the course of my fieldwork. The complexity of service user involvement in palliative care was discussed in Chapter One. In common with other studies, such as Cotterell (2006), my study indicates that approaches to service user involvement that were developed in mental health, disability or in the NHS are difficult to apply in palliative care.

The main themes identified covering both service user and staff participants included power, control and relationships and a sense of both belonging and alienation in a changing environment. A key finding from the data was that whatever the illness a service user may have or however far along the trajectory they may be and knowing they were potentially close to death, they still wanted to have a voice and to be listened to. This desire not only covered their own care but broader issues as well, certainly those affecting the hospice. The introduction of a different style of management approach to operating the hospice that occurred during the course of my fieldwork activities, prompted a great deal of upset and challenges for participants and also for the hospice management. A wish to broaden the reach of the care that the hospice could provide and to help sustain its financial future was a big driving force behind the organisational changes as the public records and interview with the CEO showed.

There were significant structural and cultural differences apparent at the hospice before and after the organisational changes were introduced. For example, prior to the changes an ad hoc approach to activities at the hospice day centre was possible. The changes provoked a deliberate move away from this ad hoc approach to an appointments-based system as part of a bid to widen access to the hospice’s resources. Understandings of service user involvement could not be separated from service users’ and staffs’ own sense of belonging or disempowerment within the changing hospice environment and culture. The organisational changes arguably underpinned the tensions that emerged from the data. I also present a discussion around an apparent managerialist approach being introduced at the hospice and its impact on service user involvement. An explanation of managerialism was presented in Chapter One.

The organisational changes at the hospice provided a major and unexpected direction for my study. My research is qualitative using case study with thematic analysis. I was therefore able to accommodate the new data being generated in the interviews. This enabled me to analyse and reflect on the findings and I decided that they held significant implications for my study topic. Using a case study approach helped with investigating and analysing the underlying reasons for the organisational changes. I was able to analyse public records about the operation of the hospice. It also enabled me to consider whether the organisational changes held further implications for service user involvement in the future, not only at the hospice in my study but also the potential for transferability to hospices generally.

I also highlight tensions between what I refer to as a sanctuary versus business model approach to hospice care that is described in detail in

Chapter One. It may well be the case that neither sanctuary nor business model approaches are ideal but effective service user involvement thrives on and requires trust between service users and those that lead or manage an organisation. Without trust, service users will not feel comfortable or feel as though they have any influence.

I have identified three key areas in my study and these provide a structure for the discussion in the next section. The areas are:

1) Service user involvement in palliative care - an under-researched topic shrouded by misunderstandings with no accepted best practice approach for its application or evaluation.

2) Power, control and relationships where cultural and managerial change coupled with political and policy change can engender feelings of distrust, disempowerment and alienation.

3) Hospice day centres and their role in facilitating service user involvement as well as for engendering feelings of self-esteem, trust and belonging among palliative care service users.

6.2. Key issues

6.2.1 Service user involvement in palliative care - an under-researched topic shrouded by misunderstandings with no accepted best practice approach for its application or evaluation.

A common feature among both staff and service user participants at the hospice was the shared lack of understanding about the meaning of the words 'service user involvement' and how it relates to palliative care particularly in the context of a hospice. This indicates that such understandings do not seem to have advanced much beyond findings in the early literature. For example, Payne et al (2005; 2008) discovered a lack of consensus among professionals and service users about the meaning of service user involvement in palliative care. This may have been compounded by the use of the words ‘service user’ that Beresford and Andrews (2012) discovered were unfamiliar to most people. The authors also found that the phrase ‘user involvement’ was perhaps “the most opaque of the terms, advanced by some as a route to personal liberation, while seen by others as a tokenistic dead-end” [Beresford and Andrews, 2012, p.12].

The 1995 Calman Hine Report (Department of Health) appeared to open the door for service user involvement in palliative care with a recommendation that cancer services should be patient-centred. Beresford (2005) noted that the hospice movement had always maintained that it was already concerned with providing individual holistic care but the author considered that the movement had been slow to address service user involvement. The authors also noted that patient satisfaction surveys played a big role in hospices but regarded their usefulness or appropriateness as an involvement tool to be questionable. A renewed emphasis and expansion of the use of patient satisfaction and other surveys was a feature at the hospice in my study following the organisational changes. This indicated a possible move towards a formal and standardised approach to service user involvement at the hospice.

Attempts to define and represent the meaning and practice of service user involvement generally has been attempted a number of times over the years. Arnstein’s Ladder of Citizen Participation (1969) was the precursor to these attempts and was described in detail in Chapter One. The Ladder has been updated and developed by others such as Forbat, Hubbard and Kearney (2009) and Tritter (2009). It does not necessarily provide a sophisticated approach and, as Tritter (2009) suggests, it presents participation as a rigid hierarchy rather than what he regarded as a complex mesh of possible activities. Nevertheless, Arnstein’s Ladder is still used as a measure of service user involvement. This does not necessarily suggest that it has led to widespread acceptance and understanding over the years of what service user involvement means particularly in relation to palliative care.

Service user involvement has been a feature of activity in the fields of mental health and disabilities that included the establishment of service user groups. There is however, a difference between service user involvement in these two fields and in palliative care. As Cotterell (2006) noted, service users receiving palliative care do not readily form themselves into groups to try to influence issues that affect them or tackle inequalities. This may be different for service users with cancer.

In 2000, cancer networks were established in the UK (National Health Service, Cancer Plan, 2000). They had resources provided by government and comprised cancer service users and caregivers of people with cancer. This initiative enabled cancer to have an influential voice in issues around palliative care. As Cotterell (2006) also pointed out, those service users involved in his research that did not have cancer seemed less inclined to speak up, did not have access to useful information on which to base decisions and therefore seemed unable to contribute as much as the cancer service users that did belong to a network. However, in 2015, a leading UK charity called Macmillan Cancer Support contended that the Health and Social Care Act (2012) led to government resources being stopped and cancer networks disbanded (Macmillan, 2015). Reflecting on the loss of cancer networks, I would suggest that this has had the effect of diminishing the voice and involvement of service users in health and palliative care. The cancer networks may well have enabled the cancer viewpoint to dominate health and palliative care discourse. They may also have served to ensure there was at least some service user involvement in decision-making in these areas. Attree et al (2010) identified cancer networks as being very effective at grassroots level for improving the flow of patient information and the care environment for example. The authors were more circumspect about the influence of the networks at the level of strategic decision-making. They concluded that for such influence to be effective, a more participatory relationship between service users and professionals was needed along with more dedicated resources for enhancing service user involvement.

It could be argued that the service user focus groups that the hospice in my study established prior to the organisational changes enabled a form of service user involvement. These focus groups comprised service users and sometimes members of staff and they discussed subjects covering aspects of their care and the hospice that could then be fed into the management as appropriate. When the organisational changes came into effect, the focus groups were discontinued without any reasons being offered. This again effectively cut off the voices of service users at the hospice in the same way that discontinuation of the cancer networks had done. Both these examples illustrate the necessity of government and management commitment to an initiative in order for it to be introduced and sustained. They also indicate how changes in governmental ideology and management culture can impact on such initiatives and leave service users in a seemingly powerless position to change anything.

From 2005 to around 2010, research into service user involvement appeared to increase. This research interest can be linked to governmental approaches and legislation in the area of health and social care as well as palliative and end of life care. The emphasis of this interest, however, was centred on clinical aspects of care and limited to the role that people could play in their own care. The health professional voice was still dominant in the research as Payne et al (2005) discovered in the years prior to 2005. It is noticeable in the literature that there has been a tailing off of research into service user involvement in palliative care since around 2010.

The findings in my study indicate that staff participants regarded service user involvement as being primarily concerned with care and the opportunities that service users had to be involved in developing their own care plans for instance. This approach diverged between staff working in different areas. For example, the relationships that the day centre nurses had developed with service users, sometimes over a number of years, appeared to be of a different order to those between nurses and service users in the in-patient unit. Service users at the day centre were living with a life-limiting illness but were likely not to be near to death and so were able to take part in activities and to express their wishes. A nurse participant said that some service users could be admitted to the in-patient unit at the hospice in a comatose state. She said that they might never regain consciousness before they died a few hours or days later that meant there was no opportunity to form a relationship with them.

Reflecting on the lack of understanding about service user involvement generally as well as in palliative care, I concluded that a starting point could involve finding a way of drawing on the wisdom and experience of service users. This experience could then be used to help develop not only their own care but also influence decisions about priorities, for example, whether on government policy in this area or at a local level in a hospice. In palliative care, Gauthier and Swigart (2003) referred to “embodied responding.” The authors say that the physical, psychosocial and spiritual elements are important for the whole individual in a hospice that can influence their decision-making in that environment. The data from interviews with service user participants in my study indicated that all these aspects that Gauthier and Swigart highlight were important to them. The consultation processes that were employed by the hospice in my study around the organisational changes did not seem appropriately fashioned to enable service users with a life-limiting illness to have meaningful engagement with the process or have much influence on the outcomes.

Other methods aside from surveys for capturing the experiences and views of service users in palliative care have started to emerge over the last few years. For example, narratives and stories written or videoed by service users themselves can provide a window into their world, expand knowledge and provide a different strand of evidence on which to base policy (Gunaratnum and Oliviere, 2009). Stories can also provide a non-threatening way of challenging professional orthodoxies.

A programme called ‘Sharing Stories for Wellbeing’ (Garden House Hospice, 2016) was run in a UK hospice in 2015 and enabled people to share their life stories in a group workshop. An evaluation of the programme reported that this approach enabled those taking part to come to terms with their diagnoses, enhanced their self-esteem and self-identity and provided a way of connecting with others. The National Institute for Health and Care Excellence (NICE) has a website dedicated to evidence-based storytelling and individual hospices seem to be carrying out storytelling activities, such as Garden House Hospice in Hertfordshire, for example (Garden House Hospice, 2016). The emphasis of these initiatives seems to be on improving the experience of care for an individual service user. Important though this obviously is, also being able to use this storytelling approach as a means for informing decision-making whether at a single hospice or more widely could provide a way of facilitating service user involvement in palliative care. The possibility of using storytelling in this way was not raised in the interviews for my study and provides a topic for future research.

There has been increased interest and activity since the 1990s around Patient Public Involvement (PPI) in the NHS and later in health research (Wilson et al, 2015). The authors detail attempts over numerous years by policy makers to facilitate service user involvement in the NHS that they suggest is an indication that more effective mechanisms are still being sought. These attempts include community health councils that were abolished in 2003; PPI forums that were abolished in 2007; local involvement networks and Healthwatch that was established in 2013. Since 2008, health research funding streams have required en explicit account of how PPI has shaped a proposal and how service users will be involved in the study (Department of Health, 2008). It should mean service users are involved not only as participants but also influencing the topics of research, conducting interviews, analysing data, agreeing conclusions and receiving appropriate academic support to fulfill the role (Involve, 2018).

Wilson et al (2015) also point to a catalyst for service user-led research in the 1980s. This involved criticism of an official report exploring the potential of care home residents to participate in the running of care homes but excluded the views of care home residents themselves (Hunt, 1981). The effective role of PPI in helping to shape research proposals has come under recent scrutiny. For example, Rose, Carr and Beresford (2018) argue that the Research Councils UK announcement of research funding streams in 2017 appears to place PPI as the only involvement strategy for service users in the field of mental health. The authors contend that the language used in the funding call emphasises clinical approaches rather than potential wider societal influences. They maintain that this ignores service user-led research and that PPI and service user-led research should be recognised as distinct entities. There has not been a similar PPI or service-user led approach to practice, provision or policy-making activities around palliative care.

6.2.2 Power and control where political and policy change coupled with cultural and managerial change can engender feelings of distrust, disempowerment and alienation.

Trust between all stakeholders is an important condition to enable service user involvement to develop in a hospice setting and be sustainable. When trust starts to break down, feelings of distrust, disempowerment and alienation among service users and staff towards management can cause serious impairments to effective service user involvement.

A sense of simultaneous involvement and disempowerment appeared to be felt amongst both service user and staff participants in my study. As Beresford (2016) describes, the black civil rights movement in the USA developed the concept of empowerment that was later picked up and further developed by mental health and disability user groups in the UK. Two strands of understanding about empowerment emerged from these beginnings:

> Personal empowerment, highlighting the need for change within us, and political empowerment – the need for wider change - while emphasising the need to address both if people are to be truly rather than tokenistically involved in making change (Beresford, 2016, p.206)

The paradoxical feelings of involvement and disempowerment for service user and staff participants in my study seemed to be prompted primarily as a consequence of the consultation activities about the proposed organisational changes at the hospice. Service users felt that although they took part in surveys and face-to-face meetings, their views were then ignored. Both groups of participants also seemed to feel that decisions had already been taken by the hospice before these consultation activities took place. The disappointment at this situation felt by service users was palpable during the interviews and this feeling also appeared to have been felt by some staff at the hospice. A nurse at the day centre, for instance, was concerned at how the views of service users appeared to have been ignored. He hinted that service users had spoken with him in confidence about how they felt and he had also noticed it for himself.

Beresford (2016) points out how people can be tokenistically involved in making change. My study indicates that tokenism can be felt directly by staff as well as indirectly on behalf of service users and directly by service users themselves. For members of staff, this situation could be interpreted as though their professional competence was being limited and controlled. This is an effect that can be promoted by a managerialist approach that is covered later in this chapter.

Arnstein's Ladder does not provide a sophisticated approach to citizen engagement as mentioned in the first section of this chapter. But I consider it to be a useful guide for providing a visual illustration of the changing nature of service user involvement at the hospice in my study. I have used Arnstein's Ladder as a template to show what has happened to service user involvement at the hospice starting from my first visit in 2011 and each year up to 2016. The reasons for the movement up and down the Ladder are presented in the discussion following the diagram.

Diagram 7.1 Arnstein's Ladder of Citizen Participation (1969) tracking service user involvement at the hospice 2011 – 2016

Arnstein's Ladder (1969)
Degrees of Citizen Participation

As the diagram above shows, at the time of my initial visit to the hospice in 2011, service user involvement was near the top of the ladder indicating a higher degree of partnership working and delegated power to service users including an ability to make decisions. There was a gradual move further up the ladder in 2012 towards 'citizen control' indicated by the introduction of service user focus groups at the hospice. The organisational changes started in 2013 and from that point there is a steady movement down the ladder. The potential reasons for such a downward movement are discussed below.

Beresford (2005) identified a change in political terminology towards the end of the 20th century. From that time onwards, there was increased talk from government about putting the patient at the centre, working in partnership and empowering the public in health and social care terms. This included palliative and end of life care and was exemplified by a consultation followed by publication of the 2008 End of Life Care Strategy (Department of Health, 2008).

Against the backdrop of the effects of the global financial crisis in 2007/8, the election of a coalition government in the UK in 2010 with a Conservative Prime Minister and the subsequent implementation of austerity policies led to cuts in funding of public services including health and social care. From this point, government attitudes and legislation started to change emphasis and the terminology started to change with an emphasis in legislation towards healthcare and the NHS with very little if any on palliative care. For example, the Health and Social Care Act 2012 introduced 152 new Health and Wellbeing Boards into England and research by the National Council for Palliative Care conducted in the same year found that less than half of them had considered dying people in their strategies (National Council for Palliative Care, 2012).

In tandem with the years of austerity measures, people are living longer and very likely to have more opportunity for developing complex conditions leading to an increase in demand for care services including palliative care. In order to cope with this, the economics of care appear to be undergoing fundamental change and can potentially influence the way that independent hospices meet the anticipated challenges (Haslam, Theodosopoulos and Tsitsianis, 2014). The prevailing approach of Conservative governments following the 2015 and 2017 general elections continues to be one of austerity and neoliberalism.

6.2.3 Neoliberalism and managerialism

Modern Neoliberalism dates from the late 1970s/early 1980s that coincided with the election of politically right-wing governments in the UK with Thatcherism and in the USA (Harlow et al., 2013). These authors also contend that it was the influence of economists such as Hayek (1944) and Friedman (1962) that when blended with right-wing politics gave dynamism to neoliberalism. It is an ideology that has gathered pace since the 1970s in the UK and has at its basic level, the hegemony of free markets and free trade (Harvey, 2005). Neoliberalism achieves its aims through the processes of managerialism with a drive towards enhanced performance and efficiency (Harlow et al., 2013). The term refers to “the power and control of managers and administrators within and over the organisations that employ them and, from a historical perspective, to the era of capitalism characterised by managerial power and control" (Keissler, 2014, p.478).

Neoliberalism and managerialism have been the subjects of research in the public sector, including health and social care, and the impact they are having on the way that the public sector is organised is being highlighted (Chevannes, 2002; Clark et al., 2004; Baines, 2011). Carlisle (2011) lamented the confusion of machine efficiency with human effectiveness in managing people and in effecting change in public sector organisations. The author contends that this approach could lose sight of potential complex dynamics and serve to produce undesirable outcomes.

> When strategists drive change from the top down, implementing uniform procedures, close monitoring, measurement, rewards and sanctions to maintain tight control, they apply a machine metaphor to the management of complex organizations and seek to make the people within them efficient as opposed to effective. (Carlisle, 2011, p. 285).

It appeared to me during the course of my fieldwork and from analysis of the data that the hospice in my study was engaged in an ideological battle. There was cultural change taking place that seemed to be attempting, paraphrasing Lynch (2014), to rework the purpose of the hospice, the role of professionals and the definition of what it is to be a service user.

Performance, efficiency, outcome measures and broadening access to resources were features of the approach being taken at the hospice since the organisational changes were introduced in 2013. Whether this meant that a neoliberal/managerialist approach was being introduced at the hospice, whether it had consequences for service user involvement and whether it ultimately matters are explored and discussed further in this chapter. I frame the ideological battle at the hospice as being a sanctuary versus business culture and this is also discussed further in the next section.

6.2.4 Sanctuary versus business culture in hospice care

A sanctuary approach can emphasise a humane experience that sees service users, frontline workers, managers at all levels and organisations as being connected (Koprowska, 2014). Bloom and Farragher (2013) identified seven sanctuary model principles for social work: “non-violence, emotional intelligence, social learning, democracy, open communication, social responsibility, and growth and change.” The authors say that this model is not a clinical intervention but rather a way of creating an organisational culture that can provide a cohesive environment in order to help people that have experienced trauma.

My initial visits to the hospice started in 2011 prior to my fieldwork and it was evident at that time that the hospice was being run as a sanctuary model along the lines described by Bloom and Farragher (2013). This was exemplified in a number of ways. For example, comments were made in my discussions with the then CEO during my first visit in 2011 when I wrote verbatim notes for my PhD journal. The CEO had a desire to drill down more deeply into the views of service users at the hospice to try and elicit any underlying issues that were not necessarily emerging from the patient satisfaction surveys that they ran. In supporting my fieldwork, the CEO hoped that service users might express their views more openly in the confidential interviews with a researcher not connected to the hospice. There was a hope expressed that the analysis of the data and conclusions could ultimately help the hospice to improve its services and approaches to service users. The CEO also informed me of the service user forums that were being run at the hospice day centre and the possibility that I could attend those to inform them about my study. A nurse participant also commented on the “homely atmosphere” at the hospice before the organisational changes and how, in her view, it was becoming more like a hospital. Service user participants had described the autonomy that they had in deciding on activities to pursue at the hospice day centre and the opportunities for socialising prior to the changes. At the time of starting the main fieldwork activity for my study in 2013, it became clear that significant cultural changes were taking place at the hospice.

The sense that there was a top down approach to organisational change at the hospice was identified through the data. The hospice CEO who was appointed in 2013, placed great emphasis on process. The fact that service users receiving care will eventually die and every effort made to ensure the deaths were as comfortable and stress-free as possible was not mentioned in the interview. This does not necessarily mean that every effort would not be made in this regard but it was interesting that this was not mentioned as being a primary function or raison-d'etre of the hospice. Rather, the emphasis was on implementing a major reorganisation where staff and volunteers appeared to be regarded as tightly controlled players in a managerialist system and service users increasingly regarded as consumers.

As mentioned in Chapter One, there has been a shift in the culture of healthcare towards marketisation and service users increasingly being seen as consumers. Rhodes and Small (2000) believed that viewing a patient as a consumer places them in a passive and compliant role in the service delivery system rather than being an active decision-maker. The idea of consumers as passive recipients may have changed in the years since 2000. Forbat, Hubbard and Kearney (2009), for example, comment that viewing service users as consumers, means they have choices and can access services as dictated by free market economics. The way that service user involvement is handled then depends on the context and ideological approaches being taken. If viewed as passive and compliant recipients of care and decisions are taken in that context, it can be disempowering for service users. This disempowerment can be further underlined by the "seduction of health discourse so that the patient ends up wanting what the system wants them to want" (Richardson, MacLeod and Kent, 2010, p.135). An example of a possible seduction of health discourse was apparent from the data around new arrangements at the hospice day centre. Although for at least three of the service user participants, it was felt not so much as seduction but rather a feeling of having no choice but to accept the changes whether they liked it or not.

6.2.5 Hospice day centres and service user involvement

The changes in arrangements at the hospice day centre are presented in this section as an example of the way in which service user views were side-lined and where consultation was tokenistic, in order to demonstrate the consequences for service users' wellbeing.

The notion of a system telling service users what they want under the guise of choice was exemplified by the introduction of new arrangements at the hospice day centre. These arrangements involved 8 weeks on, 8 weeks off approach for service users attendance and the need for them to choose their activities from a pre-determined menu of activities. The day centre also changed to a therapy centre. This was a significant change from previous arrangements where service users could drop in to the day centre when they wished during the working week and be involved in decisions about the activities they would pursue that particular day that would then be facilitated by staff. The data from the interview with the CEO indicated that the intention behind the new proscribed activities and the change in emphasis at the day centre was a desire to shift the focus on to rehabilitation and to broaden access so that more service users could make use of the facility. There was a belief that increased access to activities at the centre was not possible under the previous arrangements.

In this context, by regarding service users as consumers at the hospice it could be reasonably argued that from a managerialist perspective, the changes at the day centre were seen as a means of not only broadening its reach but also of empowering service users. It achieved this by turning them from passive recipients of care into expert shoppers as described by Beresford (2005) and Tritter (2009). The move could provide resilience tools, such as exercise regimes, that service users could continue when not at the hospice. The potential of the day centre to offer opportunities for connecting informally with other service users and staff, particularly to help combat feelings of isolation, away from medical treatments or proscribed appointment-only rehabilitation activities, did not emerge from the data. I therefore took the view that the importance of this aspect had perhaps not been fully appreciated during the organisational changes nor its role in enabling informal contacts to develop, for instance, between people living with a life-limiting illness.

The introduction of a rehabilitative approach to activities at the day centre provides a possible indication of a general move away from a sanctuary model of hospice care. Hospice UK published a report in 2013 called “Rehabilitative Palliative Care: enabling people to live fully until they die” (Tiberini and Cooper, 2017).

> Embedding a rehabilitative approach to palliative care within services is an important consideration for all hospices. Not only does this approach enable people with life-limiting and terminal conditions to live as independently and fully as possible, it allows hospices to respond to increasing demand for their services in a cost-effective way. (Hospice UK, 2018).

The use of rehabilitation approaches in palliative care and in UK hospices seems to be gaining traction and is being strongly pursued by Hospice UK as a policy initiative exemplified in the quote above. Rehabilitation has been an approach used in the provision of care for people living with long-term life-limiting conditions but it is only recently that its potential benefits are being promoted as an approach in palliative care (Tiberini and Cooper, 2017)

The main rehabilitation approaches involve “physical therapy, occupational therapy, and speech and swallowing rehabilitation” (Javier and Montagnini, 2011). These authors go on to say that rehabilitation for those with a life-limiting illness includes a multidisciplinary approach covering physical, spiritual and emotional symptoms (Javier and Montagnini, 2011). It is interesting that the authors refer to spiritual and emotional aspects as symptoms and perhaps reflects their perspectives as health professionals. There also appears to be a focus in the literature on rehabilitation in the case of service users with cancer. Javier and Montagnini (2011) describe how rehabilitation can be of benefit to those with non-malignant conditions but the approach currently appears to be influenced by cancer and a seeming emphasis on physical rehabilitation. Music can play a role in palliative care rehabilitation. According to Warth et al (2015), music therapy has been used as part of palliative care programmes for over 30 years especially for severely ill people but there are few studies making it difficult to evaluate its effects. They found that music could help with relaxation and provoke feelings of wellbeing in service users receiving palliative care. There is also very little research in the literature on service users with dementia and the accessibility of hospice day centres. It is reasonable to assume that rehabilitation for service users with dementia receiving palliative care would be different from service users who did not have cognitive impairments.

The idea of rehabilitation to support service users until they die aligns with the ethos of Dame Cicely Saunders. However, a focus solely on physical or clinical aspects of rehabilitation could potentially dominate research and influence discourse and outcomes and, by so doing, limit service user involvement and influence in palliative care.

It does not necessarily follow that a rehabilitation approach at a hospice day centre is harmful but one concern could be the manner in which it is introduced. As mentioned previously in this chapter, what emerged from my study is that the approach to making the changes at the day centre caused a great deal of upset to participants. It emerged from the data that the extent of upset being felt, especially for service users, had not been fully appreciated. The CEO indicated that if they were to run it again, the changes would probably have been made more slowly and incrementally rather than trying to instigate them all in one go. There was also a belief due to feedback from patient satisfaction surveys at the hospice that the majority of service users at the re-arranged day centre were happy with what was being offered.

The process of change at the day centre could be said to exemplify a difference between a sanctuary culture (prior to the organisational changes) and business cukture (after the organisational changes) at the hospice.

Lawton (2000) identified a tension between staff and management at the hospice where she conducted her ethnographic study.

> An underlying and often irreconcilable conflict did appear to exist between the staff and the NHS management in both the day care service and the inpatient service where I conducted fieldwork. Whilst staff were anxious to provide their patients with ‘a safe haven’ and a ‘surrogate family,’ their goals came into constant conflict with the managerial objective of ‘processing patient case loads’ as ‘efficiently’ and ‘cost effectively’ as possible. (Lawton, 2000, p. 20).

There was a wish by senior management to scale-up the numbers of service users at the newly re-configured hospice day centre but in so doing, it also served to reduce the number of sessions that each service user could attend. The changes could be interpreted as having helped to provoke feelings of alienation and the loss of a sense of belonging among three of the service user participants that had used the day centre prior to the organisational changes and at least one nurse participant. It is worth commenting that the arrangements at the day centre in Lawton’s (2000) study that involved an NHS hospice were very similar to those introduced at the hospice in my study. Service users at the NHS hospice were “limited to an eight-week ‘package’ of therapy and psychosocial support (patients normally attended for one day each week), after which their discharge back into ‘the community’ was anticipated” (Lawton, 2000, p.24).

Lawton (2000) noticed that service users did not see the day centre in her study as offering them a “rehabilitative stepping stone” (Lawton, 2000, p. 40) but rather offered them a safe haven where they felt they could be themselves and feel normal for a while. This author also noted that a formal rehabilitative approach to day care could not have worked effectively in practice because of “the impossibility of ‘rehabilitating’ or altering the context into which the patients had to return” (Lawton, 2000, p. 40).

As already discussed, a rehabilitative approach at a hospice day centre has the intention of building resilience and enabling service users to carry on with activities when they are back at home. This was the intention of the new day centre arrangements at the hospice in my study. What this approach does not take into account, as Lawton (2000) and my data show, is that attending the hospice provides opportunities for being active and engaged because of the physical and social environment it provides and this does not simply or necessarily translate back into 'the community.' In her study, she also discovered a fairly complex array of day-to-day interactions between patients, staff and hospice volunteers who had "appropriated" the day centre and produced an "alternative reality;" a 'new social world'" (Lawton, 2000, p. 41). This idea of a new social world where a sense of self could be expressed appeared to be the case for three of the service users in my study. They had used the hospice day centre for a year or more before the organisational changes were introduced and had built up their own social milieu and sense of belonging there because of it. Their feelings that this was being summarily taken away from them seemed to cause despondency and that their lives did not seem to matter anymore to the hospice. The service users did not blame individual members of staff such as the day centre nurses for this changed situation but rather they blamed the management.

This is especially the case for those service user participants living on their own with no family support. In fact, it could be argued that a rehabilitation approach could increase feelings of isolation for service users in this position. Four of the service user participants in my study lived on their own with very limited or no family support available. Their visits to the day centre played a pivotal role in their mental and emotional health by enabling them to get out of the house, stay connected to the outside world, build on their sense of belonging and enhance their self-esteem.

One of the service user participants in my study used the word "institutionalised" when asked how he felt he had been affected by the changes that had taken place at the hospice and day centre over the previous months as compared to the previous arrangements. The word institutionalised was first associated with 19th century workhouses and lunatic asylums where people would be expected to live by the rules, values and routines of the institution (Beresford et al., 2011). The notion of standardised routines and emphasis on physical aspects of care identified by Beresford et al (2011) as opposed to social and spiritual care are indicated in the changes made at the hospice in my study.

The needs of people with a life-limiting illness and living alone without a caregiver are the subject of some research in the literature. Aoun et al (2014) conducted a narrative review of research conducted on this topic from 2002 – 2013. They discovered that people in such a situation were less likely to be cared for or die at home; would experience more psychosocial distress and were more likely to enter hospital than were people with a primary caregiver. The authors recommended that more research was needed on the efficacy of informal support networks and suitable models of care that could aid care planning for a growing group of people in this situation.

Charmaz (1983, 1995 and 2005) accords with Lawton (2000) and the findings from my data by identifying how chronic illness can cause a rift between the body and a sense of self. There was a feeling from service user participants in my study that they felt a great sense of injustice was being perpetrated on them. As one participant remarked, “it means, being disabled, I don’t have a choice, I don’t have a say, I have to take whatever comes along.”

Various studies and reports agree about social aspects being an important aim for palliative day care (Higginson et al., 2000; NICE, 2004; Payne, 2006) but they also pointed to the lack of evidence about the value and contribution of day care to palliative care. Payne (2006) noted that providers had not defined social objectives for day care “in a form capable of evaluation, invalidating healthcare outcome measures” (Payne, 2006, p. 440). This author also suggests there is no effective means of analysing the provision or impact of palliative day services or enforceable guidelines that set out what approaches and activities should be included. This suggests that providers are at liberty to decide on their own approaches to palliative day care services. It also offers one explanation as to why the hospice management in my study felt they could make substantial changes in arrangements at the day centre based on their own plans.

Participants described how they had taken part in consultation activities about the proposed organisational changes at the hospice that involved surveys and meetings with the hospice management that appeared to fit with a consumer-style approach to consultation. Participants put forward their views but then later expressed disappointment if not resentment that their views appeared to have been ignored by management. A consumerist approach to service user involvement especially for those with a life-limiting illness can cause such views either to be ignored or not sought at all (Beresford, 2016).

Service users with life-limiting illnesses are not in a position to exercise choice or decide not to use a particular service in the ways that a consumer could. The data for my study from service user participants highlights the powerlessness they felt at not being able to influence decision-making at the hospice about the organisational changes. The strength of feeling that emerged from a number of service user interviews as presented in Chapter Five exemplifies their sense of powerlessness. It was also apparent that there were very limited options, if any, for alternative places of care in the local area. One service user participant who stopped going to the hospice day centre for a while as a protest at the new arrangements eventually felt she had no choice but to return. Other day care options for a person in her position did not exist in the local area.

Prior to the organisational changes at the hospice, there had been opportunities for service users to become involved through service user forums held at the day centre when they could discuss issues that were important to them. These forums were stopped after the changes and along with other changes in attendance arrangements at the day centre, service users were left with limited if any opportunities to meet and talk together informally. My findings show that this served to make service users feel disempowered and alienated.

The benefits that forums can bring in relation to service user involvement in palliative care are shown in a study by McIlfatrick and Hasson (2016). They concluded that it provided a supportive environment where voices could be heard and valued. The authors said that at a personal level, this led to a sense of empowerment amongst those taking part as well as providing opportunities to challenge professional orthodoxy. They concluded that organisational cultures needed to be supportive of user involvement and it required resources as well as leadership and openness. There is very limited research in the literature evaluating hospice day centres and their purpose. But it is possible to extrapolate from my findings and those of McIlfatrick and Hasson (2016), that facilitating forums at a hospice day centre could provide a supportive and empowering environment for enabling service user involvement.

6.2.6 Commodification of service user involvement in palliative care

The hospice CEO in my study referred to service users as ‘consumers.’ Tritter (2009) links consumerism with managerialism and explored the challenges for patient and public involvement in a consumerist world. He identified “the dominance of managerialism, marketization and bureaucratic expertise” (Tritter, 2009, p. 284). The impact of such a move to consumerism can have significant consequences (Tritter, 2009; Beresford, 2016).

Issues that emerged from the CEO data showed that as well as service users being discussed as consumers and the day centre being re-configured as a therapy centre, other aspects of consumerism also emerged. For instance, the introduction of a pre-determined menu of day centre activities for service users to choose from rather than service users guiding those choices in the first place. Beresford (2016) identifies the increasing tendency for seeing service users as consumers or shoppers with choices in a marketplace and considered it as part of a move towards a neoliberal approach in public services generally.

The assertions made by Tritter (2009) and Beresford (2016) signal significant implications for the way that service users are regarded by public services. This includes in healthcare and also, consequentially, how they are viewed in palliative and end of life care. This in turn has significant implications for service user involvement in these sectors including hospices, particularly if they introduce a medicalised/NHS/managerialist approach to care that appears to be taking place at the hospice in my study. Hospices may then move towards a more regulatory rather than rights-based approach to service user involvement. The notion of patient choice as a means for promoting individual consumerism in healthcare could have significant consequences in terms of "shifting responsibility, inequality and opportunity" (Tritter, 2009).

The commodification of service user involvement at the hospice in my study became apparent from analysis of the data. Some services provided by the public sector in the UK, particularly in hospitals, have been contracted out to the private sector. Governments prior to 2010 used private providers for some services such as radiology and pathology and management of buildings (King's Fund, 2017). The Health and Social Care Act 2012 extended opportunities for market-based approaches. However, a tender in 2017 in one area of England for delivering end of life and cancer care caused widespread criticism and led to it being dropped (King's Fund, 2017). This suggests that tendering for the care of service users with life-limiting illnesses is significantly different to tendering for provision of extraneous services and not quite yet acceptable. However, it is a direction of travel that would benefit from further research not only to explore its impact on the delivery of care services but also for its impact on service user involvement in health and palliative care.

The building of partnerships between the hospice and private sector businesses for providing care to service users and other hospice activities such as Information Technology, for example, emerged from the data as positive developments and potentially necessary moves into the future if hospices are to survive. This view appears also to be held by the current UK government. For example, in 2015 the then UK Secretary of State for Business, Innovation and Skills sounded a clarion call for businesses to get involved in funding hospices.

> The income received from the private sector is therefore essential for care to be delivered, which is why I want businesses of all shapes and sizes to back Britain’s hospices. For businesses it can provide them with sudden and unexpected commercial opportunities as they encounter different audiences in new settings. (The Telegraph, 2015).

It is useful to try and unpick some of the words in the quotation above. For example, the notion that such a move could provide “unexpected commercial opportunities” for businesses among different audiences. These audiences will presumably include service users receiving care at hospices and implies the increased marketisation of hospice care and the commodification of service users. This situation could lead to service users increasingly being seen as customers not just for care services, however, but for all sorts of products that private sector businesses may want to try and sell to them. The ethics of such an approach towards service users living with life-limiting illnesses receiving palliative care from a hospice would be deep and complex. It would also completely alter the relationship between service users, staff and the hospice. If service users became viewed as consumers or customers then this would have further implications for service user involvement in palliative care – it would commodify the dying process where the decisions and parameters are set by those intending to make a profit out of it. It would also completely alter the traditional basis of hospice care established by the hospice movement originating in the UK.

The possible move towards for-profit hospice care in the USA over the last few years had some influence on thinking at the hospice in my study when considering the future of such care in the UK (Smith and Himmel, 2013; Whoriskey and Keating, 2014). As Span (2014) says, what started as a grassroots movement in the USA to improve end of life care developed into a big business. The USA healthcare system is an insurance-based system called Medicare and in effect, if the money runs out then so can the care (Taylor et al., 2009). This can potentially lead to “disenrollment” (Span, 2014) of service users meaning they have to leave a hospice because their insurance money has run out before they have died. The knock-on effect of this, as the author further explains, was that service users would not seek to enter a hospice until very near the end of their lives that then caused extra stress and suffering for them and their families.

The introduction of an insurance or similar system for hospice care in the UK could have ramifications for the way that hospice care is approached and potentially change it beyond current recognition. The implication of the study by Wachterman et al (2011) is that service users could be cherry-picked for receiving hospice care depending on their particular life-limiting illness and the expected longevity of that service user and the potential for greater profit that could be generated. Teno et al (2014), a leading writer/researcher in end of life care in the USA, discovered that for-profit hospices in the USA had discharged patients early from hospice care for various reasons including avoidance of hospitalisation with its possibility of increasing care costs.

The introduction of an insurance-based system for hospice care in the UK does not yet appear to be on the horizon. As well as the commodification of service users, there would be a change in the relationship between service users and staff to a client/consumer/customer basis with the client choosing from a menu of prescribed services, for instance, depending on their ability to pay. They could also become targets for companies wishing to sell their goods to them. This would have implications for service user involvement in palliative care. Service users could become even more like expert shoppers as described by Tritter (2009). The author adds that there is a need to contest the need for individual consumerism and patient choice where “the interests arrayed to promote marketisation and re-define involvement as consumerism may limit the evolution of PPI (Patient Public Involvement) as an integral part of health systems." It could certainly limit the evolution of service user involvement as an integral part of palliative and hospice care.

6.3 Limitations

This section talks about the limitations of my study with a look first at the study design followed by sample size and quality. There is then a discussion about the part that reflexivity has played in my research.

My research is a qualitative study exploring service user involvement in palliative care at a single independent hospice in the UK. It became clear as my fieldwork progressed and I started to analyse the interview data that I would need to reflect on and potentially broaden my scope in order to gather appropriate data to help answer my research question. As mentioned previously in this chapter and elsewhere in this thesis, the organisational changes at the hospice involved in my study were a major topic raised in interviews that I conducted during 2013-15. It necessitated searching more widely for appropriate data to help with theorising about the implications of such changes on service user involvement at the hospice.

6.4 Study design

The methodological approach that I adopted involved case study and thematic analysis of the data. The combination of these approaches enabled me to unearth and explore complexities in the data. As Yin (2012) suggested, I behaved like a detective in evaluating the appropriateness and meaning of the evidence as I was collecting it. Case study, as Walshe (2004) identified, can help deal with complex situations that depend on context in order to address multiple perspectives. The methodological approach also meant I was able to collect and analyse evidence from a variety of sources and could cross-reference findings from each source (Denzin, 2012). For example, exploring evidence in official documented accounts about the hospice in my study that are available on the internet and cross-referencing with data generated by the interviews with participants. This enabled me to consider whether the perspectives put forward by participants about the organisational changes were unfounded or supported by official hospice accounts. This approach also meant I could extend the possibilities of discovery around the topic of my study (Flick and Steinke, 2004). The organisational changes at the hospice were a significant topic mentioned by service user participants and many staff during the interviews. It was not possible to ignore their perspectives about it and the impact they felt the changes had on their lives and relationships with the hospice and the management.

The questions used during interviews with staff and service users at the hospice progressed in a responsive and reflective way. The use of semi-structured interviewing meant there was flexibility to delve further into issues that arose. The questions list provided a structure to the interviews that enabled me to keep participants on topic as necessary while giving them space to speak openly about issues they wished to raise. This ensured that I covered the appropriate areas in all the interviews.

I interviewed staff working in many different areas at the hospice at all levels of seniority. This helped in developing a deeper understanding of the hospice and in analysing the effect of the organisational changes that were being enacted especially on service user involvement. I considered it very fortuitous that I managed to secure an interview with the new CEO as it made it possible to ask questions about the issues that other participants had raised. It also provided more data about the context of the decision-making processes at the hospice as well as further perspectives on service user involvement. Exploring these areas generated rich data that added to the overall analysis in order to reveal levels of understanding and possible answers to my research question.

During this process, I was also aware of the need for reflexivity to help the reader understand the position from which I was carrying out analysis and theorisation and to help restrict potential bias. My personal, professional and voluntary experience has been detailed in Chapter One of this thesis and reflexive points have been included at various points in the content.

Thematic analysis enabled me to identify key patterns and themes in the data. It offers “an accessible and theoretically flexible approach to analysing qualitative data” (Braun and Clarke, 2006, p. 77) and I followed the criteria suggested by these authors for analysing my data. I was very aware of the need to be alert for potential bias in the participants’ views that were included in the findings and analysis and attempted to include all those that I felt added to the focus of my study. I was also aware of keeping a tight focus on finding potential answers to my research question.

6.4.1 Sample size and quality/validity

The participants in my study were 16 members of staff/volunteers and 6 service users. I made every effort to find other service users receiving care from the hospice to add to this number and the reasons why this became difficult are described later in this section. I was very aware of the need for sensitivity towards participants in my study particularly those living with a life-limiting illness. Due to the vulnerability of service users in this position, I was aware of the need to pay close attention to the ethical dimensions of my study.

The involvement of 6 service user participants in my study provided some limitations due to the small number. There were various reasons for this including the apparent effect that the organisational changes at the hospice were having on attitudes of staff at the hospice that also emerged during the interview with the CEO. For instance, there was a change in attitude from the hospice management that involved moving away from a previous position of supporting research at the hospice that initially could have meant I would have to cease my fieldwork there. I noted in my diary that my hospice contact had put the case to the governing board for continuing to support my study to which they agreed and I was able to carry on with my fieldwork for a while longer. There was a sense, however, that there would be a need to identify service user participants in particular very quickly in case the open door approach became shut at the same time as becoming harder to achieve.

The changes in arrangements for service users at the hospice day centre meant I had to increasingly rely on members of staff to help identify individual service users to take part in my study. I had originally planned to attend some of the focus groups held at the day centre so I could inform service users directly about my research and hand out information and expression of interest forms. This was not possible following the discontinuation of the forums in 2013. I sensed a slight reticence from staff in helping identify service users on my behalf that may have been due to uncertainties about their own positions and scope of their roles, for instance, in a changing cultural environment. I was told by a number of staff that as their roles had changed and there were cuts in professional staff numbers particularly at the day centre it meant they did not have time to engage informally with service users and so establish relationships in ways that had been possible previously. This was coupled with the complexities that I was aware were already inherent in identifying and conducting interviews with service users with life-limiting illnesses (Addington-Hall et al., 2007). This in itself can mean that large sample sizes can be difficult to achieve (Viser et al, 2015). For example, I had made an appointment to interview a service user living in a local care home that was receiving care from the hospice and had agreed to be interviewed. Unfortunately, I was contacted the night before the interview to be told that her condition had deteriorated to such a degree that she would not be able to participate after all.

There were strengths in my study provided by the participants that I interviewed. Three of the service user participants, for example, had experienced the hospice day centre before and after the organisational changes came into effect. They therefore provided a useful bridge between the different arrangements operating at the day centre before and after the changes and the impact these had on each of them and their perceived relationships with the hospice. Another service user participant only started using the day centre after the changes in arrangements and had his own perspectives on the situation including some of the difficulties he perceived with his views seemingly not being heard or acted on either by management.

6.5 Reflexivity

I have mentioned reflexivity at various points in this thesis. According to Russell and Kelly (2002), “through reflection researchers may become aware of what allows them to see, as well as what may inhibit their seeing." Researchers need to be aware of the influences they may have on research processes and how in turn the processes affect them. Finlay (2006) put forward "the 5'C's" (Finlay, 2006, p. 69) or dimensions for evaluating resonance and relevance of qualitative research outcomes.

I was always aware that my own personal, professional and voluntary experience might influence my own thinking when analysing the data, for instance. In reflecting on my own experience, I recognised that it could bring advantages to my research as well as potential disadvantages. For example, the literature review indicated that the majority of studies conducted on service user involvement in palliative care have come from health professionals (Payne, 2008). I am not a health professional but rather a layperson and service user and so bring a different perspective to the topic. A potential disadvantage of this was whether I might feel a natural inclination to overly sympathise with the accounts of service user participants. Through keeping notes and constant dialogue with my supervisors I was able to continuously reflect on all stages of my research. This process enabled me to question myself and whether I was making assertions that may be based on my own assumptions or personal feelings that were not necessarily evidentially clear from the data. I strove to provide a logical and coherent analysis and also apply "ethical, literary and creative dimensions" (Finlay, 2006, p. 70) in order to stay as open as possible to different interpretations around the lived experience of the participants and to help ensure the validity of my findings. I felt it was crucial not to get too 'caught up' in the accounts of service user participants in particular bearing in mind my own experience of caring for my parents towards the end of their lives. I understood and recognised some of the frustrations that the service user participants were feeling and the danger of becoming overly sympathetic and biased towards their viewpoints. The first step in handling this was to recognise the possibility of bias while being careful not to overcompensate and becoming completely unsympathetic.

In the case of my study, the organisational changes at the hospice had a significant influence on participants and were mentioned by them during the interviews that I conducted from 2013 onwards. I felt it was necessary to analyse the data to draw out issues and themes but also to dig as deeply as possible into it in order to theorise on a wider scale to allow for transferability of my findings. Although the organisational changes were taking place at this one independent UK hospice they held implications for other UK hospices that may be experiencing similar pressures especially in funding and might decide to undergo fundamental organisational change to meet future challenges. Such moves would hold significant implications for service user involvement in palliative care in hospices more generally as well as signal a significant move away from the traditional tenets of the hospice movement.

6.9 Chapter conclusion

This chapter has included a discussion of the themes that were identified in my data with indications of where they related to literature on this topic area. It has also included a discussion about the limitations of my study. It could be argued that not making comparisons with other hospices might be a limitation but concentrating on a single hospice is valid as it enabled in-depth analysis of the data and for deeper understandings to emerge.

What has emerged from the data is a sense of dislocation felt by both service users and staff participants at the hospice due primarily to the organisational changes introduced in 2013 and continued over the course of my fieldwork up to 2016. The apparent change in management philosophy and the introduction of a managerialist approach with service users increasingly being seen as consumers had significant implications for relationships between service users, staff and management at the hospice. It also had implications for service user involvement indicated by an increasing reliance on patient satisfaction surveys. These surveys were used by management as the main means for generating feedback and input from service users on the care being provided. There was no mechanism at that time for drawing on service users' wisdom or experience to help inform decision-making or develop priorities at the hospice.

CHAPTER SEVEN: CONCLUSION

The research question for my qualitative study is:

What are the perspectives of professional staff and service users towards service user involvement in palliative care within the context of organisational and cultural change in a UK independent hospice?

I used a case study approach with thematic analysis. I established a working relationship with an independent UK hospice that began in 2011 and enabled ethical access for identifying service users living with a life-limiting illness and hospice staff for taking part in my study. I interviewed 15 paid staff working at the hospice and six service users in three waves over the years 2013 – 2016. After analysis of data from service user and staff participants, I took a strategic decision to interview the hospice CEO that led to three sets of findings and themes that are presented in Chapter Five. The themes from service users and staff show similarities in simultaneous feelings of involvement and disempowerment as well as of belonging and alienation. The themes drawn out from the CEO data reflect his senior role and position of power.

My analysis showed, congruent with the literature, that there continue to be misunderstandings about service user involvement in palliative care in a hospice context; that power and control are important factors where a managerial style can set the cultural tone and influence the behaviour of service users and staff as well as affect relationships between all stakeholders; that organisational change, if implemented too quickly and without a transition plan, can have negative impacts and lead to feelings of alienation and distrust; that there is an increasing reliance on patient satisfaction surveys at hospices for gathering feedback data in order primarily to compare and contrast the numbers of service users accessing hospice care with other hospices and care facilities; that hospice day centres are generally viewed as part of care provision services with an increasing emphasis on rehabilitation of service users; that day centres are not regarded as providing an environment for facilitating discussions and debate that taps into the wisdom and experience of service users to help influence decision-making at a hospice; that external pressures including political and economic can influence management decisions and the cultural direction adopted at a hospice.

My study involved one independent UK hospice and this meant that I could not compare the findings with data gathered from other hospices. While such comparisons might have elicited useful data, I believe that using a case study approach on a single site enabled me to immerse myself in the context of the hospice including the managerial behaviour and political and economic environment in which it was operating. Through analysis of the data, I was able to extrapolate implications from the results. This opened up further questions about current thinking around my research question and possible pointers for research in the future.

The literature showed that approaches towards developing service user involvement in mental health and disability fields are not appropriate to facilitating service user involvement in palliative care generally or in a hospice. Cotterell (2006) identified that service users receiving palliative care are not naturally drawn towards forming themselves into groups in order to discuss their concerns with management or to lobby for legislative change. I would argue from the evidence in my study that hospice day centres can provide a suitable environment for hosting service user palliative care groups. The reasons for this are presented next.

The organisational changes that took place at the hospice including the day centre and the impact they had on service users and staff has been described in detail in this thesis. The advantage of these changes taking place during the years of my fieldwork (2013 – 2016) was that it enabled me to do a before and after comparison of the workings of the day centre. Three of the service user participants used the day centre before and after the changes and therefore provided a bridge between the two approaches. Before the changes, the service users described their ability to decide when to attend the day centre, decide what activities they would do once there and then staff would facilitate them. They also described how it provided opportunities to meet informally with other service users and staff and discuss any concerns that could then be passed on to management if appropriate. The analysis of the interviews indicated that there was a large degree of trust between these service users and particular staff, mainly nurses that worked in the day centre, and with management. I would argue that the organisational changes altered the previous culture by breaking through these relationships. This resulted in the sowing of seeds of distrust, not necessarily between service users and individual staff but mainly between service users and management and between staff and management.

In this thesis, I have also mentioned the service user forums that had been in operation during my initial visits to the hospice in 2011/12 and were described to me by the then CEO. The forums took place at the day centre and provided an environment for service users to speak openly about topics of their choosing, whether related to care provision or other aspects of the hospice or general issues. The organisational changes in 2013 put a stop to these service user forums. A very rigid and controlled system of attending the day centre was introduced. It was renamed the Wellbeing and Therapies Centre and an emphasis placed on rehabilitation provided within a formal appointment system with service users choosing activities from a pre-determined menu. An 8 weeks on, 8 weeks off policy was eventually introduced after pressure from the hospice service user group and possibly outside influences. This enabled service users to continue to drop in to the day centre but again, in a controlled way and only on a particular day of the week and they had to choose a day and stick with it during their 8 weeks on. If a service user was too ill to attend on their chosen drop in day, then they had to wait until the following week before they could next drop in. On their 8 weeks off, service users had to stay at home unless they had a clinical or other appointment at the Therapies Centre.

The management style at the hospice that was introduced from 2013 was very much about control and top-down decision-making reflecting a managerialist approach. The consultation activities that were enacted by hospice management involved taking part in consultation meetings and completing surveys that three of the service user participants took part in. This approach felt tokenistic to them as their views were ignored. I would argue that only using general meetings and surveys as means of consultation is incompatible for use with service users with a life limiting illness. The service user forums approach would have provided a means for discussion and enabled useful ideas to emerge. But it does seem from the data, including accounts from online hospice documents and the interview with the CEO, that the management had already decided the direction the hospice and day centre were going in and the consultation activities were window dressing.

In the thesis, I described the CEO as being like a lightening rod for a lot of criticism and anger from three service user participants. I felt it was important to delve further into and analyse if there was any justification for such feelings by trying to secure an interview with the CEO. He agreed to do this and I believe it added significantly to my study, particularly in relation to analysing management behaviour and how it can influence culture and relationships between stakeholders that can have an effect on the topic of my study. The observation from one member of staff that the hospice was becoming more like a hospital was very telling. This was further exemplified by the departments and staff including the CEO, that moved from the main hospice site to an office at an industrial estate around two miles away. In the interview, the CEO remarked that the main hospice site would concentrate on the core work of the hospice that, in his view, was clinical care.

The CEO favoured describing service users as consumers, as he said in the interview. He also said he was influenced by how for-profit hospices in the USA organised themselves using an insurance system. He did not suggest that this would be happening at his particular hospice where care was provided for free. Rather he viewed it as a possible general direction of travel for UK hospices that he believed would be introduced at some point in the future. It seemed with the emphasis that the organisational changes placed on broadening fundraising, marketing and Information Technology (IT) with subsequent increases in staff numbers in those areas that the CEO was attempting to strengthen the financial sustainability of the hospice into the future. With his stated views in the interview on generating partnerships with private companies, it also seemed he was preparing the ground for when an insurance-style system for healthcare and therefore, hospice care, may be introduced.

The CEO’s emphasis was on increasing accessibility of hospice services to as many people as possible using all means at his disposal. While this is not a negative aspiration, the way in which it is handled could serve to take hospices away from the original ethos of the UK hospice movement as espoused by Dame Cicely Saunders. Hospices could turn into something else in the future perhaps just health facilities like hospitals but specifically for end of life care. The emphasis would be on clinical care provision rather than on seeing a person coming towards the end of their lives in a holistic way. I would argue that such a scenario would carry great significance for service user involvement in palliative care in a hospice context. It could promote the notion of service users as consumers or customers who choose activities from a prescribed menu based on their ability to pay and be subject to marketing programmes from private companies to purchase their goods as happens in the USA.

I believe that my study indicates that there is a need for more focused research on how hospices organise themselves and the impact of cultural and managerial approaches, particularly during cultural change, coupled with political and policy changes. My literature review indicated there is a lack of research into hospices and their operation, particularly in relation to strategic and financial planning, and the role that political and economic influences play. There is also a lack of research into the role and purpose of hospice day centres. What little research there is, concentrates on the process of providing care or other activities in the day centre. There is very little research on attitudes and views of service users, that is, people living with life-limiting illnesses, on what they would like to see from hospices and day centres.

I think that the palliative care community should be concerned about the views of service users being sidelined in the pursuit of expanding access to hospice services. A primary focus on expansion and accessibility can involve a concentration on gathering numbers; a concentration on care provision rather than on enhancing the quality of life and empowering those with a life-limiting illness. Quality of life for a service user receiving holistic care from a hospice should include enhancing self-esteem; reducing isolation by engendering a sense of belonging and enabling social contact and the building of relationships; providing an environment for open expression and an opportunity to influence decisions whether individual or hospice-wide. All these ingredients would, I believe, lead to feelings of empowerment and set the ground for enabling service user involvement in palliative care. Management style would play a big part in this. It would still require an impetus and support from senior management at a hospice to enact such an approach. In that sense, it is not in the same category as service user involvement in mental health and disabilities fields but it is tailored to the particular circumstances of service users with life-limiting illnesses. I believe this would provide a worthwhile starting point to enable and empower palliative care service users find their voice.

7.1 Implications for future practice, research, education and policy

This section looks into the implications of my study findings for practice, policy, education and future research in this topic area. Some of the recommendations are distinct to these areas while others crossover into two or more of them.

A key finding from my study, and mentioned a number of times in this thesis, is that service users living with a life-limiting illness want their views and voices to be heard and to be valued and respected. The data from my study indicated a deep yearning on behalf of service user participants to have had real involvement in decision-making at the hospice particularly during the organisational changes rather than the feeling that their views were ignored or dismissed by management. When trust starts to break down then feelings of distrust, disempowerment and alienation can rise. These feelings can occur not only amongst service users but also amongst staff, particularly towards the management that can seriously impair relationships and impair effective service user involvement.

Unlike an assumption that arose from the data from staff participants, being asked to get involved in decision-making not only about their own care but also wider issues to do with the hospice was not perceived by service user participants as a burden. Their individual keenness to take part in my research indicated this point very strongly. Therefore, it behoves those contemplating conducting future research into service user involvement whether in palliative care or hospice care to take this into account when devising the study design. A heavy reliance on the voices of staff and/or family caregivers in research projects will miss out a vital component and potentially lead to skewed findings with implications for other research and potentially for policy making.

Hospices in particular should ask the service users they care for if they would like to actively take part in research projects that they are running. Attempts should be made to involve those with a range of illnesses and not only target those with cancer. This would mean not just patient surveys but in-depth investigations where the service user has a proper rather than tokenistic role. It struck me as quite strange that the hospice in my study had not been seeking to involve service users receiving care in their own research projects; nor were service users involved in training/education courses being run for internal and external medical staff and clinicians. In my view, listening to and learning from a person living with a life-limiting illness would greatly add to research findings and enhance the attitudes and future approach of the professionals attending towards their work. I have witnessed and experienced this myself with my own involvement with service user groups in palliative care. I have attended numerous seminars and conferences on health and palliative care that involved professional staff as well as service users with life-limiting illnesses and heard service users speak for themselves either from the main platform or contributing from the audience. Their words are powerful and deserve to be captured and added to evidence. Involvement of service users in this way could help to break down barriers between service users receiving palliative/hospice care and professionals in a way that could not be perceived as challenging professional orthodoxy but rather as providing learning opportunities.

It also became clear during my research that service user involvement in palliative care or hospice care needs to be approached in a different way to involvement in other areas such as disability and mental health. As Cotterell (2006) discovered, those receiving palliative care do not tend to recognise each other or reach out and decide to form their own groupings to help promote their voices and views and try to influence policy, education or practice. The approach therefore has to be more individualistic. In a hospice setting, it would require commitment from the management to facilitate the conditions for such involvement to be introduced and sustained and would mean facilitating rather than seeking to control. This is how it happened with the service user forums at the hospice in my study that had been facilitated by management but were then discontinued due to the organisational changes. My study shows that the management approach and culture that is engendered in a hospice plays a big part in dictating what kind of service user involvement will be pursued. This is further exemplified in my study by responses to what happened at the hospice day centre.

The role and impact of hospice day centres from the perspectives of service users is a gap in knowledge as highlighted in the literature review and could therefore be a useful topic for future research and carry implications for future practice. In my study, service user participants valued their relationship with the day centre. The responses of three of the service user participants in particular to the changes in attendance arrangements at the day centre highlight the impact it had on them and how deeply they felt that their views had been ignored during the consultation period and yet they were arguably among the people most affected. Although there have been some studies looking into hospice day centres, Spencer (1998), Payne (2006) and Stevens (2008) all identified a continued dearth and sparseness of such research in the use and impact of such centres. Studies that I unearthed after 2008 seemed to concentrate more on the process of providing services at hospice day centres and numbers of service users taking them up rather than on evaluating the benefits and usefulness for individuals.

Kennett and Payne (2005) analysed service user (patient) accounts of attendance at a UK hospice day centre that used a psychosocial model of care. The authors discovered that attending the day centre proved to be very beneficial for the service users who experienced such feelings as a lightening of their mood, enjoyment, a sense of belonging and community where mutual support was available that could help them deal with such issues as problems in their family relationships. The study concluded that the quality of life of the patients was enhanced by their attendance at the day centre. Notwithstanding the Kennett and Payne (2005) study, Stevens (2008) identified that there was still a need for empirical studies to provide more quality evidence on hospice day centres from the perspectives of those that used them. Lawton (2000) provides very useful insights on service user and staff perspectives at the hospice day centre in her study and if coupled with my study, could potentially provide a useful base for further research in this area.

The subject of trust and involvement for service users with a life-limiting illness that are living alone without a caregiver is the subject of some research in the literature. There were four service user participants in my study in this position and helps to further explain the importance of the day centre in their lives in combatting loneliness, for example, and providing social connections with others. Aoun et al (2014) found that people living alone were less likely to be cared for or die at home; would experience more psychosocial distress and were more likely to enter hospital than were people with a primary caregiver. People are generally living for longer and there is likely to be an increase in the numbers of people living alone. Research into the consequences of this scenario could be pursued including the role that hospices could play in not only providing palliative care for people that are alone but also providing the means to lessen feelings of isolation and disempowerment that may not be felt as keenly as those with family caregivers.

As well as helping to promote physical quality of life, I contend that hospice day centres could be used to facilitate forums for discussion and debate among service users, sometimes in conjunction with staff, around issues not only to do with the hospice but also wider aspects of palliative care, for instance. The discontinued service user forums at the hospice in my study could have been used, as one nurse participant mentioned, to sound out and gather views as part of the consultation process but they were not used in this way. McIlfatrick and Hasson (2016) discovered that the forums in their study provided a supportive environment where voices could be heard and valued. Hospices have a wealth of knowledge and experience among the people that work in them and the service users that receive care from them. Tapping into that knowledge and using it effectively could open up tremendous lines of engagement and education for practice in palliative care as well as useful data for use by strategic decision-makers and policy makers. I would contend such an approach would be much more effective than a reliance on annual patient satisfaction surveys, for example, or written surveys that elicit experiences and opinions in a restrictive way and use quantitative methods to evaluate findings.

Service user participants in my study felt a closer affinity with the day centre rather than being aware of or involved with the hospice service user group or have any awareness that it might be able to take up issues on their behalf. There was a general lack of knowledge about the hospice service user group and the activities it pursued or the influence it had amongst service user and staff participants generally apart from amongst very senior staff participants. It would seem that research into the purpose and role of hospice service user groups would be very useful in order to enhance knowledge and practice.

An emphasis on a rehabilitative approach to hospice care and moves towards reablement and therapies as highlighted in this thesis, indicate there may be a move by other UK hospices to follow suit. Such moves could hold implications for service user involvement and the voices and views of service users being either ignored or not addressed. They could potentially herald a move towards an emphasis on physical or clinical aspects of rehabilitation in palliative and hospice care. This situation could then start to dominate research and influence discourse and outcomes, a scenario not too hard to imagine if hospices develop partnerships or closer collaborative working with NHS bodies such as hospitals. A dominance of health discourse can seduce service users into wanting what the system tells then they want as Richardson, MacLeod and Kent (2010) discovered. The appropriateness and effectiveness of using a reablement and rehabilitation approach in palliative care needs further research. Studies exploring the opinions and views of service users towards the strengths and limitations of rehabilitation and reablement services in a hospice setting could reveal some very useful findings that could influence developments in future practice and research.

Without evidence-based evaluation of hospices, how they operate and the services they provide, I contend there will continue to be inequities of access to hospice care and differences in approaches to service user involvement. Hospices in the UK do not form a homogeneous grouping and this can have an impact on the ability to make effective strategic and policy decisions at a national level around palliative care as Haslam, Theodosopoulos and Tsitsianis (2014) discovered. My study was therefore appropriate in concentrating on a single hospice and by using case study, provided an opportunity for generating and analysing complex layers of data that could hold implications for the development of hospices generally into the future. It shows that the circumstances and the manner in which the levers of service user involvement at a hospice can be pulled relies heavily on management attitudes towards it and the cultural environment that is generated. Further research and implications for practice and policy of the impact of management approaches and cultures in UK hospices would be welcome. The pressures exerted by the socio-political-economic context within which hospices have to operate cannot be ignored. Uncertainties around how public services in the UK will be paid for in the future are important determinants for how hospices may decide to organise themselves for future sustainability. The possibility that more hospices may decide to adopt a neo-liberal/managerialist approach and increasingly start to view service users as consumers, is eminently feasible. The push for more hospices to adopt a rehabilitative approach to palliative care could be the start of such a process. Increased privatisation of public services is another external pressure that could fall into palliative and hospice care in the UK. As mentioned in Chapter Six, the King's Fund reported in 2017 that a tender for delivering end of life and cancer care caused criticism that led to it being dropped. So it is not yet quite acceptable but it shows a direction of travel and could happen on more occasions over time. Research into the implications of privatising palliative and end of life care services is another important area, the findings of which could hold implications for practice and policy making in this area as well as for service user involvement.

Other scenarios are possible. In this thesis, I have framed the changing cultural situation at the hospice as an ideological battle and categorised it as a sanctuary versus business approach. Slightly rewording this to a sanctuary and business approach could provide a hybrid model of hospice care that includes elements of both in a collaborative approach. But there could still potentially be other consequences. For example, if hospices move increasingly towards a healthcare or NHS style approach then service users could still be seen as individual consumers as Tritter (2009) contended. If a health discourse becomes dominant, service users receiving palliative care run the risk of being disempowered and end up wanting or accepting what the system tells them that they want (Richardson, MacLeod and Kent, 2010).

In conclusion, I argue that more independent and qualitative evidence-based research is needed in order to adequately evaluate the strategic direction of hospices in the future. This includes the cultural implications that their choices pose for the hospice movement generally. A managerialist style, a move towards a regulatory rather than rights based approach, privatisation of public services and the pursuit of consumerism at UK hospices are significant factors. All these aspects could influence stakeholder perspectives towards hospices and their purpose. They could also, consequentially, influence perspectives towards service user involvement in palliative care and hospice care.

APPENDICES AND REFERENCES

REFERENCES

Adams, E. (2010) ‘The joys and challenges of semi-structured interviewing’, *Community Practitioner,* 83(7), pp. 18-21

Addington-Hall, J. (2002) ‘Research sensitivities to palliative care patients,’ *European Journal of Cancer Care*, 11(3), pp. 220-224. Available at: http://onlinelibrary.wiley.com/doi/10.1046/j.1365-2354.2002.00343.x/full (Accessed 21 October 2016)

Addington-Hall, J., Bruera, E., Higginson, I. and Payne, S. (2007) *Research Methods in Palliative Care*. Oxford University Press

Altheide, D. and Johnson, J. (2011) ‘Reflections on interpretive adequacy in qualitative research’, in Denzin, N. and Lincoln, Y. (eds) *The SAGE Handbook of Qualitative Research.* Thousand Oaks, CA: SAGE, pp. 581 - 594

Anheier, H. (2000) ‘Managing non-profit organisations: Towards a new approach’, *Civil Society Working Paper.* London School of Economics. Available at: http://eprints.lse.ac.uk/29022/ (Accessed: April 2017)

Antoniou, J. (2010) ‘Mental Health, Service User Involvement and Recovery’, *The British Journal of Psychiatry*, 197(5), pp. 417

Arnstein, S, 1969, ‘A ladder of citizen participation’, *Journal of the American Planning Association,* vol. 35, no. 4, pp. 216-224 http://lithgow-schmidt.dk/sherry-arnstein/ladder-of-citizen-participation.html

Arksey, H. and O’Malley, L. (2005) ‘Scoping studies: towards a methodological framework’, *International Journal of Social Research Methodology’*, 8(1), pp. 19-31

Ashling, R. (2016) ‘Advancing Home Hospice Care Through Technology’, *Long Term Living*, 65 (1), pp.14. Available at: http://search.proquest.com.ezproxy.brunel.ac.uk/docview/1771758139?pq-origsite=summon (Accessed 2017)

Aspinal, F., Hughes, R., Dunckley, M.and Addington-Hall, J. (2006) ‘What is important to measure in the last months and weeks of life?: A modified nominal group study’, *International Journal of Nursing Studies*, 43, pp. 393-403

Attree, P., Morris, S., Payne, S., Vaughan S., Hinder S. (2010) ‘Exploring the influence of service user involvement on health and social care services for cancer’, *Health Expectations,* 14(1), pp. 48-58

Baines, M. (2011) ‘Pioneering days of palliative care’, *European Journal of Palliative Care,* 18(5), pp. 223-227

Beaver, K., Luker, K. and Woods, S. (2013) ‘Conducting research with the terminally ill’, International Journal of Palliative Nursing, 5(1). Available at: https://www.magonlinelibrary.com/doi/abs/10.12968/ijpn.1999.5.1.9926 (Accessed: 2017)

Belousov, M. (2016) ‘On the Problem of the World in Husserl’s Phenomenology’, Russian Studies in Philosophy, 54(1), pp. 20-34. doi: 10.1080/10611967.2016.1169099

Beresford, P. (2005) ‘Service User: regressive or liberatory terminology’, *Disability and Society*, 20(4), pp. 469-477

Beresford, P. and Branfield, F. (2006) ‘Developing inclusive partnerships: user-defined outcomes, networking and knowledge – a case study’, *Health and Social Care in the Community*, 14(5), pp. 436-444

Beresford, P. (2007) ‘User involvement, research and health inequalities: developing new directions’, *Health and Social Care in the Community*, 15(4), pp. 306-312

Beresford, P., Fleming, J., Glynn, M., Bewley, C., Croft, S., Branfield, F. and Postle, K. (2011) *Supporting People: Towards a person-centred approach*, Bristol: The Policy Press

Beresford, P. and Andrews, E. (2012) ‘Caring for our future: what service users say’, JRF Report. Available at: https://www.jrf.org.uk/report/caring-our-future-what-service-users-say (Accessed: 2016)

Beresford, P. and Carr, S. (2012) *Social Care, Service Users and User Involvement*, Jessica Kingsley Publishers

Beresford, P. (2013) ‘Beyond the usual suspects’ *Research Report:* Shaping Our Lives. Available at: *https://www.shapingourlives.org.uk/documents/BTUSReport.pdf* (Accessed: 2015)

Beresford, P. (2016) *All Our Welfare*. Bristol: Policy Press

Bloom, S. and Farragher, B. (2013) ‘Restoring Sanctuary: A New Operating System for Trauma-Informed Systems of Care’. *Oxford University Press*

BMJ (2005) ‘Dame Cicely Saunders, founder of the modern hospice movement, dies, *British Medical Journal* Available at: http://www.bmj.com/content/suppl/2005/07/18/331.7509.DC1 (Accessed at: 2017)

Boelk, A. and Kramer, B. (2012) 'Advancing Theory of Family Conflict at the End of Life: A Hospice Case Study', *Journal of Pain and Symptom Management*, 44(5), pp. 655-670

Booth, A., Papaioannou, D. and Sutton, A (2012) 'Systematic Approaches to a Successful Literature Review. *SAGE*

Bradbury-Jones, C., Coleman, D., Davies, H., Ellison, K., Leigh, C. (2010) 'Raised emotions: A critique of the Peshkin approach to reflection', *Nurse Education Today*, 30(6), pp. 568-572

Bradshaw, P. 2008, 'Service user involvement in the NHS in England: genuine user participation or a dogma-driven folly?' *Journal of Nursing Management*, 16, pp. 673-681

Branfield, F. and Beresford, P. (2006) 'Making user involvement work: Supporting service user networking and knowledge', *Joseph Rowntree Foundation*

Braun, V. and Clarke, V. (2006) 'Using thematic analysis in psychology, *Qualitative Research in Psychology*, 3(2), pp. 77-101

Braun, V. and Clarke, V. (2014) 'What can thematic analysis offer health and wellbeing researchers?', International Journal of Qualitative Studies in Health and Wellbeing, 9. Available at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4201665/ (Accessed: 2017)

Brearley, S. (2007) 'Patient and public involvement in healthcare', Consumer Policy Review, 17(5), pp. 227-230

Butcher, H, 2010, 'Service User Involvement in Cancer Care', NHS *National Cancer Peer Review Programme*. National Cancer Action Team. Available at: www.cquins.nhs.uk/download.php?d=NCAT_INTEL_PEER_SerUserIn.pdf (Accessed: 2017)

Carlisle, Y. (2011) 'Complexity dynamics: Managerialism and undesirable emergence in healthcare organizations', *Journal of Medical Marketing*, 11(4), pp. 284-293

Carter, H., MacLeod, R., Brander, P. and McPherson, K. (2004), 'Living with a terminal illness: patients' priorities', *Journal of Advanced Nursing*, 45(6), pp. 611-620

Charlesworth, K., Jamieson, M., Davey, R. and Butler, C. (2016), 'Transformational change in healthcare: an examination of four case studies', *Australian Health Review*, 14, pp. 163-167

Charmaz, K. (1983) 'Loss of self: a fundamental form of suffering in the chronically ill', *Sociology of Health and Illness*, 5(2), pp. 1983

Charmaz, K, 1990, "'Discovering' Chronic Illness: Using Grounded Theory", Social Science and Medicine, vol. 30, no. 11, pp 1161-1172

Charmaz, K. (2006) *Constructing Grounded theory: A practical guide through Qualitative Analysis*. SAGE

Charmaz, K. (2008) 'Constructionism and the Grounded Theory Method', in Holstein, J. and Gubrium, J. (eds) *Handbook of Constructionist Research*. New York: The Guilford Press, pp. 397-412

Charmaz, K. and Belgrave, L. (2012) 'Qualitative interviewing and grounded theory analysis', in Gubrium, J., Holstein, J., Marvasti, A. and McKinney, K. (eds) *The SAGE Handbook of Interview Research: The Complexity of the Craft*, SAGE pp. 347-365 doi**:** http://dx.doi.org/10.4135/9781452218403.n25

Charmaz, K. (2014) Grounded theory in global perspective, Qualitative Inquiry, 20(9). Available at: http://journals.sagepub.com.ezproxy.brunel.ac.uk/doi/full/10.1177/1077800414545235 (Accessed: 2017)

Chevannes, M. (2002) 'Social construction of the managerialism of needs assessment by health and social care professionals', *Health and Social Care in the Community*, 10(3), pp. 168-178

Cicely Saunders International (2016) *About CSI*. Available at: http://www.kcl.ac.uk/lsm/research/divisions/cicelysaunders/about/cicely/international.aspx (Accessed: 2017)

Clark, D. (2014) 'Early origins of St Christopher's Hospice', *University of Glasgow End of Life Studies.* Available at: http://endoflifestudies.academicblogs.co.uk/early-origins-of-st-christophers-hospice/ (Accessed: 2017)

Clark, D. (2015) 'Works of love: Cicely Saunders and the hospice movement'. *Transformation.* Available at: https://www.opendemocracy.net/transformation/david-clark/works-of-love-cicely-saunders-and-hospice-movement (Accessed: 2017)

Clark, D. (2016) *To comfort always: A history of palliative medicine since the Nineteenth century*. Oxford Medical Histories.

Clarke, D., Sanders, D., Stewart, M. and Whiteley, P. (2004) *Political Choice in Britain*. Oxford Scholarship Online. Available at: http://www.oxfordscholarship.com/view/10.1093/019924488X.001.0001/acprof-9780199244881 (Accessed: 2016)

Clarke, V. and Braun, V. (2013) 'Teaching thematic analysis: Overcoming challenges and developing strategies for effective learning'. *The Psychologist*, 26(2), pp. 120-123

Collis, J. and Hussey, R. (2014). *Business Research*. 4th edn. Palgrave: Macmillan

Connor, S. and Bermedo, M. (2014) 'Global Atlas of Palliative Care at the end of life', *World Palliative Care Organisation (WPCA). Available at:* http://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf (Accessed: 2016)

Corbin, J. and Strauss, A. (1990) Grounded Theory Research: Procedures, Canons and Evaluative Criteria', *Qualitative Sociology*, 13(1), pp. 3-21

Corbin, J. and Strauss, A. (2008) *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*. 3rd edn. SAGE

Cornell, C. and Nwoka, J. (2015) 'The Systems Theory of Management – A Study of Aldgate Congress Resort Limited Port Harcourt', *International Journal of Scientific and Research Publications*, 5(9), pp. 1-7

Cotterell, P. (2006) 'Living with life limiting conditions: A participatory study of people's experiences and needs', PhD *Thesis*. Brunel University

Cotterell, P., Harlow, G. and Morris, C. (2008) 'The impact of involvement on service users', *INVOLVE Conference*. Available at: http://www.invo.org.uk/posttypeconference/the-impact-of-involvement-on-service-users/ (Accessed 2010)

Cotterell, P., Harlow, G., Morris, C., Beresford, P., Hanley, B., Sargeant, A., Sitzia, J. and Staley, K. (2011) "Service User involvement in cancer care: the impact on service users", *Health Expectations*, 14(2), pp. 159-169

Coulter, A. and Ellins, J. (2006) 'Patient-focused interventions: A review of the evidence', *Picker Institute Europe.* Available at: *http://www.health.org.uk/sites/health/files/PatientFocusedInterventions_ReviewOfTheEvidence.pdf (Accessed: 2017)*

Cresswell, J. (2009) *Research Design: Qualitative, Quantitative and Mixed Methods Approaches*. SAGE

Croft, S., Chowns, C. and Beresford, P. (2012) 'Getting it right. End of life care and user involvement in palliative care social work'. *Association of Palliative Care Social Workers*. Available at: http://www.apcsw.org.uk/uploads/3/0/8/4/3084378/getting_it_right.pdf (Accessed: 2016)

Curry, L., Nembhard, I. and Bradley, E. (2009) 'Qualitative and Mixed Methods Provide Unique Contributions To Outcomes Research'. *Circulation*. 119(10), pp. 1442-52

Daykin, N., Sanidas, M., Tritter, J., Rimmer, J. and Evans, S. (2010) ‘Developing user involvement in a UK cancer network: professionals’ and users’ perspectives’, *Journal of Critical Public Health*, 14(3), pp. 277-294 doi: 10.1080/09581590400004402

Deber, R., Kraetschmer, N., Urowitz, S. and Sharpe, N. (2005) ‘Patient, consumer, client, or customer: what do people want to be called?”, *Health Expectations*, 8, pp. 345-351

Denzin, N. and Lincoln, Y. (2005a) *The SAGE Handbook of Qualitative Research.* 3rd edn. SAGE

Denzin, N. and Lincoln, Y. (2011) *The SAGE Handbook of Qualitative Research*. 4th edn. SAGE

Denzin, N. (2012) ‘Triangulation 2.0’, *Journal of Mixed Methods Research*, 6(2), pp.80-88 doi: 10.1177/1558689812437186

Department of Health. (1998) ‘A policy framework for commissioning cancer services: A report by the Expert Advisory Group on Cancer to the Chief Medical Officers of England and Wales’. *The Calman Hine Report* Available at: http://webarchive.nationalarchives.gov.uk/20080817211349/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4071083 (Accessed: 2018)

Department of Health. (2001) ‘Health and Social Care Act’. Available at: http://www.legislation.gov.uk/ukpga/2001/15/contents (Accessed: 2017)

Department of Health. (2006) ‘National Health Service Act’. Available at: https://www.legislation.gov.uk/ukpga/2006/41/part/1 (Accessed: 2018)

Department of Health. (2007) ‘Cancer Reform Strategy’. Available at: http://webarchive.nationalarchives.gov.uk/20130104165259/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081006 (Accessed: 2018)

Department of Health. (2008) ‘End of Life Care Strategy’. Available at: http://www.cpa.org.uk/cpa/End_of_Life_Care_Strategy.pdf (Accessed: 2014)

Department of Health. (2008) ‘The Health and Social Care Act 2008: code of practice on the prevention and control of infections and related guidance’. Available at: https://www.gov.uk/government/publications/the-health-and-social-care-act-2008-code-of-practice-on-the-prevention-and-control-of-infections-and-related-guidance (Accessed: 2017)

Department of Health. (2012) ‘Health and Social Care Act’. Available at: http://www.legislation.gov.uk/ukpga/2012/7/contents/enacted (Accessed: 2017)

Dixon-Woods, M., Shaw, R., Agarwal, S. and Smith, J (2004) 'The problem of appraising qualitative research', Quality and Safety in Healthcare, 13, pp. 223-225. doi: 10.1136/qshc.2003.008714

Dowling, M. (2004) 'Hermeneutics: an exploration', *Nurse Researcher*, 11(4), pp. 30-9

Draper, N. and Smith, H. (1998) *Applied Regression Analysis***.** 3rd edn. Available at: http://onlinelibrary.wiley.com/book/10.1002/9781118625590 (Accessed: 2017)

Drucker, P. (1992) *Managing the Non-Profit Organization*, Routledge

Drucker, P. (1994) 'Theory of the business', *Harvard Business Review*, September/October, pp. 95-106.

Drucker, P. (1999) 'Management challenges for the 21st century', *Elselvier*

Eisenhardt, K. (1989) 'Building Theories from Case Study Research', *The Academy of Management Review*, 14(4), pp. 532-550

Enteman, W. (1993) Managerialism: *The Emergence of a New Ideology*. Madison: University of Wisconsin Press

Etkind, S., Bone, A., Lovell, N., Higginson, I and Murtagh, F. (2018) 'Influences on Care Preferences of Older People with Advanced Illness: A Systematic Review and Thematic Synthesis', *Journal of the American Geriatric Society*, 66, pp. 1031-1039

Evans, S., Tritter, J., Barley, V., Daykin, N., McNeil, J., Palmer, N., Rimmer, J., Sanidas, M. and Turton, P. (2003) 'User involvement in UK cancer services: bridging the policy gap', *European Journal of Cancer Care*, 12, pp. 331-338

Fagerberg, I. and Norberg, A. (2009) 'Learning by doing: or how to reach an understanding of the research method phenomenological hermeneutics', *Nursing Education Today*, 29(7), pp. 735-9

Field, D., Payne, S., Relf, M. and Reid, D. (2006) 'Some issues in the provision of adult bereavement support by UK hospices', *Social Science and Medicine*, 64(2), pp. 428-438

'Fighting For Life' (2018) *Play*. Available at: https://fightingforlife.org.uk

Finlay, L. (2006) 'Rigour, Ethical Integrity or Artistry? Reflexively Reviewing Criteria for Evaluating Qualitative Research', *British Journal of Occupational Therapy*, 69(7), pp. 319-326

Finlay, L. (2008) ‘A Dance Between the Reduction and Refexivity: Explicating the “Phenomenological Psychological Attitude’, *Journal of Phenomenological Psychology*, 39(1), pp. 1-32

Finlay, L. and Gough, B. (2003) *Reflexivity: A Practical Guide for Researchers in Health and Social Sciences*. Wiley-Blackwell

Flick, U., von Kardorff, E and Steinke, I (2004) *A Companion to Qualitative Research.* SAGE

Forbat, L., Hubbard, G. and Kearney, N. (2009) ‘Patient and public involvement: models and muddles’, *Journal of Clinical Nursing,* 18, pp. 2547-2544

Fossey, E., Harvey, C., McDermott, F. and Davidson, L. (2002) ‘Understanding and evaluating qualitative research’, *Australian and New Zealand Journal of Psychiatry*, 36(6), pp. 717-32

Francois, K., Lobb, E., Barclay, S. and Forbat, L. (2017) ‘The nature of conflict in palliative care: A qualitative exploration of the experiences of staff and family members’, Patient Education and Counseling, 100, pp. 1459-1465

Fredricksson, M., Eriksson, M. and Tritter, J. (2018) ‘Who wants to be involved in health care decisions? Comparing preferences for individual and collective involvement in England and Sweden’, BMC Public Health, 18(18), pp. 1-10

Friedman, M. (1962) *Capitalism and Freedom*. The University of Chicago Press. Available at: http://circuloliberal.org/livros/capitalismo-e-liberdade.pdf (Accessed: 2017)

Fudge, N., Wolfe, C. and McKevitt, C. (2008) ‘Assessing the promise of user involvement in health service development: ethnographic study’, BMJ, 336:313. Available at: https://www.bmj.com/content/336/7639/313

Garden House Hospice, Hertfordshire. Available at: https://www.fons.org/library/report-details/73169

Gauthier, D. and Swigart, V. (2003) ‘The contextual nature of decision making near the end of life: Hospice patients' perspectives’, *American Journal of Hospice and Palliative Care*, 20(2), pp. 121-128

Gentles, S., Jack, S., Nicholas, D. and McKibbon, K. (2014) Critical approach to reflexivity in grounded theory’, The Qualitative Report, 19(44). Available at: http://nsuworks.nova.edu/cgi/viewcontent.cgi?article=1109&context=tqr (Accessed: 2017)

Gillham, B. (2009) *Research Interviewing – the range of techniques*. Open University Press

Glaser, B. (1992) *Basics of Grounded Theory Analysis: Emergence versus Forcing*. California: Sociology Press

Glaser, B. and Strauss, A. (1967) *The Discovery of Grounded Theory: strategies for qualitative research.* Transaction Publishers

Gott, M., Stevens, T., Small, N. and Ahmedzai, S. (2002) ‘User involvement in cancer care: exclusion and empowerment’. *Health Expectations*, 5(1), pp. 90-91

Gott, M. (2004) ‘User involvement in palliative care: rhetoric or reality?’, in Payne, S., Seymour J. and Ingleton, C. (eds). *Palliative care nursing: principles and evidence for practice.* 1st edn. Buckingham: Open University Press, pp. 75–89

Gott, M., Ingleton, C., Gardiner, C., Richards, N., Cobb, M., Ryan, T., Noble, B., Bennett, M., Seymour, J., Ward, S and Parker, C. (2013) ‘Transitions to palliative care for older people in acute hospitals: a mixed-methods study’, *Health Services and Delivery Research, 1.11 Available at: https://www.ncbi.nlm.nih.gov/books/NBK259463/ (Accessed 2017)*

Gough, D., Thomas, J. and Oliver, S. (2012) Clarifying differences between review designs and methods’, Systematic Reviews, 1(28), pp. Available at: https://systematicreviewsjournal.biomedcentral.com/articles/10.1186/2046-4053-1-28 (Accessed: 2017)

Greatrex-White, S. (2008) Thinking about the nature of research findings: a hermeneutic phenomenological perspective, *International Journal of Nursing Students,* 45(12), pp. 1842-9

Guba, E. and Lincoln, Y. (1994) Competing paradigms in qualitative research’, in Denzin, N. and Lincon, Y. (eds) *Handbook of Qualitative Research*. SAGE, pp. 105-117

Gunaratnum, Y. and Oliviere, D. (2009) *Narrative and Stories in Health Care – Illness, Dying and Bereavement.* Oxford University Press

Gysels, M., Shipman, C. and Higginson, I. (2008) ‘Is the qualitative research interview an acceptable medium for research with palliative care patients and carers?’, *BMC Medical Ethics*, 9(7). Available at: https://bmcmedethics.biomedcentral.com/articles/10.1186/1472-6939-9-7 (Accessed: 2017)

Haarsma, F., Moser, A., Beckers, M., van Rijswijk, H., Stoffers, E. and Beurskens, A. (2015) ‘The perceived impact of public involvement in palliative care in a provincial palliative care network in the Netherlands: a qualitative study’, Health Expectations, 18, pp. 3186-3200

Halaweh, M. (2012) ‘Integration of Grounded Theory and Case Study: An exemplary application from E-commerce security perception research’, *Journal of Information Technology Theory and Application*, 13(1). Available at: http://aisel.aisnet.org/jitta/vol13/iss1/3/

Hall, W. and Callery, P. (2001) ‘Enhancing the Rigor of Grounded Theory: Incorporating Reflexivity and Rationality’, Qualitative Health Research, 11(2). Available at: http://journals.sagepub.com/doi/abs/10.1177/104973201129119082?journalCode=qhra (Accessed: 2016)

Handy, C. (1981) *Understanding Organizations*. Penguin

Hanley, B., Bradburn, J., Barnes, M., Evans, C., Goodare, H., Kelson, M., Kent, A., Oliver, S., Thomas, C. and Wallcraft, J. (2004) ‘Involving the public in NHS, public health and social care research: Briefing notes for researchers’. 2nd edn. Eastleigh: INVOLVE. Available at: http://wrap.warwick.ac.uk/40433/ (Accessed: 2016)

Harlow, E., Berg, E., Barry, J. and Chandler, J. (2013) ‘Neoliberalism, managerialism and the reconfiguring of social work in Sweden and the United Kingdom’. *Organization*, 20, pp. 534-550. Available at: https://chesterrep.openrepository.com/cdr/handle/10034/336285 (Accessed: 2017)

Hart, C. (2009) *Doing a Literature Review: Releasing the Social Science Research Imagination*. SAGE

Harvey,D. (2005) *A Brief History of Neoliberalism*. Oxford University Press

Haslam C., Andersson T., Tsitsianis N. and Yin YP. (2013) ‘Accounting for the UK hospice business model’, *Redefining Business Models. Oxon: Routledge,* pp 236–243

Haslam, C., Theodosopoulos, G. and Tsitsianis, N. (2014) ‘Business models in health care: Accounting for the sustainability of palliative and end of life care provision by voluntary hospices' in England’. Available at: http://bura.brunel.ac.uk/bitstream/2438/10371/1/Fulltext.pdf (Accessed: 2017)

Hawker, S., Payne, S., Hardy, M. and Powell, J. (2002) ‘Appraising the evidence: reviewing disparate data systematically’, *Qualitative Health Research*, 12(9), pp. 1284-99

Hayek, F. (1944) *The Road to Serfdom*. Routledge

Heath, H. and Cowley, S. (2004) ‘Developing a grounded theory approach: a comparison of Glaser and Strauss’, *International Journal of Nursing Studies*, 41, pp. 141-150

Higginson, I., Hearn, J., Myers, K. and Naysmith, A. (2000) ‘Palliative day care: what do services do?’ *Palliative Medicine*, 14(5), pp. 277-286

Hospice UK (2017) Available at: https://www.hospiceuk.org

Hospice UK (2018) ‘Rehabilitative palliative care’. Available at: https://www.hospiceuk.org/what-we-offer/clinical-and-care-support/rehabilitative-palliative-care (Accessed: 2018)

Miller, E. and Gwynne, G. (1981) ‘Settling accounts with the parasite people: a critique of ‘A Life Apart’. Disability Challenge, 1, pp. 37–50. Available at: http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/UPIAS-Disability-Challenge1.pdf (Accessed: 2017)

INVOLVE (2012) ‘Briefing notes for researchers: involving the public in NHS, public health and social care research’, *INVOLVE*, Eastleigh. Available at: http://www.invo.org.uk/wp-content/uploads/2014/11/9938_INVOLVE_Briefing_Notes_WEB.pdf (Accessed: 2012)

INVOLVE 2018. Available at: http://www.invo.org.uk

Javier, N. and Montagnini, M. (2011) ‘Rehabilitation of the Hospice and Palliative Care Patient’, *Journal of Palliative Medicine*, 14(5), pp. 638-648

Johnston, B. and Smith, L. (2006) ‘Nurses and patients’ perceptions of expert palliative nursing care’, *Journal of Advanced Nursing*, 54(6), pp. 700-709

Jootun, G., McGhee, G. and Marland, G. (2009) ‘Reflexivity: promoting rigour in qualitative research’, *Nursing Standard*, 23(23), pp. 42-46

Joseph Rowntree Foundation (2001), ‘User involvement and the seriously ill’. Available at: http://www.jrf.org.uk/sites/default/files/jrf/migrated/files/271.pdf (Accessed: 2012)

Jupp, V (2006) *The SAGE Dictionary of Social Research Methods*. SAGE

Karnilowicz, W. (2011) ‘Identity and psychological ownership in chronic illness and disease state’, *European Journal of Cancer Care*, 20, pp. 276-282

Kars, M., van Thiel, G., van der Graaf, R., Moors, M., de Graeff, A. and van Delden, J. (2016) ‘A systematic review of reasons for gatekeeping in palliative care research’, Palliative Medicine, 30(6), pp. 533-548

Keeney, S., Hasson, F. and McKenna, H. (2000) ‘Consulting the oracle: ten lessons from using the Delphi Technique in nursing research’, *Journal of Advanced Nursing*, 53(2), pp. 205-212

King’s College, London (2015). *Cicely Saunders Archives*. Available at: https://cicelysaundersarchive.wordpress.com/2015/04/21/resurrecting-the-concept-of-dying-well-conference-paper-on-dame-cicely-saunderss-archives/ (Accessed: 2018)

King's Fund (2017) *Policy.* Available at: https://www.kingsfund.org.uk/publications/articles/big-election-questions-nhs-privatised (Accessed: 2017)

Kirkpatrick, I. (2006) 'Taking Stock of the New Managerialism in English Social Services', *Social Work and Society International Online Journal,* 4(1). Available at: http://www.socwork.net/sws/article/view/173/564 (Accessed: 2017)

Kitchen, P. (2002) 'Internal communication during change management', *Corporate Communications: An International Journal*, 7(1), pp. 46-53
Kockelmans, J. (1994) *Edmund Husserl's Phenomenology*. Purdue University Press

Klikauer, T. (2013) 'Managerialism: A critique of an ideology'. Palgrave/Macmillan

Koprowska, J. (2014) *Communication and Interpersonal Skills in Social Work*. 4th edn. Learning Matters

Kubler Ross, E. (1969) *On Death and Dying*. New York: Macmillan

Kubler Ross, E. (1972) 'Death with Dignity, Hearings before the special committee on aging', United States Senate. Available at: *http://www.aging.senate.gov/imo/media/doc/publications/871972.pdf*

Kuhn, T. (1962) *The structure of scientific revolutions*. Chicago Uni. Chicago Press.

Lather, P. (1992) Critical Frames in Educational Research: Feminist and Post-structural Perspectives', Theory into Practice, 31(2), pp. 87-99

Lather, P. (2006) Paradigm proliferation as a good thing to think with: teaching research in education as a wild profusion', International Journal of Qualitative Studies in Education, 19(1), pp. 35-57

Laws, K. and McLeod, L. (n.d.) 'Case study and grounded theory: Sharing some alternative qualitative research methodologies with systems professionals', *Faculty of Education, The University of Sydney NSW.* Available at: https://pdfs.semanticscholar.org/0c99/84659342d356f4dbdf5dc0fc7732c18fa936.pdf (Accessed: 2017)

Lawton, J. (2000) *The Dying Process: Patients' experiences of palliative care*. Routledge

Lee, S., Kristjanson, L. and Williams, A. (2009) ‘Professional relationships in palliative care decision-making’, Support Care Cancer, 17, pp. 445-450
Lutz, S. (2011) ‘The History of Hospice and Palliative Care’, *Current Problems in Cancer*, 35(6), pp. 304-309

Lynch, K. (2014) ‘Control by numbers: new managerialism and ranking in higher education’, *Critical Studies in Education*, Routledge. Available at: https://www.sussex.ac.uk/webteam/gateway/file.php?name=critical-studies-in-education-lynch.pdf&site=41 (Accessed: 2017)

Mackenzie, N. and Knipe, S. (2006) Research dilemmas: Paradigms, methods and methodology, Issues in Educational Research, 16. Available at: http://www.iier.org.au/iier16/mackenzie.html (Accessed: 2016)

Macmillan Cancer Support. (2012) Available at: https://www.macmillan.org.uk/documents/getinvolved/campaigns/theroleofcancernetworksinthenewnhs.pdf

Macmillan Cancer Support. (2015) Available at: https://www.macmillan.org.uk/documents/campaigns/canceralliancesreport.pdf

Malterud, K., Siersma, V. and Guassora, A. (2015) ‘Sample size in Qualitative Interview Studies: Guided by Information Power’, Qualitative Health Research. Available at: https://www.researchgate.net/profile/Ann_Dorrit_Guassora/publication/284904065_Sample_Size_in_Qualitative_Interview_Studies_Guided_by_Information_Power/links/5669634708ae1a797e374435.pdf (Accessed: 2016)

Marie Curie. (2016) ‘Researching better care’. Available at: https://www.mariecurie.org.uk/research (Accessed: 2017)

Marie Curie (2). (2016). Submission to the Health Select Committee’s Inquiry into the Implementation of the Health and Social Care Act 2012. Available at: https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/april-2013/inquiry-into-the-health-and-social-care-act-2012.pdf (Accessed: 2017)

Marie Curie (3). (2016) ‘What are palliative and end of life care’. Available at: https://www.mariecurie.org.uk/help/terminal-illness/diagnosed/palliative-care-end-of-life-care

Magretta, J. (2002) ‘Why business models matter’, *Harvard Business Review*, 80(5), pp. 86-92

McCormick, T. and Conley, B. (1995) ‘Patients’ perspectives on Dying and on the Care of Dying Patients’, Western Journal of Medicine, 163, pp. 236-243

McDowell, C. and Clark-McDowell, T. (2007) *Islands of Grace: Creating Sanctuary in Daily Life*

McIlfatrick, S. and Hasson, F. (2016) User involvement in palliative care: Evaluating the Process and Contribution of a User/Carer Forum Initiative, Palliative Medicine, 30(6)

Merriam, S. (1988) *Case Study Research in Education: A Qualitative Approach*, San Francisco, Jossey-Bass

Mockford, C., Staniszewska, S., Griffiths, F. and Herron-Marx, S. (2012) 'The impact of patient and public involvement on UK NHS health care: a systematic review', *International Journal for Quality in Health Care*, 24(1), pp. 28-38

Murray, S. and Sheikh, A. (2008) 'Care for all at the end of life', *British Medical Journal*, 336(7650), pp. 958-959

Murtagh, F., Preston, M. and Higginson, I. (2004) 'Patterns of dying: palliative care for non-malignant disease', *Clinical Medicine (London),* 4(1), pp. 39-44

National Council for Palliative Care (2012). Available at: http://www.ncpc.org.uk/news/half-new-nhs-boards-ignoring-end-life-care

National Health Service (2000). *NHS Cancer Plan. Available at https://www.thh.nhs.uk/documents/_Departments/Cancer/NHSCancerPlan.pdf* (Accessed: 2018)

National Institute for Clinical Excellence – NICE. (2004) 'Improving supportive and palliative care for adults with cancer'. Available at: https://www.nice.org.uk/guidance/csg4 (Accessed: 2018)

National Institute for Clinical Excellence – NICE (2016) 'Community engagement: improving health and wellbeing and reducing health inequalities'. Available at: https://www.nice.org.uk/guidance/ng44 (Accessed: 2018)

National Institute for Clinical Excellence (2016) *Storytelling.* Available at: https://www.evidence.nhs.uk/Search?ps=30&q=storytelling (Accessed: 2018)

National Hospice and Palliative Care Organization - NHPCO (2016) 'History of Hospice Care'. Available at: http://www.nhpco.org/history-hospice-care (Accessed: 2018)

NHS Choices (2016) 'End of life care'. Available at: http://www.nhs.uk/Planners/end-of-life-care/Pages/what-it-involves-and-when-it-starts.aspx (Accessed: 2018)

NHS Digital (2017) ‘Patient-led Assessments of the Care Environment – PLACE. Available at: https://digital.nhs.uk/search?q=PLACE&s=s (Accessed: 2018)
NHS England (2013) ‘Transforming Participation in Health and Care: The NHS belongs to us all’. Available at: https://www.england.nhs.uk/wp-content/uploads/2013/09/trans-part-hc-guid1.pdf (Accessed: 2018)

Ocloo, J. and Matthews, R. (2016) ‘From tokenism to empowerment: progressing patient and public involvement in healthcare improvement’, *British Medical Journal*. Available at: http://qualitysafety.bmj.com/content/early/2016/03/18/bmjqs-2015-004839 –

O’Leary, Z. (2004) *The essential guide to doing research*. SAGE

Osterwalder, A. (2013) ‘A better way to think about your business model’, *Harvard Business Review*. Available at: https://hbr.org/2013/05/a-better-way-to-think-about-yo (Accessed: 2017)

Palumbo, R. (2016) ‘Contextualising co-production of health care: a systematic literature review’, International Journal of Public Sector Management, 29(1), pp. 72-90

Payne, S., Gott M., Small N., Oliviere D. (2005) ‘User involvement in Palliative Care: a scoping study’, *University of Sheffield. Available at: http://www.ncpc.org.uk/sites/default/files/UI_ScopingStudy.pdf (Accessed: 2018)*

Payne, M. (2006) ‘Social objectives in cancer care: the example of palliative day care’, *European Journal of Cancer Care*, 15, pp. 440-447

Payne, S., Hawker, S., Kerr, C., Roberts, H., Jarrett, N. and Smith, H. (2007) ‘Experiences of end of life care in community hospitals’, *Health and Social Care Community*, 15(5), pp. 494-501 – chap 3 pg 16

Payne, S., Gott M., Small N., Oliviere D. (2008) ‘Listening to the Experts: A summary of User Involvement in Palliative Care: a scoping study’, *National Council for Palliative Care*

Peshkin, A. (1988) ‘In Search of Subjectivity. One’s Own’, *Educational Researcher*, 17(7), pp. 17-21

Pezalla, A., Pettigrew, J. and Miller-Day, M. (2012) ‘Researching the researcher-as-instrument: an exercise in researcher self-reflexivity’, *Qualitative Research*, 12(2), pp. 165-185

Pollard, K. and Evans,D. (2013) ‘Theorising user involvement from a researcher perspective’, in Staddon, P. (ed) *Mental Health Service Users in Research: Critical Sociological Perspectives*. Bristol: Policy Press, pp. 39-51

Realpe, A. and Wallace, L. (2010) ‘What is co-production’, *Health Foundation.* Available at: http://wrap.warwick.ac.uk/61814/ (Accessed: 2017)

Rhodes, P. and Small, N (2000) ‘Too ill to talk? User involvement in palliative care. *Routledge*

Richardson, K., MacLeod, R. and Kent, B. (2010) ‘Ever decreasing circles: terminal illness, empowerment and decision-making’, Journal of Primary Health Care, 2(2), pp. 130-135

Ritchie, L., Tolson, D. and Danson, M. (2017) ‘Dementia in the workplace case study research: understanding the experiences of individuals, colleagues and managers’, *Ageing & Society*, pp. 1-30, Cambridge University Press. Available at: https://www.cambridge.org/core/journals/ageing-and-society/article/dementia-in-the-workplace-case-study-research-understanding-the-experiences-of-individuals-colleagues-and-managers/C9EB981FD7B232F0696B9A8410871972 (Accessed: 2017)

Rolls, L. and Payne, S. (2004) Childhood bereavement services: issues in UK service provision, *Mortality*, 9(4), pp. 300-328

Rose, D., Fleischman, P. and Schofield, P. (2010) ‘Perceptions of User Involvement: a User-Led Study’, *International Journal of Social Psychiatry*, 56(4), pp. 389-401

Rose, D., Carr, S. and Beresford, P. (2018) ‘Widening cross-disciplinary research for mental health’: what is missing from the Research Councils UK mental health agenda?, *Disability and Society*, doi: 10.1080/09687599.2018.1423907

Russell, G. and Kelly, N. (2002) ‘Research as Interacting Dialogic Processes: Implications for Reflexivity’, *Forum: Qualitative Social Research*, 3(3). Available at: http://www.qualitative-research.net/index.php/fqs/article/view/831

Sale, J., Lohfeld, L. and Brazil, K. (2002) ‘Revisiting the Quantitative-Qualitative Debate: Implications for Mixed-Methods Research’, *Quality and Quantity*, 36(1), pp. 43-53

Samuel, M. (2017) ‘What is reablement?’, *Community Care*. Available at: *http://www.communitycare.co.uk/2010/09/20/what-is-reablement/* (Accessed: 2017)

Sargeant, A., Payne, S., Gott, M., Small, N. and Oliviere, D. (2007) ‘User involvement in palliative care: motivational factors for service users and professionals’, *Progress in Palliative Care,* 15(3), pp. 126-132

Savage, J. (2007) ‘Reflecting through Peshkin’s I’s’, *International Journal of Music Education*, 25 (3), pp. 193-204

Schwandt, T. (2007) *The SAGE Dictionary of Qualitative Inquiry*. 3rd edn. SAGE

SCIE (2018) – *Reablement.* Available at: *https://www.scie.org.uk/reablement (Accessed: 2018)*

Scottish Health Council (2016) *The Participation Toolkit*. Available at: http://www.scottishhealthcouncil.org/patient__public_participation/participation_toolkit/the_participation_toolkit.aspx#.V8QRk2U4mgQ (Accessed: 2018)

Shotter, E. (2006) ‘Dame Cicely Saunders: obituary’, *Journal of Medical Ethics*, 32, pp. 309

Silverman, D. (2010) *Doing Qualitative Research*. 3rd edn. SAGE

Smith, F. and Himmel, S. (2013) ‘Changing the way we die: Compassionate end of life care and the hospice movement’, Viva Editions

Span, P. (2014) *Differences in Care at For-Profit Hospices*. Available at: https://newoldage.blogs.nytimes.com/2014/03/03/differences-in-care-at-for-profit-hospices/ (Accessed: 2018)

Spender, D. (1980) *Man Made Langua*ge. Thorsons

Stake, R. (2000) ‘Case Studies’, in Denzin, N. and Lincoln, Y. (eds.) *Handbook of Qualitative Research*. SAGE, pp. 435-453

Stevens, T. (2008) ‘Involving or using?’, in Payne, S., Seymour, J. and Ingleton, C. (eds.) *Palliative care nursing: principles and evidence for practice*. 2nd edn. Buckingham: Open University Press, pp. 55–70.

Stone, P., Gwilliam, B., Keeley, V., Todd, C., Kelly, L. and Barclay, S. (2013) ‘Factors affecting recruitment to an observational multi-centre palliative care study’, *British Medical Journal*. Available at: http://spcare.bmj.com/content/early/2013/01/07/bmjspcare-2012-000396 (Accessed: 2017)

Strauss, A. (1987) *Qualitative Analysis for Social Scientists*. Cambridge University Press.

Strauss, A. and Corbin, J. (1998) *Basics of Qualitative Research Techniques and Procedures for Developing Grounded Theory.* 2nd edn. SAGE

Sweeney, A. and Wallcraft, J. (2010) ‘Quality Assurance/Monitoring of Mental Health Services by Service Users and Carers’, *WHO-EC Partnership Project on User Empowerment in Mental Health Available at:*

https://www.scie.org.uk/publications/guides/guide45/files/WHO_paper_final_draft.pdf?res=true (Accessed: 2017)

Taylor, T., Ostbye, T., Langa, K., Weir, D. and Plassman, B. (2009) ‘The accuracy of Medicare claims as an epidemiological tool: the case of dementia revisited’, *Journal of Alzheimer’s Disease*, 17(4), pp. 807-15

Teno, J., Plotzke, M., Pedro, G. and Vincent, M. (2011) ‘A National Study of Live Discharges from Hospice’, *Journal of Palliative Medicine*, 17(10), pp. 1121-1127

Tiberini, R. and Cooper, M. (2017) ‘Living fully until you die: where rehabilitation and palliative care come together’, *Research in Practice for Adults blog*, 10 April. Available at: https://www.ripfa.org.uk/blog/living-fully-until-you-die-where-rehabilitation-and-palliative-care-come-together/ (Accessed: 2018)

The Centre for Health and Public Interest – CHPI (2017). Available at: https://chpi.org.uk/papers/reports/pfi-profiting-from-infirmaries/

The Telegraph (2015) *Why businesses should back Britain’s hospices*. Available at: https://www.telegraph.co.uk/news/politics/conservative/12016689/Why-businesses-should-back-Britains-hospices.html (Accessed: 2016)

Theodosopoulos, G. (2011) ‘Voluntary hospices in England: A viable business model?’ *Accounting Forum,* Elsevier. Available at: http://isiarticles.com/bundles/Article/pre/pdf/7703.pdf (Accessed: 2017)

Tritter, J. and McCallum, A. (2006) ‘The snakes and ladders of user involvement: Moving beyond Arnstein’, *Health Policy*, 76, pp.156-168

Tritter, J. (2009) ‘Revolution or evolution: the challenges of conceptualizing patient and public involvement in a consumerist world’, *Health Expectations*, 12, pp. 275 – 287

Vachon, M. (1995) ‘Staff stress in hospice/palliative care: a review’, Palliative Medicine, 9(2), pp. 91-122

Van Manen, M. (2014) *Phenomenology of Practice*. Left Coast Press, Inc

Wachterman, M., Pilver, C., Smith, D., Ersek, M., Lipsitz, S. and Keating, N. (2016) ‘Quality of end of life care provided to patients with different serious illnesses’, *Journal of the American Medical Association*, 176 (8), pp. 1095-1102

Wallcraft, J. and Bryant, M. (2003) ‘The Mental Health Service User Movement in England’, *Policy 2:The Sainsbury Centre for Mental Health. Available at: http://studymore.org.uk/policy_2.pdf (Accessed: 2017)*

Walshe, C., Caress, A., Chew-Graham, C. and Todd, C. (2004) ‘Case studies: A research strategy appropriate for palliative care?’ *Palliative Medicine*, 18, pp. 677-684
Walshe, C. (2011) The evaluation of complex interventions in palliative care: An exploration of the potential of case study research strategies, Palliative Medicine, 25(8), pp. 774-781

Warth, M., KeBler, J., Hillecke, T., Bardenheuer, H. (2015) ‘Music Therapy in Palliative Care’, *Deutsches Arzteblatt International*, 112(46), pp. 788-794

Webb, C. (1992) ‘The use of the first person in academic writing: objectivity, language and gatekeeping’, *Journal of Advanced Nursing*, 17(6), pp. 747-52

Whoriskey, P. and Keating, D. (2014) ‘Dying and profits: The evolution of hospice’, *The Washington Post.* Available at: https://www.washingtonpost.com/business/economy/2014/12/26/a7d90438-692f-11e4-b053-65cea7903f2e_story.html (Accessed: 2017)

Wilson, P., Mathie, E., Keenan, J., McNeilly, E., Goodman, C., Howe, A., Poland, F., Staniszewski, S., Kendall, S., Munday, D., Cowe, M. and Peckham, S. (2015) ‘ReseArch with Patient and Public InvOlvement: a RealisT evaluation – the RAPPORT study’, *Health Services and Delivery Research*, 3(38), pp. 1-8

Woods, S., Beaver, K. and Luker, K. (2000) ‘Users’ views of palliative care services: ethical implications’, Nursing Ethics, 7(4), pp. 314-326

World Health Organisation (WHO), 2018, ‘Definition of Palliative Care’. Available at: http://www.who.int/cancer/palliative/definition/en/ (Accessed: 2018)

Wright, D., Hopkinson, J., Corner, J. and Foster, C. (2006) ‘How to involve cancer patients at the end of life as co-researchers’, *Palliative Medicine*, 20, pp. 821-827

Yin, R. (2003) Case Study Research Design and Methods. 3rd edn. SAGE

Yin, R. (2012) *Applications of Case Study Research*. SAGE

Zott, C., Amit, R. and Massa, L. (2011) The Business Model: Recent Developments and Future Research, Journal of Management, 37(4), pp. 1019-1042

APPENDICES

Appendix 1:Ethics approval documents: Letter to staff participants:

School of Health Sciences
and Social Care
Brunel University
Mary Seacole Building
Uxbridge Campus
Middlesex UB8 3PH

Date: XXX

PhD research:
Your perceptions of involvement in palliative care

Dear

I am writing to invite you to take part in a research study that I am undertaking. I am asking if you would like to be involved as a participant because you are working in palliative care with XXXX Hospice.

I am a PhD research student studying part-time at Brunel University in West London. I am hoping to interview staff and service users about their perceptions of involvement in palliative care. An information sheet about the research is attached to this letter along with a reply slip. If you could, please take the time to read the information provided and decide if it is something you would like to take part in. If it is, then please fill in the reply slip with your name and contact details and post back to me using the enclosed stamped-addressed-envelope or email me with your details to: XXXX

Any information you provide at the interviews will be confidential.

This is an independent research project that has the endorsement of XXXX Hospice.

Thank you very much for taking the time to read this letter and the attached information.

Best wishes
Helen Findlay

Letter to service user participants:

School of Health Sciences
and Social Care
Brunel University
Mary Seacole Building
Uxbridge Campus
Middlesex UB8 3PH

1 September 2011

PhD research:
Your perceptions of involvement in palliative care

Dear

I am writing to invite you to take part in a research study that I am undertaking. I am asking if you would like to be involved as a participant because you are working in palliative care with XXXX Hospice.

I am a PhD research student studying part-time at Brunel University in West London. I am hoping to interview staff and service users about their perceptions of involvement in palliative care. An information sheet about the research is attached to this letter along with a reply slip. If you could, please take the time to read the information provided and decide if it is something you would like to take part in. If it is, then please fill in the reply slip with your name and contact details and post back to me using the enclosed stamped-addressed-envelope **or** email me with your details to: helen.findlay@brunel.ac.uk Any information you provide at the interviews will be confidential.

This is an independent research project that has the endorsement of XXXX Hospice.

Thank you very much for taking the time to read this letter and the attached information.

Best wishes
Helen Findlay

Information sheet for service user participants:

PhD Research
Information sheet for participants:
Service Users

School of Health Sciences
and Social Care
Brunel University
Mary Seacole Building
Uxbridge Campus
Middlesex UB8 3PH

‘Your perceptions of involvement in palliative care’

Purpose of the PhD research

My name is Helen Findlay. I am a PhD research student studying part-time at Brunel University, West London. My previous academic background is in politics and policy-making including social care policy and I have many years experience of working in the private, public and voluntary sectors.

The purpose of my research is to look at and compare the perceptions and understandings surrounding service user involvement in palliative care involving people who are receiving palliative care (i.e. service users) and those providing palliative care (i.e. staff). The aim is to look into people’s experiences and compare the similarities and differences between the perceptions of service users and staff and draw out some themes.

This is an independent research project that has the endorsement of XXXX Hospice.

What will the research involve?

The aim of the research is to explore your perceptions and thoughts about your care and your involvement in your hospice care as well as your understanding about service user involvement generally and what it means to you. Also to explore what kind of involvement you would ideally like to have in your own care and how much influence you feel you have in it.

The research will involve participants taking part in one face-to-face interview with the researcher in an agreed location. The interview should last about an hour and will be audio-recorded to ensure accuracy. There will be a consent form that I will have with me for you to read through and sign just before the interview starts. I will supply you with a copy of the signed form.

The interview will not be very formal and will be conducted more like a conversation. I am interested in exploring your views and there are no right or wrong answers. If an interview with you is scheduled and then you do not feel well enough at the time, it can be re-scheduled. If during the interview itself you feel at all unwell or find it upsetting in any way, then with your consent I can contact a member of hospice staff member who can offer you support if needed. Then the interview can continue if you feel able to after a break or it can be re-scheduled and completed at a later date. If you do not feel able to continue or do not wish to then that is fine. My wish is to provide a situation for the interview with you that enables you to feel comfortable and secure.

What will happen to the information you provide as a participant?
The information given by you and all participants will remain entirely confidential and your name will not be divulged to anyone else. The data collected will be kept securely (for example, password protected computer; locked cabinet; personal details kept separate from the interview data) and will only be accessible by me as the researcher and by my PhD research supervisors at Brunel University. The data collected from the research interviews will be retained ~~if~~ whether you continue to the end of the study or not.

All the data collected, in anonymous audio and transcript forms, will be kept for at least 10 years in a secure environment to ensure it covers the full term of the research study and will then be destroyed.

Themes and quotes that may be drawn out of the responses from participants will be shared with my PhD Advisory Group. This Advisory Group will have 8-10 members who will provide support to me in the research. It will include academics ~~that~~ who have a health, palliative care or service user involvement background; also staff who provide palliative and/or end of life care; carers and former carers of people receiving palliative care and service users receiving palliative care. The role of this group, who won't have contact with the research participants and who won't be participants themselves, will be to provide a forum for discussion. They will offer views on such things as the questions being asked; on the themes being drawn out from the responses and if they think there are any gaps. This group will not hear or see 'raw' data (ie the audio tapes or complete written versions of the interviews) only the themes drawn out from analysis of the information collected. There may be some quotes pulled out from the interviews that the Advisory Group members will have sight of to help with highlighting the themes but these will remain anonymous.

As a participant you will not be identified in any reports emanating from the research. The final PhD thesis may include quotations from the interviews but these will be used anonymously.

In the event of any unexpected issues being raised with the researcher during the interview process that indicate you may be at risk of harm then the researcher will seek immediate advice from her supervisors about them and whether further action may be necessary.

Your rights as a participant in this PhD research

Your decision to get involved as a participant in this research is entirely voluntary. Your decision to take part or not to take part will have no bearing whatsoever on any of your treatment or care at the hospice. You are entitled to decline to answer any question in the interview itself and you can withdraw at any time without having to give an explanation. If you decide to participate, you will be offered a short interim report of findings as soon as possible.

There is no obligation to take part in this research. But if you decide that you would like to take part as a participant and see how it goes, then an appropriate environment will be agreed with hospice staff and yourself with a staff member nearby to offer you support as necessary.

This research is being carried out to help fill gaps in current research literature around service user involvement in palliative and end of life care. It will enable first-hand accounts to be drawn from people who are receiving and also providing palliative care and their perceptions of what this involvement means. As well as helping to advance knowledge of this subject, this research will also help to establish whether any patterns and themes can be identified that could assist in developing a better understanding of what such involvement entails and whether these themes can improve the experience of service users in palliative care. Your contribution could play a significant role in helping to achieve this.

Do you have any questions?

If you have any questions, please feel free to write to me, Helen Findlay, at the address below or email: XXXX or the research supervisors whose contact details are listed below.

If you are interested in taking part . . .

Please fill in and return the enclosed reply slip to me at the address below using the stamped-addressed envelope contained in this information pack or email me with your details at: XXXX

Thank you very much for taking the time to read this information sheet and for showing interest in this research.

Research ethics approval for this research has been obtained from the School of Health Sciences and Social Care Research Ethics Committee, Brunel University.

PhD Researcher:

Helen Findlay

School of Health Sciences and Social Care, Brunel University, Mary Seacole
Building, Uxbridge Campus, Middlesex UB8 3PH

Tel: XXXX
Email: XXXX

Supervisors:

Professor Peter Beresford OBE
School of Health Sciences and Social Care, Brunel University, Mary Seacole
Building, Uxbridge Campus, Middlesex UB8 3PH

Email: XXXX

Dr Frances Reynolds
School of Health Sciences and Social Care, Brunel University, Mary Seacole
Building, Uxbridge Campus, Middlesex UB8 3PH

Email: XXXX

Should you have any complaints then please send them directly to:

Dr Simon Bradford
Chair, School of Health Sciences and Social Care Ethics Committee, Brunel
University, Mary Seacole Building, Uxbridge Campus, Middlesex UB8 3PH

Email: XXXX

Information sheet for staff participants:

PhD Research
Information sheet for participants:
Staff

School of Health Sciences
and Social Care
Brunel University
Mary Seacole Building
Uxbridge Campus
Middlesex UB8 3PH

‘Your perceptions of involvement in palliative care’

Purpose of the PhD research

My name is Helen Findlay. I am a PhD research student studying part-time at Brunel University, West London. My previous academic background is in politics and policy-making including social care policy and I have many years experience of working in the private, public and voluntary sectors.

The purpose of my research is to look at and compare the perceptions and understandings surrounding service user involvement in palliative care involving people who are receiving palliative care (ie service users) and those providing palliative care (ie professional staff). The aim is to look into people’s experiences and compare the similarities and differences between the perceptions of service users and professional staff and draw out some themes.

This is an independent research project that has the endorsement of XXXX Hospice.
The research will look into the following issues:

- Thoughts on what the words ‘service user involvement’ mean to you.
- Any personal experience of service user involvement.
- Perceptions and understandings of service user involvement generally and as it may apply in palliative care.
- Awareness of any service user involvement activities at the hospice and involvement with them, influences on care and possible barriers.
- Information available about service user involvement through the hospice.
- Awareness of any formal requirements of service user involvement in palliative care.
- Thoughts on what service user involvement in palliative care could ideally look like.
- Opportunity to add reflections and perceptions on service user involvement in palliative care.

What will the research involve?

The research will involve participants taking part in one face-to-face interview with the researcher in an agreed location. The interview should last up to an hour and will be audio-recorded to ensure accuracy. There will be a consent form that I will have with me for you to read through and sign just before the interview starts. I will supply you with a copy of the signed form.

What will happen to the information you provide as a participant?

The information given by all participants will remain entirely confidential and your name will not be divulged to anyone else. The data collected will be kept securely (for example, password protected computer; locked cabinet; personal details kept separate from the interview data) and will only be accessible by me as the researcher and by my PhD research supervisors at Brunel University.

Themes and anonymised quotes that may be drawn out of the responses from participants will be shared with my PhD Advisory Group. This Advisory Group will comprise 8-10 members who will provide support to me in the research. It will include academics who have a health, palliative care or service user involvement background; also staff who provide palliative and/or end of life care; carers and former carers of people receiving palliative care and service users receiving palliative care. The role of this group, who won't have contact with the research participants and who won't be participants themselves, will be to provide a forum for discussion. They will offer views on such things as the questions being asked; on the themes being drawn out from the responses and if they think there are any gaps. This group will not see 'raw' data (ie entire interviews) only the themes drawn out from analysis of the data collected. There may be some quotes pulled out from the data that the Advisory Group members will have sight of to help with highlighting the themes but these will remain anonymous. No individual participants will be identified in any reports emanating from the research.

All the data collected, in anonymised audio and transcript forms, will be kept for at least 10 years in a secure environment to ensure it covers the full term of the research study and will then be destroyed.

Your rights as a participant in this PhD research

Your decision to get involved as a participant in this research is entirely voluntary. You are entitled to decline to answer any question in the interview process and can withdraw at any time without having to give an explanation. If you decide to participate, you will be offered a summary of findings at the conclusion of the research.

There is no obligation to take part in this research. But if you decide that you would like to take part as a participant then an appropriate time and environment will be agreed on with the hospice and yourself.

This research is being carried out to help fill gaps in current research literature around service user involvement in palliative care. It will enable first-hand accounts to be drawn from people who are receiving and also providing palliative care, their perceptions of what this involvement means with similarities and differences compared.

As well as helping to advance knowledge of this subject, this research will also help to establish whether any patterns and themes can be identified that could assist in developing a better understanding of what such involvement entails, whether these themes can help further inform the involvement of service users in palliative care and offer up possible other areas for future research around this topic. Your contribution could play a significant role in helping to achieve this.

Do you have any questions?

If you have any questions, please feel free to write to me, Helen Findlay, at the address below or email: helen.findlay@brunel.ac.uk or the research supervisors whose contact details are listed below.

If you are interested in taking part . . .

Please fill in and return the enclosed reply slip to me at the address below using the stamped-addressed envelope contained in this information pack or email me with your details at: XXXX

Thank you very much for taking the time to read this information sheet and for showing interest in this research.

Research ethics approval for this research has been obtained from the School of Health Sciences and Social Care Research Ethics Committee, Brunel University.

Date: XXXX

PhD Researcher:

Helen Findlay

School of Health Sciences and Social Care, Brunel University, Mary Seacole Building, Uxbridge Campus, Middlesex UB8 3PH

Tel: XXXX
Email: XXXX

Supervisors:

Professor Peter Beresford OBE
School of Health Sciences and Social Care, Brunel University, Mary Seacole Building, Uxbridge Campus, Middlesex UB8 3PH

Email: XXXX

Dr Frances Reynolds
School of Health Sciences and Social Care, Brunel University, Mary Seacole Building, Uxbridge Campus, Middlesex UB8 3PH

Email: XXXX

Should you have any complaints then please send them directly to:

Dr Simon Bradford
Chair, School of Health Sciences and Social Care Ethics Committee, Brunel University, Mary Seacole Building, Uxbridge Campus, Middlesex UB8 3PH

Email: XXXX

Consent form for participants:

PhD Research
Participants'
CONSENT FORM

School of Health Sciences
and Social Care
Brunel University
Mary Seacole Building
Uxbridge Campus
Middlesex UB8 3PH

Title of Project: **'Your perceptions of involvement in palliative care'**

Name of Researcher: Helen Findlay

Please initial box

1. I confirm that I have read and understand the Participants Information Sheet dated.................... (version............) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐

3. I agree to my interview being audio-recorded and that data I supply in audio and transcribed (written from the audio recording) will be stored in a secure data centre and destroyed after 10 years. ☐

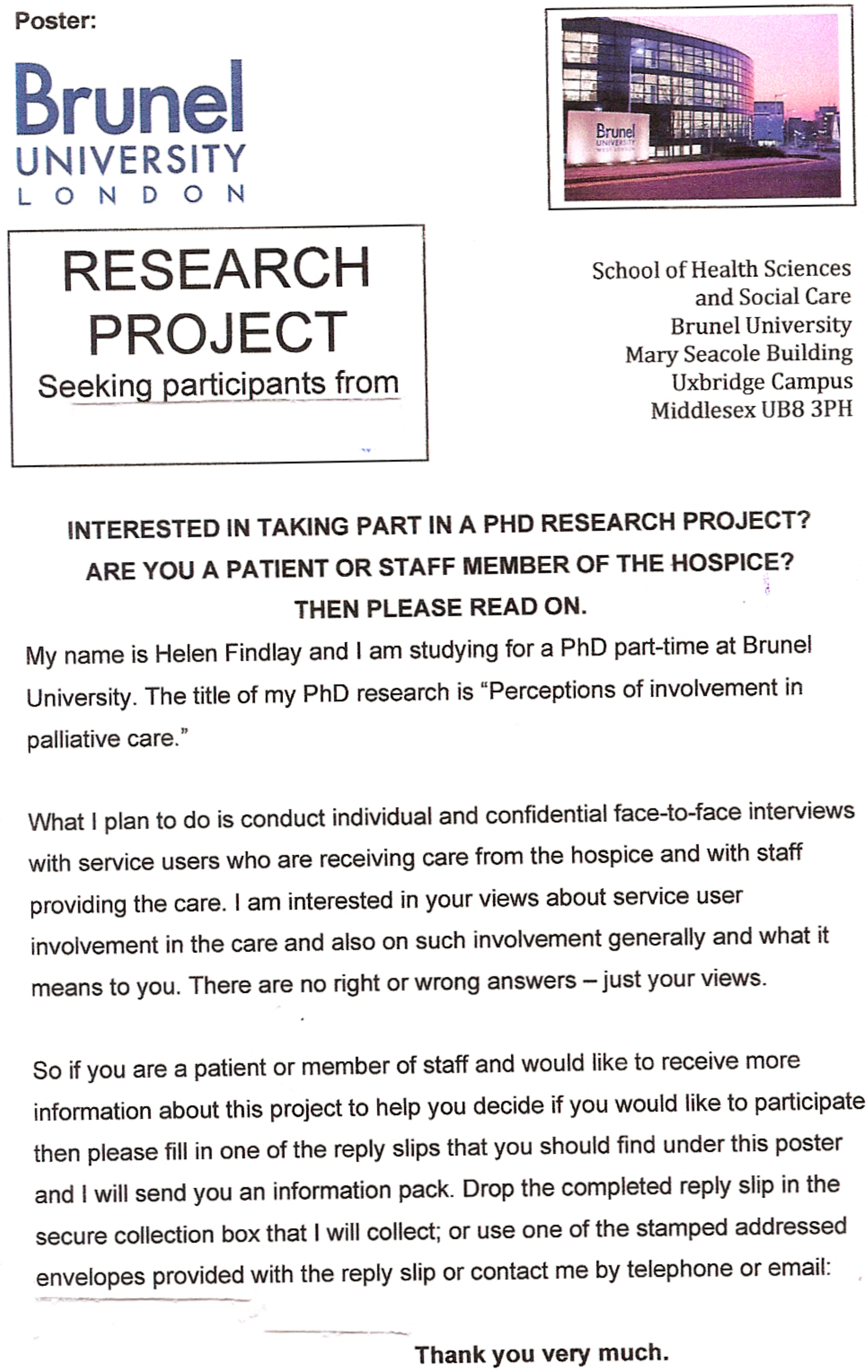
4. I agree that the words I say may be used as anonymous quotations when the study is written up or published. ☐

5. I agree to take part in the above study. ☐

Name of Participant	Date	Signature
Name of person taking consent	Date	Signature

When completed: 1 copy for participant; 1 copy for researcher site file

Poster:



Poster:

Brunel
UNIVERSITY
LONDON

School of Health Sciences
and Social Care
Brunel University
Mary Seacole Building
Uxbridge Campus
Middlesex UB8 3PH

RESEARCH PROJECT

Seeking participants from

INTERESTED IN TAKING PART IN A PHD RESEARCH PROJECT?

ARE YOU A PATIENT OR STAFF MEMBER OF THE HOSPICE?

THEN PLEASE READ ON.

My name is Helen Findlay and I am studying for a PhD part-time at Brunel University. The title of my PhD research is “Perceptions of involvement in palliative care.”

What I plan to do is conduct individual and confidential face-to-face interviews with service users who are receiving care from the hospice and with staff providing the care. I am interested in your views about service user involvement in the care and also on such involvement generally and what it means to you. There are no right or wrong answers – just your views.

So if you are a patient or member of staff and would like to receive more information about this project to help you decide if you would like to participate then please fill in one of the reply slips that you should find under this poster and I will send you an information pack. Drop the completed reply slip in the secure collection box that I will collect; or use one of the stamped addressed envelopes provided with the reply slip or contact me by telephone or email:

Thank you very much.

Reply slip:

REPLY SLIP

Project title: **Perceptions of involvement in palliative care**
Name of Researcher: Helen Findlay

I would like to be a participant in the above project and agree to be contacted to discuss it further.

My name is: ____

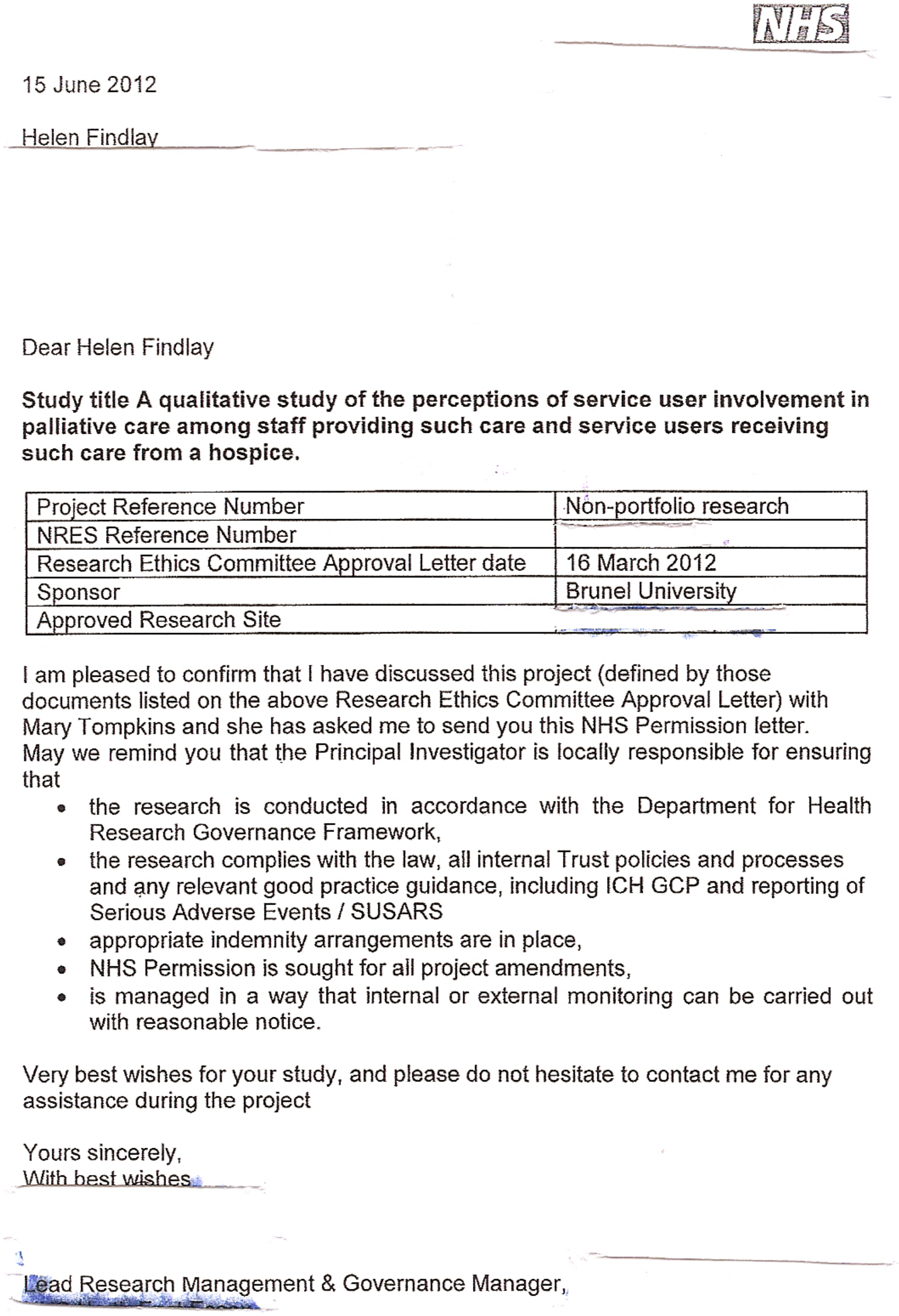
My contact details are: Tel/mobile: ___________________________

Email: ____

Postal address:
____

When you have filled in this reply slip please send it to Brunel University via the post using the enclosed stamped addressed envelope **or email your details to: XXXX**

Appendix 2: Ethics approval letters



NHS

15 June 2012

Helen Findlay

Dear Helen Findlay

Study title A qualitative study of the perceptions of service user involvement in palliative care among staff providing such care and service users receiving such care from a hospice.

Project Reference Number	Non-portfolio research
NRES Reference Number	
Research Ethics Committee Approval Letter date	16 March 2012
Sponsor	Brunel University
Approved Research Site	

I am pleased to confirm that I have discussed this project (defined by those documents listed on the above Research Ethics Committee Approval Letter) with Mary Tompkins and she has asked me to send you this NHS Permission letter.
May we remind you that the Principal Investigator is locally responsible for ensuring that

- the research is conducted in accordance with the Department for Health Research Governance Framework,
- the research complies with the law, all internal Trust policies and processes and any relevant good practice guidance, including ICH GCP and reporting of Serious Adverse Events / SUSARS
- appropriate indemnity arrangements are in place,
- NHS Permission is sought for all project amendments,
- is managed in a way that internal or external monitoring can be carried out with reasonable notice.

Very best wishes for your study, and please do not hesitate to contact me for any assistance during the project

Yours sincerely,
With best wishes

Lead Research Management & Governance Manager,

NHS
Health Research Authority

16 March 2012

Dear Ms Findlay

Study title: **A qualitative study of the perceptions of service user involvement in palliative care among staff providing such care and service users receiving such care from a hospice.**
REC reference: **11/EE/0511**

Thank you for your letter of 17 January 2012, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered at the meeting of the Committee held on 16 March 2012. A list of the members who were present at the meeting is attached.

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

[Omit this sub-section if no NHS sites will be taking part in the study, e.g. Phase 1 trials in healthy volunteers]

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Covering Letter	from Helen Findlay	18 November 2011
REC application	IRAS Parts A&B 85	22 November 2011
Protocol	(no version number)	18 November 2011
Response to Request for Further Information	from Helen Findlay	17 January 2012
Advertisement	1	16 January 2012
Interview Schedules/Topic Guides	1	01 September 2011
Investigator CV	Ms Helen Findaly	
Investigator CV	Frances Reynolds	07 October 2011
Investigator CV	Peter Beresford	07 October 2011
Letter from Sponsor	from David Anderson-Ford	24 August 2011
Letter of invitation to participant	Staff 3	16 January 2012
Letter of invitation to participant	Service Users 2	16 January 2012
Letter from [redacted]	from [redacted]	21 July 2011
Reply Slip	1	16 January 2012
Participant Consent Form	2	16 January 2012
Participant Information Sheet	Service Users 2	16 January 2012
Participant Information Sheet	Staff 3	16 January 2012
Statement of Sponsorship/Indemnity from David Anderson-Ford		24 August 2011
Evidence of insurance or indemnity	AON	04 August 2011

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

[redacted] **Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely

Enclosures:	*List of names and professions of members who were present at the meeting and those who submitted written comments [if final opinion was confirmed was given at a meeting]*
	"After ethical review – guidance for researchers" *[SL-AR2]*

School of Health Sciences and Social Care

Brunel
UNIVERSITY
LONDON

School of Health Sciences and
Social Care
Brunel University,
Uxbridge
Middlesex UB8 3PH
Telephone: +44 (0)1895 274000
Web www.brunel.ac.uk

24 August 2011

Proposer: Helen Findlay

Title: **A qualitative study of the perceptions of service user involvement in palliative care among staff providing such care and service users receiving such care from a hospice**

Reference: **11/08/PHD/11**

Letter of Approval

The School Research Ethics Committee has considered the amendments recently submitted by you in response to the Committee's earlier review of the above application

The Chair, acting under delegated authority, is satisfied that the amendments accord with the decision of the Committee and has agreed that there is no objection on ethical grounds to the proposed study. Approval is given on the understanding that the conditions of approval set out below are followed:

- *The agreed protocol must be followed. Any changes to the protocol will require prior approval from the Committee.*

NB:

- **Research Participant Information Sheets and (where relevant) flyers, posters, and consent forms should include a clear statement that research ethics approval has been obtained from the School of Health Sciences and Social Care Research Ethics Committee.**
- **The Research Participant Information Sheets should include a clear statement that queries should be directed, in the first instance, to the Supervisor (where relevant), or the researcher. Complaints, on the other hand, should be directed, in the first instance, to the Chair of the School Research Ethics Committee**
- **Approval to proceed with the study is granted subject to receipt by the Committee of satisfactory responses to any conditions that may appear above, in addition to any subsequent changes to the protocol.**
- **The School Research Ethics Committee reserves the right to sample and review documentation, including raw data, relevant to the study.**

David Anderson-Ford
Research Ethics Officer
School of Health Sciences and Social Care

Appendix 3: Interview table: Service user participants

	Ex-caregiver	**‘Polly’**	**‘Bob’**	**‘David’**	**‘Stanley’**	**‘Milly’**
Familiarity with the words ‘service user’						
i. A person receiving palliative care	✓	✓	✓	✓	**x**	**x**
ii. Also refers to family carers	✓	**x**	**x**	**x**	**x**	**x**
Understanding of the term ‘service user involvement’						
i. Familiar with the term	✓	**x**	**x**	**x**	**x**	**x**
ii. Awareness of legislative requirements such as professional ethics; hospice codes on service user involvement	✓	**x**	**x**	**x**	**x**	**x**
Personal experience of ‘service user involvement’ in palliative care (even if didn’t use this term in interview)						
i. As a carer	✓	**x**	**x**	**x**	**x**	**x**
ii. As a service user	**x**	✓	✓	✓	**x**	✓
iii. Had involvement in service user activities at the hospice	✓	✓	✓	✓	✓	✓
iv. Felt involvement was taken notice of	✓	**x**	**x**	**x**	**x**	**x**
v. Belief that each individual has a right to choose the kind of care they want	✓	✓	✓	✓	✓	✓

vi. Should gather views & stories of people, listen to them, help shape services	✓	✓	✓	✓	✓	✓
	Ex-caregiver	**‘Polly’**	**‘Bob’**	**‘David’**	**‘Stanley’**	**‘Milly’**
Hospice Service User Group						
i. Awareness that the hospice service user group exists	✓	**x**	**x**	**x**	**x**	**x**
ii. It would be good to work more with the hospice service user group	✓	No view	No view	No view	**x**	**x**
iii. Could offer an example of direct influence that the service user group has had on hospice decision-making	✓	**x**	**x**	**x**	**x**	**x**
iv. Believe the service user group has an influence on hospice practice	✓	**x**	**x**	**x**	**x**	**x**
Family carers						
i. Holistic approach to work taken at hospice	✓	✓	✓	✓	✓	✓
ii. Regarded the patient voice as stronger if a family carer is with them	✓	DK	**x**	**x**	✓	**x**
iii. Considered that individual carers have a strong voice in the hospice	✓	**x**	**x**	**x**	**x**	**x**
Professional boundaries and legislation						
i. Palliative care perceived as being of different order & culture to	✓	✓	✓	✓	✓	✓

clinical ie hospital care						
ii. Perception that staff are able to talk with them about dying	✓	✓	✓	✓	**y/n**	✓
iii. System processes & needs of an organisation can "trump" people's needs at end of life	**x**	✓	✓	✓	**x**	✓
	Ex-caregiver	**'Polly'**	**'Bob'**	**'David'**	**'Stanley'**	**'Milly'**
iv. Some awareness of legislation on service user involvement in palliative care	✓	**x**	**x**	**x**	**x**	**x**
Awareness of changes in hospice over last couple of years and effects						
i. Aware that there are recent organisational changes since first started coming to the hospice	N/A changes introduced after pilot interview	✓	✓	✓	✓	✓
ii. Aware that changes have been made to their own care	N/A	✓	✓	✓	✓	✓
iii. Perception that are more time constraints & staff busier than used to be	N/A	✓	✓	✓	**x**	✓
iv. Perception that hospice is moving towards a 'managerialist' approach	N/A	✓	✓	✓	**x**	✓
v. Feelings of distress caused by organisational changes at the	N/A	✓	✓	✓	**x**	✓

hospice						
vi. Perception that more emphasis being placed on clinical care eg like a hospital	N/A	✓	✓	✓	x	✓
Consultations about changes at the hospice						
i. Involved in consultation activities with hospice re organisational changes	N/A	✓	✓	✓	✓	✓
ii. Expressed feelings of anger & alienation due to lack of influence	N/A	✓	✓	✓	x	✓
iii. Feeling disempowered in decisions re own care with hospice	N/A	✓	✓	✓	**y/n**	✓
iv. Felt had influence on decisions because taken part in consultations	N/A	x	x	x	x	x

Appendix 3) Interview table: Staff

	Ex-Nurse Manager Educator	**In-patient Nurse**	**In-patient nurse/**	**Clinical**	**Cancer**	**Educator**	**Family**	**Business Partner**	**Comp Therapy**	**Director, Education**	**Hospice Chaplain**	**IT manager**	**Day centre**	**Volunteer 1**	**Volunteer 2**
Understanding of the words ‘service user’															
Person receiving palliative care/ family member	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Orgs & indivs that hospice interacts with	x	x	x	x	x	✓	x	✓	x	x	x	✓	x	x	x

eg GPs, student nurses & external bodies															
Understanding of the term 'service user involvement'															
Familiar with the term	**x**	**Y/N**	**x**	**x**	✓	✓	✓	✓	✓	✓	✓	**Y/N**	✓	✓	**x**
Awareness of legislative requirements eg professional ethics; hospice codes	✓	**x**	**x**	**x**	**x**	✓	✓	**x**	**x**	**x**	**y/n**	**x**	**y/n**	**x**	**x**
Personal experience of service user involvement															
As a carer	**x**	**x**	**x**	**x**	**x**	✓	**x**	✓	**x**	✓	**x**	**x**	**x**	**x**	✓
As a service user	**x**	**x**	**x**	**x**	✓	**x**	**x**	**x**	**x**	**x**	**x**	**x**	**x**	**x**	**x**
	Ex-Nurse Manager Educator	**In-patient Nurse**	**In-patient nurse/ infection control**	**Clinical Nurse**	**MacMillan**	**Educator**	**Family Support**	**Business Partner**	**Comp Therapy Manager**	**Director, Education & Research**	**Hospice Chaplain**	**Head of IT**	**Day centre Nurse**	**Volunteer 1**	**Volunteer 2**
Service user involvement a "burden" on those directly receiving palliative care															
Service user more likely to talk when time passed	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	**y/n**	**x**	✓	✓

after diagnosis															
Service user “too traumatised” straight after diagnosis & not able to talk at that point	✓	✓	✓	✓	✓	✓	✓	✓	**x**	✓	✓	**y/ n**	✓	✓	✓
Staff perhaps be too ‘parental’ in trying to protect a patient	✓	✓	✓	✓	✓	✓	✓	**x**	✓	✓	**y/ n**	**x**	**x**	**x**	**x**
Positive about service user involvement															
Biggest input on involvement from service user decided when start care at hospice eg care plan	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Belief that each indiv has a right to choose the kind of care they want	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	**y/ n**	✓	✓	✓
Should gather views/stories from people & listen to what want to help shape services	**x**	✓	✓	✓	✓	✓	**x**	✓	✓	✓	✓	**y/ n**	✓	✓	✓
	Ex-Nurse Manager	**In-patient Nurse**	**In-patient nurse/**	**Clinical**	**MacMillan**	**Educator**	**Family**	**Business Partner**	**Comp Therapy**	**Director, Education**	**Hospice**	**Head of IT**	**Day**	**Volunteer**	**Volunteer**
Awareness of hospice service user															

group and what it does															
Awareness that the hospice service user group exists	✘	✓	**x**	✓	✓	✓	**x**	**x**	✓	✓	✓	**x**	✓	**x**	✓
Desire to work more with the hospice service user group	✓	✓	✓	✓	✓	✓	✓	**x**	**x**	✓	**y/n**	**x**	✓	**y/n**	**y/n**
Offered example of direct influence that service user group had on hospice decision-making	**x**	**x**	**x**	✓	✓	✓	**x**	**x**	**x**	✓	✓	**x**	**x**	✓	✓
View it as only concerned with social related activity	✓	✓	✓	✓	**x**	**x**	✓	**x**	**x**	**x**	**x**	**x**	**x**	**x**	**x**
Believe service user group has an influence on hospice practice	**x**	**x**	**x**	✓	✓	✓	**x**	**x**	**xDK**	✓	**x**	**x**	**y/n**	**x**	✓
Believe activities are a matter only for senior management in the hospice & at Board level	✓	✓	✓	**x**	**x**	**x**	✓	**x**	**x**	**x**	**x**	**x**	✓	**x**	**x**

	Ex-Nurse Manager Educator	In-patient Nurse	In-patient nurse/ infection control	Clinical Nurse Manager	MacMillan Cancer Care	Educator	Family Support Therapist	Business Partner	Comp Therapy Manager	Director, Education & Research	Hospice Chaplain	Head of IT	Day centre Nurse	Volunteer 1	Volunteer 2
Perspectives on influence of service user involvement in hospice from individuals receiving palliative care when family carer also involved															
Holistic approach to work at hospice	✓	✓	✓	✓	✓	✓	✓	x	✓	✓	✓	✓	✓	✓	✓
Regarded patient voice stronger if family carer is with them	✓	✓	✓	✓	✓	✓	x	✓	x	✓	✓	y/n	x	y/n	✓
Considered that individual carers have a strong voice in the hospice	x	✓	x	✓	✓	✓	x	x	x DK	✓	x DK	x DK	y/n	x DK	x DK
Awareness of professional boundaries & legislation on service user involvement in palliative care															
Palliative	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	x	✓	✓

care perceived as being of different order & culture to clinical ie hospital care															
	Ex-Nurse Manager Educator	**In-patient Nurse**	**In-patient nurse/**	**Clinical**	**MacMillan**	**Educator**	**Family**	**Business Partner**	**Comp Therapy**	**Director, Education &**	**Hospice Chaplain**	**Head of IT**	**Day centre**	**Volunteer 1**	**Volunteer 2**
Has ‘feeling’ of what ‘ought’ to be doing as individual providing palliative care	✓	✓	✓	✓	✓	✓	✓	x	✓	✓	✓	✓	✓	✓	✓
Awareness of professional/ hospice codes covering own role	✓	✓	✓	✓	x	✓	✓	x	✓	✓	✓	✓	✓	✓	✓
Perception that physicians have difficulty in talking about dying	x	✓	x	✓	✓	✓	x	Y/N	✓	✓	✓	x DK	DK	y/n	x DK
Danger of “tick box approach” to palliative care	✓	✓	x	x	✓	✓	✓	x	✓	Y/N	✓	x DK	✓	x	x
Some awareness of legislation on service user involvement in palliative care	✓	x	x	✓	✓	✓	✓	x	x	x	✓	x	x	x	x
System processes & needs of an	x	x	Y/N	x	✓	✓	x	✓	✓	x	✓	x	✓	✓	x DK

organisation can “trump” people’s needs at end of life															
Perception that doctors could be too dominant	x	x	x	✓	✓	✓	x	x	✓	✓	x	x	DK	x	x
Laws seen as “illogical” for individuals at the end of their lives	x	x	x	x	x	✓	x	x	✓	x	x	x	DK	x	x
	Ex-Nurse Manager Educator	**In-patient Nurse**	**In-patient nurse/**	**Clinical**	**MacMillan**	**Educator**	**Family**	**Business Partner**	**Comp Therapy**	**Director, Education &**	**Hospice Chaplain**	**Head of IT**	**Day centre**	**Volunteer 1**	**Volunteer 2**
Awareness of changes in hospice over last couple of years															
View that hospice is not just a building, it operates in the community	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Aware there are recent changes since first started working at the hospice	x	✓	✓	✓	x	✓	x	✓	✓	✓	x	✓	✓	✓	✓
Own role has changed over last 12 months	x	x	✓	✓	x	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Perception that are more time constraints & busier than used to be	x	✓	✓	x	x	✓	x	x	x	✓	x	✓	✓	x	✓
Perception	x	✓	✓	✓	✓	✓	x	✓	x	y/n	x	✓	✓	✓	x

that hospice is moving to 'managerialist' approach															
Aware of distress being caused to service users by organisational changes at the hospice		**x**	**x**	**x**	✓	✓	✓	**x**	✓	**x**	**y/n**	**x**	✓	✓	**x**
Perception that hospice becoming more clinical or like a hospital	**x**	**x**	✓	**x**	**x**	✓	**x**	**x**	**x**	**x**	**x**	**y/n**	**y/n**	**x**	**x**
	Ex-Nurse Manager Educator	**In-patient Nurse**	**In-patient nurse/**	**Clinical**	**MacMillan**	**Educator**	**Family**	**Business Partner**	**Comp Therapy**	**Director, Education &**	**Hospice Chaplain**	**Head of IT**	**Day centre**	**Volunteer 1**	**Volunteer 2**
Comments of MacMillan Cancer counsellor only on cancer networks & cancer service user groups															
Cancer service user groups may be stronger compared to non-cancer service user groups in palliative care					✓										
"Individuals challenge palliative doctors now"					✓										
The Chemo					✓										

Therapy Unit at the local hospital seen as a strong voice in the local community															
The service user voice not seen as very strong outside cancer					✓										
Professionals may have a fear of getting palliative care wrong if not cancer					✓										
Perception that the hospice is moving to a 'managerialist' approach					✓										
	Ex-Nurse Manager Educator	**In-patient Nurse**	**In-patient nurse/**	**Clinical**	**MacMillan**	**Educator**	**Family**	**Business Partner**	**Comp Therapy**	**Director, Education &**	**Hospice Chaplain**	**Head of IT**	**Day centre**	**Volunteer 1**	**Volunteer 2**
Awareness of distress being caused to service users by the organisational changes at the hospice					**x**										
Perception that the hospice was potentially becoming more clinical or like a hospital					✓										
Awareness of the roles															

of volunteers at the hospice (1200 of them)															
Some awareness of what hospice volunteers do	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	**x**		✓	✓
Roles & input of hospice volunteers is generally understood	✓	✓	✓	**x**	**x**	✓	✓	✓	✓	✓	✓	**x**		✓	✓
Some acknowledgment that hospice find it difficult to carry on without volunteers	**x**	**x**	**x**	**x**	✓	✓	**x**	**Y/N**	✓	✓	✓	**x** **DK**		✓	✓

Appendix 4: Literature review table 1995 – 2018 (alphabetical order)

STUDY	PARADIGM	METHODOLOGY	RESEARCH AIMS/ QUESTIONS	SAMPLING	DATA COLLECTION METHOD	ANALYTIC STRATEGIES	TYPES OF FINDINGS	RESEARC REPORT
Aspinal et al 2006	Interpretive	Participatory	To investigate what is important to measure at the end of life from the perspectives of UK patients, bereaved relatives & healthcare professionals	Focus groups; recording, transcribing. Over 18, speak English, able to give written informed consent; patients judged to be psychologically & physically capable of participating by hospice day care staff	10 focus groups using modified nominal group technique; 75 participants (10 patients; 35 professionals; 30 bereaved relatives).	Thematic analysis. Issues proritised using ratings & rankings incorporating cross-group comparison	7 themes identified: symptom management; choice & control; dignity; quality of life; preparation; relationships; co-ordination & continuity	Diffs betwee professional groups & pati groups identif in cross-comparison e professional groups had ‘symptom co as first priorit whereas bereaved gro had ‘quality o life’ & ‘relationships important; patients grou had ‘preparat & ‘co-ordinati and continuit priorities
Beresford & Branfield 2006	Interpretive	Case study	To describe 3 projects undertaken by ‘Shaping Our	-	Data from 3 projects in report: *Shaping Our Lives*	Descriptive	Service user concepts of outcome & quality may	Need to deve effective partnerships include servic

STUDY	PARADIGM	METHODOLOGY	RESEARCH AIMS/ QUESTIONS	SAMPLING	DATA COLLECTION METHOD	ANALYTIC STRATEGIES	TYPES OF FINDINGS	RESEARC REPORT
			concepts of outcomes & quality in health & social care		*People Think of the Social Care Services They use, 2003* (Joseph Rowntree Foundation)		current models. Importance of networking & knowledge-sharing for service users & user organisations in order to influence policy	key stakehol & to enable service users be centrally involved in developing models of outcome measures. Importance o networking between serv users conside important. Ma be important for unpaid car to be involved risk of service users being marginalised, needs more explicit & deliberate inclusive approach. Otherwise run risk of bias by omission
Boelk &	Interpretive	Grounded Theory	Advance theory	15 family	In-depth	Dimensional	Initial matrix	Raised

STUDY	PARADIGM	METHODOLOGY	RESEARCH AIMS/ QUESTIONS	SAMPLING	DATA COLLECTION METHOD	ANALYTIC STRATEGIES	TYPES OF FINDINGS	RESEARC REPORT
Kramer 2012			of family conflict at end of life by exploring perceptions of professionals & family caregivers experiencing conflict in non-profit hospice context	caregivers & 37 hospice professionals	interviews with family caregivers; focus groups with professionals	analysis	expanded to include further categories to aid understanding of family conflict	awareness of family contex understandin family conflict end of life. Lo standing fami issues, dynar & problems m surface & ma exacerbated when faced w life-limiting illness. Professional training & hospice delive system may underestimate the complexit some family systems inclu cruelties that have taken pl & depth of dysfunction th may dramatic influence qua of care at enc life. “Care as

STUDY	PARADIGM	METHODOLOGY	RESEARCH AIMS/ QUESTIONS	SAMPLING	DATA COLLECTION METHOD	ANALYTIC STRATEGIES	TYPES OF FINDINGS	RESEARC REPORT
								usual may no sufficient”
Carter et al 2004	Interpretive	Participatory	Explore what people living with terminal illness considered were areas of priority in their lives; looked at different views of patients about what important about aspects of disease & treatment for patients themselves	10 people living with terminal cancer (7 women, 3 men all over 50 years of age); included participants recruited from hospice. ‘convenience sampling’ used ie those recruited & consented were included	Interviewing. Naturalistic enquiry mode ie themes collated after interviews. Interviews recorded & transcribed	Narrative analysis & grounded theory; thematic analysis; looked at of QOL (Quality of Life) tools in relation to end of life care & their limitations eg taking charge not represented in QOL tool; concept of ‘good’ death as outcome has problems because primarily professionally conceived; could be too generalised & not specific	30 categories within 5 themes emerged: personal/intrinsic factors; external/extrinsic factors; future issues; perceptions of normality & taking charge which integrally connected to all the other themes. Taking charge concerned ability to define & actualise their needs. Participants focused on “living with a terminal illness” than focusing on future death	Taking charg aspect of find seen as important for patient empowermen barriers to thi include forma power structu in working environment t emphasises r of the professional; actively-negotiated interactive process seen enhance patie control & pow in decision-making

STUDY	PARADIGM	METHODOLOGY	RESEARCH AIMS/ QUESTIONS	SAMPLING	DATA COLLECTION METHOD	ANALYTIC STRATEGIES	TYPES OF FINDINGS	RESEARC REPORT
						enough. Put forward notion of ‘appropriate’ death ie to suit individual		
Cotterell 2006 (PhD thesis)	Emancipatory research; feminist theory; qualitative	Constructivist	Exploring experience & needs of people living with life limiting conditions	Involved service user advisory group (SURAG) & 25 participants	Mail shot in 1 locality seeking participants w cancer & other conditions; face-to-face interviews; discussion groups	Critical reflective thinking as researcher & with SURAG	7 themes discovered: diagnosis; fear; anger/ frustration; grief; relationships; difference/ individuality; independent/ dependent	Experience o living with life limiting conditions; of needs not me different experience w cancer & non cancer; lack c awareness among non-cancer re palliative care value placed cancer users access to hospice day centre
Cotterell et al 2011	Interpretive	Participatory & user led	To explore the impact of involvement on the lives of service users affected by	Setting: across UK Participants: 64 – engaged in involvement activities in	8 focus groups with user groups; 9 face-to-face interviews with involved	Thematic analysis. Participatory approach where service users affected	Findings identified 3 main themes for involvement: expectations & motivations;	Provides overview of qualitative findings; prov direct quotes from research

STUDY	PARADIGM	METHODOLOGY	RESEARCH AIMS/ QUESTIONS	SAMPLING	DATA COLLECTION METHOD	ANALYTIC STRATEGIES	TYPES OF FINDINGS	RESEARC REPORT
			cancer	cancer services, palliative care and research	individuals at local, national & regional levels	by cancer involved as integral members of research team & worked on all aspects of research task	positive & challenging aspects. Outlines how lack of implementation of direction & vision of involvement activities & expectations has led to frustrations; involvement also led to enhanced life opportunities for active users with cancer	participants t underpin the identified
Croft, Chowns & Beresford 2012	Qualitative; participatory	Report of 2012 survey using questionnaire aimed at UK palliative care social workers towards service user involvement	Set out findings of 2012 survey, check progress & proposals for future research	20% response rate to survey; specialist palliative care social workers in 42 settings in NHS & voluntary sector including 29 hospices	Questionnaire (as described in sampling)	Thematic	Significant contradictions about user involvement in palliative care; hospices considered had always put patient at centre as part of original ethos	References t different type user involvem ladders base Arnstein's lad and non-hierarchical approach (mention Treseder 200 adapted by

STUDY	PARADIGM	METHODOLOGY	RESEARCH AIMS/ QUESTIONS	SAMPLING	DATA COLLECTION METHOD	ANALYTIC STRATEGIES	TYPES OF FINDINGS	RESEARC REPORT
				across UK				Chown 2012) Issues that emerged: lac consensus around what involvement means; a lot consists of contirubting t leaflets, publi & giving feed so at consulta level. Highligh benefits, gain challenges to user involvem plus barriers including lack resources, competing priorities. Identified urg need to deba contemporary understandin term 'service involvement'
Daykin et al 2010	Interpretive	Qualitative & Quantitative	To identify key principles for	One UK cancer	Formal consensus	120 priority statements	That consensus development	Provides overview of

STUDY	PARADIGM	METHODOLOGY	RESEARCH AIMS/ QUESTIONS	SAMPLING	DATA COLLECTION METHOD	ANALYTIC STRATEGIES	TYPES OF FINDINGS	RESEARC REPORT
			the development of user involvement in a cancer network	network involving 357 individual stakeholders; collaboration between NHS, 2 universities & 2 voluntary sector organisations; seeking perspectives of users & professionals towards user involvement in cancer network	development method – Delphi technique utilising series of questionnaires & also Nominal Group Technique to facilitate structured group discussions	identified then ranked by a formula	process is key to understanding professional attitudes to user involvement; identified power dynamics between professions & between professionals & users	methods use how data analysed & highlighted examples fro questionnaire responses
Etkind et al 2018	Qualitiative & quantitative	Systematic review	Explore influences on care preferences of older people with advanced illness	Hospital & community care setting. Of 12,142 search results, 57 articles included	Search of Medline, Embase, PsycINFO, Web of Science & Open Grey	Thematic synthesis of qualitative articles; narrative synthesis of quantitative articles	Family & care context, illness & individual factors interact to influence care preferences	Family particularly important as influence on preferences which then influenced by complex interaction of family, illness care factors

STUDY	PARADIGM	METHODOLOGY	RESEARCH AIMS/ QUESTIONS	SAMPLING	DATA COLLECTION METHOD	ANALYTIC STRATEGIES	TYPES OF FINDINGS	RESEARC REPORT
Evans et al 2003	Grounded theory	Participatory	Explore knowledge, experience & importance of user involvement to people with cancer & carers	31 people with cancer & 5 carers in one cancer network in England	Semi-structured interviews	Thematic analysis	Few participants understood what service user involvement was; many saw it as involvement in decisions re own care or taking part in drug trials	Lack of info a cancer servic in general & treatment opt appeared bar to service use involvement i treatment rela decisions; importance o communicatio with healthcar professionals seen as important to service user involvement; policy suppor involvement b little practical structure to enable it; & therefore see 'alien'
Forbat et al 2009	Empirical & interpretive	Cross-sectional study	To explore range of models of involvement	Data gathered from larger study: Intervention across 3 sites	Focus groups of people with cancer & lung cancer team in 5 health boards	Thematic analysis	Range of ways of conceptualising involvement emerged; few	Slow applicat of involvemer due to myriad ways it is conceptualise

STUDY	PARADIGM	METHODOLOGY	RESEARCH AIMS/ QUESTIONS	SAMPLING	DATA COLLECTION METHOD	ANALYTIC STRATEGIES	TYPES OF FINDINGS	RESEARC REPORT
				& non-intervention at 2 control sites	across Scotland; individual interviews with CEOs of all 5 boards		moved beyond use of patient satisfaction surveys; use of public meetings to communicate decisions about closures to services	leading to muddle; Clinicians nee support for cla on operation involvement i to work
Francois et al 2017	Interpretive	Qualitative	To understand staff & relative perspectives on conflict & serious disagreement in adult palliative care including triggers, risk factors & impact	Semi-structured interviews with 25 staff & 7 bereaved relatives	Individual interviews at multidisciplinary palllative care setting in Australia	5-stage thematic analysis of data	Refers to “triadic” healthcare relationship (patient-relative-healthcare team). Relatives identified systemic rather than interpersonal causes as provoking conflict	Data indicate emotional undertow of conflict in palliative care Identified common trigg of conflict: eg breakdown in communicatio relatives involvement i decision-mak patient & fam mistrust of th healthcare system; religi beliefs & cultu differences ab treatment goa

STUDY	PARADIGM	METHODOLOGY	RESEARCH AIMS/ QUESTIONS	SAMPLING	DATA COLLECTION METHOD	ANALYTIC STRATEGIES	TYPES OF FINDINGS	RESEARC REPORT
								refual of treatment & misunderstan of prognosis
Fredriksson, Eriksson & Tritter 2018	Cross-sectional study	Quantitative	Comparing preferences for individual & collective involvement (PPI) in England and Sweden	3125 respondents – 1625 in England; 1500 in Sweden	Four questions asked in random sampling via Public Health England Public Opinion Survey 2014 conducted by IPSOS Mori; plus omnibus survey carried out by TNS Sifo	Multinomial regression model	68% of respondents overall wanted passive patient role; 44% wanted involvement in decisions about organisation & provision of services	Health systen needs to integrate effe approach to F in individual treatment decisions & ir shaping local health & socia care priorities More work needed to understand desire to be involved & actually *being* involved
Fudge et al 2008	Ethnographic	Participatory	Understand how policy of user involvement interpreted in health service organisations & factors that	Service users, NHS managers & clinicians in 2 London boroughs	Observation, semi-structured interviews with users & staff, documentary evidence of stroke service	Thematic analysis of transcripts, reflexive diary, notes & stroke programme documents	Findings not necessarily applicable to other conditions apart from stroke but useful more broadly to the policy of	Service user involvement initiated & led professionals profs decided areas of servi improvement users could

STUDY	PARADIGM	METHODOLOGY	RESEARCH AIMS/ QUESTIONS	SAMPLING	DATA COLLECTION METHOD	ANALYTIC STRATEGIES	TYPES OF FINDINGS	RESEARC REPORT
			influence how put into practice				user involvement	participate in. covered satisfaction surveys to us providing pee support in are with least sup from clinician Vagueness in understandin user involvem Users & profs viewed & practised sui different way
Gauthier & Swigart 2003	Constructivist	Grounded theory	To study the process of decision-making for adults with a terminal illness including influences & most meaningful situations for making decisions	Participants: over 18 years of age; no cognitive impairment as assessed by hospice staff & so able to participate voluntarily; English-speaking; aware of terminal	Hospice agency professional staff identified appropriate cases; approached via leaflet & 4 methods to contact researcher; first recruit interviewed then others	Grounded theory methods used as guide	Analysis method allowed for substantive theory to be developed offering tentative model of the process of decision-making for terminally ill adults in hospice care. Found to be complex process of	Noted that perception of control of decision-mak between user professional needed more research; considered th this research moves literat conceptually forward by providing a

STUDY	PARADIGM	METHODOLOGY	RESEARCH AIMS/ QUESTIONS	SAMPLING	DATA COLLECTION METHOD	ANALYTIC STRATEGIES	TYPES OF FINDINGS	RESEARC REPORT
				status. 14 participants (8 women, 6 men) from 2 hospices volunteered to take part. Breakdown of details about participants provided in a table	concurrently as recruitment process continued; theoretical sampling purposefully choosing participants to expand on emerging concepts; semi-struc interviews: focus on health & personal decisions & perceived facilitators & barriers to decision-making; family members present in 5 cases during interviews; to aid theoretical sampling & validate		interactive events. Quotes from participants included in table and in text. Concept of accommodating living – increasing physical dependence was consistent pattern of experience for participants; also embodied responding ie realising terminality, accommodating living & engaging uncertainty (diagram included)	grounded the about decisio making in cor of living with a terminal illnes

STUDY	PARADIGM	METHODOLOGY	RESEARCH AIMS/ QUESTIONS	SAMPLING	DATA COLLECTION METHOD	ANALYTIC STRATEGIES	TYPES OF FINDINGS	RESEARC REPORT
					findings, 7 patients were re-interviewed; field notes to record non-verbal behaviour & observations			
Haarsma et al 2015	Qualitative interpretive	Descriptive	In-depth study of practice of public involvement in palliative care	6 palliative care networks in 1 province in the Netherlands: participants were 16 patient reps & 12 professionals	18 in-depth interviews; 3 focus groups	Based on Arnstein's involvement classification & content analysis	Impact of involvement in palliative care in terms of citizen control & partnership greatest in relation to quality of care & dissemination of info. Tensions perceived between patient reps & professionals in relation to operational & strategic involvement	Improvement public involvement i palliative care required posit attitudes, ope communicati sufficient resources & l term support
Johnston & Smith 2006	Interpretive	Phenomenology	To report on perceptions of	Involves 2 acute hospitals	Convenience sample of 22	Content analysis (Miles	29 categories in 8 themes	Emphasised importance o

STUDY	PARADIGM	METHODOLOGY	RESEARCH AIMS/ QUESTIONS	SAMPLING	DATA COLLECTION METHOD	ANALYTIC STRATEGIES	TYPES OF FINDINGS	RESEARC REPORT
			patients & palliative care nurses on expert palliative nursing care & examine differences between them	& 2 hospices in Scotland. Registered nurses & patients with terminal illness were interviewed. Criteria: patients - life expectancy of between 2 weeks to 2 years; speak English; Nurses – registered nurse; at least 2 years experience; postreg qualification in palliative care.	registered nurses & 22 dying patients. Pilot study of 10 participants conducted before main study. Data collected over 18 month period. In-depth interviews with second repertory grid interview 7-14 days after first interview; nurse data collected before patient data. 13 patients unable to do second interview due to health, refusal or death. Interviews audio-taped	& Huberman) and thematic analysis	identified. ‘connecting’ was central theme – someone to talk to; willing to listen; getting to know me; avoiding me Dying patients also had desire to maintain independence & remain in control	communicatio & listening sk of professiona & role involve more than jus experience & qualifications dying patients can & wish to take part in research
Karnilowicz 2011	Narrative form of	Auto-ethnographic	To explore psychological	-	Literature search &	Auto-ethnographic	Approach used to confront	Self-identity i often subject

STUDY	PARADIGM	METHODOLOGY	RESEARCH AIMS/ QUESTIONS	SAMPLING	DATA COLLECTION METHOD	ANALYTIC STRATEGIES	TYPES OF FINDINGS	RESEARC REPORT
	research connecting personal to cultural; places the self within a social context	study	ownership & identity related to prostate cancer & chronic illness		personal experience		dominant forms of representation & power; power differential especially evident in health industry. Analysis of disease & illness from perspective of less powerful through examining patients’ lived experience of their illness	greatest chan when confron with “epiphan experience eg terminal diagnosis. Patients may to regain ownership ov themselves o choose other spouse to tak over the role. Professionals need to devel psychosocial-cultural environment l suited to enab patient’s posi self-identity w psychological ownership. Relationship between practitioner & person with th disease need become

STUDY	PARADIGM	METHODOLOGY	RESEARCH AIMS/ QUESTIONS	SAMPLING	DATA COLLECTION METHOD	ANALYTIC STRATEGIES	TYPES OF FINDINGS	RESEARC REPORT
								collaborative empowering.
Kars et al 2016	Literature review	Systematic review	To identify potential gatekeepers in palliative care research & reasons for it	Search databases: PubMed, Embase, Cumulative Index to Nursing and Allied Health literature & PsycINFO from 2000 – May 2015. 18 years & over & dementia excluded. 30 papers included	Preferred Reporting Items for Systematic Reviews	Meta-analyses & thematic synthesis	5 groups of potential gatekeepers identified: healthcare professionals; research ethics committees; management; relatives & researchers	Fear of burde vulnerable patients was most importa reason for gatekeeping. hospice & homecare settings, purs of comfort ca may trigger protective attitude. Also, perceived lac skills in recrui patients with advanced illn Patients perspective concerning st participation i needed to understand & address gatekeeping i palliative care research

STUDY	PARADIGM	METHODOLOGY	RESEARCH AIMS/ QUESTIONS	SAMPLING	DATA COLLECTION METHOD	ANALYTIC STRATEGIES	TYPES OF FINDINGS	RESEARC REPORT
Lee et al 2009	Qualitative interpretive	Grounded Theory	Exploring decision-making from the perspectives of patients with advanced illness	In hospitals, hospices & community in Australia.14 patient participants aged 28-93 years of age, most with cancer; 1 with neurological condition & 1 heart disease; 7 family carers & 18 health professionals from medical, nursing, counselling	Using interviews & field observations. Further interviews conducted with a number of participants related to emerging themes in palliative care inpatient units & in community	Line-by-line comparison with open, selective & axial coding	Patients' experiences of lack of involvement prompted by relationship with professionals that important to a patient's ability to be involved in decisions about their palliative care; lack of professional involvement due to ways of working eg manner & focus; trustworthiness; culture & environment. Some patients not 'likeable' seen by professionals as only deserving of obligatory care	Importance o relationship between patie & professiona that seen as responsibility professionals patients to att it. Role of reflective prac to examine professional in decision-making with patients. Pati responded be to professiona who treated t as individuals
McCormick	Interpretive	Qualitative	To understand	6 patients with	Interviewed 6	Thematic	Reflexive.	Provides dire

STUDY	PARADIGM	METHODOLOGY	RESEARCH AIMS/ QUESTIONS	SAMPLING	DATA COLLECTION METHOD	ANALYTIC STRATEGIES	TYPES OF FINDINGS	RESEARC REPORT
& Conley 1995			needs of dying patients from their own perspectives	life-threatening illness	patients with life-threatening illness	analysis	Addressed patients illness & treatment history, personal perception of treatment plan, perceived needs & desires re communication with physicians & other thoughts & feelings they wished to volunteer; plus perceived barriers	quotes from patients interviewed; draws out the & conclusions from it; identif proper communicatio with physician as most important asp of their resear findings
Mockford et al 2012	Literature review	Systematic review	Identify impact of Public Patient Involvement (PPI) on NHS & economic cost	UK studies from 1997-2009 that included service user involvement in NHS healthcare services	17 key online databases & websites. 6110 references retrieved; 64 chosen for full data extraction; 28 studies remained for analysis	Key themes identified & narrative analysis	Indications that PPI has range of impacts on NHS. PPI evidence base limited by poor quality of impact reporting & little descriptive detail or robust measurement	Evidence bas for PPI in NH needs to be significantly developed particularly around servic user involvem & its impact o NHS healthca services. Bala of power in involvement

STUDY	PARADIGM	METHODOLOGY	RESEARCH AIMS/ QUESTIONS	SAMPLING	DATA COLLECTION METHOD	ANALYTIC STRATEGIES	TYPES OF FINDINGS	RESEARC REPORT
								seems to rest with organisa or system rat than partners working with patients & pu Need to re-evaluate met & approaches involvement. Imbalances o power betwee patients, publ healthcare pr & organisatio
Ocloo & Matthews 2016	Literature review	Literature search	To explore why involvement of patients & public in healthcare is patchy, slow & often concentrated at lower levels of involvement	Selective narrative literature search up to 2016 & omitted anything before 1969	Using authors' knowledge to search databases, plus google & hand searches	Narrative review	Discovered number of benefits of involvement including improving patient choice, shared decision-making, changes to service delivery.	PPI often see trapped in vic cycle. Uncert about how to involvement Evidence of impact of involvement a sub-optimal le
Palumbo 2015	Literature review	Systematic review	Contextualise concepts of "service co-	254 records identified from databases	Search of databases	Author devised ad hoc research	Co-production of health care services implies	Professional hostility & pat unwillingness

STUDY	PARADIGM	METHODOLOGY	RESEARCH AIMS/ QUESTIONS	SAMPLING	DATA COLLECTION METHOD	ANALYTIC STRATEGIES	TYPES OF FINDINGS	RESEARC REPORT
			production” & “value co-creation” to health services & challenge traditional bio-medical model	Scopus-Elselvier * PubMed up to 2014. 65 included in review. No grey literature nor books included		protocol	creating partnerships between professionals & patients but barriers prevent implementation of such a model so enabling the bio-medical model to continue	makes co-production difficult to rea However, scientific literature consistently claims that c production pa way for increa health outcon enhanced pat satisfaction, better service innovation & savings. Co-production involves freed of choice but sees patients members of health care teams who establish relationships providers of to co-create value
Payne et al	Literature	Scoping study	To discover	Scoping study	Literature	Thematic	Service user	V little resear

STUDY	PARADIGM	METHODOLOGY	RESEARCH AIMS/ QUESTIONS	SAMPLING	DATA COLLECTION METHOD	ANALYTIC STRATEGIES	TYPES OF FINDINGS	RESEARC REPORT
2005	review		studies re service user involvement in palliative care up to 2005		review; focus groups	analysis	involvement in palliative care is under-researched area	conducted on topic. Most studies conducted by health professionals little by servic users; prof vo pre-dominate
Richardson, MacLeod & Kent 2010	Interpretive & reflexive	Phenomenology & hermeneutics. Explores lived experience of patients attending outpatient clinic of a community hospice; examine & reveal language buried within meanings of words	To explore issues around empowerment & daily decision-making with terminally ill patients	14 participants receiving palliative care in one location in New Zealand; age range 48-84 years; cancer sufferers, 1 heart disease	Face-to-face interviews	Reflection & immersion in text; analysis & constant reflection of issues re power & control inequities in nursing practices	3 themes identified: lived space chaos; contracting worlds & capitulation; attests that health profs should be mindful of level of control they exert & need to become partners in care	Outlines the process by wh total immersio text was achieved usin phenomenolo with van Manem's hermeneutics
Sargeant et al 2007	Interpretive	Participatory	To identify motivational factors for service users & professionals to engage in user	Participants identified through National Council for Palliative Care	51 semi-structured telephone and face-to-face interviews conducted with	Interview transcripts & field notes entered on to QSR NVIVO database &	User involvement mainly developed through top-down	SU's felt empowered through their involvement; group meetin enhanced

STUDY	PARADIGM	METHODOLOGY	RESEARCH AIMS/ QUESTIONS	SAMPLING	DATA COLLECTION METHOD	ANALYTIC STRATEGIES	TYPES OF FINDINGS	RESEARC REPORT
			involvement activities in palliative care	user group plus snowball technique & Hospice Information Directory. Already involved in user involvement activities	service users, palliative care professionals & experts; audio-taped & transcribed; 4 user involvement programmes observed & field notes made.	thematically analysed followed by consultation meeting with 48 service users & professionals to discuss preliminary findings. Data from this added to database & contributed to analysis. Quotes from participants used to illustrate different themes	professional agenda; few highly motivated service users & palliative care professionals v influential in starting & maintaining user involvement.	feelings of se worth & felt valued for ski knowledge; k driving factor opp to contrib to improveme in services. Barriers: prof agenda domi tokenism; For professionals personal & pr values were intrinsic motivators; de to empower patients & ca initial driver fr external serv directives to implement us involvement e Clinical Governance Directives. Barriers: time consuming, feeling

STUDY	PARADIGM	METHODOLOGY	RESEARCH AIMS/ QUESTIONS	SAMPLING	DATA COLLECTION METHOD	ANALYTIC STRATEGIES	TYPES OF FINDINGS	RESEARC REPORT
								threatened, a on to current roles, lack of leadership
Woods, Beaver and Luker 2000	Interpretive	Participatory	To gather service user perspectives on palliative care services from people with terminal illness living in a city in the north-west of England	Referrals from General Practices involving 15 patients, 10 carers and 19 bereaved carers all involving cancer diagnosis	Semi-structured interviews with patients and carers carried out with 42 in own homes and 2 elsewhere; tried to interview patient & carer separately; quantitative & qualitative data collected during interviews	Thematic analysis	Identifies moral complexity of family involvement in palliative care; Identifies ethical issues implicit within users perceptions of palliative care services; complexity of role of family members & their relationship with professionals; issues of confidentiality eg when does it become a barrier to effective palliative care	Identifies nee for more integrated palliative care services; bett training in communicatio skills for professionals greater flexibi in the way palliative care services are provided