



# **Social capital and atmosphere of care settings for older people: A comparative study of two care sectors**

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## Abstract

### Background

Social capital is a resource that is created by people through networks, interactions, trust and social norms that can help facilitate mutual gain. Atmosphere (or social climate) is the 'personality' or feel that one gets from entering a place and plays a large role when individuals are choosing a care setting. Social capital may provide insights into our understanding of life within these care settings, but has not been extensively investigated.

### Aims

This comparative study of care homes and hospices aimed to address three research questions: 1. What is the relationship between the social capital of older residents/patients and the atmosphere of the setting in which they are cared? 2. Are the quality and quantity of interactions between staff and those being cared for different between the two care sectors? 3. What is the role that visitors and volunteers play in the life of those being cared for within the two care sectors?

### Methods

A mixed methods approach was used designed as two overlapping phases in two care homes and two hospices. Phase one comprised quantitative structured observation of the quality of interactions, and questionnaires measuring the atmosphere of the care setting from a staff member and volunteer perspective. Phase two comprised semi-structured interviews conducted with different groups of people who live, work and visit the care sectors.

### Findings

There were 2115 observed interactions conducted in total across both care sectors. In the care home sector, staff members were involved in and initiated the largest proportion of interactions. In the hospice sector, volunteers were involved in and initiated most interactions. There were no significant differences between care settings in terms of quality of interaction. Hospice settings were found to have a more positive atmosphere than care homes. Three key themes were identified from interviews. Integration describes the way that visitors and volunteers help integrate the communities inside the care settings with those outside. Demarcation refers to the physical boundaries of the care settings and the roles and restrictions that are placed on those that work and volunteer within the care settings. Cohesion was observed when the people in a care setting worked together to provide a mutual service, for a common goal.

### Conclusion

Visitors and volunteers play an important role in the care of older people and can improve the social capital of the care settings. Hospices were found to have higher levels of social capital, and more positive atmosphere than care homes. Improving the social capital of older people within these care settings while controlling for the negative aspects of social capital could result in a better atmosphere that can be experienced by those who live, work and visit these care settings.

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# Chapter 1: Introduction

I originally embarked on my PhD with the broad aim of conducting a study to investigate the social capital of care home settings for older people. Having completed an undergraduate and masters' degree, I had worked as a mental health and learning disabilities support worker in the health and social care field. The social life and atmosphere of different care sectors and settings is an area that had interested me for some time as I had observed that the social environment varied, sometimes drastically, between different care settings. Other than the Care Quality Commission (CQC) who work to ensure an appropriate quality of care in care settings, there is no single regulatory body to determine how a care setting should operate. It seemed largely down to the owners and managers to determine the ethos and values of these care homes, and to employ a workforce able to work based on these sets of values. I began to wonder what constituted a good social environment and what can affect a care setting in promoting this given the individual differences between the people being cared for in these settings. After reading around the concept of social capital and the 'atmosphere' of different care settings, the study developed to explore these concepts further in two different care sectors of care home and hospice.

The study undertaken that constitutes my doctoral thesis examined social capital in care homes and hospices and its relationship with the atmosphere of the care setting. This chapter provides a brief overview of the two care sectors, care home and hospice, and the key concepts that this study explores, social capital and atmosphere. The care sectors and concepts will then be discussed in depth within the literature review chapter that follows.

There is an ageing population within the UK. From 1983 to 2008, the proportion of the total population aged 75 years and over in England increased by a third from 6% (2.9 million people) to 8% (4.0 million people). The population aged 75 and over is projected to increase to 7.2 million in 2033 (Office for National Office for National Statistics 2008). In people aged 75 years and over between 2006 and 2008, 58.4% of deaths occurred in hospital, 12.1% in nursing homes, 10% in older people's care homes, and 3.1% in hospices (South West Public Health Observatory 2010). With an increasingly older population in the future there will likely be a larger population of older people residing in care homes and

attending hospices, with these services being required to provide the best possible care with limited resources.

## 1.0 Care sectors

### 1.0.1 Care Homes

Care homes provide support for those who are unable to live independently due to physical and/or mental health problems caused by an illness or ageing. Care homes provide care to older people to manage health problems and assist with activities of daily living such as personal care and provide support with administering medication. The Office for National Statistics (ONS) found that in England and Wales in 2011, there was 103,000 people aged over 85 years living in care homes not requiring nursing care and 69,000 people in care homes with nursing care needs (Office for National Statistics 2013). The independent healthcare sector was estimated to be worth £13.4 billion for older people's residential care (Age-UK 2013).

Care home residents have a diverse range of complex health issues. Nursing care and residential care provide largely the same level of support with daily activities and personal care; however, those that reside in nursing homes tend to have medical conditions that require the expertise of a registered nurse.

### 1.0.2 Hospice

Hospices provide care for people who have been diagnosed as terminally ill and provides for medical, emotional, social, practical, psychological, and spiritual needs of patients, as well as the needs of the family and carers (NHS 2012). Hospice care provides palliative care for symptoms such as pain, enabling patients to die with dignity. In 2012 there were 19,401 deaths that occurred in hospices in the UK in people aged 65 years and over (Office for National Statistics 2012). Volunteers to aid in social activities are common within the hospice sector and evidence has illustrated the importance of volunteers when discussing the future of hospice and palliative care in the UK (Addington-Hall and Karlsen 2005).

## 1.1 Why Care Homes and Hospices?

The Gold Standard Framework (Shaw, Clifford et al. 2010) for optimising care at the end of life is becoming increasingly used in care homes because if older people do not die in

hospitals there is a greater chance that they will die in care homes than in hospices (South West Public Health Observatory 2010). There may be a 'blurring of lines' between end of life care in hospices and care homes as a result of a greater need to provide certain types of care in the different care sectors. There is some evidence to suggest this is already happening. Since 2005, hospice Austria, an umbrella group comprising around 250 hospice and palliative care organisations, has been investigating a programme which aims to improve long-term care of older people. The programme has started a project to merge hospice and palliative care within nursing homes, allowing nursing homes to administer palliative and hospice care to care home residents (Beyer, Bitschnau et al. 2011). It is not uncommon for hospice patients, once the symptoms have been controlled and home care is not feasible, to be transferred into a nursing home setting when the demand on the inpatient hospice setting has become too high (Maccabee 1994).

It has been an observation that hospices tend to attract more volunteers than care homes, yet this difference has never been investigated from a social perspective to find out what influence this may have on the people who reside within these different care sectors. Additionally, the impact that volunteers can have on the atmosphere of a care home and hospice has received minimal attention. A study conducted in the USA reported that some nursing home residents received hospice and palliative care while in the nursing home setting (Buchanan, Choi et al. 2002) showing a shift in the care needs of people who reside in care homes. This study showed that the nursing homes admitted hospice care patients to support them at the end of their life suggesting little difference between hospice and care home practice in providing end of life care. Meier (2015) has advocated that in the future, nursing homes must integrate palliative care into their everyday practice as due to an ageing population, care homes will need to provide long term management of complex health needs and end of life care of the residents.

Other research has shown that there is little difference between the way that residential care homes and nursing homes address end of life care (Sloane, Zimmerman et al. 2003), suggesting that residential and nursing care homes may provide similar end of life care to hospices. This potential 'blurring of lines' has not been examined in the UK, and none of the research reviewed has looked at care homes and hospices together. The exploration of social capital (discussed briefly in the next section) and the atmosphere of these two different care sectors could provide useful insights on the nature of the care that these two sectors provide. It may also highlight the similarities and differences between the two types of care as family members of those who die in a hospice setting are more likely to report

that their family members were treated with respect than those who die within a care home setting (Teno, Clarridge et al. 2004).

## 1.2 The key concepts explored in this thesis

### 1.2.1 Social capital

Social capital is a concept that was developed by early sociologists (Bourdieu 1986, Coleman 1988, Putnam 1995) as a way to explain the value of social interactions, what these interactions can achieve and why these interactions are important in modern society. It also helps explain the social structures and networks that people form and what benefits people can draw from these networks. It is often seen as a resource that people can draw upon to help facilitate mutually beneficial goals (Coleman 1988, Putnam 1995). The early pioneers (Bourdieu 1986, Coleman 1988, Putnam 1995) of the concept all propose their own definitions and views about what social capital is and what it involves. Putnam sees social capital at the societal level in which social capital may benefit communities to function more efficiently through the use of societal norms, trust and networks, whereas Coleman conceives of social capital more at the individual level in which members of a group can aid each other to achieve goals through social networks and reciprocity. There are many types and levels of social capital which are discussed in the literature review in chapter two. Field (2008) summarises the concept of social capital by highlighting the importance of social relationships and many of the early pioneers of social capital (Coleman 1988, Putnam 1995) agree that social capital is a resource that is generated through social relationships that can help facilitate action for the benefit of the individual or collective. Social capital plays a part in society and in the lives of older people, and may provide insights into our understanding of life within the care home and hospice care sectors, but has not been extensively investigated. Social capital is argued to be more important for the health of older people than younger people (Muckenhuber, Strongegger et al. 2012) so it seems an important concept to investigate within care settings for older people.

### 1.2.2 Atmosphere (social climate)

The atmosphere of a care setting, which has been operationalized in this study and described by others (Moos, Gauvain et al. 1979) as social climate, can be viewed as the personality of an environment that gives unity and coherence to the care setting (Lemke and Moos 1987). The atmosphere of the care setting can give either positive (such as

cleanliness and homeliness) or negative (such as unclean and chaotic) impressions. There is evidence to suggest that measures of the quality of the atmosphere and social support can help predict psychosomatic complaints and feelings of depression after a negative life change event (Holahan and Moos 1982) highlighting the benefit of positive atmosphere. It has been recognised that levels of depression and social support and interaction are important factors to consider in care home populations (Lee, Woo et al. 2002, Sackley, Hoppitt et al. 2006, McDougall, Matthews et al. 2007). These factors are also relevant to the atmosphere of a care setting, yet few studies in the UK have examined this concept in care homes for older people and hospices.

### 1.3 The need for the proposed study

Transition into a care setting can be a traumatic time for older adults and their relatives and life inside a care setting can be drastically different from what individuals have previously been used to. Social capital has also been shown to be more important for older people than for younger people (Muckenhuber, Stronegger et al. 2012). A consistent theme throughout the literature, as discussed in the next chapter, is that network size and social interactions, as seen in the concept of social capital appear to be important for life in both care homes and hospices. Some studies have examined interactions and networks in care homes but not from a social capital perspective. Only one study was found that has examined social capital in care homes (Andrew 2005) but this study only used a single self-report question asking about trust, which is only one component of social capital. Many of the concepts of social capital appear to benefit the atmosphere of a care setting. There is however, a lack of research around these two concepts that makes it difficult to draw conclusions about the nature of the relationship between social capital and the atmosphere of a care setting that may benefit older people.

The purpose of this study is to help address this gap in the research and to use the concept of social capital as a theoretical framework on which to base this study. The investigation will examine the interactions that residents in the two different care sectors (care home and hospice) have with other individuals in the care setting. It will also examine the role that volunteers and visitors play, and examine how these relate to the atmosphere of the care setting.

## 1.4 Research Aim and Questions

The aim of the study was to gain a better understanding of the social capital and atmosphere within the different care settings of care home and hospice. This allows for the examination of any similarities and differences, and the potential ‘blurring of lines’ between the two care sectors from a social perspective as opposed to a medical perspective based on the types of physical care that the care settings provide. The study sought to answer the following questions:

1. What is the relationship between the social capital of older residents/patients and the atmosphere of the setting in which they are cared?
2. Are the quality and quantity of interactions between staff and those being cared for different between the two care sectors?
3. What is the role that visitors and volunteers play in the life of those being cared for within the two care sectors?

## 1.5 Thesis structure

The thesis consists of six chapters. The literature review, chapter two, provides a more detailed exploration and discussion of the available literature in the areas of care homes and hospices, and the concepts of social capital and atmosphere before providing the rationale and the need for the proposed study, and what the study set out to achieve.

The methods are described in chapter three providing an overview of the study design, methodology and procedures that were followed throughout the data collection process. The methods chapter also describes the sampling and participants, methods of analysis and a discussion of issues that arose prior to and during the data collection process and how these issues were overcome.

Chapter four presents the qualitative and quantitative observational findings. It reports what was found during phase one in relation to the observational and survey methods used, while the qualitative observations presented help to place some of the quantitative findings into context.

Chapter five, the interview findings chapter reports the qualitative findings of phase two, the interview component of the study, providing an account of the key themes to emerge from the data.

The final chapter, chapter six, provides an overview of the study, the key findings in relation to the research questions and the wider literature, and discusses the research in terms of its strengths, weaknesses, implications for policy and practice and further research within the care sectors.

# Chapter 2: Literature Review

## 2.0 Introduction

This chapter presents and reviews the existing literature in relation to four key areas: the settings of care home and hospice and the concepts of social capital and 'atmosphere'.

Key literature around the concepts of social capital, 'atmosphere', care homes, and hospices were identified to produce a focused and critical review of the literature. The EBSCOhost online reference system was searched allowing papers to be reviewed from a number of databases: AMED – The Allied and Complementary Medicine Database; CINAHL complete; MEDLINE complete; PsycARTICLES; and PsycINFO. Key search terms for the care sectors included nursing; residential; care home; hospice; older people; and palliative care while search terms for the theoretical concepts included social capital; atmosphere; and social climate. The search terms were first used in conjunction to specifically look for papers involving all the concepts in both the care sectors. When this yielded no results, the search terms were used in different combinations to find papers that were relevant to the theoretical concepts within the care home and hospice settings. Discussions with the subject specialist librarian helped to refine the search terms and combine them to obtain the most relevant literature. No date restrictions were placed on the search, this enabled me to observe the evolution and development of the literature. Literature was examined in relation to care homes and hospices to gain an understanding of the social life and resources that are available within these care sectors. Once key papers were found, their reference lists were reviewed for potential papers to include in the review. As well as reviewing reference lists, articles that cited a key paper were also reviewed. For example articles that cited key papers about social capital were reviewed in order to see how the concept had developed over time and who used a particular definition of social capital. Papers were also obtained through informal discussions with colleagues about topics that were relevant to the literature review such as social networks, but not directly about the concepts of social capital or atmosphere themselves.

The first section provides a brief account of the two care sectors, care homes and hospices, in the UK that were examined in this study. The review then discusses in more detail the transition into the care sectors and the health and wellbeing of people who are cared for

within the two care sectors. The chapter then discuss loneliness and other social factors, followed by the sense of 'community' within the care sectors. The chapter then reviews the concepts of social capital, and 'atmosphere' in more detail than was previously covered in the introduction chapter. The chapter concludes with a discussion explaining why these two particular care sectors were selected for this research study, alongside the rationale for the study.

## 2.1 The Care Home Sector

Care homes aim to meet the care needs of people who are unable to live independently because of mental health, learning or physical disabilities. The focus of the present study was older people's care homes in the form of nursing and residential care homes. Care homes in the 1950s were categorised under the National Assistance Act of 1948 according to the type of funding and the nature of home ownership (Townsend 1964). The four main types of care home were: (1) former public assistance institutions retained by local authorities; (2) small homes run by local authorities; (3) homes run by voluntary bodies; and (4) homes run by private individuals for financial reward. Townsend noted that care homes in the past have given impressions of being "grim and sombre" with large numbers of residents sleeping in dormitories, however some residents still maintained simple jobs and received a small wage. Photos taken of these homes at the time suggest the main changes to the layout and design in care homes between the 1950s and the present day are that care homes no longer have dormitories as they once did. Instead, care homes now often have individual or shared rooms if needed. Care homes are provided by a range of provider types but their classification is now based on the nature of the health needs of the residents. Care homes are now classified as either providing residential or nursing care. Residential homes provide support with activities of daily living and personal care, whereas nursing homes additionally provide qualified nursing staff and are able to attend to the medical needs of the residents. Today, there are less local authority homes, with most care homes being privately owned for profit (Care Home Selection 2017).

Care homes today are a place where residents can live their remaining years receiving the support they require. Some care homes also provide a day care service providing either day care or respite services to residents and their family or carers. In 2011, there were 103,000 people aged over 85 years living in care homes not requiring nursing care and 69,000 people in care homes with nursing care needs (Office for National Statistics 2013). The market for the independent sector healthcare was estimated to be £13.4 billion for older

people's residential care (Age-UK 2013) and this is likely to increase with an ageing population.

Over recent years in the UK there has been a trend for the privatisation and marketisation of the residential and nursing home care sector that is likely to continue (Scourfield 2007). Scourfield (2007) argues that this trend could result in lower levels of consumer choice and user involvement, which in turn will mean ownership and provision of residential and nursing care homes to be largely determined by economic factors. In relation to the trend of home ownership, it has been shown in the United States that expenditure on care homes related to resident care activities and staff development are significantly higher in not-for-profit care homes than for-profit care homes (Kash, Castle et al. 2007). This could suggest that economies in not-for-profit care homes are being better utilised for resident benefit than in for-profit care homes as excess money is being channelled back into the care setting. This not-for-profit ownership of a care setting is rare in the care home sector, but common within the hospice care sector whose foundations begin in charity.

There is evidence to suggest that socio-economic factors can determine who will be admitted into long term care, with those in the lowest income quintile in Finland having higher odds of being admitted into a care home (Nihtilä and Martikainen 2007). As care homes are becoming more commonly owned by private, for profit organisations, and there is evidence that it is likely the poorest who will attend long term care facilities, more cost effective models of operating are needed to ensure a high level of care is maintained.

Research (Lievesley, Crosby et al. 2011) using data from the United Kingdom's largest private health care provider, BUPA, has demonstrated the diversity of health conditions that residents in residential and nursing care homes have. Health conditions included dementia, depression and multiple chronic physical health conditions such as cardiovascular disease, stroke and diabetes, highlighting both mental and physical health problems occur within the care home sector. To help manage the needs of older people in the community, as well as family members and carers of older people, some care homes provide day care services or respite services for residents and their family or carers. This enables residents to spend either a day or short period of time in the care home. This provides the family member or carer a short respite period.

## 2.2 Hospice care sector

Hospices provide care for people who have been diagnosed as terminally ill and aim to meet the medical, emotional, social, practical, psychological, and spiritual needs of patients, as well as the needs of the family and carers (NHS 2012). Hospice care provides palliative care, including symptom control such as pain management, enabling patients to die with as much dignity as possible. In 2012, 19,401 deaths that occurred in hospices in the UK were people aged 65 or over, which accounted for approximately 30% of all hospice deaths in 2012 (Office for National Statistics 2012). Volunteers to help with social activities in particular are common within the hospice sector and evidence has illustrated the importance of including volunteers when discussing the future of hospice and palliative care in the UK (Addington-Hall and Karlsen 2005).

Traditionally and historically the care of the dying was informed by religious concerns, but over time it moved toward a medical domain although religion still has a strong presence within the hospice movement (Lewis 2007). The hospice movement in the UK originated from Dame Cicely Saunders who through her work as a doctor, identified a need for a place specifically to provide end of life care (Wigan & Leigh Hospice 2011). Over time the hospice movement has developed into a movement that aims to provide care and support medically, psychologically, emotionally and spiritually to patients with incurable illnesses as well as their families. Hospices tended to provide dedicated places for patients to go and spend the last days of their life and provide services to support the patient through that time. However, this is no longer the main focus of hospices. Hospices provide a variety of services but are no longer restricted to inpatient services. Hospice services can often include hospice at home, where hospice care is provided at home to enable people to die with dignity, pain free and in comfort within their own home. Most hospices also provide day centre care where patients attend a day once a week for any help they may need regarding their illness (e.g. symptom control) and to participate in social activities. This allows family carers time to rest while the needs of the patient are being met, similar to the day services provided by some care homes. In addition to day services, hospices also provide home care services where health professionals and volunteers deliver care in a patient's home. Inpatient beds are considered to be reserved for patients that are at the very end of their life while day centre services are becoming increasingly common with social activities in the hospice still being a primary service that is provided in conjunction with the medical services (Higginson, Hearn et al. 2000). In the UK, patients in a day centre setting are also more likely to remain in the services for longer periods of time, with the

average length of stay in hospice day care estimated to be 4.5 years with a range of 1 to 12 years (Higginson, Hearn et al. 2000).

In the USA, inpatient services often provide care within the last six months of life (National Hospice and Palliative Care Organization [NHPCO] (2007) (cited in Waldrop and Rinfrette (2009)) while other sources (NHPCO 2015) report that this duration has shortened, as in 2014, 35.5% of patients either die or are discharged within 7 days of admission to the hospice. This reflects the difference between inpatient care and day centre care. In the USA, hospice care extends into nursing and residential care homes with 58.9% of patients receiving care where they reside and 31.8% receiving care at a hospice inpatient facility in 2014 (NHPCO 2015). Traditionally, hospice patients primarily have a diagnosis of cancer. However, increasingly over the last few decades hospices accept patients with a variety of long term 'life limiting illnesses.

## 2.3 Care transitions

The decision to enter a residential or nursing care home and the transition into the care setting is an important, and often stressful life event for older people and their families (Ellis 2010). There have been attempts to understand the impact that this transition has had on older people's lives (Lee, Woo et al. 2002, Ellis 2010). Transition into residential care within the previous twelve months of a resident's life has been shown to be associated with a high mortality risk (Robards, Evandrou et al. 2014). Within the same study, residents living in residential housing for more than a year show a similar probability of dying to those living in sheltered housing. However, risk or mortality is the lowest for older people who remain in their own homes (Robards, Evandrou et al. 2014). A more positive transition into a care setting is typically associated with stronger social interactions, and stronger social networks that the residents have with family members, and professional networks that the residents have with health professionals and care providers. Networks in this thesis is defined as the individuals or groups of people that a person has access to, and interacts with either socially or professionally. Social interactions in this thesis are understood by using the definition of positive social interaction that are interactions involving good, constructive, friendly interactions and conversations (Dean, Proudfoot et al. 1993). These interactions are considered to be voluntary between individuals or groups of individuals that do not just serve a purpose or role related some aspect of their work role. A published review found that interactions with the residents, family members and health

professional's prior to care home placement, and throughout the transition process, helped the residents make informed decisions about moving into a care home (Lee, Woo et al. 2002). The social networks with family and friends that the residents already possessed prior to entering the care home also has a significant influence on their transition into care, as information gained through the social networks can give a positive or negative impression of the care home setting. Nurses and relatives can have a significant impact on how the transition is experienced by the resident, in that nurses are able to confirm or invalidate the views and opinions about a care setting that a person may have upon entering the care home (Ellis 2010). The authors of this study also recommended that nurses may benefit from improved communication strategies to help support the resident with their transition to care home life. Ellis suggested this may improve the experiences of the resident by improved interactions, and by helping the resident feel more comfortable and supported in their new environment. Studies with relatives of residents found that positive interactions between relatives of residents and staff members can lead to the relatives having a better experience and feelings of being included and secure when a family member goes into care (Davies and Nolan 2004). However, negative interactions where family members are not included in the care of the resident can worsen relatives' experiences making them feel 'left out' of their family member's care, resulting in feelings of isolation as reported in Davies and Nolan (2004).

Increased social networks for the residents upon entry into a care home have also been associated with faster adjustment to care home life, making it easier for the resident to adjust. One study compared planned and unplanned entries into care homes and found that residents who had planned entries into care homes adjusted to the new life faster, but both groups adjusted faster if their social network size increased early on after entry into the care home (Wilson 1997). This work is supported by a more recent study conducted in Hong Kong that found that residents who did not develop close networks and relationships with staff upon entry to a residential care home felt they received less support from staff than those residents who did develop close relationships and networks with staff members (Cheng 2009). The feeling of increased support was also the case for those residents who reported higher numbers of social network members in the care home. This study however was conducted in a different cultural setting to that present within the UK care home sector so caution is needed when generalising the findings to western cultures. These findings highlight the importance of interaction and networking within the care setting, and particularly social interaction. This was supported in the review by Lee, Woo et al. (2002)

who concluded that improved networks both inside and outside the care home had a significant impact on psychological wellbeing. Entry into the care home was often associated with loss of privacy and control over activities of daily living which lead to feelings of a devalued self (Lee, Woo et al. 2002). Conversely, improved social networks were seen as a way to improve these feelings of a devalued self through meaningful social interaction.

While medical and health research within the hospice sector is abundant, social research in relation to hospices is lacking when compared to research in a care home sector. Transition into a hospice setting tended to focus more on the process and experience of developing a terminal illness than the entry into hospice care itself. Research that has examined the transition into a hospice setting focused on the nurses rather than the patients (Rosser and King 2003). Rosser and King (2003) concluded that nurses needed increased support to help ease their own transition into a hospice setting in response to their own learning needs and expectations of what the setting would be like. Surprisingly little research has examined the experience from a patient's perspective.

Research involving family caregivers' experiences of transitioning to a hospice setting found that their acceptance of the impending death, challenges in negotiating the health care system across the continuum of care, and changing patient-family dynamics were consistent themes to emerge (Schulman-Green, McCorkle et al. 2004). There has been little work on the role of volunteers and staff members roles in the transition period when entering hospice care, yet as when entering a care home, effective communication has been found to be important in the transition process (Waldrop and Rinfrette 2009)

## 2.4 Health, wellbeing and quality of life in care settings

Residents within a care home have complex health needs, yet few data are available on the health needs of residents in the UK, with data often coming from proxy respondents such as care home staff or a residents relative (Moore and Hanratty 2013). The prevalence of dementia in care homes has been estimated to be as high as 62% (Matthews and Dening 2002). Other research (Bowman, Whistler et al. 2004) determining the prevalence of dementia in care homes estimated more than 50% of residents had dementia, history of stroke or other neurological illness. This study also found that the care needs of the

residents were driven by progressive chronic illness with psychological needs often being neglected, with potential to impact on the resident's wellbeing.

One of the main health problems faced by older people in any care setting is reduced mobility, and perceived loss of dignity through the use of mobility aids such as harnesses (Taylor, Sims et al. 2014). Coming to terms with having reduced mobility can have a significant impact on the resident's life not just physically, but also psychologically (Taylor, Sims et al. 2014). Acceptance of mobility loss and staff assistance; motivation to remain mobile; and acquiescence and loss of control during mobility events can contribute to the quality of life of the resident as reported by Taylor, Sims et al. (2014)

Although much of the focus in care homes is directed towards attending to the physical health needs of the residents, it is their psychosocial needs that are most often associated with quality of life (Hall, Opio et al. 2011). When the prevalence of depression in a care home population was compared to older people living in their own home, 27.1% of residents in care homes had depression in comparison to 9.3% of those who were living independently. The study also found that care home residents displayed more symptoms of depression such as having a depressed mood, crying, wishing to be dead, and having a bleak looking future (McDougall, Matthews et al. 2007). Other research has looked at the number of care staff that could recognise depression in residents and found that the recognition rate was low (Bagley, Cordingley et al. 2000). The rate of recognition was only 15-27% in those residents who had a formal diagnosis of depression, with no difference in recognition being seen between nursing staff and care assistants. If the needs of residents cannot be recognised by staff, then they cannot be met. In another study examining the met and unmet needs of care home residents, the physical needs of residents were often met, but their mental health, social interaction, daytime activities and companionship needs were often unmet and were linked with psychological problems such as depression and reduced wellbeing (Hancock, Woods et al. 2006). It is possible that improved meaningful interaction through improved communication about residents' needs between staff and residents might help reduce these unmet needs and improve the wellbeing of the residents.

Many other factors have been associated with the quality of life of care home residents such as building design and layout (Parker, Barnes et al. 2004), however it has been shown that leisure activities, connections with family, meaningful relationships, a social life and independence were all important indicators of a resident's quality of life (Hall, Opio et al.

2011). These social factors were identified as important aspects of quality of life, more so than health. Psychosocial needs may be more often associated with quality of life in care home residents because the physical health needs of the resident may be better managed than other psychosocial needs. It could also be that residents may change their standards and values associated with quality of life as a result of having a chronic illness and disability (Schwartz and Sprangers 2000). Other research has shown that involvement in activities and meaningful interactions with others within social networks promotes positive feelings in older adults (Clark and Bowling 1990, Bowling 1991). This in turn can have direct effects on the wellbeing of older adults in a care setting. More recent research has shown that there has been a shift in addressing the care needs of care home residents with more attention given to the psychosocial needs of residents, more support from staff and more activities taking place to try and combat low levels of quality of life (Drageset 2004, Drageset, Kirkevold et al. 2011). However, research has suggested that the social needs of residents are still often not met to a high enough standard (Sackley, Hoppitt et al. 2006).

In contrast to care home residents, hospice patients are most likely to have a diagnosis of a life limiting illness such as cancer. Some reports in the USA indicate that cancer is no longer the main presenting illness in the hospice sector with only 36.6% of patients having a cancer diagnosis, and 63.4% having a non-cancer diagnosis including but not limited to illnesses such as dementia, heart disease, lung disease, and motor neurone disease (NHPCO 2015).

The purpose of a hospice is to provide for the health and social needs of the patient as best as possible and to provide pain management and other forms of symptom management such as breathlessness to improve quality of life. Addington-Hall and O'Callaghan (2009) used the Views of Informal Carers – Evaluation of Services (VOICES) questionnaire to compare hospice inpatient care with hospital care from the view point of the relatives and found that there was no difference in experience of pain and breathlessness of the patient between the two care settings. However, from the perspective of bereaved relatives, hospice inpatient care provided better pain control, better communication with patients and their families, and medical, nursing and personal care provided treated the patient with more dignity (Addington-Hall and O'Callaghan 2009).

Other research has shown that palliative and hospice care improves patient centred outcomes for symptoms such as pain and depression, as well as patient and family satisfaction (Meier 2011). When compared with usual care, palliative care prolonged life

and helped patients receive the care needed to avoid unnecessary emergency department visits and hospital stays by increasing the care provided at home and in the community (Meier 2011). The author of this study concluded that an enhanced palliative care work force working in different care sectors such as care homes, could increase the reach of optimal care for seriously ill patients and enhance the quality of care provided in these care sectors (Meier 2011, Meier 2015). It is not clear whether the enhanced medical care in other care settings can improve quality of life, or whether it is better utilisation of social and professional networks to access these services, as well as providing other benefits such as more social interaction, that can enhance the quality of life experienced by the patients.

The quality of life that is experienced by individuals receiving hospice care has been shown to be above average in research conducted in the USA (Tang, Aaronson et al. 2004). Tang, Aaronson et al. (2004) found that it was social support (defined as the perception that one receives care and support from others), perceived higher spirituality and better pain management that predicted the best quality of life for day patients in a hospice setting. Some evidence suggests that quality of life improved upon entry into hospice care (Cohen, Boston et al. 2001). The participants of this particular study showed improvements in physical, emotional and interpersonal status (meaning social wellbeing and feeling closer to others), as well as an improved spiritual outlook and better preparation for the end of life.

Cohen, Boston et al. (2001) also found that the setting itself had an impact on the quality of life of the patients with a lack of privacy and too much noise being mentioned by patients as negative aspects of a hospice, but the tranquillity and 'liveliness' of the hospice was seen to enhance their quality of life. The study reported that a patient's quality of life goes beyond symptom control, and suggested that it may be the quality of care, the palliative care setting itself and the social atmosphere that contributes significantly to the quality of life.

## 2.5 Loneliness and social factors within a care setting

### 2.5.1 Loneliness

Older people in general have increased feelings of loneliness as they age (Victor and Bowling 2012). In a study of 999 individuals aged over 65 years, 39% of participants reported some level of loneliness and this increased with changes to living arrangements, social networks and physical health. These challenges are also apparent during the transition to a care home setting indicating that the process of entering a care home may

increase loneliness levels. One study (Dykstra, Van Tilburg et al. 2005) however did not find increased loneliness in a care setting and found entry into residential care did not affect feelings of loneliness. Rather the study found that social network expansion was associated with lower levels of loneliness showing that maintaining a social network is important for residents' wellbeing. Loneliness is defined by Dykstra, Van Tilburg et al. (2005) as a negative experience that occurs when an individual's social networks and relationships are deficient in some way.

Loneliness has been identified in residents in a care setting with one study reporting 56% of residents experiencing loneliness (Drageset, Kirkevold et al. 2011). A number of factors were associated with loneliness including the level of available social support, emotional closeness to a significant other, the ability to perform activities of daily living, meaningful interactions and social network size (Drageset 2004, Drageset, Kirkevold et al. 2011). It was also noted that loneliness was linked with levels of wellbeing in residents of care homes and by improving the factors associated with loneliness, resident wellbeing may also be improved (Drageset 2004).

Social networks have been linked to quicker adjustment to care home life (Wilson 1997). Tools and analytical techniques such as social network analysis have been used in studies examining the social networks of people receiving care. Studies have found that when patients are terminally ill and receiving home care, social networks have the potential to increase in size. Patients also had stronger ties with social network members they had originally prior to entry to the care setting which shows the potential for end of life care to increase social capital (Leonard, Horsfall et al. 2013). Analytical techniques such as social network analysis have been used in long term care facilities for older people to gain insight into the size and structure of the networks. This technique was found to provide a measure of the social integration of adults in the care facility (Abbott, Bettger et al. 2012). Social integration when moving into care could have a significant impact on the levels of isolation and loneliness experienced by the residents. Social network analysis has also been used in dementia specialist units to distinguish between socially integrated and socially isolated residents (Abbott, Bettger et al. 2013). This has the potential to identify interventions to help those who are socially isolated and reduce loneliness levels in care. Potential increases in social networks through end of life care by a multi-disciplinary team and access to volunteers (Leonard, Horsfall et al. 2013), are becoming increasingly more common in care homes and could help lower levels of isolation and loneliness among residents in care.

Loneliness can be a significant problem for people who are dying. One study found that dying patients managed feelings of loneliness differently from the general population, showing that the general population scored highly on social support networks and increased activity whereas those who were dying had coping strategies that were focused on religion and faith, with less focus on social support networks (Rokach, Matalon et al. 2007). This could be due to a lack of availability of social support networks and ability to access these. A hospice setting could improve these coping strategies by providing increased social support networks while still providing access to religious or faith services although there is evidence to suggest that people in hospice care, as well as their carers, feel increased levels of loneliness and isolation compared with the general population (Bercovitch 2007).

Evidence has shown that although loneliness is present within a hospice sector, loneliness is experienced differently by those dying, their caregivers, and the general population (Rokach, Matalon et al. 2007). Patients appear to be less lonely in a hospice than in other settings such as an oncology unit (Rasmussen 1998). Patients in the hospice setting had more social interactions with relatives and nurses. It was noted however that the interactions were 'doing' rather than 'being', i.e. nurses had a task to accomplish as opposed to interacting socially, suggesting a model of care focused more towards the physical care needs of the patient than patients' psychosocial needs. This task focused care may have declined in recent years however due to the rise of person centred ways of working. The shift to more person centred ways of working in all types of care is seen as providing the best quality care (Department of Health 2015). People with dementia, their families, and care staff see person centred care as promoting the continuation of self and normality; knowing the person; providing meaningful activities; and being in personalised environments (Edvardsson, Fetherstonhaugh et al. 2010). Person centred interventions are now in abundance yet many are not evidence based (Fossey, Masson et al. 2014) and person centred care is not yet imbedded in the organisational culture of short stay and respite care providers (Kirkley, Bamford et al. 2011). Although there is evidence to suggest that person centred care is still lacking in some environments, there is evidence demonstrating the value of person centred care as it can reduce agitation in people with dementia (Chenoweth, King et al. 2009) and is valued by people with dementia and their families, and care staff (Edvardsson, Fetherstonhaugh et al. 2010). Some research (Rigby, Milligan et al. 2014) has examined the effects of the building design and environment within an inpatient hospice setting and found that older people tended to remain within

the privacy of their rooms; yet when the patients did make use of the communal areas it was often the garden as it provided feelings of being close to nature. The authors also found that during the day, bedroom doors remained open. Patients with the greatest need were moved closer to the nurses' station at one end of the corridor. At the other end of the corridor there was an increased feeling of loneliness as the staff visited these rooms less often. Rigby, Milligan et al. (2014) conclude from their study that there must be a balance between the need for supervision and independence, and that staff working practices should ensure the environment is person centred in order to improve the social wellbeing of older patients.

What can occur in a hospice care setting, but is comparatively rare in a care home setting, is that patients can be discharged from the hospice despite a hospice being historically viewed as a place to go to at the end of life. Research has found that many of the issues that patients faced when transitioning into hospice such as loneliness, uncertainty, anger and frustration were also felt when patients were discharged from the hospice (Watson Campbell 2015). Transitioning into, but also out of the hospice setting, can cause distress to patients reducing their wellbeing. It has been reported that religious services play a key role through which patients with cancer at the end of life cope with loneliness, anger and symptom distress (Scott, Law et al. 2014).

### 2.5.2 Social factors

Social factors such as social networks, social interaction, social support, and the social lives of older people play an important part of life in a care setting. Loneliness has been linked with certain social factors such as social support, interactions and networks. These results have been supported in research that has shown the importance of family connectedness, friendships and minimal social isolation as important for resident wellbeing, and that residents often took part in activities as a means of participating in social interaction (Thomas, O'Connell et al. 2013). Despite this, some research has shown that on the basis of observations in a care home there are low levels of activities and interaction (Sackley, Hoppitt et al. 2006). Sackley, Hoppitt et al. (2006) found that during 60.7% of the time, residents are sitting and not engaging in activity, with only 10.5% of the time spent in conversation with other residents or staff. Inactivity within some care homes may lead to an increased risk of depression and decreased resident wellbeing.

Activities from the care providers' perspective are often valued and care staff often encourage residents to take part in them. However, it has been found that encouraging

residents to take part in activities not centred around their individual interests leads to feelings of isolation as if they were 'not at home' (Knight and Mellor 2007). A lack of social support (perception that one receives care and support from others) was associated with twice the odds of care home placement and increased psychiatric morbidity, as well as reduced self-rated health (Andrew 2005). Whereas increased trust was associated with better self-assessed health and lower psychiatric morbidity in care home residents.

Social interaction is an important aspect of life for older people. Both in and outside a care setting, social network size and closeness to others has been shown to be important to combat loneliness, (Drageset 2004, Drageset, Kirkevold et al. 2011) and meaningful interactions are an important way to maintain these networks. As noted above, research has found that social interaction is sparse in a care home setting (Sackley, Hoppitt et al. 2006). Although some research (Knight, Haslam et al. 2010) has recognised interaction is lacking, it can be increased by improving the collective decision making of the residents who reside in the care facilities. Other research examining conversation and communication styles and strategies in care homes has shown there is limited meaningful interaction in these settings, particularly with residents with dementia as those interactions tended to be based on an 'interview style' with staff leading and directing the communication (Baker, Angus et al. 2015). Other research has found that types of communication in care homes tends to focus around 'personal conversation'; 'addressing the resident'; 'checking in' (such as asking how a resident is feeling today) and 'emotional support and praise'. This has highlighted the need for affective verbal communication to develop in both scope and depth to optimise resident wellbeing (Carpac-Claver and Levy-Storms 2007).

It has been shown that effective communication through including care home residents in decision making, for example with respect to the décor of the setting, empowers residents (Knight, Haslam et al. 2010). This has resulted in a number of benefits such as: enhanced resident identification with staff members and other residents (meaning that the resident identifies more closely with other residents and staff members); enhanced resident citizenship (meaning the residents felt more helpful to other residents and staff); led to higher levels of self-reported wellbeing; and has increased the use of communal areas for that resident. It also resulted in increased engagement with the setting and others around them, improving the wellbeing of the residents (Knight, Haslam et al. 2010). Care home residents with dementia often invested much effort in seeking engagement with those

around them (Ward, Vass et al. 2008). Despite this residents with dementia are often excluded from monitoring, planning and provision of care.

In comparison with care homes, social factors such as social networks, social interaction, social support, and the social lives of older people also play a significant role within the hospice sector. Volunteers are a major part of the hospice culture in terms of fundraising and social activities (Addington-Hall and Karlsen 2005). Addington-Hall and Karlsen (2005) found that 39% of staff felt like they received a great deal of support from volunteers, 54% adequate support, while 7% perceived they needed more support from volunteers. In this study volunteers had similar responses to hospice nurses and doctors indicating that they were as knowledgeable about the setting as other staff in the hospice and played an important role. Only 9% of volunteers felt they had clearly defined roles within the hospice despite being such a key part of the hospice culture. Volunteers played a crucial role in the social life and interactions of the care setting while at the same time having a similar level of knowledge and presence in the setting as the paid health professionals (Addington-Hall and Karlsen 2005). Yet volunteers had much more blurred boundaries and roles than other staff members (Addington-Hall and Karlsen 2005) as volunteers could take on a variety of roles from serving food, engaging socially with patients and cleaning the hospice, whereas staff members are limited to their main job.

Social interactions are key in any environment and play a crucial role in how society functions. Social interactions are especially key in end of life care, particularly between patients, carers and health care professionals (Briggs 2010). Briggs (2010) found that although there are signs of good practice among end of life care agencies and professionals, greater care is needed by professionals to ensure positive interactions in their day-to-day interactions with patients and carers. This will help to ensure a better quality of end of life care.

It has been argued that interventions aimed at achieving social objectives such as enhanced emotional and spiritual care or services for family and carers are needed to ensure good quality palliative care services (Payne 2006). Hospice care, particularly hospice day care units are an example of a place where social objectives are often identified. Social objectives, including reduced social isolation and increased social interaction are often key aspects of day care hospices and allow patients to rehearse personal reactions to their illness in a protective and sympathetic environment with others sharing similar experiences (Payne 2006). Terminal illness is associated with loss of quality of life, reduced social

interaction, low mood, changed family dynamics and physical limitations, yet admission to a day care centre has been found to bring benefits of improved mood, enjoyment and a sense of community and mutual support (Kennett and Payne 2005). This suggests that attending a day centre hospice can improve quality of life.

Caring for a person who is at the end of their life can be an isolating and stressful experience. Increased social support and having a belief or faith in a religion are significant predictors of family caregiver's higher levels of quality of life (Leow, Chan et al. 2014). This suggests that hospice care, particularly day hospice, may improve quality of life not only through treatment and management of life limiting illnesses, but also through the social support and improved social networks for patients and their families (Kennett and Payne 2005). When day hospices use a community participation and development approach, the social network size of patients with terminal illnesses living at home and their family carers increases (Leonard, Horsfall et al. 2013) This study found that the strength of the ties between the original members of a social network also increases as shown through social network analysis. The authors concluded that the study is evidence that caring for an individual does not have to be isolating. The presence of community development with people caring for someone at the end of their life can help reduce feelings of isolation.

There is evidence that the main reason for referrals to a day hospice is for social reasons, and not medical issues, with the most common reason for referral being social interaction, respite for the carer and psychological support (Higginson, Hearn et al. 2000). This is supported in work by Kernohan, Hasson et al. (2006) who found in their study that there were multiple reasons for a patient to be referred to a day hospice, with 61% of participants were referred to day hospice primarily for emotional or spiritual support. 42% were also referred for respite for their carer or to meet other patients in a similar situation as a secondary reason for referral. These studies do not however report who made the referrals, whether it was a referral made by the patient themselves or a family member, or a medical professional. These studies showed that social support and interaction were a main concern for patients and that the hospice was able to help in managing these concerns, particularly through the use of social activities. Kernohan, Hasson et al. (2006) found that the most valued activities in the day hospice were a welcome with a hot drink on arrival; time to have a conversation with other patients and people in the hospice setting; activities such as arts and crafts, activities to keep fit, and social outings. Other research in a day hospice centre found that the creative arts gave participants feelings of enjoyment, excitement, achievement, mutual support and a sense of purpose which were

interpreted by the author as positive expressions of social integration, self-esteem and a sense of hope (Kennett 2000). It was also noted by Kernohan, Hasson et al. (2006) that although many participants indicated that they might not actively join in with the activities, they did enjoy listening to others' comments and stories. This shows that the opportunities for social interaction and engagement are not restricted only to taking part in the activities, but also by the presence of activities in the hospice.

## 2.6 Care setting community

Care homes often try to produce strong community ties both inside the care home and outside with ties in the local community (Hämel 2016). Research has shown however, that some care homes deliberately maintain small communities and try to provide a 'sheltered zone' for residents to engage with the wider community in a safer way (Hämel 2016). In the same study, Hämel (2016) found care homes often had difficulty in 'opening their doors' to new concepts of care to enhance the care they provided, while others strived for integration with the community. The environment has a significant effect on the sense of community (McAllister and Silverman 1999). Therapeutic activities that promote resident independence, person centred staff roles, and a physical setting that facilitates social interaction enables the formation of a sense of community. In contrast, regimented programmes, a medical rather than a social model of care, and a physical setting that discourages social interaction and bonding can inhibit the formation of a community feeling (McAllister and Silverman 1999).

The co-operation of relatives and volunteers with staff within the care setting is important for a feeling of community (Hämel 2016). The family and visitors of residents in care are considered an important aspect of care home life (Russell and Foreman 2002) and a sense of community relies on the inclusion of family members. Caregivers can help generate a sense of community and it has been positively linked with family adjustment and satisfaction with care of the family member (Petrovic-Poljak and Konnert 2013). Staff conflict was negatively associated with a sense of community as measured through semi-structured interviews and self-report questionnaires (Petrovic-Poljak and Konnert 2013). However, there has been some attempt at asking visitors about the residents satisfaction of a nursing home as a proxy measure for resident self-reported satisfaction, but some argue that this is unreliable (Gasquet, Dehé et al. 2003).

Visitors in a care home often play a significant role in the care setting and visitor presence during meal times is associated with increased length of time that staff spend feeding

residents and increased resident contact with staff (Durkin, Shotwell et al. 2014). Families are often keen to maintain relationships with family members who have gone into care despite feelings of abandonment felt by some older people who have gone into a care home (Russell and Foreman 2002). Families often seek to establish closer co-operation with staff regarding the care of the resident and value increased involvement in the progress and care of the resident (Russell and Foreman 2002). The relationships between staff and visitors are important for achieving a sense of community but the relationships can also be dependent on the relationship the staff have with the resident, as staff who report better quality relationships with residents also have a more positive perception of family members who visit the care setting (Petrovic-Poljak and Konnert 2013).

In spite of volunteers often playing a key role, particularly in hospices they are comparatively rare in care homes. Volunteers can help create a sense of community as a way of increasing social networks and improving relationships with other individuals who work and are cared for in the care setting, yet their role can often remain ambiguous. The blurred boundaries of their contribution to care and unspecified roles can create tensions between professionals, families and other volunteers. As a result, these tensions may hinder rather than promote the feeling of community formation (Sévigny, Dumont et al. 2009). Volunteers have been shown to have difficulty in determining their place and role in a palliative home care environment. This difficulty may produce obstacles in implementing an interdisciplinary team in home care. This can produce tensions within a care home setting with different groups of individuals working in the same environment (Sévigny, Dumont et al. 2009).

The sense of community within a care setting may be dependent on the organisational culture of that particular care setting. Organisational culture is a contested concept with many definitions, but can be seen as a social construct based on normative beliefs and values and is expressed in terms of behaviour and attitudes (Scott, Mannion et al. 2003). Organisational culture has been shown to be an important part of providing good quality care in care homes; and a particular culture cannot be achieved by introducing a set of core principles and values, or the “right” leader into a care setting alone (Killett, Burns et al. 2016). Some research has demonstrated that the organisational culture of a care home is determined by factors such as: person centred activity and engagement; an openness to change; shared purpose in providing person centred care; and a sense of community between those that live and work within the care home. It is suggested that it is the

relationship between these elements that enables a positive culture to thrive (Killett, Burns et al. 2016), rather than the presence of these elements alone.

Having a positive organisational culture within a care home setting has shown to be important in providing good quality care. In the UK, person centred care is considered a crucial quality marker, particularly for people living with dementia (Department of Health 2015). Despite the value of person centred care and organisational culture, there is some evidence to suggest that person centred care is not embedded in all organisational cultures of providers of respite and short-stay services for people with dementia (Kirkley, Bamford et al. 2011). Kirkley, Bamford et al. (2011) report that some respite care providers describe their service as being person centred due to policy pressures. Yet respite services in their study had not undergone the necessary cultural shift from previous models of care that emphasise respite care, as opposed to person centred care. This lack of a cultural shift was argued to be a factor in why the services still used outmoded models of care, yet reported that they were person centred.

Older people receiving palliative care in a rural area have been shown to have increased feelings of community connectedness. Some evidence shows that this could be because of feelings of an increased reliance on the support from others (Duggleby, Penz et al. 2011). Key contributors to generating a sense of community are visitors and volunteers within the multi-disciplinary hospice sector. One of the attractive features of a day hospice setting is that it provides respite for the main carer (Higginson, Hearn et al. 2000). Because of this the main carer is unlikely to visit. This does not however stop other family and friends visiting while they are receiving care in a day hospice. Staff members also consider visitors to be an important and an integral part of the care team for the patient who receives palliative care (Gray, Adam et al. 2011). A phenomenological study investigating patient's perceptions of visiting in a hospice identified two key themes; 'coping' and 'control' (Thomas 2001). From the patient's perspective, visitors were perceived as helping them with coping and promoting feelings of being in control. Thomas (2001) suggested that patients having more control over visiting times may enhance coping mechanisms of the patient. This idea is supported by other research that found that patients indicated a need for more control over visiting arrangements (Cooper, Gray et al. 2008). Although visitors could sometimes be perceived as intrusive, Cooper, Gray et al. (2008) found that patients also acknowledged benefits of visitors in a hospice including helping maintain links with the outside world.

Volunteers are often considered an integral part of hospice life and culture and can have a significant impact on the wellbeing of patients as well as having a strong influence over the hospice community environment (Addington-Hall and Karlsen 2005, Addington-Hall and O'Callaghan 2009). There are many motivations for volunteering in a hospice setting such as a desire to help others and to learn about and to feel better about oneself. In one study, a main motivation for younger volunteers was to pursue career goals while a strong motivation for older and retired volunteers were stronger social motivations, meaning that their motivations stem from social engagement rather than career goals (Planalp and Trost 2009). These reasons for volunteering highlight the mutual benefit of volunteering in a hospice while at the same time show the strong social engagement ties, particularly for older people.

Research conducted in Canada found more barriers than enablers in referring patients to community-based hospice volunteer programs in the patient's home (Claxton-Oldfield and Marrison-Shaw 2013). Two of the main barriers reported by volunteer coordinators were that patients and families did not want more people coming in and out of the patient's home as it would provide extra burden to the patients and their families, and patients and families did not want to hear the terms "hospice" or "palliative care" because of perceived stigma. These issues do not appear to be present within the hospice setting itself, suggesting that there may be enhanced community support in a day hospice than palliative care at home as people have overcome the barrier presented by the stigma attached to the hospice care setting. Overcoming this stigma can help to create a sense of community for those who are present within the hospice setting. There is some evidence that differences in perspectives can cause tension between hospice volunteers and volunteer co-ordinators for bereavement services which can affect how the services provided by volunteers are planned and implemented (Payne 2002). This tension between hospice volunteer groups could in turn negatively affect the sense of community within the hospice setting.

Although visitors and volunteers are an integral part of hospice communities and provide many benefits to staff members, patients, and families, they may also create some issues as patients may view visitors and volunteers as intrusive (Cooper, Gray et al. 2008, Claxton-Oldfield and Marrison-Shaw 2013). Tensions between volunteers and volunteer coordinators caused by the differences in perspectives could have an effect on how support services provided by volunteers such as bereavement services are planned and implemented (Payne 2002). Hospice care is often considered a gold standard in end of life care and yet there are still many policy related issues that surround visitors and volunteers

within these settings and how this impacts the sense of community that is experienced within hospice care settings.

## 2.7 Social Capital

### 2.7.1 What is Social Capital?

Social capital is a contested theory that was initially developed by early sociologists (Bourdieu 1986, Coleman 1988, Putnam 1995) to understand the value, importance, and impact of social interactions in modern society. It is often perceived as a resource that people can draw upon to help facilitate mutually beneficial goals (Coleman 1988, Putnam 1995). It also helps to explain the social structures that people form and what benefits people can draw from these social networks. The three original proponents (Bourdieu 1986, Coleman 1988, Putnam 1995) of social capital define the concept in particular ways that are not always complementary. The definitions of social capital proposed by three key theorists of social capital are shown in Table 1. More recent definitions are usually based on one or more of the three early definitions proposed (Paldam 2000, Fulkerson and Thompson 2008). Field (2008) writes that social capital emphasises the importance of social relationships. Two of the early pioneers of social capital (Coleman 1988, Putnam 1995) agree that social capital is a resource that is generated through social relationships that can help facilitate action for the benefit of the individual or collective. It may suggest that if relationships are important and can benefit individuals, then a lack of relationships may have a negative effect on individuals. Bourdieu's concept of social capital revolves more around social class and gaining '*credit*' from being a member of a group.

Social capital commentator	Social Capital Definition
Bourdieu	<i>'The aggregate of the actual or potential resources which are linked to possession of a durable network of more or less institutionalized relationships of mutual acquaintance and recognition – or in other words to membership of a group – which provides each of its members with the backing of the collectivity-owned capital, a 'credential', which entitles them to credit, in the various sense of the word'</i>
Putnam	<i>'Features of organisation such as networks, norms and social trust that facilitate coordination and cooperation for mutual benefit'</i>
Coleman	<i>'Social capital is not a single entity but a variety of different entities, with two elements in common: they all consist of some aspect of social structures, and they facilitate certain actions of actors, whether persons or corporate actors, within a structure'</i>

Table 1: Definitions of social capital produced by three key social capital commentators

Some authors have reviewed the literature around social capital to attempt to produce an overall, unified concept (Lin, Cook et al. 2001, Lin 2002). Lin examined social capital in terms of network theory, and defined it as *“resources embedded in social networks accessed and used by actors for actions”*. This definition is similar to that proposed by Coleman and Putnam in that resources that are inherent in social networks can help facilitate action for network members. Coleman (1988) discussed social capital, its definitions and forms, and the role social capital plays in other forms of capital within the family setting such as financial and human capital. Financial capital is a physical resource that aids achievement measured by family wealth. Human capital is a resource that provides the potential for a cognitive environment for a child that aids learning of new information and skills for work, and is measured by the parent’s education levels. Coleman defined social capital as being:

*‘not a single entity but a variety of different entities, with two elements in common: they all consist of some aspect of social structures, and they facilitate certain actions of actors, whether persons or corporate actors, within a structure’*

Coleman claims that social capital is defined by its function and is made up of a variety of different components with two elements in common. These elements are that the components of social capital all consist of some aspect of social structure, and they facilitate the actions of individuals either as a person or within a social structure. This implies that social capital is a resource that helps facilitate actions from an individual, or group such as a community that would otherwise not happen without the presence of social capital, suggesting that it is an enabling concept to help achieve the goals of the individual or community.

Coleman argues that social capital comes in three forms or components: 1) obligations and expectations, 2) information channels, and 3) social norms. Obligations and expectations within Coleman's concept of social capital involves trust, in that if person A does something for person B, then person B has an obligation to repay person A, and person A has to trust that person B will reciprocate in the future. Coleman claims that this form of social capital involves two elements: *'trustworthiness of the social environment, which means that obligations shall be repaid, and the actual extent of obligations held'*. Coleman claims that a high level of trust with these obligations among a group is necessary for the groups' existence, and that without this trustworthiness between group members, i.e. a lack of social capital then there would be such a level of social disorganisation that the group would not function or exist. This demonstrates the importance of social capital in a care setting as low levels of trust can hinder the health of patients in care (Hall, Zheng et al. 2002).

Coleman's second component of social capital highlights the importance of information channels. Coleman argues that information is important in the ability to take action, and as social capital is a resource that facilitates action, the gathering of information must be a part of social capital. Information is important in providing a basis for action, and can be acquired through social relationships. Without this information then no action would take place.

The third of Coleman's components, social norms is *'the norm that one should forgo self-interest and act in the interests of the collective'*. Coleman goes on to discuss the importance of social norms in society, and their ability to facilitate action. Social norms may facilitate action at the individual level, motivating people to take action through selfless acts, and can help facilitate action at a community level, such as doing selfless acts to benefit a collective rather than the individual (Coleman 1988). Social structure and

organisation helps facilitate social capital as individuals create relationships with other members of society and maintain these relationships when they continue to provide benefits as seen in the form of social capital (Coleman 1988). Social norms facilitate actions but can also inhibit other actions, helping to maintain other components of social capital such as trust. If it is against the norm to break the trust of another member within a social group, then the group trust can be maintained which helps facilitate further action for the good of the group.

Coleman's concept of social capital establishes the idea that social capital is a resource that is made up of three key constituent components that all interact within social relationships created and maintained through social structures. Social structures for example are seen as social networks at an individual level, or social group such as a community at a larger level. These social structures help to facilitate an individual to take action for the good of the individual and community. It is a resource that enables social groups and communities to function effectively to work towards mutual goals.

Putnam (1995) recognised social capital as a concept that can help facilitate change and action within a society and social structure, much like the works of Coleman (1988) but Putnam goes on to add to the concept of social capital that coordinated actions improve the efficiency of society (Fulkerson and Thompson 2008). Putnam (1995) defines social capital as

*'Features of organisation such as networks, norms and social trust that facilitate coordination and cooperation for mutual benefit'.*

This definition implies that social capital is a concept that helps societies function and grow by facilitating actions that have mutual benefit to members of a society or community. To achieve this goal, Putnam argues that the social capital of a society must have three components that cooperate and support one and other. These components being 1) moral obligations and norms of reciprocity; 2) social values including trust; and 3) social networks and civic engagement (Helliwell and Putnam 1995, Siisiainen 2003). Putnam (1995) claims that these three major components of social capital are necessary to help facilitate actions that benefit a society and that these components are correlated.

Putnam's first component of social capital is obligations and reciprocity, which is similar to a component within Coleman's concept of social capital. This component focuses on society functioning by people helping each other in the hope that the act will be returned

to them at a later date. Putnam and Coleman both claim that this helps society function as members of a society having obligations with each other helps people facilitate actions within a society as they have an obligation to do so.

Putnam claims that the second component, social values and trust is important in society at a national level, but is declining. Putnam argues that trust at a governmental or national level has declined over past decades, suggesting that if trust is decreasing in America then there may be a reduced level of social capital. This component of social capital is linked with the third component of Putnam's component of social capital supporting his argument that social capital is declining in America.

Putnam's (1995) third component of social capital is to do with social networks and civic engagement. Putnam argues that social networks and civic engagement help a community and society cooperate and function to facilitate mutual goals that benefit the community. Putnam argues that this component of social capital is decreasing in America as witnessed by low turnout at elections and poor attendance at community functions such as town meetings.

Putnam's concept of social capital is similar to Coleman's in terms of it being a concept and resource that can be used to facilitate action within a society, but Putnam goes on to add to the concept of social capital that coordinated actions improve the efficiency of society (Fulkerson and Thompson 2008). Putnam's concept of social capital relies on there being three key components of social capital that are all linked and can correlate with one another. If each component is linked to the others, then a decline in one component would affect the other component and result in an overall decline in social capital, as Putnam argues is the case in America.

The third major contribution to the concept of social capital was from a sociologist (Bourdieu 1986) who is often recognised for early works within social capital (Adler and Kwon 2002, Siisiainen 2003). Bourdieu has also created a definition that has been widely used throughout social capital research. Bourdieu (1986) defined social capital as:

*'The aggregate of the actual or potential resources which are linked to possession of a durable network of more or less institutionalized relationships of mutual acquaintance and recognition – or in other words to membership of a group – which provides each of its members with the backing of the collectivity-*

*owned capital, a 'credential', which entitles them to credit, in the various sense of the word'.*

Siisiainen (2003) saw Bourdieu's concept of social capital as having two main components, the first being a resource that is connected with group membership and social networks, and the second being based on mutual cognition and recognition. Bourdieu argued that the first component, voluntary membership to groups such as a political party, is key to social capital as this provides resources that may be used by an individual, either for personal benefit or for the benefit of the group. The second component of social capital is described as the product of the internalization of the social structures (Siisiainen 2003) suggesting that membership of a network is related to the mutual cognition of network members. Bourdieu developed social capital in line with his theoretical ideas on social class, as he argues that there are three 'capitals' that all have their own influence on class: social, economic and cultural (Bourdieu 1986, Siisiainen 2003).

As seen by the definition, Bourdieu's concept of social capital focuses more on the networks that individual's form and gaining '*credit*' with that group. This perspective of social capital is more suited to understanding the relationships between social class and has been influenced by the attempt to understand the classes as Bourdieu had intended when developing the concept, as the networks between classes are more important than the trust between the individuals within the social class (Siisiainen 2003). As a result of Bourdieu's concept of social capital focusing more on social class, concept is used much less in health research, and remains in the field of sociology.

Unlike other researchers (Coleman 1988, Putnam 1995), Bourdieu's concepts of social capital does not involve components such as trust, and does not mention trust explicitly within the concept (Siisiainen 2003). Bourdieu's perspective of social capital and its development with other capitals in relation to social class differs from other authors, as they have examined social capital in terms of family structure (Coleman 1988) and from a political perspective involving democracy (Putnam 1995).

### 2.7.2 Levels of Social Capital

In a paper evaluating social capital as a concept and examining definitions and trends, Fulkerson and Thompson (2008) compared the paradigms from both a Coleman perspective and a Putnam perspective. The authors suggest that Coleman's concept of

social capital focuses on the aspects of social structures that facilitate actions between actors, while Putnam understands aspects of social capital to include social organisation, trust, norms of reciprocity and networks of civic engagement that facilitate coordinated action between individuals, or groups of individuals, and in turn make societies and institutions more efficient. This summarises the difference in perspective by the early pioneers when examining social capital, and yet also shows the similarity between the perspectives, in that both incorporate similar aspects about social structure and organisation that facilitate action. However, in the case of Coleman, action occurs between people for mutual gain and benefit whereas Putnam and Bourdieu argue that the action takes place to make society and institutions more effective as a whole. This shows the difference in levels that social capital can be interpreted against. Social capital is a theoretical concept that can be created, possessed and used by an individual, to benefit the individual or a society. This shows two clear levels of social capital, one being at the individual level, while the other is at a community or societal level.

Putnam (1995) also writes about the levels of social capital within his component of social capital labelled civic engagement but extends the number of levels to include social capital at a national level. Putnam focuses more on the national and community levels of social capital and their decline within America, again differing from Coleman's perspective of the individual and group levels of social capital. Putnam examines civic engagement within a community through events such as public meetings at town halls, and examines civic engagement at the national levels through national votes for government and demonstrates that these are declining. This shows that Putnam recognised different levels of social capital and also claimed to take a measure of the levels through the different activities that took place within a community and nationally. Putnam also recognised levels of social capital in other components such as trust, where he discusses levels at a neighbourhood and community level, and also at a governmental level showing trust on a national level. This again demonstrates that within the concept of social capital, there are numerous levels that must be recognised. Putnam also includes in his concept of social capital that social capital could generate negative outcomes as well as positive outcomes for a society or group of people.

### 2.7.3 Types of Social Capital

Some researchers argue that social capital has become a ‘go to’ concept to explain a variety of social relationships and phenomenon (Paldam 2000) which has lead researchers to report on the differing types of social capital (Adler and Kwon 2002, Harpham, De Silva et al. 2006). Putnam (2001) distinguishes between two types of social capital that are important for modern society, ‘bridging’ and ‘bonding’ social capital (Putnam 2001). Putnam claims that bridging social capital refers to relationships between different social groups and networks that are outward looking of a group that includes people across many diverse social boundaries. In contrast to bridging social capital is bonding social capital, which according to Putnam, is inward looking of a group and refers to relationships within a group such as a family or social network an individual is currently in. Table 2 identifies the main components, levels and types of social capital that are reported on in the literature for the three key social capital theorists.

<b>Social capital commentator</b>	<b>Components of social capital</b>	<b>Levels of social capital</b>	<b>Types of social capital</b>
Bourdieu	Group membership and social networks; and mutual cognition and recognition	Individual and group level, to explain the larger structure of society and social class.	Focuses on bridging social capital
Putnam	moral obligations and norms of reciprocity; social values including trust; and social networks and civic engagement	National and community levels of social capital.	Focuses on bonding social capital
Coleman	Obligations and expectations; information channels; and social norms.	Individual and group level social capital.	Focuses on bonding social capital

*Table 2: Comparing the components, levels and types of social capital for the three key social capital commentators*

Bridging and bonding social capital has been referred to in other works, but the concept of the types is the same. Adler and Kwon (2002) write about this type of social capital but it is referred to as internal and external social capital. They also propose that different definitions fall within these types of social capital. The authors report that Coleman’s (1988) definition of social capital, along with Putnam’s (1995) definition, fall within the area of examining social capital from a bonding social capital perspective examining the

relationships from an inward perspective, while Bourdieu's concept of social capital and definition refers more to bridging social capital, an outward perspective looking at the differences between differing social classes.

Other types of social capital that have been reported on are structural and cognitive social capital (Adler and Kwon 2002, Harpham, De Silva et al. 2006, Forsman, Nyqvist et al. 2012). In a paper examining social capital and the mental health of older adults, Forsman, Nyqvist et al. (2012) recognise the differing types of social capital and offer definitions. The authors suggest social capital is often written about in research in terms of dimensions, the cognitive dimension being a type of social capital that is to do with perceived social support and trust, while the structural type of social capital concerns social networks and social participation. Social capital has been organised into these two types as one type concerns people's feelings and perceptions of a given component of social capital, while the other is concerned with the physical aspects of their social lives such as their social networks and groups.

Harpham, De Silva et al. (2006) also recognised the presence of structural and cognitive types of social capital and makes a distinction between the two when measuring social capital within their research investigating maternal social capital and child health. In their research they make the distinction between cognitive and structural social capital by saying that structural social capital is '*objective measures of what people 'do' such as membership of networks*' while cognitive social capital is '*subjective measure of what people 'feel' such as notions of trust and reciprocity*'. By making this distinction, Harpham, De Silva et al. (2006) and Forsman, Nyqvist et al. (2012) are able to see what dimension of social capital is having an effect on an outcome, as opposed to being able to only see that social capital as a whole is having an effect giving greater accuracy within the study's findings.

#### 2.7.4 Social capital, health and wellbeing

The literature on social capital and its relationship with health is difficult to interpret due to the variety of methods used to measure the concept. Social capital in its entirety cannot be measured directly due to the complexity of the concept. The dominant method of measuring social capital has been through the use of surveys, although it is recognised that there is a need for a variety of methods to measure a complex concept (Van Deth 2003). The difficulty in interpreting study findings in relation to one another is due to studies using different survey questions for different components of social capital. Findings are mixed

and sometimes contradictory with some studies showing a positive association between social capital and some aspects of health (Poortinga 2006, Norstrand, Glicksman et al. 2012), while others found no associations between social capital and some aspects of health (Wahl, Bergland et al. 2010, Holt, Schulz et al. 2012). An explanation for these mixed findings is the diversity of definitions and measurement methods of social capital used (Paldam 2000). There is however, in most studies, a link between some aspects of social capital and some aspects of health and wellbeing. The key literature on social capital, health and wellbeing is summarised in Table 3.

The literature suggests that the health of individuals is partly dependent on the characteristics of relationships and the social structures in which people live (Cattell 2001). For older people, the places they live can vary based on the care needs of the individual, and in some cases a change of living circumstances can result in greatly reduced social ties (Victor and Bowling 2012). One study reviewed the literature on social capital, wellbeing and quality of life and at the time found that of 93 publications, only two publications specifically discussed social capital and palliative care services (Lewis, DiGiacomo et al. 2013). Social capital in the form of social networks, social support and trust is shown to be an important aspect of the care that palliative care services provide although recently more research has addressed this gap (Lewis, DiGiacomo et al. 2014, Rosenberg, Horsfall et al. 2015).

There is some evidence to suggest it may be the information people gain through social networks about health promotion which in turn improves their wellbeing; and the social norms that people obtain through social capital that can influence their health behaviours (Ziersch, Baum et al. 2009). In most studies, there is a link between some aspects of social capital and some aspects of health and wellbeing. This suggests that social capital at some level is important to people's lives with regard to their wellbeing although these mechanisms have not been fully investigated.

Cognitive impairment is highly prevalent within a care home setting (Matthews and Dening 2002, Bowman, Whistler et al. 2004) yet it is unknown how the presence of dementia affects the ability of a care home resident to gain and draw on social capital. One study has shown that at the later stages of Alzheimer's disease, cognitive function remained higher for participants with larger social network sizes (Bennett, Schneider et al. 2006). There is also evidence suggesting that it is the quality, not the quantity, of network interactions that is associated with dementia, with participants who felt satisfied with their relationships

having a 23% decrease in dementia risk (Amieva, Stoykova et al. 2010). This study however was unable to establish the direction of the relationship between social networks and dementia. It could be the case that social networks may be protective against dementia, or that dementia may limit the development of social networks. It could be argued that social networks as part of structural social capital may become more important in the presence of dementia due to increased vulnerability.

There is evidence that suggests that people with cognitive impairment may also lack some aspects of cognitive social capital such as reciprocity. Gove, Small et al. (2017) found in their interview study involving general practitioners (GPs) that GPs described a lack of reciprocity as one way in which people with dementia are perceived within society, and that these feelings contribute to the stigma attached to dementia within society. GPs were also reported to have commented on the possibility that people affected by dementia have a lack of opportunity and skills required to reciprocate human and social contact, as well as lack the opportunity to contribute to society. It is suggested by Gove, Small et al. (2017) that GPs are in a key position to challenge dementia stereotypes. By challenging the stigma attached to dementia, there is the potential to enable people with dementia to engage more meaningfully with society, and have or experience an improved quality of life through greater social inclusion.

Table 3: Studies examining the relationship between social capital, health and wellbeing, ordered chronologically

Study Authors	Definition of Social Capital	Aim of Study	Location of Study	Study sample	Measurements used for Health and Social Capital <sup>1</sup>	Key findings
Harpham, De Silva et al. (2006)	The resources that people can access through their social connections. Cognitive social capital refers to attitudes about connections. Structural social capital refers to behaviours that form from the connections	To explore the association between maternal social capital and child physical and mental health	Vietnam	2907 mothers and their children	Physical health of children measured by reports of mothers of any illness in the last 24 hours, 2 weeks and presence of serious illnesses in all of life. Mental health measured by Strengths and difficulties questionnaire (SDQ)  Social capital measured by a shortened version of the Adapted Social Capital Assessment Tool (A-SCAT).	Maternal social support and high cognitive social capital show the most consistent associations with child health at age one, and with the child's mental health at age eight.
Poortinga (2006)	Bonding social capital refers to the horizontal ties between members of a network who see themselves as similar and can be compared to the concept of social cohesion. Bridging social capital comprises links across different groups in society.	To investigate the health effects of social capital, and in particular bonding social capital	England	7394 interviews were conducted on a sample aged 16 and over.	Health measured by a self-rated health status question.  Social capital was measured by a number of questions surrounding personal levels of social networks and support, social trust and civic participation.	Personal levels of social support are associated with self-rated health. Social trust was significantly associated with self-rated health. Bonding social capital collectively contributes to people's self-rated health above personal social networks and social support alone.

<sup>1</sup> All studies in table used cross-sectional quantitative methodology.

Study Authors	Definition of Social Capital	Aim of Study	Location of Study	Study sample	Measurements used for Health and Social Capital <sup>1</sup>	Key findings
Caperchione, Lauder et al. (2008)	The way society is organised, the extent to which interaction is encouraged among the citizenry, and the degree to which individuals trust and associate with each other	To investigate the association between social capital and health related quality of life	Australia	1208 adults (aged 18 and over)	Mental and physical health measured by SF-12 questionnaire  Social capital measured by 9 questions taken from British General Household Survey of Social Capital Module	Social capital has a significant association with high physical health. No association between social capital and mental health. Older people had significantly worse levels of social capital than younger participants.
Modie-Moroka (2009)	A resource produced when people cooperate for mutual benefit	To explore and describe relationships among neighbourhood characteristics, social capital and health outcomes among low-income urban residents in an area of Botswana	Botswana	388 low-income adults aged 18 and over	Health was measured by World Health Organisation Quality of Life questionnaire (WHOQoL)  Social Capital was measured by a Perceived Social Capital questionnaire, 37 items exploring trust, collective efficacy, community concern and integration, civic actions and personal involvement in the community.	Social capital negatively predicted levels of physical health. Found a weak positive correlation between social capital and overall health status, psychological wellbeing and quality of life but not to a significant level.
Ziersch, Baum et al. (2009)	The aggregate of the actual or potential resources which are linked to possession of a durable network of more or less institutionalised relationships of mutual acquaintance and recognition	To compare the relationships between social capital and health for rural and urban residents of south Australia	South Australia	1,402 urban participant, 611 rural participant	Physical and mental health was measured using the SF-12 questionnaire  Social capital was measured using a number of questions for six different dimensions of social capital; trust, reciprocity, networks, civic activities, help, and neighbourhood cohesion.	Mental health was seen to be associated with social capital in both rural and urban areas, but physical health was seen to be associated with social capital in only urban areas.

<b>Study Authors</b>	<b>Definition of Social Capital</b>	<b>Aim of Study</b>	<b>Location of Study</b>	<b>Study sample</b>	<b>Measurements used for Health and Social Capital<sup>1</sup></b>	<b>Key findings</b>
Wahl, Bergland et al. (2010)	Features of interpersonal trust, norms, reciprocity and social engagement that foster community and social participation	To explore the relationship between social capital, coping, self-esteem, health and quality of life in a sample of participants receiving social assistance benefit	Norway	451 long term social assistance recipients	Mental and physical health was measured using the SF-12 questionnaire.  Social capital was measured by asking 3 questions about the participants trust in others, honesty of others, and whether or not people would likely help them or not.	No association between social capital and physical health. A positive association between social capital and mental health as well as coping and self-esteem.
Oksanen, Kivimaki et al. (2011)	Features of social structures, such as the levels of interpersonal trust, norms of reciprocity, and mutual aid that act as a resource for individuals to facilitate collective action.	To examine the association between workplace social capital and all-cause mortality.	Finland	28,043 individuals (82% female) aged 22 to 60 years	Mortality was based on the participants being deceased at the time of the second questionnaire. Health behaviours were recorded with simple questions such as smoking status, estimated alcohol consumption etc.  Social capital was recorded by an 8 item measure specifically designed for workplace social capital.	Higher workplace social capital is associated with lower mortality rates. People who had lower social capital scores had a higher behavioural health risks such as smoking and higher incidence of chronic illness.

Study Authors	Definition of Social Capital	Aim of Study	Location of Study	Study sample	Measurements used for Health and Social Capital <sup>1</sup>	Key findings
Shelton, McNeill et al. (2011)	Structural factors – include existence and quantity of social ties, as well as roles and responsibilities that stem from one’s position and life circumstances. Functional – including perceptions of social support and social cohesion. Normative – including social norms for physical activity	To examine an association between structural, functional and normative social factors and physical activity	America	1,112 residents from low income housing areas	Physical activity measured with a pedometer.  Social capital, referred to as social factors are measured by questions relating to; for structural factors – the size of social networks, participation in organizations and social participation, role responsibilities in household and financial duties and conflicting demands. Functional factors – 5 questions about emotional, financial and social support, social cohesion (defined as connectedness among groups), and a measure of trust. Normative factors – 2 questions about perceived social norms.	Some aspects of social capital (social networks) are more important than others (social participation). Residents with smaller social networks were significantly less active than those with larger networks.
Holt, Schulz et al. (2012)	Collective benefit that comes from reciprocally cooperative and helpful relationships with others	To examine if spiritual and religious capital contribute to the literature on social capital	America	803 African American men (424) and women (379) aged 21 and over	Mental and physical health was measured using the SF-12 questionnaire.  Social capital was measured by a pre-existing instrument with 9 items measuring social support, interconnectedness and community participation	Spiritual and religious capital did not add anything extra to social capital. Social capital predicted positive emotional functioning, but not physical functioning in both men and women, although there was an association with physical functioning but not to a significant level

Study Authors	Definition of Social Capital	Aim of Study	Location of Study	Study sample	Measurements used for Health and Social Capital <sup>1</sup>	Key findings
Li and Delva (2012)	Features of social networks, norms and trust that enable participants to act together more effectively to pursue shared objectives.	To examine how different dimensions of social capital were associated with smoking behaviour	America	998 adult Asian American men	Smoking status measured by the participant being a current smoker, including previously smoked and quit, or only smoked occasionally and non-smoker at the time of the study.  Social capital measured by 5 questions around family connectedness, friends connections, neighbourhood cohesion, family cohesions and family conflict	Social capital and smoking among Asian men varied with regard to specific dimensions of social capital. Structural aspects of social capital saw no association with smoking behaviour. High levels of neighbourhood cohesion were associated with lower smoking odds.
Norstrand, Glicksman et al. (2012)	Features of social organization such as trust, norms, and networks that can improve the efficiency of society by facilitating coordinated aims	To examine the relationship between social capital and mental/physical health of older adults and examine to see if mental and physical health differ with respect to social capital	America	3,219 adults aged 60 and over	Physical health was measured by a single self-rating question for self-rated health. Mental health was measured by 10-item version of the Centre for Epidemiological Studies Depression Scale.  Social Capital was measured by 6 item questionnaire taken from the Social Capital Community Benchmark Survey.	Participation in groups, sense of belonging and neighbours willingness to help are positively associated with physical health. Trust in neighbours, sense of belonging and neighbours willingness to help are associated with depressive symptoms.
Iida and Rozier (2013)	Consists of some aspect of social structure and actions of the individuals embedded in the structure	To explore the association between mother-perceived neighbourhood social capital and child's oral health status	America	67,388 children and their mothers	Health measure by perceived rating of child's oral health, number of unmet dental needs and dental visits over the last year  Social Capital measured by a 4-item Social Capital Index (SCI) measuring reciprocal help, support and trust in neighbourhood.	Mothers with reported low levels of social capital reported more unmet dental care needs. Mothers with lower social capital were more likely to forgo preventative dental visits.

### 2.7.5 Social capital as an overall concept

Social capital has been described as the '*glue*' of a society that helps in generating excess cooperation helping people work together (Paldam 2000). This excess cooperation is then described by some (Coleman 1988, Putnam 1995) as a resource that helps facilitate individuals to take action within a group or network of people that benefit those networks and society. Individuals generate this resource as a way to make society more efficient (Putnam 1995, Fulkerson and Thompson 2008) and to help facilitate action that is mutually beneficial to members of a society or group that would otherwise not be possible without this resource (Coleman 1988). The broad scope of social capital has led to the concept containing numerous components, types, levels and dimensions as summarised in Table 2.

Some authors (Portes 2000, Siisiainen 2003) hint towards the idea that it is the nature and discipline of the research being conducted that guides which definition is best used for a particular study. This in turn may lead to the possibility that there will never be a single definition that defines the concept of social capital. The idea that the nature of the research guides the use and definition of social capital can be seen as each paper investigating social capital uses either the definition that best suits the research, or creates its own definition for that particular study. An example of this can be seen in a study examining social capital with regard to smoking behaviour (Li and Delva 2012) who have used the definition proposed by Putnam (1995), as it examines social behaviour within social groups. Other research (Ziersch, Baum et al. 2009) examining social capital and health with regard to urban and rural locations uses the definition proposed by Bourdieu (1986) as it may be the networks of these locations that play a role in the health of residents in urban and rural locations more so than their levels of trust as proposed in other definitions such as Coleman (1988). As there is no single definition, some studies (Harpham, De Silva et al. 2006, Modie-Moroka 2009) have created their own definition. Many studies surrounding health research and social capital (Wahl, Bergland et al. 2010, Oksanen, Kivimaki et al. 2011, Li and Delva 2012, Norstrand, Glicksman et al. 2012) have either focused on using the definition proposed by Putnam (1955) or a variation of this definition making this one of the most popular definitions for health research.

### 2.7.6 End of life and social capital

Many older adults will die under either hospice care or in a care home care setting (South West Public Health Observatory 2010). Some authors claim that end of life caring provides

a chance to increase social capital by enhancing social networks for the carer and those that are cared for (Leonard, Horsfall et al. 2013). It has been suggested that the holistic approach of the current model of practice needs to move to a more social model of practice and incorporate workers and help from social work as well as increasing social networks and mobilising with better effect the patient's friends, wider family members and members of the patient's community for support. These informal support networks have the potential to help '*naturalise*' dying while also providing support to the family members so they become less isolated.

Social capital has received greater attention in end of life and palliative care in recent years and authors have provided information about how they see a social capital framework that can apply to a palliative care setting (Lewis, DiGiacomo et al. 2013). Bonding social capital refers to networks and ties with people who are similar to themselves in some way, such as a similar social class, while bridging social capital refers to bridges that are made across some divide that separates people such as social class or race. An example of this in end of life care could be seen as bonding social capital providing resources provided by close network members and relations such as informal carers, giving a sense of belonging through social engagement. Bridging social capital can enable access to information through local services such as hospice and palliative care services and volunteer groups. This can lead to a sense of community participation and cohesion (Moore and Kawachi 2017). Research supporting the use of a social capital framework in palliative care concluded that there is a major gap between the ideals of palliative care and the reality of many carers experiences of being isolated and concludes that understanding and strengthening the social networks and ties for carers will aid in closing the gap (Rosenberg, Horsfall et al. 2015).

It is possible to die 'well' at home, provided that the individual has and is supported by a strong network of community carers, and that caring for someone at the end of their life builds social capital and compassionate communities through developing social networks (Horsfall, Noonan et al. 2012). The services that have the potential to provide the resources that are necessary to create, support and maintain these networks, such as a day hospice, could help facilitate and ensure the survival of informal caring networks by developing a community's capacity to provide the care that is needed. Despite this need, some evidence has shown that lower socio-economic groups are at a disadvantage (Grande, Addington-Hall et al. 1998). These disadvantaged groups may lack the individual and community networks

and relations to meet the care needs at the end of life demonstrating the importance of sufficient social support networks.

## 2.8 Social capital in the context of this research

As discussed in chapter 2 section 2.7.3, cognitive social capital may have wide implications for social interactions of many kinds, perhaps particularly so within a care setting. In different care sectors many factors that affect those that are cared for are influenced by policy and funding concerns. Social capital theory could be used to explain the implications of funding concerns and the impact this can have on residents and patients within a care setting. For example, a lack of trust in policy makers may indicate a lower level of social capital within the residents of a care home which may not be present in hospice patients due to different funding concerns. Despite hospices having funding and policy making issues, hospices tend to still be able to provide more services than care homes and have better resources available to them such as more specialised medical personnel. Despite a potential for low levels of trust and cognitive social capital, the staff members of a care home or hospice have obligations to provide the best care possible to residents and patients in line with the company ethos and practice guidelines. This would suggest inherent high level of trust between staff members and residents and patients, who trust the staff to provide personal care which would suggest a high level of cognitive social capital in these care sectors.

Within the social capital literature, trust is often discussed with reciprocity, particularly when the definition proposed for social capital is that of Putnam (1995) who suggests a major component of social capital is moral obligations and norms of reciprocity. It has been suggested that trust creates a basis for reciprocity, which can in turn create trust (Siisainen 2003). The relationship between trust and reciprocity can be self-sustaining. Trust among network members can improve the likelihood of reciprocity and voluntary associations, with associations strengthening over time, thereby increasing levels of trust between individuals (Putnam 1993). Therefore the more social capital is used, the more it grows (Coleman 1988).

Staff members in a care home do not provide care in order to receive anything back directly from the people they care for. In a similar way to care home staff, hospice volunteers provide their time to help support people at the end of their life yet often do not receive anything back directly. Often the reasons for volunteering are not for what the people they support can provide them in return, but for what the volunteers themselves get out of the

act of volunteering. Staff and volunteers may not expect direct reciprocity and so are motivated by altruistic reasons; a desire to help others; to improve career prospects; or for more social motivations such as seeking social contact or personal growth (Planalp and Trost 2009, Stelzer and Lang 2016). While patients may not give anything back to volunteers or staff directly, they do facilitate them to satisfy their own desires to help others. Within a care home environment, it has been hypothesised that reciprocity is an important factor in staff burnout (Duffy, Oyeboode et al. 2009). Yet studies that tested this hypothesis found that reciprocity between care staff and those being cared for, and reciprocity between care staff and the organisation does not predict levels of staff burnout (Duffy, Oyeboode et al. 2009). Instead other factors such as supportive social networks and environments are suggested to help reduce negative experiences such as burnout (Garrett and McDaniel 2001). For these reasons, reciprocity and trust may not be as important in a care home or hospice setting as other components of social capital such as social networks and social interaction which have been shown to be important to optimise resident and patient wellbeing (Carpiac-Claver and Levy-Storms 2007, Addington-Hall and O'Callaghan 2009, Abbott, Bettger et al. 2013).

As trust and cognitive social capital will be assumed to be implicit in these care sectors, the focus of this study is on the structural aspect of social capital in the form of social networks. In particular, the quality of interactions to maintain these networks, as well as people's views about the roles and function of social network members, particularly voluntary network members. Putnam reports that voluntary associations have declined over the last few decades (Putnam 1995). Voluntary associations may be a key indicator of the level of structural social capital within these two care sectors, particularly in hospices where volunteers are commonplace.

New models of care are needed to respond to the increasing demand for high quality care for older people. Social capital has been reported to be more important for older people than younger people (Muckenhuber, Stronegger et al. 2012) but little work has examined the social capital of older people within a care setting. It is well documented that the social ties of residents can often diminish in a care home, yet are considered important by residents, family members and staff members (Dykstra, Van Tilburg et al. 2005, Cheng 2009, Drageset, Kirkevold et al. 2011). Voluntary associations are an important part of social capital (Putnam 1995) and this suggests along with other work (Leonard, Horsfall et al. 2013) that hospices may have higher levels of social capital than care homes. No work was found that has examined this idea. It is also suggested that the hospice care sector

provides high quality care for people in terms of social support and access to wider support networks as a result of social capital (Leonard, Horsfall et al. 2013). It has been argued that there is a need to implement a hospice model of palliative and social care within a care home environment (Froggatt 2001, Meier 2011, Miller 2015). Social capital is a concept that is relevant to both care home and hospice sectors, yet has a greater potential and reach in a hospice environment as end of life caring has the potential to increase social capital (Leonard, Horsfall et al. 2013). While other concepts such as organisational culture are relevant within a care home and hospice setting, a better understanding of social capital may enable the development of new ideas that can improve the quality of care for older people within a care setting.

For this study a definition of social capital was created based on the works of two key theorists in this area, Coleman (1988) and Putnam (1995). For Coleman, social capital comprises of multiple elements including social structures such as the presence of networks to generate social norms, trust and reciprocity, and the ability to facilitate action among actors within a structure. Putnam's concept of social capital focuses more on the organisation of networks, norms and social trust to facilitate mutual benefit of a collective society. Therefore, in this thesis I will use the term social capital to refer to a resource that is created by the presence of social networks that uses social interactions to create and maintain these networks. Individuals may draw upon these networks to create a sense of trust, social norms and reciprocity to facilitate mutual benefit and action within a social structure.

## 2.9 Atmosphere

### 2.9.1 What is the atmosphere of a care setting?

'Atmosphere' within this thesis has been operationalized as the social climate of a care setting. The concept of 'social climate' is described by Moos and Lemke (1996) as the 'personality' or 'feel' of a place that can be sensed when an individual enters the environment, and is sometimes considered similar to the atmosphere of a place. It is described by some to give unity and coherence to a care setting and was measured in a residential care setting by Moos using the Sheltered Care Environment Scale (SCES)(Lemke and Moos 1987, Moos and Lemke 1996). Social climate or the atmosphere of an environment has been researched in other settings by other names, such as ward atmosphere in a hospital setting (Friis 1986, Røssberg and Friis 2003). Ward atmosphere has been conceptualised as the atmosphere of the ward, or the personality of the ward

unit (Moos 1997). The Ward Atmosphere Scale (WAS) was developed as a way to measure this concept (Moos 1974). The WAS scale contains 10 subscales which can be organised into three domains: the relationship domain, the personal growth domain and the organisational domain.

The atmosphere of an environment can give either positive (such as cleanliness and homeliness) or negative (such as uncleanliness and chaotic) impressions. There is evidence to suggest the quality of atmosphere and social support can help predict psychosomatic complaints and feelings of depression after a negative life change event (Holahan and Moos 1982). It has been recognised that levels of depression and social support and interaction are important factors to consider in care home populations (Lee, Woo et al. 2002, Sackley, Hoppitt et al. 2006, McDougall, Matthews et al. 2007).

### 2.9.2 Atmosphere and care homes

Although research about the social environment or atmosphere of care homes is lacking, there is evidence to suggest that the atmosphere of a care setting is important for the staff in helping them manage their work life stress and maintain self-esteem. One study conducted in the UK found that some aspects of atmosphere (cohesion and resident influence) are associated with improved ways of managing challenging behaviours of residents in older peoples care homes (Moniz-Cook, Woods et al. 2000). There is also evidence to suggest that the atmosphere of a care setting is important for nurses as the atmosphere of a work place was negatively associated with nurse 'burnout' (Garrett and McDaniel 2001). Burnout in this study included emotional exhaustion, depersonalization and reduced sense of personal accomplishments which are all factors that staff can experience within the care field.

There is evidence to suggest that atmosphere is correlated to the quality of life of residential care home residents (Mitchell and Kemp 2000). When examining the impact of demographic characteristics, health status, social involvement, facility characteristics and atmosphere on the quality of life of residents, the atmosphere variables had the strongest correlations of all measures with quality of life (Mitchell and Kemp 2000). Mitchell and Kemp used the SCES measure of atmosphere but only used four of the seven sub-scales which makes it difficult to compare with other studies that have used different sub-scales of the SCES. Other research has shown that different sub-scales of the SCES measure of atmosphere are central to the quality of life of the residents (Timko and Moos 1991) and

some research has shown that relatives of residents have named the atmosphere of a care home as a key factor in selecting a home for their relatives to reside (Netten, Darton et al. 2002). As relatives base important decisions on the atmosphere of a care setting, it warrants significant research despite the complexity and difficulty of the topic itself and its measurement.

Other factors that may seem to be related to the environments of a care home, such as the organizational culture, also has significant effects on the outcomes and wellbeing of the residents (Norbergh, Hellzen et al. 2002). Norbergh, Hellzen et al. (2002) showed that a creative organizational climate for residents with dementia in a group dwelling unit such as a care home spent more time with staff than those in a less creative climate. This suggests that a more creative environment with higher levels of organizational culture increases the time residents spend with staff and may broaden their social networks with other people. This is also seen in a hospice sector where a large focus is put on the social aspects of care such as activities by volunteers.

Despite atmosphere being shown to be important in care home settings, one study found that between 1996 and 2001, care homes with a more positive social environment were the homes that were most likely to close down (Darton 2004). This was due to a variety of reasons, but the most common reason among nursing and dual registration homes (nursing and residential) was reported as 'business failure' (Darton 2004). The study found that small converted properties that are privately managed were the type of care homes that had a more positive atmosphere than larger capacity homes that are run by corporate providers. It was these smaller homes that were closing which results in a reduced choice for potential residents. This could be seen as evidence to support the idea that with an ageing population, the care of older people is being directed by funding concerns rather than the needs and concerns for the older people that are entering the care setting.

### 2.9.3 Atmosphere and hospice

Research on the atmosphere of a care setting for end of life patients is lacking, and yet, as indicated earlier, the importance of a supportive atmosphere at a sensitive time at the end of a patient's life has positive effects for the patient and their families as well as the care staff. There is evidence that humour and a sense of community between staff and patients as well as a caring atmosphere are present in both a hospice setting and a oncology ward, but a hospice setting was shown to differ from an oncology ward by having higher levels of

interdisciplinary collaboration, and a pronounced use of touch as a caring tool (Gates 1991). This use of touch as a caring tool could also be experienced in a care home setting.

When creating a supportive atmosphere in a care setting such as a hospice, five categories have been identified (Edvardsson, Sandman et al. 2005). These were: experiencing welcoming, recognising oneself in the environment, creating and maintaining social relations, experiencing a willingness to serve and experiencing safety. These categories were considered important in contributing to an atmosphere of ease and a supportive environment for patients as well as staff and relatives. This work as well as the work conducted by Gates (1991) used qualitative methodology in the form of interviews and observations. No specific tool for use in the hospice and care home sectors was found in the literature reviewed.

#### 2.9.4 Atmosphere and social capital

Many of the factors of the atmosphere in a care home are also relevant in the concept of social capital such as social support, social networks and the interactions that residents have with the people around them. Social networks are important during times of change and uncertainty in the work environment (Garrett and McDaniel 2001) which are relevant to the concept of atmosphere. If the atmosphere of a care setting is important for staff and resident/patient wellbeing and how the care settings are chosen, then factors which affect the atmosphere could be discovered. Social capital has been seen to be important for people within these same care sectors of care home and hospice. It seems plausible that the two concepts may be associated with each other although no research seen has yet examined this proposition, either quantitatively or qualitatively.

#### 2.10 Why Care homes and hospices?

Hospices attract many more volunteers than care homes yet this difference has never been investigated. Nor has the impact that volunteers can have on the atmosphere or social capital of the care settings, as volunteers are considered vital in hospices yet are a comparatively scarce resource in care homes. Putnam (1995) recognises that voluntary social networks are an important part of social capital which could mean that as hospices have more volunteers, they also have higher levels of social capital compared to care homes but there has been no study that has formally reviewed this suggestion. In a review

of the literature around social capital, health, wellbeing and quality of life, only two publications out of 93 specifically discussed social capital and palliative care services (Lewis, DiGiacomo et al. 2013). This study highlighted a lack of research in the area of palliative care and social capital. The Gold Standard Framework for optimising care at end of life is becoming increasingly used in care homes because if older people do not die in hospitals there is a greater chance that they will die in care homes than hospices (South West Public Health Observatory 2010). This may suggest that there is becoming a 'blurring of lines' between end of life care in hospices and care homes although this has not been examined in the UK, and none of the research reviewed here had explored care homes and hospices together. There is some evidence to suggest this is already happening in other countries, for example in Austria the Interlinks programme, which aims to improve long-term care of older people has started a project to merge hospice and palliative care with nursing homes, allowing nursing homes to administer palliative and hospice care to care home residents (Beyer, Bitschnau et al. 2011, Beyer and Pissarek 2015).

The role of palliative care has increased considerably since the 1960's, although its provision in nursing home settings came much later (Stevenson, Huskamp et al. 2007, Wowchuk, McClement et al. 2007). Yet many patients still do not have access to hospice care until the weeks immediately prior to death showing an increased need for palliative care access for care home residents (Miller 2015). Where palliative and end of life care is at the heart of the care delivered by nursing homes, this is associated with lower likelihoods of residents requiring feeding tubes, injections, restraints, suctioning and end of life hospital and emergency room use (Miller, Lima et al. 2015). This suggests that a greater knowledge of palliative care could mean an improved quality of life and care for care home residents, as well as reduced burden on hospitals with fewer admissions. A survey of 292 family members whose relatives had recently died in a nursing home but were given hospice and palliative care, found that the quality of care of physical symptoms was perceived to significantly increase from 64% to 93% once hospice care was introduced to their relative. After hospice care had been introduced into the care home, the quality of care of emotional symptoms including depression, anxiety and loneliness also significantly improved from 64% to 90% and the number of hospitalisations were reduced (Baer and Hanson 2000). Individuals who received hospice care in an institutional setting such as a nursing home were significantly more likely to be older, female, unmarried and have a primary diagnosis other than cancer when compared with patients who received hospice care in their own homes (Stevenson, Huskamp et al. 2007).

End of life and palliative care in a care home setting is an area that warrants further research. Specialist palliative care services are now seeking to provide palliative care within more general care settings in order to meet the needs of people living with diseases other than cancer (Froggatt 2001). This shift in approach can be seen in two ways. Firstly, specialist palliative care practitioners may act in an advisory capacity to the care homes, assisting with the care of particular residents at the end of their life. Secondly, through the use of formal end of life education such as educational and training courses for nursing home staff. While the use of these two approaches is likely to continue, it is suggested that the effectiveness of these initiatives will not be maximised unless there is close collaboration between individuals and organisations involved in the multi-agency delivery of care for older people at the end of their lives (Froggatt 2001).

Despite a need for end of life care to be implemented in care home settings, there are a number of challenges (Wowchuk, McClement et al. 2007). These include lack of provider knowledge about palliative care; care provider attitudes and beliefs about death and dying; staffing levels and lack of available time; families' expectations regarding residents' care; and lack of medical support. Wowchuk, McClement et al. (2007) argue that these factors are internal to the care setting, and that the care provider has some level of control over the adoption of these practices to provide optimal end of life care for its residents. While this literature review by Wowchuk, McClement et al. (2007) provides important findings already published within the field, a systematic review may be able to shed further light onto which factors hold the most importance in combating the challenges found in implementing palliative and end of life care in a nursing home setting. A systematic review of the literature would provide more direction for initiatives that aim to combat these challenges by allowing initiatives to focus on the most significant challenges in providing palliative care in the nursing home.

The evidence reviewed seems to support the view that hospice care in a care home setting can play a significant part in increasing the quality of life, care, and wellbeing of residents in a care home not just in a physical way, but also an emotional and social way (Baer and Hanson 2000, Stevenson, Huskamp et al. 2007). Some people suggest that hospice and palliative care models of end of life are in need of being rethought as these models are being looked to for end of life care in non-cancer patients and other care settings such as care homes (Brown and Walter 2013). A study conducted in the USA reported that some nursing home residents do receive hospice and palliative care while in the nursing home setting (Buchanan, Choi et al. 2002). Palliative care provision is becoming more common

(Beyer, Bitschnau et al. 2011) in an ageing population that is putting increasing demands on healthcare services. This study showed that the nursing homes admitted hospice care patients to support them at the end of their life suggesting little difference in the readiness to manage end of life patients in hospice and care homes. Research has shown that there is little difference between the ways that residential care homes and nursing homes provide end of life care (Sloane, Zimmerman et al. 2003). This is particularly relevant in a UK context as more professionals are calling for greater palliative care presence in care homes (Meier 2015). This would suggest that a 'blurring of lines' between care homes and hospice care is not only taking place, but that it is positive for the wellbeing of the residents and patients within these care settings.

## 2.11 Conclusions and the need for the present study

Transition into a care setting such as a care home or hospice can be a traumatic time for older adults and their relatives and life inside a care setting is often significantly different from the life individuals have previously been used to. Some models of end of life care that have originated in hospice and palliative care are being looked to for guidance in developing end of life practice for non-cancer patients in other settings, partly in response to the growing numbers of older people (Brown and Walter 2013). Brown and Walter (2013) suggest mobilising wider family, friends, and members of a patients' community to help support them could have significant benefits for both the patients and the family carers. Social capital has also been shown to be more important for older people than for younger people (Muckenhuber, Stronegger et al. 2012). Social capital has been examined and found that it can have a significant role at the end of a person's life (Lewis, DiGiacomo et al. 2013, Rosenberg, Horsfall et al. 2015) yet has not been examined in a care home sector, where statistically more people die than in hospices (South West Public Health Observatory 2010). A consistent theme throughout the literature is that network size and social interactions, as seen in the concept of social capital, appear to be important for life in both care homes and hospices in improving quality of life, social relations, well-being and the quality of care that is received while reducing feelings of loneliness and isolation. The atmosphere of a care sector also appears to be linked with the interactions and social networks of a care setting and have a key role to play in the atmosphere and wellbeing of the people who reside and work in these settings. The patient and their support networks are seen more entirely in a hospice. The hospice team values input and includes members

of the patients' family and carers, not just the patient themselves. This is something that appears to be less apparent in a care home sector suggesting hospices have higher levels of social networks and interaction and hence higher levels of social capital. There also appears to be better opportunity to build social capital within a hospice sector than in the care home sector. A diagnosis of a terminal or life limiting illness may increase social capital through increased social networks and interaction provided by the hospice care sector that a care home may not provide (Leonard, Horsfall et al. 2013).

Some studies have examined interactions and social networks in care homes and hospices but not from a social capital perspective despite the literature suggesting social capital could play a key role in the life and well-being of the people who receive care in care homes and hospices. Only one study was found that has examined social capital in care homes (Andrew 2005) but this study only used a single question asking about trust. The purpose of the study presented in this thesis, therefore, is to help address this gap in the research and to use the concept of social capital as a theoretical framework on which to base this study, as social capital cannot be measured directly due to the complexity of the concept.

## 2.12 Research Questions

The proposed study sought to answer the following questions:

1. What is the relationship between the social capital of older residents/patients and the atmosphere of the setting in which they are cared?
2. Are the quality and quantity of interactions between staff and those being cared for different between the two care sectors?
3. What is the role that visitors and volunteers play in the life of those being cared for within the two care sectors?

# Chapter 3: Methods

## 3.0 Introduction

This chapter details the study methods used. The first section provides an overview of social capital and how the concept has been operationalized in this study, before discussing the study design and methodology, followed by an account of the study settings and procedures followed. The study was undertaken in two overlapping phases, an observational phase (phase one) and an interview phase (phase two). For phase one the participants, tools, procedures, and the analysis are reported. The final section reports the participants, procedures and analytical process for the second phase of the study. The research questions that this study addressed were:

1. What is the relationship between the social capital of older residents/patients and the atmosphere of the setting in which they are cared?
2. Are the quality and quantity of interactions between staff and those being cared for different between the two care sectors?
3. What is the role that visitors and volunteers play in the lives of those being cared for within the two care sectors?

## 3.1 Study design and methodology

A pragmatic stance to answer the research questions was taken, valuing the benefit of both qualitative and quantitative research paradigms (Johnson and Onwuegbuzie 2004) to address them. As a result, the research presented in this thesis adopted a pragmatic mixed methods approach as the most appropriate epistemology for this study, using both quantitative methods in the form of structured observations and questionnaires, and qualitative methods in the form of an observational log to record free text entries, and semi-structured interviews.

Research paradigms are a theoretical mind set and belief that underpins the approach to research (Kinash 2006). Positivist research is concerned with gaining knowledge of the world using objective methods of scientific enquiry. In contrast, a constructivist approach relies heavily on qualitative approaches that recognise that there is no objective reality.

Constructivists see the world as context specific, and use qualitative methods to understand people's actions and thoughts through the point of view of the individual. Some have argued that these differences in the constructivist and positivist paradigms are incompatible which led to the development of a more pragmatic research paradigm (Teddlie and Tashakkori 2009). A pragmatic approach helps justify and overcome some of the methodological issues in social sciences (Morgan 2007) by combining both qualitative and quantitative methods to answer research questions that cannot be fully answered within a single paradigm (Johnson and Onwuegbuzie 2004, Creswell and Clark 2007, Teddlie and Tashakkori 2009). For this study a pragmatic mixed methods stance was chosen in an attempt to address the multidimensional nature of the research questions, rather than conduct two distinct studies answering different research questions.

The study was structured in two phases. The observational phase used both quantitative and qualitative non-participant observation. It has been argued that observations are necessary to gain an insightful understanding into care home life (Clark and Bowling 1990). Included in phase one was also a survey to measure the atmosphere of the care sectors (Lemke and Moos 1987) observed in this study.

The interview phase used an interpretive description methodology (Thorne, Kirkham et al. 1997, Hunt 2009, Thorne 2016) and an inductive qualitative method in the form of one-to-one semi-structured interviews. The interviews sought to provide an understanding of the role that visitors and volunteers played in the life of those being cared for within the two care sectors included in the study, care home and hospice. The choice of care sectors is justified and described in chapter 2 section 2.10. The interviews also aimed to help our understanding and provide insight into the levels of social capital and the atmosphere of the care sectors. Interpretive description allows the examination of a phenomenon with a goal of discerning underlying themes and patterns among subjective perspectives, while also taking into consideration and accounting for variations between individuals (Hunt 2009). Interpretive description recognises that objective knowledge is unreachable through empirical analysis, and that realities are subjective and contingent in the form and content on the individual who hold them (Guba and Lincoln 1994). In the terms of this study, this means identifying themes with respect to the role of visitors and volunteers within the care sectors, while taking into account the differing perspectives of individuals that belong to different groups of participants such as staff members, patients of a hospice and residents of a care home. Interpretive description also requires the researcher to recognise their own

bias derived from their clinical practice (Thorne, Kirkham et al. 1997) and take this into account through the analytical process.

## 3.2 Description of the study sites and preliminary work

The study was conducted in two hospices and two care homes in the East of England. Initial contact was made via phone call or email to the care setting manager to establish if they were willing to discuss participation in the study. If the managers were open to discussion about the research I arranged a meeting to discuss the study in more depth with the manager. To assist with the research study design and to refine the research questions, during the meeting I arranged to visit the care settings a second time to spend time in each environment. I spent a total of 40 hours voluntary work within a privately managed and owned care home to enable me to better understand the nature of the care settings, and to assist in the design of the study to ensure minimal impact on the everyday running of the care home. In addition to this, seven hours were spent in each of the two day-care hospice settings, which later became the two hospice study sites. This work ensured that the methods and data collection procedures were designed with both care sectors in mind, and that the same procedures could be used in both care homes and hospices without the need to change or adapt the study for the different settings. It also helped to ensure minimal disruption for patients, residents and the staff of the care settings.

### 3.2.1 The study care homes

Of the two care homes, one was privately owned and was a converted 17<sup>th</sup> century manor house, offering residential care for up to 28 residents with capacity for two day care guests. The care home has one main communal sitting area where most of the observations were conducted, as well as a smaller second lounge, a dining room, a meeting and activities room, and a conservatory that also acted as a second dining room at meal times. To enter the care setting I was let in the front door by a member of staff as the door was always locked. On entry to the care home was the main lounge area. It was a homely looking lounge filled with arm chairs placed in a circle at one end of the room, with other arm chairs placed in small groups at the other end of the room. There was always music playing for entertainment in the main lounge and this room was where most of the activities took place. I was shown around the care home and given an induction before I started the voluntary work shifts every evening where I helped in the kitchens, delivered food and

drinks to residents, and spent time talking to the residents and staff about the care home and the research.

The second care home was a larger capacity converted period building with a recently established nursing and residential living wing extension offering a residential care area and a nursing care area. It also had a dementia specialist wing and was owned and managed by a charity who also offered day care services for around three to ten day care guests per day. The care home had capacity for up to 89 residents including those that resided in the dementia specialist wing. The specialist dementia wing was in a separate building to the main care home but was located in the same grounds. Residents of the nursing and residential care areas resided in different locations of the care home, and often dined separately, but on some occasions the residents from the residential and nursing wings took part in activities together. When I entered the care home, I was greeted by the receptionist. The receptionist would let visitors through the locked door into the main building of the care home. I entered the care home on the main corridor used by residents and staff members which led to the dining area, lounge areas and to the residential and nursing care sleeping areas. The corridor was decorated with arm chairs for residents and visitors to use. I was led to the main lounge area by the receptionist where I could observe the usual running of the care home, and was introduced to the activities coordinator who showed me round the care home and what a typical day in the home was like.

The day care residents at both care homes received the same care and attention as full time residents for the whole day, but day care residents slept in their own homes. These residents travelled to and from the care home on days when they attended the care home at times that have been pre-arranged and agreed with the manager, but often this was between 10am and 4pm. This allowed a respite period for family or other carers while enabling residents to engage socially and participate in activities with other residents. It also provided an opportunity to bring new faces into the care homes for residents to spend time with and engage socially. Often initial contact with the care home was through attending day centre services prior to becoming a resident.

### 3.2.2 The study hospices

Of the two hospice settings, one was an NHS run hospice that offered in patient services and day centre services. The NHS hospice was described as a specialist palliative care unit, providing the same level of care, support and services as other hospices including activities, access to volunteers and a Chaplin service. The main difference between the specialist

palliative care unit and other hospices was an increased presence of medical staff and medical treatment was provided more often when compared to other hospices. The day centre had a large communal room which is divided into a sitting area, an activities area and a quiet area located at the side of the main room. In addition, there were several treatment rooms, private rooms that could be used by patients if needed, a laundry room, as well as a separate dining room at meal times. When I entered the hospice through the main sliding doors, I was greeted by the receptionist at the reception desk. The receptionist directed me down the long corridor that led to the day centre. When I entered the day centre it was decorated with arm chairs and paintings on the walls which gave a homely impression. I was greeted by a volunteer who immediately offered tea or coffee, and spoke with me about the hospice and the research before directing me to where I was able to sit and observe the running of the hospice.

The second hospice was a charity funded hospice offering inpatient and day centre services for end of life and palliative care. This charity funded hospice described itself as a safe and supporting environment for patients with life-threatening and long-term illnesses, and provided access to a range of services overseen by a nurse in an informal setting. Services that were provided included clinical assessments, physiotherapy and occupational therapy as well as 'feel-good' therapies such as hairdressing, manicures and pedicures, arts and crafts and creative writing groups as well the provision of a chaplain for spiritual support. There was a large communal room with a seating area for patients and visitors, an area for activities that was also used as a dining area, and a separate quiet area for talks and discussions. In a separate part of the building there were also a number of treatment rooms and quiet rooms for patients to have some privacy if needed. When I entered the hospice I was greeted at the reception by the receptionist, who then showed me to the day centre through a café/dining area with an adjoining lounge area for visitors. Once I entered the day centre I saw it was decorated with arm chairs and paintings on the walls, music was playing and patients were already chatting to volunteers. I was greeted by volunteers who offered me hot drinks and showed me around the hospice before directing me to the lounge area with the patients where I could observe the everyday running of the hospice.

The nature of hospices has changed over recent years, with day care services becoming more popular and more of the 'norm' for patients accessing hospice care as it allows respite for their family and carers. It also enables the patient to be regularly monitored regarding illness progression while also educating the patient to manage their condition and their pain effectively, maximising their independence towards the end of their life.

Generally, within the hospices that I visited for the purposes of this research, the patients who were admitted as an inpatient were severely ill and unable to receive the palliative care they needed outside of a hospital setting. If their life limiting illness was able to be stabilised the patient often then returned home and subsequently attended the day centre.

The focus of this study was on the day care centres of these two hospices. While the choice of care home and day hospice populations is discussed in section 2.10, the justification for the inclusion of day hospice rather than in-patient hospice is that patients attending the day centre hospice received the same level of care that historically hospices have always provided, but the purpose of the setting is more comparable to that of a care home setting. Often when the patients were admitted to the hospice ward, they were too ill to participate in research and were often entirely reliant on the hospice care staff. The patients that attended the day centre services were more comparable with the residents of a care home in terms of mobility and ability to move between the communal and private areas of the hospice and able to take advantage of the opportunity for patients to interact with one another.

There is also evidence, as identified in the literature review in chapter 2, to suggest that patients in a hospice setting are treated with more respect and are more likely to have their emotional needs met in a hospice setting when compared to a care home setting (Teno, Clarridge et al. 2004). Day hospices are included as a comparator to care homes as there has recently been a call for the hospice model of palliative care to be implemented into the care home setting (Miller 2015). By comparing day hospice settings to care home settings, this study is able to determine what social environments work well from a social capital perspective. These findings can then help determine the feasibility of implementing the social model of care from the hospice setting into the care home setting.

At first glance the populations within the care home and day hospice settings are dissimilar. The hospice movement has changed over recent years and patients admitted to hospice are now often in the last few weeks of life whereas care home residents can often live in or attend the care home over a period of years. Length of stay in a day hospice is more comparable to that of a care home, with patients attending a day hospice an average of 4.5 years with a range of 1 to 12 years (Higginson, Hearn et al. 2000). Hospice day centres are now much more common and operate in a similar fashion to day care that is provided in a care home setting, with a focus being put on activities and providing meals. In contrast, in patient hospice centres focus primarily on making the patient as comfortable as possible at

the end of their life. While the hospice and care home settings primary purpose is different, the populations that can attend these settings are comparable in terms of their physical ability, more so than care home residents and hospice in-patients. Older people who attend one care setting can often attend the other, with the only key difference being the presence of a terminal illness which would warrant them attending a day centre hospice over a day centre that is provided by a care home.

Pseudonyms have been used to identify each study site to preserve anonymity and are used throughout the rest of the thesis. The study sites are named as follows:

- Care home one (the privately run care home) is Manor Lodge.
- Care home two (the charity funded care home) is Harbour House.
- Hospice one (the NHS run hospice) is Queen Elizabeth Hospice.
- Hospice two (the charity funded hospice) is Saint Stephen Hospice.

### 3.3 Phase one: Observations and questionnaires

In phase one, both observational and questionnaire data were collected. The observational component was designed to give an insight into what life within these care settings is like in terms of social networks and interactions, thereby giving a proxy measure of structural social capital (Adler and Kwon 2002, Harpham, De Silva et al. 2006). The questionnaire was designed to provide a measure of the atmosphere of the care sectors.

#### 3.3.1 Participants and sampling – structured observations

All participants in the communal areas at the time of observation were included in the observations. Participants were coded into 4 groups: staff members; residents/patients; visitors such as relatives and health care professionals; and volunteers. For the observational data of phase one, time sampling was used (Webb, Campbell et al. 1966, Bryman 2012). Time sampling observation allows the number of specific behaviours such as social interactions to be recorded from multiple data points from within a certain time frame. Observations were taken in 15 minute blocks, with a 15 minute 'rest period' between each observation block (Clark and Bowling 1990).

#### 3.3.2 Participants and sampling – SCES questionnaire

For the second aspect of phase one of the study, opportunity sampling was used when administering the questionnaire to measure the 'atmosphere' of the care setting (Neuman 2005). Participants who completed the questionnaire had to either be staff members, visitors such as relatives who visited the care setting more than once, and volunteers. The questionnaire adopted for this study was originally designed by Lemke and Moos (1987) to be given to either residents or staff members of a care setting. For the purpose of the study for this PhD, a decision was made not to include residents or patients in this part of the research as they had already provided data in the form of observations, and I wished to avoid over-burdening them. Participants who met the criteria of being either a staff member, visitor or volunteer were asked to complete the questionnaire.

#### 3.3.3 Instruments

##### 3.3.3.1 Observational tool – Quality of Interaction Schedule (QUIS)

For this study, interaction has been operationalized to mean any action between two or more individuals that can be either verbal or non-verbal, but all individuals involved must be aware and conscious of the interaction (i.e. a resident cannot be asleep while a staff

member performs some level of care). After searching the literature for a suitable instrument to obtain the data required, a pre-existing observational tool called the Quality of Interaction Schedule (QUIS) (Dean, Proudfoot et al. 1993) was identified and used to record and rate the interactions that were observed in each of the four care settings. No other quantitative observational tool was identified that could provide the type of data required to record the quality of interactions of residents and patients in the care sectors. The tool (Appendix I) was originally developed as a way to evaluate residential care facilities for older people with mental illness. It is an observational tool that was designed to categorise social interaction between residents and others such as the staff members into one of five ordered categories ranging from positive to negative interactions: positive social, positive care, neutral, negative protective and negative restrictive. Non-participant observations were chosen as participant observation would not allow the collection of the type of data required for the QUIS observational tool. In the present study, QUIS was used with a time sampling technique adapted from Clark and Bowling (1990) to allow observation blocks to be 15 minutes long, with a 15 minute rest period between each observational block. The five categories of QUIS are positive social, positive care, neutral, negative protective, and negative restrictive.

Positive social interactions are interactions that are based on positive, constructive, social, friendly interactions and conversation. A 'positive social' interaction may also include responding to concerns raised by residents/patients. Examples may include general friendly greetings to individuals or conversation between individuals that is social in nature, or asking how someone is.

Positive care interactions are about the appropriate delivery of care that make the resident/patient feel safe, secure, and cared for in a professional manner. This can be achieved by offering reassurance, and by being polite and respectful to the resident/patient. Examples of this include providing explanation whilst delivering care, assisting a resident with eating food, assisting people with attending the toilet, administering medication and providing aid with mobility.

Neutral interactions are brief, indifferent interactions not meeting the definition of other categories. Interactions that would not be expected to impact on the feelings of the resident/patient, and have no positive or negative aspects. Examples of this may include putting plates down with verbal or non-verbal contact or an undirected greeting or

goodbye, meaning interactions that are generic to the room and not directed to an individual or group of people.

Negative protective interactions are those where care is provided but involves removing the resident from danger, keeping safe and caring but in a restrictive manner without explanation or assurance, in a way that disregards dignity for the individual. Examples of negative protective interactions include being told to wait for medication or help with something or being given a safety cup to drink from without explanation.

Negative restrictive interactions oppose or resist the resident's/patient's freedom of action without good reason or ignores them as an individual. These interactions leave the resident/patient feeling ignored or devalued as a person. Examples of this could involve being moved without providing a reason, ignoring calls for help, telling individuals not to swear or show anger, and telling individuals they cannot have something without providing a reason or explanation.

QUIS was originally designed to examine interactions between residents of a care home and others in that setting but has been used a variety of studies and settings. For example, it has been used in care home settings by Dean, Proudfoot et al. (1993), and in a clinical setting such as an acute hospital ward (Barker, Griffiths et al. 2016) as well as for hospital inspections by Healthcare Improvement Scotland (Healthcare Improvement Scotland 2011). As well as following the described categories, interactions were also recorded based on who initiated the interaction, and if the interaction was a one-way or two-way interaction, if the interaction was verbal or non-verbal in nature, and who the interaction was with.

If an interaction contained more than one type of interaction, for example an interaction began to do with the care of an individual but then contained social elements as outlined by QUIS, then the interaction was based on the ordering of the categories used in QUIS with the highest category observed in the interaction being the category recorded. If an interaction contained any social element then the interaction became a positive social interaction. The justification for this was that as these settings are designed to provide care, social interactions go a step further and it requires more effort to 'go the extra mile', improving the quality of interactions.

An interaction was deemed to have begun when the attention of someone involved in the interaction directs their attention to an individual or group, such as through speech,

actively listening or through physical contact; or when a resident or patient interprets the actions or speech of another individual as an opening of an interaction; or when a resident or patient attempts to get the attention of someone, for example a staff member, either verbally or non-verbally (i.e. through the use of a buzzer).

An interaction was recorded as complete when attention from the participants moved to another person or task. If one person in the interaction left the area but for a purpose that the interaction was about, the separation was still included as part of the interaction. For example, if a resident asked a staff member for a drink, the interaction was recorded as started when the resident first received the attention of the staff member. If the staff member left to get a drink the interaction was still recorded as on-going. The interaction ended when the drink had been provided and attention from both participants was moved elsewhere. If both participants left to go somewhere private such as a bedroom, the interaction was recorded until both participants left the communal area and entered the private space. Although the interaction was still on-going for those participants, the interaction was no longer taking place in a communal area so the interaction for the purposes of this study was recorded as ended.

QUIS was also combined with a qualitative log, which allowed me to record diagrams of the observational area and any field notes. The aim of the field notes was to put the observations into context. Researcher observations and notes recorded in the qualitative observational log included diagrams of where residents often sat in communal areas, what happened in general in the communal areas such as the routine of the care settings and descriptions of things that took place. The qualitative log recorded descriptions of the care setting that the QUIS could not capture in a structured way such as people walking through the setting but not interacting with anyone. This helped put the results of the study into context by looking at the layout and design of the care settings.

#### 3.3.3.2 Measuring atmosphere – Sheltered Care Environment Scale (SCES)

The atmosphere of an older persons' care home has been measured using a specifically designed tool called the Sheltered Care Environment Scale (SCES) (Lemke and Moos 1987). The SCES contains 63 items with 'yes/no' responses measuring seven subscales covering three dimensions (Moos and Lemke 1996). The seven subscales are cohesion, conflict, independence, self-disclosure, organisation, resident influence, and comfort (see Table 4). Of these seven subscales, only five were used in this study (Appendix II). The conflict and

resident influence subscales were not included in the questionnaire as it was deemed that these subscales were not appropriate for the hospice setting based on the experience that I had gained from spending time at, and volunteering in the two hospices included in the study. These two subscales were also considered less relevant to certain groups of participants (staff members, visitors and volunteers) such as the visitors and volunteers who may not have as accurate knowledge of these issues as the other participants. Patients in a day hospice were considered less likely to have a significant influence over hospice policy, and as patients were only there for one day a week it was considered less likely that conflict would arise. Removing these subscales also reduced the time it would take to complete the questionnaire for participants thereby reducing the burden that was being placed on them in these busy care settings. The SCES subscales can be used individually and the SCES has been also shown to be reasonably reliable and valid in measuring the atmosphere of older people's care facilities (Lemke and Moos 1990).

The SCES was designed and used within a residential care setting (Moos and Lemke 1996), but for the purposes of this research, it was also used in the hospice setting. There are other scales that have been designed to measure the atmosphere of more clinical hospital-based settings (Friis 1986, Røssberg and Friis 2003). However, it was considered that these other tools would not have worked particularly well in a residential care setting as they were more focused towards a clinical environment which was less relevant in a care home setting. The SCES was considered to be the best tool available for use in a residential care facility, that could also capture the atmosphere of a day centre hospice which is often designed to be more 'homely' and patient friendly than a traditional hospital ward setting. Alternatives to measuring a care settings atmosphere could have been the Ward Atmosphere Scale (Friis 1986, Røssberg and Friis 2003). It was apparent however, that although the scale was suited to a clinical environment and would be useful in an inpatient hospice setting, it would not be a valid tool for use in a care home sector. The SCES was considered a better way to examine the concept of atmosphere in a care home and day care hospice setting more so than other tools such as the ward atmosphere scale. The hospice setting tries to move away from a presenting a clinical environment even though they are often based on a hospital site. Instead the hospice tries to show a more friendly and homely environment more comparable to a nursing home than a hospital ward.

The SCES was chosen based on its flexibility in being able to be used with either the patient or staff participant groups, or both. It was felt that as the residents were already providing data in the form of observations that the SCES should be administered to the staff

members instead of residents to reduce the burden on the residents. It was also felt that due to the level of cognitive impairment among the residents of the care home, the SCES would not be suitable to give to the residents. The SCES was also administered to visitors and volunteers. Although unpaid, volunteers are often considered part of the care team by paid staff members and as such were included as participants in this component of the data collection. Visitors had the potential to give a different insight into what they thought the atmosphere of the care setting was like, giving a valuable insight to the atmosphere from an ‘outside’ perspective.

<b>Dimension</b>	<b>Subscale</b>	<b>Description</b>
Relationship	<b>Cohesion</b>	Staff support of residents and resident support of each other
	Conflict	Resident criticisms of each other and the facility
Personal	<b>Independence</b>	How much residents are encouraged to be self-sufficient and in personal affairs
Growth	<b>Self-Disclosure</b>	Extent to which residents openly express their feelings and personal concerns
System Maintenance and Change	<b>Organisation</b>	Extent to which residents know what to expect in terms of order, routines, procedures and clarity of rules in the facility
	Resident Influence	Residents influence on regulations and freedom from restrictions
	<b>Physical Comfort</b>	Comfort, privacy, pleasant décor and sensory satisfaction are provided by the physical environment

*Table 4: Sheltered Care Environment Scale dimensions, subscales and brief description. Bold subscales indicate the scales used in the present study*

### 3.3.4 Procedures

#### 3.3.4.1 Gaining access to the care settings

The beginning of the data collection process was to make contact with potential care settings to gain an insight into their willingness, availability and suitability to participate in the research. Care homes that had previous contact with a member of the research team were first approached and asked about their willingness to participate in the study. Due to

the low number of hospices in the East of England, hospices were chosen based on ease of access. Initial contact was made either via email or phone call with the care manager to discuss the research briefly. If the manager was open to the idea of research in the care setting then a face-to-face meeting was organised where the study was discussed in more detail. To help with the research study design and refine the research questions, during the meeting I arranged to visit the care settings again to spend more time in each location. I spent a total of 40 hours voluntary work within a privately managed and owned care home. This allowed me to better understand the care setting and help design the study in a way that would ensure minimal impact on the everyday running of the care home setting. In addition to this, seven hours were spent in each of the two day care hospice settings.

If, after the voluntary work was complete and time had been spent in each care setting to ascertain its suitability as a study site, the manager was open and receptive to the research and provided consent in principle at this stage, then an official letter of approach was sent to them (Appendix III, Appendix IV). The letter provided details about the study and what it would involve for the resident/patients of the care setting, the staff members and the visitors and volunteers. The managers were also offered the opportunity to examine all other participant information and research tools to keep managers fully involved and engaged. If the manager agreed and consented to the study taking place at their care setting then I attended either pre-existing staff and/or resident/patient meetings, or arranged a general information meeting for all staff and residents/patients who were able to attend. The purpose of the meeting was to provide information about the study, what it involved for the participants and what they could expect to happen, inform the participants of the opt-out procedure for the observations as well as their other rights as participants in the research. Posters (Appendix V, Appendix VI) and leaflets (Appendix VI, Appendix VII) were also provided to residents/patients of the care home/hospice providing written information about the study and their rights as participants.

If some staff members and residents/patients were not able to attend the information meeting then I would see these individuals separately and inform them of the study and provide them with the information that they would have received at the meeting. Once consent and advice could be taken from the consultees of individuals who lacked mental capacity and everyone was informed about the research and their rights as participants in the research, dates and times for when the observations could begin were organised with the care manager.

### 3.3.4.2 The initial data collection plan

There were several unforeseen challenges that had to be overcome to gain access to the care settings to conduct the fieldwork. This section describes the key challenges that were faced when beginning the data collection process and the methods that were used to overcome these issues to ensure data collection could begin and be completed within a timeframe for timely completion of the study. The initial plan for the data collection process (Figure 1) was set out as the intended method and order to collect all the data. Study site three in Figure 1 was a private care home which later withdrew from the research when attempts to make contact were unsuccessful.

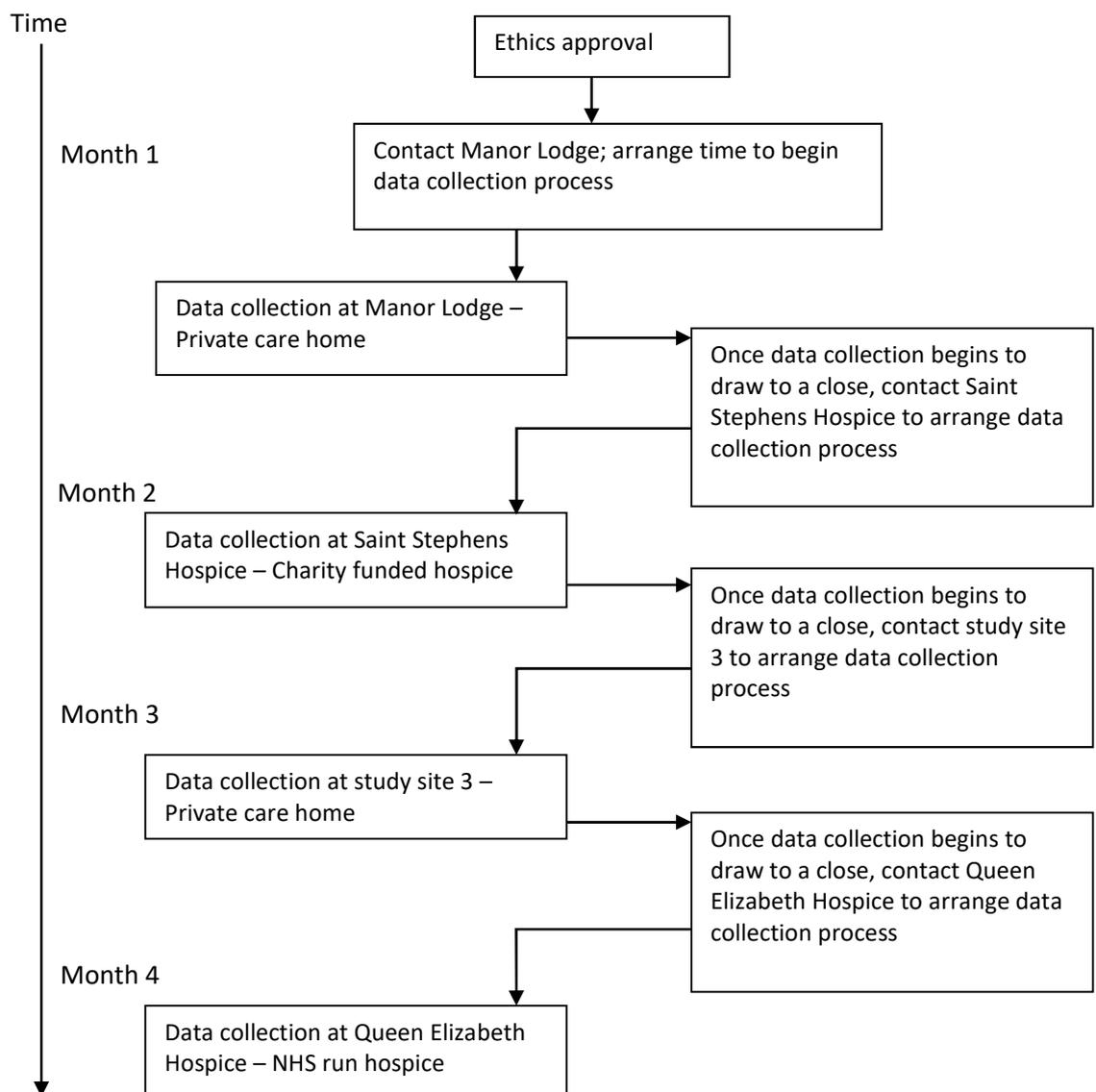


Figure 1: Initial plan of the data collection process and the order of the study sites

### 3.3.4.3 Challenges encountered in setting up the study

There were a number of unforeseen circumstances that arose which caused a delay in gaining access to the care settings and beginning the data collection process. These delays can be thought of in terms of two broad categories, difficulties with making contact with the care settings and delays regarding administration.

#### *Contact with study sites*

Within the two care home study sites, the delay in the data collection process was caused due to difficulties in establishing contact with the care home manager. Manor Lodge initially seemed particularly enthusiastic about participating in the research in general and willing to act as a study site early on in the research study allowing me to complete a number of voluntary work hours and answer questions to help design the study to have the least impact on residents and members of staff. After ethical approval was obtained however, the manager of Manor Lodge was unable to be contacted as a result of being on a training course for several weeks. Once the manager returned from the training course there were also a number of deaths in the home and felt that it would be better for the research to be postponed until new residents had settled into their new home. These unavoidable delays resulted in me changing the original data collection plan and obtaining access to a different study site.

A similar problem was encountered at the beginning of data collection at the second care home. This study site was initially recruited through the use of the Enabling Research in Care Homes (ENRICH) network and was first approached by the network on my behalf who set up an initial meeting to discuss the research. Of the four study sites, this care home had the least experience of being involved in research, as such the intention was to spend time building a relationship with the care home staff and manager while data collection was conducted at the other study sites. This would have meant that by the time data collection was due to start, a good working relationship would have been established in advance. Once data collection could begin at this site I tried to contact the care home manager through phone calls, email and visits to the care home, but this proved unsuccessful. It also proved difficult for the ENRICH network themselves to contact the care home manager about the study. After a month of trying to contact the care home, it was decided to begin recruitment of another care home into the study to replace this care home. A new care home, Harbour House, was identified through personal contacts and a brief meeting was

held with the care home manager to assess their willingness to take part in the research. Harbour House is a charity funded care home and part of a small national chain of care homes and had previously taken part in several research projects. The manager initially agreed to participate in the research once data collection had been completed at the other sites.

### *Administration delays*

Issues that arose causing delays within the hospice study sites revolved around administration delays and unforeseen administrative processes. Study site two was Saint Stephens Hospice and was intended to be the second location for data collection. The justification for moving the data collection process to this site next was based on pragmatic grounds as it was the furthest away from my academic base and required substantial travel time to get there. This part of the data collection was planned for the summer months to make the most of the longer days and better weather. It was also the second site that had been recruited into the research early on in the process so had been aware of the research for a longer period of time than the remaining study sites. The research became delayed at this site however, due to the site having their own local ethics committee which was not initially apparent in discussions with the manager when negotiating access to the hospice. To avoid delaying the research any further, ethical approval was immediately applied for from this committee. The approval letter received from the national committee and the letter confirming that the study was also undergoing NHS R&D approval were sent to the ethics committee at Saint Stephens Hospice with all other documentation. Due to it being a local ethics committee for the hospice, the process to review the study took around 6 weeks and could have been completed as soon as all documents were received by the committee with no deadline date being set. This process was also delayed however by a member of the committee being away at the time.

There were several administration delays when negotiating access to the final study site, Queen Elizabeth Hospice, the NHS managed hospice. It was expected to take the longest time to access this study site as NHS R&D approvals needed to be obtained before data collection could begin. Delays in gaining access to the other study sites meant that NHS R&D permissions were obtained and approval was given before data collection began.

#### 3.3.4.4 The actual data collection process

The initial delays when trying to gain entry to the study sites in the original order that was planned meant that the beginning of the data collection process was delayed by three months. Figure 2 below shows a flow chart of the actual process of data collection. During the delays, as much preparatory work that could be undertaken, was undertaken, so when the data collection began, it would run as smoothly as possible.

This process was set out based on pragmatic grounds to allow the data collection process to transition smoothly between study sites with minimal disruption to the care setting. It would also allow sufficient relationships to be built with people within the care settings before the data collection process could begin. An example of this was allowing time for me to build a relationship with the second care home as they were new to research and allowed me to ease them into the research process while collecting data at the other study sites first. The ordering of the study sites also allowed the completion of other administration processes to be complete without delaying the research. An example of this is that for study site 4, the NHS run hospice, a research passport and NHS R&D permissions needed to be obtained. The process of obtaining these could be undertaken while data collection was in progress at the other study sites.

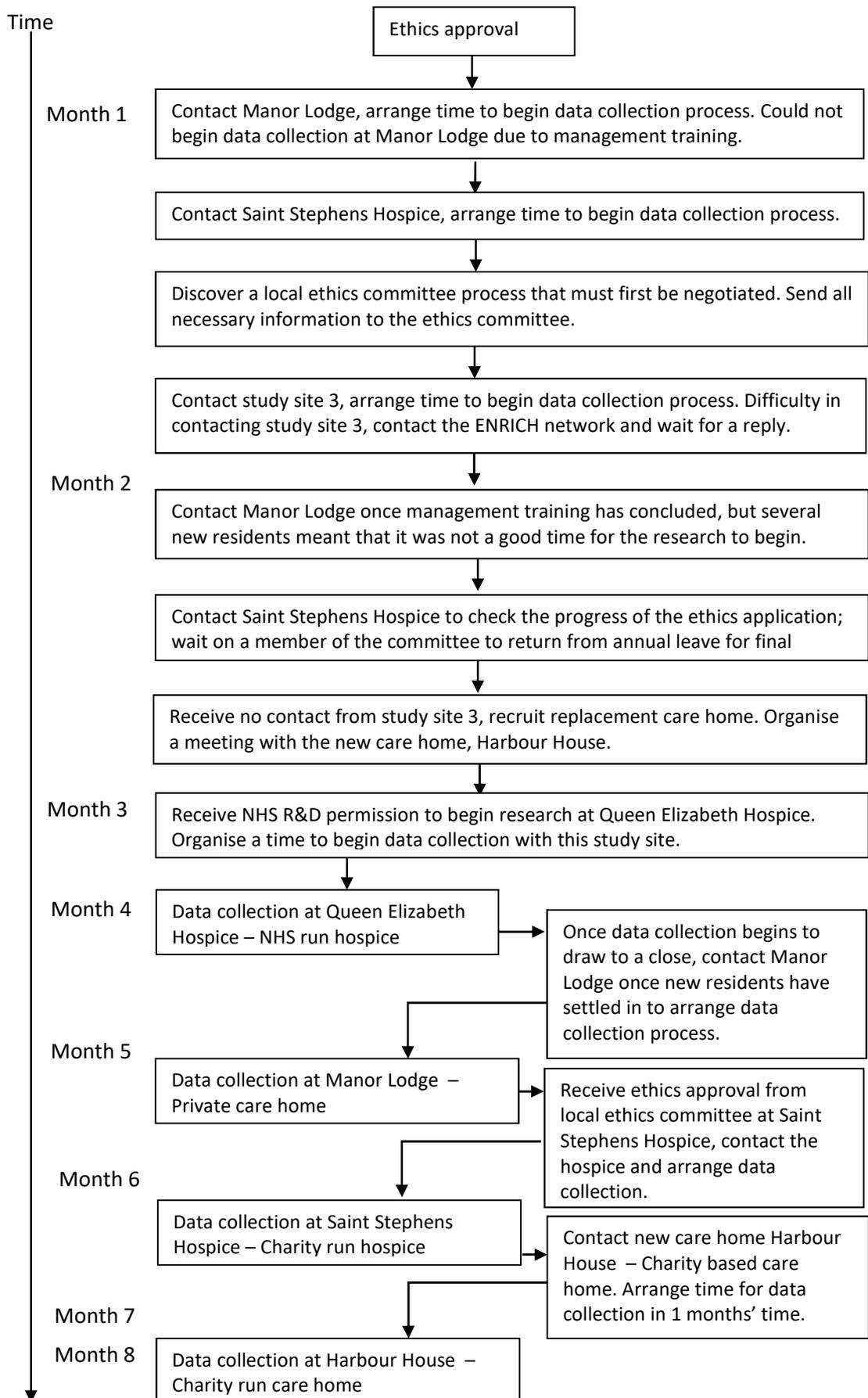


Figure 2: Actual process of entry into care settings and data collection

#### 3.3.4.5 Ethical issues and the Mental Capacity Act.

Mental capacity is the ability to make an informed decision about a particular issue, such as health care treatment or participation in research. It is inevitable that research with older people, particularly those who reside in care homes, will involve people who lack or have fluctuating mental capacity due to some form of cognitive impairment. As a result, those who lack mental capacity can only be included in research if they meet certain conditions as outlined in the Mental Capacity Act (2005). The Mental Capacity Act (2005) was introduced to bring together pre-existing legislation to put the needs and wishes of the person who lacks capacity at the centre of any decision making process. Key features of the Mental Capacity Act are that a person must be considered to have capacity to make informed decisions unless it has been established that they do not have capacity. Capacity must not be assumed to be lacking due to a person's age, appearance or behaviour as capacity may fluctuate over time and can be affected by many factors. An individual who lacks capacity is unable to make particular decisions due to an impairment or condition that affects the brain or mind. This may be temporary or permanent.

The 2005 Mental Capacity Act plays an important role in research that is conducted in settings such as care homes or that involves people who often lack capacity due to a cognitive condition such as dementia. Sections 30-34 of the Mental Capacity Act cover its use in research and outlines the principles that must be followed to ensure the safety and wishes of the individual are put at the centre of any decision made with regard to participation in research. The Mental Capacity Act outlines the procedures and processes that should be followed by researchers regarding personal and nominated consultees to provide advice about participation in the research on behalf of the individual who lacks capacity.

By wishing to include vulnerable adults and adults who lack capacity, a national ethics committee operating under the Health Research Authority was applied to for ethical approval for the research study presented in this thesis. The ethics committee has the authority to approve research involving adults who lack mental capacity, and also approve research taking place at an NHS site as long as the research does not change usual practice (i.e. is interventional) in any way. It was requested by the ethics committee that although participants with capacity could decide to 'opt-out' of the observations if they wished, participants who lacked mental capacity should have to 'opt-in' to the observations. This

involved checking for any advance decisions the individual may have left about participation in research. If no advance decision was found then the procedure involved sending information in the form of a letter (Appendix IX) with an accompanying leaflet (Appendix VII, Appendix VIII) to someone who would potentially be willing to act as a personal consultee to the resident/patient. The personal consultee was someone close to the resident/patient such as a family member or close friend. The letter informed the potential consultee about the study, the role of a personal consultee, and what would be expected of them should they wish to act as a personal consultee. The leaflet provided further information about the study and what it would involve for the participants. If they agreed to act as a personal consultee then they signed the consultee declaration form (Appendix X) and answered the question that asked for their advice about the wishes of the resident/patient who lacked capacity regarding participating in the study. If they provided their consent to act as a personal consultee then the completed consultee declaration form was returned to me by sending it either to the university using the pre-paid envelope that was provided with the questionnaire, or the care provider where I could collect it.

If no personal consultee could be found then a nominated consultee was sought. The nominated consultee was someone who knew the resident/patient well but was not personally related to them, such as a carer or keyworker. The procedures for obtaining advice from the nominated consultee remained the same as obtaining advice from the personal consultee. Neither personal nor nominated consultees were involved in the research as a participant thereafter. If no consultee could be found then the resident/patient who lacked capacity were not included in the study. In addition to the consultee process, process consent as described by Dewing (2008) was also followed. Process consent works towards inclusion of people affected by dementia in research and are often used when a person has limited mental capacity and can no longer provide informed consent. Process consent involves obtaining formal consent through ways such as consultee processes, but also ensures consent is given informally based on a person's feelings and actions. For example if a person showed signs of distress to taking part in the research then they would be considered to have withdrawn consent, despite the recommendation of the consultee. Figure 3 shows a summary of the consent process for different aspects of the study design. Full ethical approval was given by the Social Care Research Ethics Committee on the 21<sup>st</sup> July 2015, reference number 15/IEC08/0035 (Appendix XI).

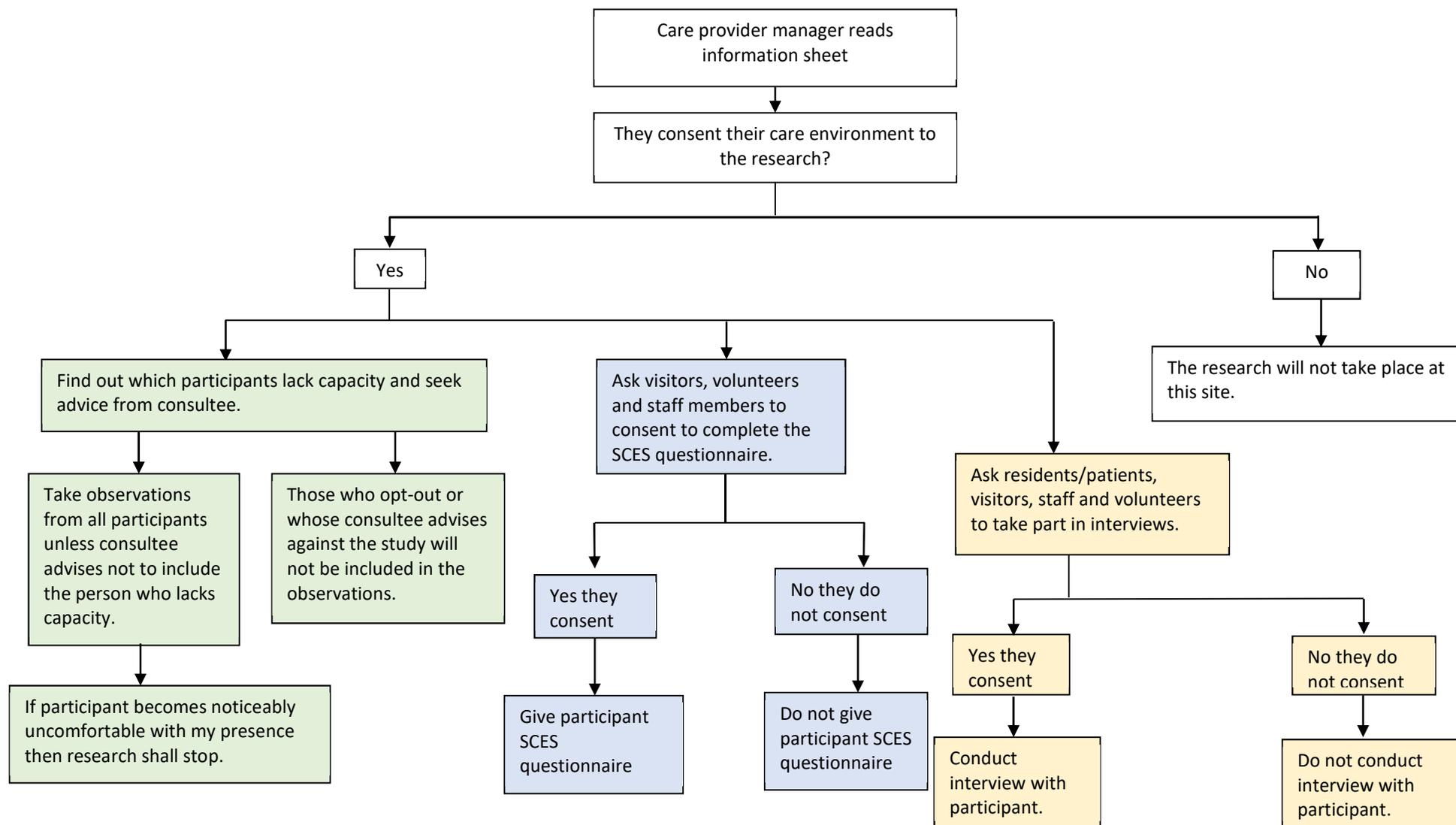


Figure 3: Summary of consent process for the different aspects of the study

Phase one: Observational aspects of the study.
  Phase one: Questionnaire aspects of the study.
  Phase two: Interview aspects of the study

#### 3.3.4.6 Structured Observations – Quality of Interaction Schedule (QUIS)

Once permission was gained to access the care setting, and participants had been informed of the study and their rights as participants such as withdrawing from the research without consequence and assurance of confidentiality, the care manager and I arranged mutually convenient times when the observations could take place. When the observations began, I placed myself in a communal area of the care setting that provided the best view of the whole area but did not interfere with the everyday work of the staff or the activities of residents/patients. If there were no participants at a particular time in the communal area, the observations were then taken from a different communal area. The main communal areas observed were the main lounge area, the secondary lounge or activities room, or dining room. If participants opted out of the observations they were omitted from observations entirely, but if my presence at the study site caused any discomfort (such as signs of stress, anxiety or agitation) to the resident/patient then I relocated to a different communal area away from that resident/patient.

Observations were split into either a morning period or afternoon period, and over a variety of days including weekdays and weekends to obtain a representative sample of a general working week. Specific start and end times depended on the care setting. In the day hospice, usual hours that the patients attended were from 10am until around 3 or 4pm. Observations began when patients arrived and ended when they left. In the care home setting, the communal areas and areas where activities took place were in use from around 9am until around 9pm. Day residents in the care home however worked on a similar schedule to the day hospice and arrived at the care home at around 10am and returned home around 4pm, but sometimes as late as 6pm. Observations in the care home took place at varied times between 9am and 9pm to gain a representative sample of the whole working day. Observations took place over 15 minute blocks (Clark and Bowling 1990) followed immediately by a 15 minute rest period giving me the opportunity to add any extra notes to the qualitative log to ensure detailed observations. This process was repeated through morning, afternoon and weekend observations until a total of 12.5 hours of observations had been recorded, within 50 individual observation blocks per setting. The target number of total observations at the four care settings was 200 observation blocks. The volume of data collected did not rely on the number of interactions observed, but rather the amount of time that was spent conducting observations. It was feasible that care settings could have very few observed interactions while others had a large number of observed interactions. Observations only ended once the target number of hours was

reached, regardless of the number of interactions that took place. By doing this it was then possible to compare care settings in terms of the number of interactions for the same amount of time. It was not possible to report the number of interactions per capita. The focus of this study was the number and quality of interactions for a given block of time, rather than for a particular participant. All interactions within a communal area were recorded, not just certain participants within the communal area. The number and quality of each interaction for specific participants could not be recorded due to the number of individuals entering and leaving the communal areas. Each interaction that was observed recorded the approximate duration of the interaction, the interaction code as set out by QUIS, whether the interaction was verbal or non-verbal, the direction of interaction such as one-way or two-way, who initiated the interaction, who the interaction was with, and a brief description of the interaction.

#### 3.3.4.7 Recruitment of participants for the Sheltered Care Environment Scale (SCES) questionnaire

The participants for the SCES included staff members, volunteers and visitors to the care setting. These potential participants were already aware of the research due to the posters and leaflets that were in place in the settings, and the meeting that was held to inform participants about the study. I approached potential participants by introducing myself, explaining the study, and asking if they would be interested in completing a questionnaire (SCES). If the participants showed interest in participating then they were provided with an information sheet (Appendix XII, Appendix XIII) attached to a copy of the questionnaire (Appendix II), allowing them to see the questionnaire before completing it.

Participants provided implicit consent by returning the completed questionnaire to me either in person, by leaving it in a designated collection box, or by returning it in a prepaid envelope. Visitors to the care setting who were less familiar with me were approached by myself, but also a staff member if one was available to facilitate introductions between the potential participant and myself.

Figure 4 details the target sample that was to be collected for phase one of the study. It reports the target number of observations and questionnaire responses that were aimed to be obtained for each of the care sectors.

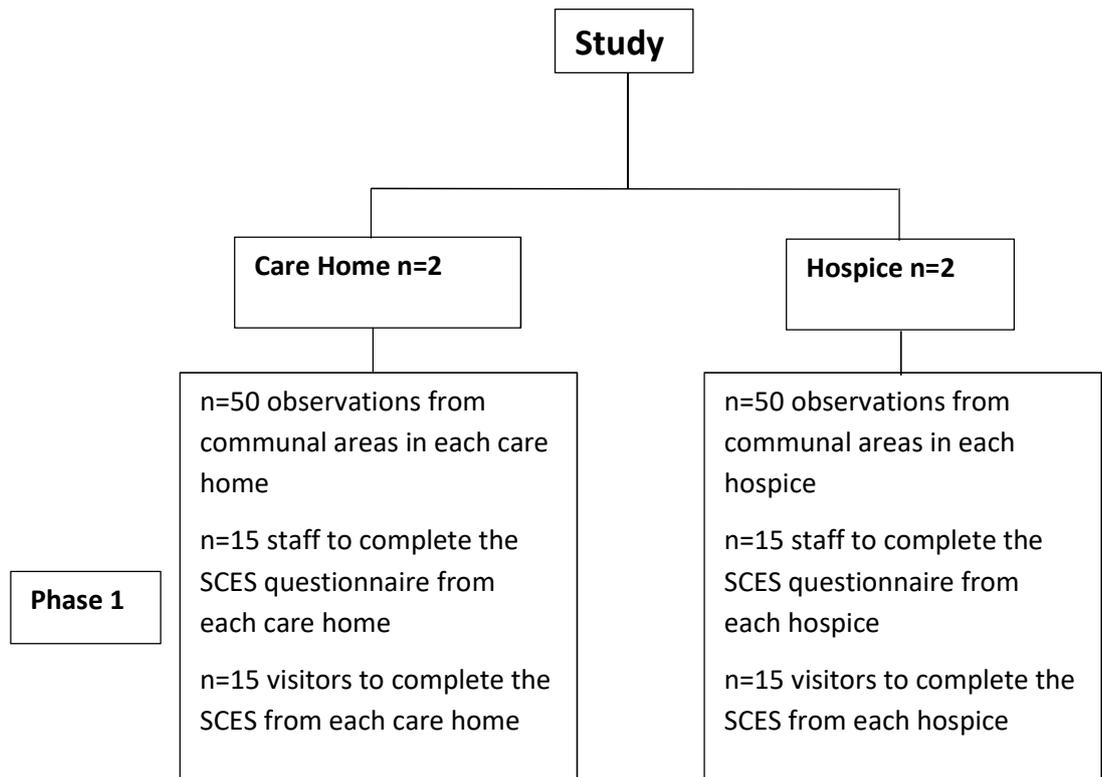


Figure 4: Outline of the target data that was to be collected for phase one of the study.

### 3.3.5 Analysis

#### 3.3.5.1 Data management of the QUIS observational data

The five QUIS observation categories (positive social, positive care, neutral, negative protective, negative restrictive) were dichotomised so that positive social and positive care ratings were combined into one category, while neutral, negative protective and negative restrictive ratings formed the other category. The justification for dichotomising the interaction rating was that it combined the five categories into two broader categories of positive interactions and negative interactions as has previously been done in other research using QUIS (Barker, Griffiths et al. 2016). The neutral category being distinct from positive and negative categories has been included in the negative category grouping. This was because a neutral interaction, while having no negative aspects, lacks effort to make the interaction positive for the resident or patient, and therefore lacked the quality that a positive interaction provides, yet could be added easily into an interaction.

#### 3.3.5.2 Analysis of the QUIS observational data

QUIS scores were first analysed descriptively in terms of number of interactions, mean duration of interaction and types of interaction in each care setting to provide a profile of

life in the two different care settings. A binary logistic regression model was used to compare the quality of interaction between care sectors while controlling for other covariates. Covariates such as the direction of interaction, duration of interaction, who initiated the interaction, and if the interaction was verbal or non-verbal were included in the regression model to help control for any confounding variables within the regression model.

This analysis had advantages over other methods of analysis for example calculating the mean score of the quality of interactions within care homes and hospices and performing independent t-tests, as regression models can be examined, and a number of variables can be adjusted for.

Unlike Linear regression, logistic regression makes few assumptions that require formally testing as many of the assumptions are regarding the design of the study and format of the data (Field 2009, Pallant 2013, Statistics 2013). A key requirement for logistic regression is that the outcome variable is dichotomous. The outcome variable for this regression analysis was the quality of interaction rating which was dichotomised into positive and negative categories. One assumption that is made in a logistic regression is the linearity of logit for a continuous predictor variable within the regression model. Logistic regression does not assume a linear relationship between the predictor and outcome variables, but it does assume a linear relationship between the log odds of the outcome variable and a continuous predictor variable (Field 2009).

All models were restricted to interactions that were either initiated by a resident or patient in the care settings, or interactions that were initiated by other individuals but included residents or patients in the interaction. It should be noted early on that all observations were recorded over the working day of the care settings. This means that the observations in the care home setting are more spread out over a longer day than the hospice setting. As there was only a single observer, there is no inter-rater reliability calculation.

#### 3.3.5.3 Data management of the SCES questionnaire

Negatively-worded items of the SCES questionnaire were reverse coded to ensure all questions were scored in the same direction. Any questionnaires that had three or more missing responses (out of a possible nine) in a given subscale had that subscale omitted from the analysis. There were not enough questionnaire responses returned to use techniques such as multiple imputation to handle missing data. The mean scores were then

calculated for each subscale of the questionnaire (Cohesion, Independence, Self-Disclosure, Organisation and Comfort).

#### 3.3.5.4 Analysis of the SCES questionnaire data

Descriptive statistics were first produced such as the number of responses and mean scores of each subscale of the questionnaire for each study site. The mean scores were compared using independent t-tests to compare any differences in the atmosphere either between care sector (care home and hospice). If a large enough number of questionnaire responses were collected at each site, then within sites (between the two care homes or the two hospices themselves) t-tests would be used to examine any differences in the types of settings that the study was conducted at.

The planned hypothesis test for the SCES data was the independent t-test comparing the means for each subscale of the questionnaire between the care home and hospice care settings. To see if the data met the assumptions of the independent t-test, histograms were produced of the distribution of the subscales to test for normality. True normality is considered unlikely to be obtained in any sample (Elliott and Woodward 2007). There are a variety of methods to test for the assumption of normality (Ghasemi and Zahediasl 2012). Normality can however be looked at visually using normality plots (Altman and Bland 1995, Field 2009). With large enough samples (around > 30 or 40) it is suggested that the violation of this assumption should not cause significant problems for the analysis, implying that parametric tests can be used even when the data are not normally distributed (Elliott and Woodward 2007, Pallant 2013). The assumptions of the independent t-test were first checked using histograms and boxplots and as some subscales violated the assumption of normality, the non-parametric Mann Whitney U test was also conducted as a sensitivity test to confirm the findings of the t-tests as the assumptions are more relaxed with the non-parametric alternative, although they have less statistical power.

### 3.4 Phase two: Interviews

The second phase of the study involved conducting semi-structured interviews with residents/patients, care home and hospice staff, visitors and volunteers. The interviews were intended to examine in greater depth the relationship that the residents and patients at these care sectors had with the visitors and volunteers of these settings from the perspectives of the different participant groups. Visitors and volunteers are key social

components of both care homes and hospices and help to expand the social networks of those that are cared for within these care settings. Putnam suggests that voluntary associations have declined over the last few decades (Putnam 1995) and voluntary associations may be a key indicator to the level of structural social capital within these two care settings as discussed within the literature review (chapter two) of this thesis.

### 3.4.1 Participants and sampling

Participants in this second phase of the study included residents and patients of the two different care sectors who had mental capacity to consent to the interviews. Other participants included staff members, volunteers at the care settings, and visitors who included relatives and friends over the age of 18 years who had visited the care settings more than once and were therefore familiar with the environment. Opportunistic sampling was utilised and any potential participant who belonged in one of these categories and had capacity to consent and were over the age of 18 was approached to take part in the interviews until the target number of 10 participants for each site (40 in total) was met.

### 3.4.2 Interview schedule

A semi-structured interview schedule was developed (Appendix XIV) to address the third research question: What is the role that visitors and volunteers play in the life of those being cared for within the two care sectors? Additionally, the interviews also aimed to help increase the overall understanding of social capital and the atmosphere within the care settings. The interview schedule consisted of a number of pre-worded introductory statements and prompts to check that consent had been obtained and that the participant was happy for the interview to be audio-recorded. The interview schedule had three main sections. The first section contained discussion topics about the volunteers within the care setting, the second section contained topics about the visitors that visited the care setting, and the final section was about the atmosphere of the care setting to gain a qualitative perspective to augment the information attained in the SCES questionnaire. The interview schedule included questions that were open-ended and encouraged the participants to provide examples and tell 'stories' about experiences relating to visitors and volunteers (Jacob and Furgerson 2012). The interview schedule also included prompts that I could use should the participant only give short answers or was unable to think of any examples. The interview schedule was designed to produce an interview lasting around 30 minutes. The

justification for this was that anything longer ran the risk of placing undue strain on residents/patients, and take up too much time out of a staff member's day. Interview questions were reviewed and refined following feedback from supervisors but due to limitations of time, the interview schedule was not piloted.

### 3.4.3 Procedures

All interview participants were aware that the study was taking place as the research had been running for at least one week in the care setting before the interviews were undertaken. There were also posters and leaflets on display, and meetings were held to inform all available participants about the research and what it involved. Staff members were approached to help identify suitable resident and patient participants by informing me which residents and patients had capacity to consent and who would be the best suited to have a discussion with me about the role that visitors and volunteers play within the care settings. If available, staff members were also asked to facilitate introductions between me and the residents/patients to ease the potential participant into the research by providing an individual who the resident or patient was familiar with and knew in a professional capacity. Staff members were also asked to help facilitate introductions with any visitors that were approached to take part in the interviews. I approached staff members and volunteers independently as they were more familiar with my presence in the care setting. To avoid risk of coercion, all participants were informed both verbally and in the information sheets that there would be no negative consequences if they decided not to take part.

Once contact had been made with a potential participant brief details were provided about the interview and if the participant was open to the idea of participating, they were provided with an information sheet. Residents and patients received a different information sheet (Appendix XV, Appendix XVI) to the other groups of participants (Appendix XVII, Appendix XVIII). The information in the residents' and patients' information sheet was presented in a larger font and was designed to be read aloud if the participant preferred. If the potential participant agreed to participate in the interview then at the beginning of the interview they were provided with a consent form to sign (Appendix XIX). The interview was arranged for a mutually convenient time. A discussion was had with the participants just prior to the interview about how much time they could realistically give to the interview as the interview was intended to be around 30 minutes in length. Many

participants, primarily staff members, could not spare 30 minutes so the interview was shortened to the amount of time they were able to give. This was particularly the case with staff members and often the interviews had to be paused due to the staff member needing to complete a task or help a resident/patient due to the busy nature of these care settings.

The interview was conducted in a private room on the site where the study was being conducted. A digital voice recorder was set up in the room to capture the interview for later transcription. I made a few statements about the study and asked some questions to ensure that the participant had provided full informed consent and was happy that the interview was being audio-recorded. After the interview, the digital recordings of the interview were uploaded onto a computer and were then transcribed verbatim. The resulting transcripts were then saved on a secure university server providing all the security benefits of data stored on the university networks, such as password protection and secure firewalls. Figure 5 details the procedure and target number of interviews to be conducted in each care sector for phase two of the study. As well as conducting the interviews, any participant who has not already completed a SCES questionnaire was invited to do so either prior to or after the interview took place.

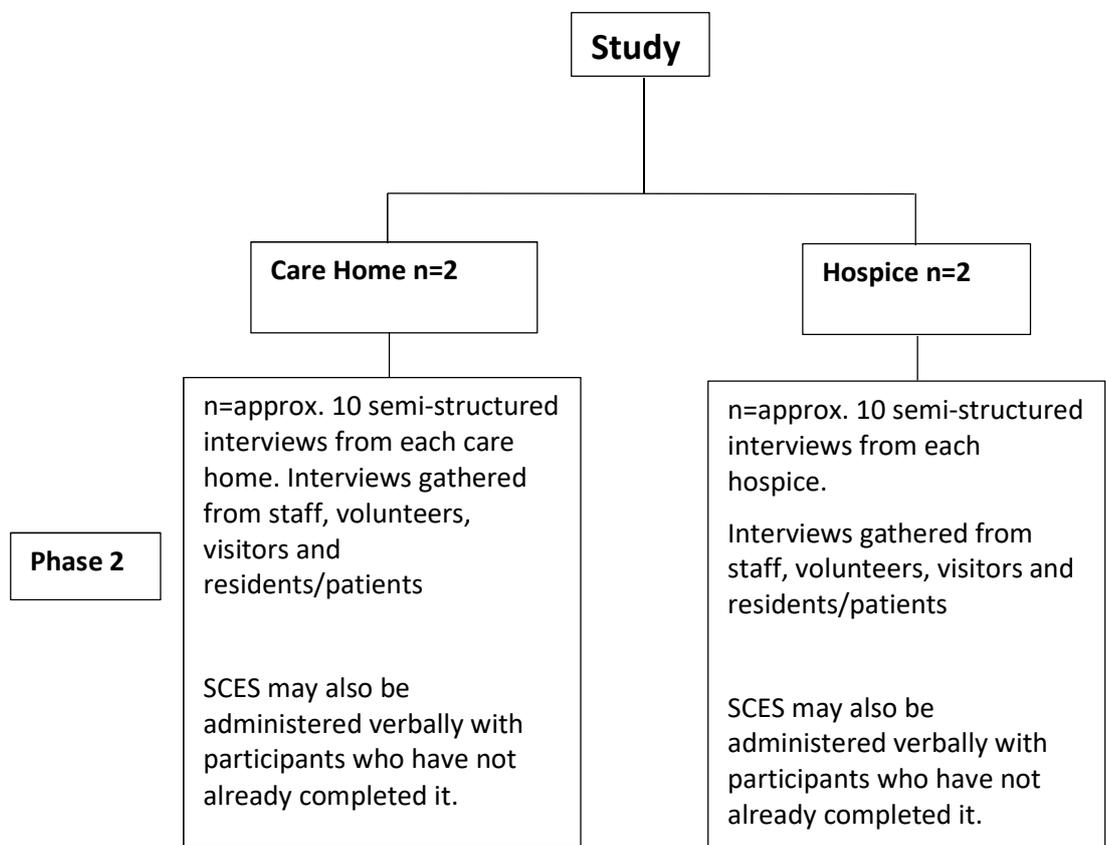


Figure 5: Outline of the target data that was to be collected for phase two of the study.

#### 3.4.4 Analytical process

Thematic analysis was used to analyse interview data, based on the principles identified by Braun and Clarke (2006). This analytical method was chosen as it is flexible and allowed me to look at the dataset and discover key themes that emerged utilising a coding framework.

Thematic analysis does not conform to any single theoretical framework, but neither is it atheoretical. Braun and Clarke (2006) report a framework of thematic analysis that revolves around the level of depth of the analysis referred to as the semantic or explicit level, also known as a deductive analysis, and the latent or interpretive level, also known as an inductive analysis. The semantic approach identifies themes that are in the explicit meaning of the data and involves examining the significance of the theme and the broader implications based on a theory. In contrast, the latent approach involves looking more at the underlying ideas behind the identified themes and involves looking at the assumptions and underlying concepts behind the themes and is often used to generate a theory or overall concept. This analysis drew on both approaches, as this enabled insights into the role of visitors and volunteers from multiple perspectives, while allowing emerging ideas and themes to be explored in relation to social capital and the atmosphere or the care settings.

A theme is defined as *“Something important about the data in relation to the research question, and represents some level of patterned response or meaning within a data set”* (Braun and Clarke 2006). For the purposes of this research, a theme was anything that was related to the role that visitors and volunteers played in the life of those being cared for, as well as anything that could elaborate on the social capital and atmosphere of the different care settings. The participants provided information about the roles of the visitors and volunteers, what they did for those being cared for in terms of social interactions and social networks, as well as providing examples to try and highlight and explain what they mean by what was said in the interviews. The amount of space in a dataset that a possible theme takes up should not qualify it as a theme, and the prevalence in a dataset should not be crucial in determining what constitutes a theme.

In terms of how the actual analysis was performed, the guidelines set out in Braun and Clarke (2006) were followed. These guidelines can be used throughout any thematic analysis and are not dependent on the philosophical frameworks. Braun and Clarke's guidelines set out a six-stage method for conducting the analysis from the verbatim

transcript. The first stage is to 'familiarise oneself with the data'. This was achieved by transcribing all the interviews verbatim, checking the transcript against the original recording for accuracy and re-reading the transcript. Notes were taken throughout this process to act as a basis for codes in a later stage of the analysis. Places where questions were asked by the interviewer were noted as possible places in the transcript for key information, examples by the participants were also noted so I could come back and examine them more closely in the later stages of the analysis.

The second stage of the analysis consisted of creating generalised initial codes such as the roles of visitors and volunteers, what they brought or did for the residents and patients in these care sectors and what they brought to the atmosphere of the care settings. The codes were not as broad as overall main themes, but were later combined, condensed and grouped together to generate the themes that were apparent in the dataset as seen in the third stage of the analysis. Data from the different care settings was analysed first (care home and then hospice) before the data were then examined from different types of participants such as resident and staff members. The codes and a sample of transcripts were given to my supervisors to review, and confirm or challenge the codes that were seen.

Once my supervisors and I were satisfied with the coding framework the third stage of the analysis could begin. The third stage of the analysis involved searching for actual themes. This was achieved by sorting the initial codes into groups. Concept maps (appendix XXIII) were produced using NVivo in order to work through the relationships, patterns and links that were seen between the codes. Once the codes and relationships between the codes had been determined, codes that were related to one another were grouped together under broad headings. Once the codes could no longer be grouped these groups of codes were given initial overall names which became themes showing trends in the data across the whole dataset. The themes were examined in terms of their importance or relevance to the research questions. The themes could also be matched to extracts from the transcripts to gain an overall picture of how much supporting evidence the theme had within the dataset. The third stage provided a list of themes that were found in the dataset as a result of the analysis.

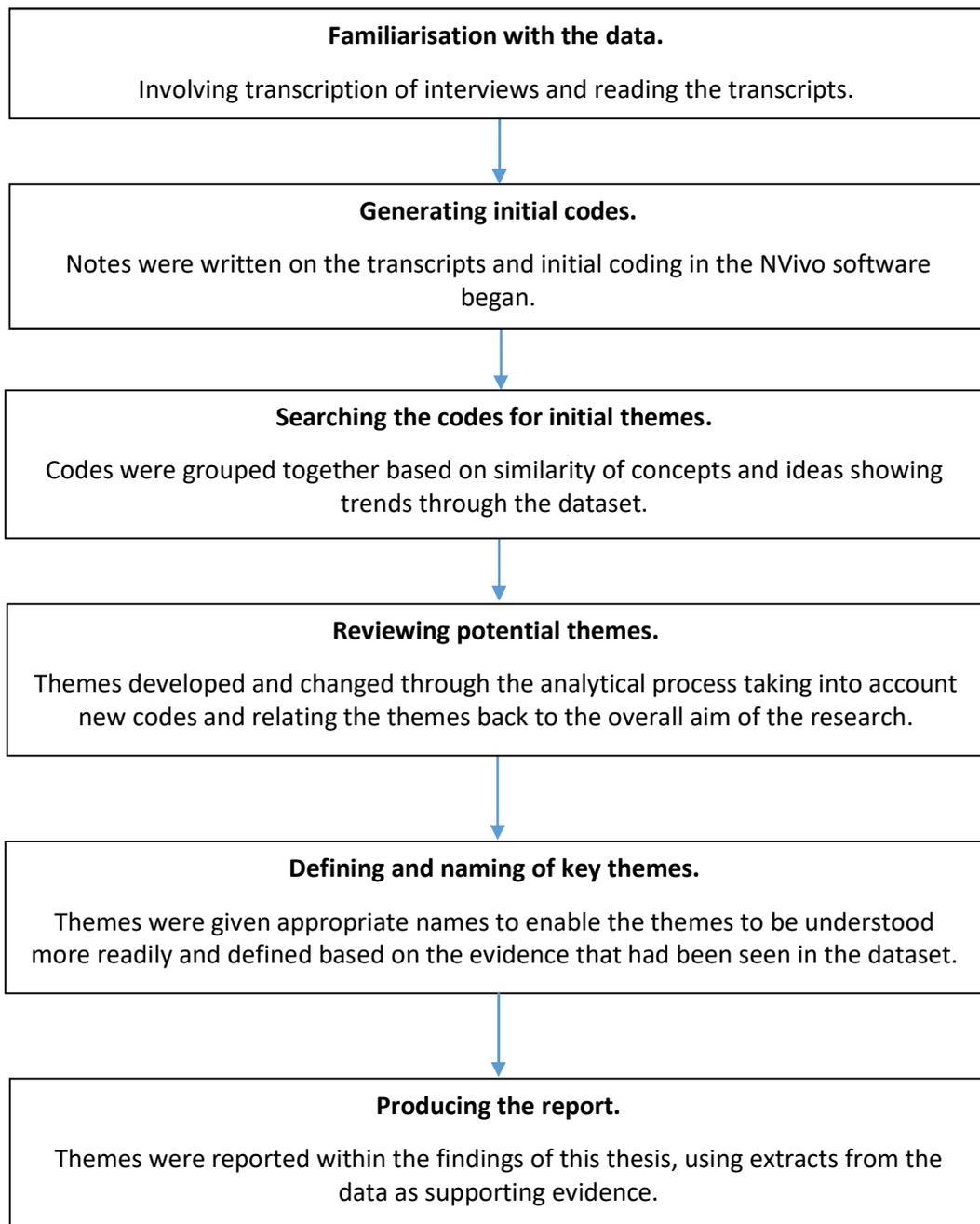
The fourth stage involved reviewing and refining of themes. This was accomplished by examining the themes of the whole dataset and reviewing them and the evidence to support each theme so that the most relevant and prominent themes underpinned by the

greatest amount of evidence could be retained. Other themes that did not have enough evidence to support them were discarded or considered as subthemes.

The fifth stage of the analytical process was defining and naming the themes. This stage assembled the themes and created an overall name for the theme based on the evidence, codes and extracts that are contained within the theme and helped create it.

The sixth and final stage of the analytical process was to produce the report. The final stage of the analysis described by Braun and Clarke (2006) is condensing the large amount of data down into a concise report to answer the research questions.

The analysis was conducted using both computer software NVivo 11 and coding by hand on hard copies of the transcripts. The early stages of the analysis to familiarise oneself with the data was completed through transcription, checking the accuracy of the transcription while simultaneously making notes. Due to the volume of interview data and the time frame of the study, some interviews were transcribed by a third party transcription company. Familiarisation with these transcripts involved listening to the recording and checking the accuracy of the transcript, then re-reading the transcript before any notes or codes were first produced. Initial codes were also completed on hard copies of the transcripts. Due to the large volume of data, the software was needed to help organise the data into the different types of participants (resident and patient, visitor, volunteer and staff member) and to allow the codes and later themes to come together into groups. The analysis of the transcripts that involved examining each transcript individually was completed by hand, but once the data could start to be looked at as a whole and could be brought together into a single dataset the computer software was used for organisational purposes and to allow extraction of relevant quotes and evidence for the themes to be completed with relative ease. A coded transcript is provided as an example in appendix XXII. Figure 6 shows a flow diagram of the thematic process that was followed under the guidelines of Braun and Clarke (2006).



*Figure 6: Diagram of the thematic process followed based on the framework outlined by Braun and Clarke (2006).*

The research design and target data to be collected for the entirety of the study is set out in Figure 7. The figure details the target sample that was to be collected for each phase of the research and in what care setting, as well as the order in which the data was collected. The amount of data and numbers stated in this chapter are what I was aiming to collect during my data collection period.

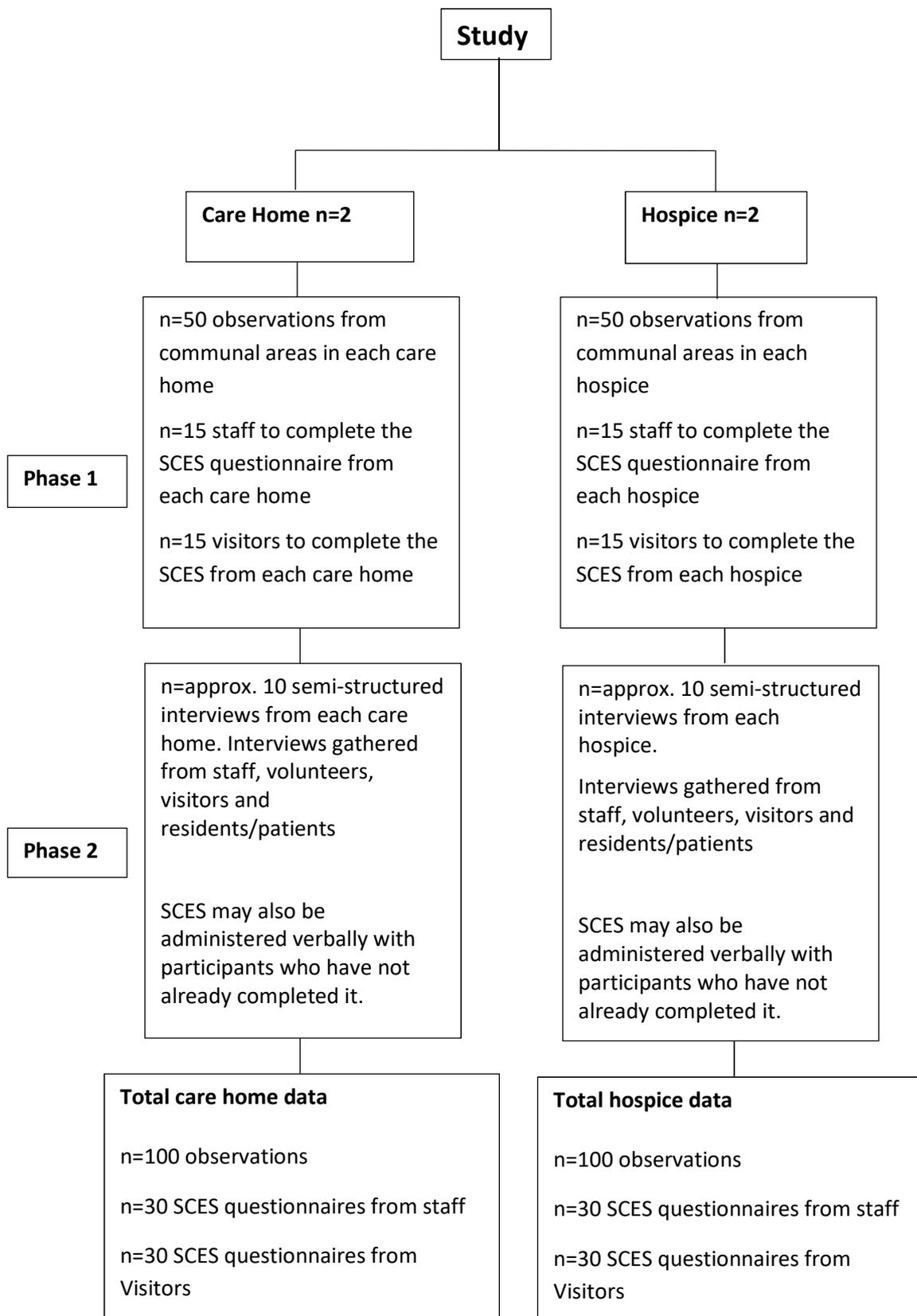


Figure 7: Planned design and order of the data that was collected.

SCES = Sheltered Care Environment Scale

### 3.5 Data Synthesis

Mixed methods research is an intellectual and practical synthesis of qualitative and quantitative research findings that is often considered a third methodological paradigm. A mixed methods approach recognises the importance of traditional qualitative and quantitative research and data collection techniques but provides the most informative, complete and useful research results (Johnson, Onwuegbuzie et al. 2007). There are a variety of ways in which qualitative and quantitative data from mixed methods studies can be integrated into a single more complete study, as well as drawing on mixed methods research to better answer questions proposed by systematic reviews (Harden 2010). This thesis followed the triangulation protocol (Farmer, Robinson et al. 2006). While some methods of data synthesis such as a “mixed methods matrix” or “following a thread” take place during the analysis phase of the research process, the triangulation of findings takes place after the qualitative and quantitative data have been analysed, and findings interpreted (Moran-Ellis, Alexander et al. 2006, O’Cathain, Murphy et al. 2010). Once the data had been analysed, findings from the qualitative and quantitative aspects of the study were compared to look for any instances of convergence where findings agreed with each other, as well as any discrepancies between the qualitative and quantitative findings. Qualitative and quantitative findings were then interpreted in light of one another which lead to a better understanding of the research question (Fielding and Fielding 1986).

# Chapter 4: Phase one – Observational findings

## 4.0 Introduction

This chapter presents the findings from the first phase of the study. First, the chapter describes the four care settings based on fieldwork notes recorded within the qualitative log to put the results into context. The next section reports the Quality of Interaction Schedule (QUIS) observations findings. The third and final sections report the findings of the Sheltered Care Environment Scale (SCES) questionnaire.

## 4.1 Qualitative description of the care settings

The main lounge areas of the four care settings were largely based on a similar layout and design. There was a large central communal area with chairs arranged to encourage interaction. All the study sites had furniture and decorations that attempted to create a homely atmosphere, for example pictures on the walls, comfortable armchairs as opposed to solid easy to clean chairs, and table clothes on the tables. Within all the care settings, but especially within the hospice settings, efforts were made to keep medical equipment out of sight but nearby in case of emergency. For example the lifting equipment was stored out of sight in a store room despite being used regularly, and oxygen tanks were kept out of sight behind chairs and furniture. Diagrams on rooms' layouts are presented for Manor Lodge (Figure 8), Harbour House (Figure 9), Queen Elizabeth Hospice (Figure 10), and Saint Stephens Hospice (Figure 11). The diagrams show the layout and design in each care setting and where I placed myself to record observations.

The diagram of Manor Lodge (Figure 8) shows the layout for the care home. The main lounge and dining areas are adjacent to each other, with a smaller less used lounge to the left of the main lounge. The other areas in the home were mainly bedrooms with some smaller dining areas that were rarely used. For the majority of the observations I placed myself in an area that gave me a view of the whole main lounge area and the dining room when it was in use. Residents who used the lounge areas tended to stay in the main lounge in the group of chairs arranged in a circle around the radio.

### Manor lodge



Figure 8: Diagram of Manor Lodge

Harbour House (Figure 9) had the most comparable layout to the hospice setting. There was a large open lounge area where many of the activities took place and also overlooked a garden area that was used in the summer time. There was a dedicated art room to the left of the main lounge area. This care home had an onsite bar located next to the lounge that was open for an hour before lunch and an hour in the evening. The bar was also used as a second lounge area or meeting area for residents before meal times where the residents would then go to the dining room together located in a different area of the care home. I placed myself on the edge of the bar area which gave me a view of the bar and the main

lounge area. When residents were in the art room instead of the lounge I moved to that area to maintain a view of all interactions.



Figure 9: Diagram of Harbour House

Queen Elizabeth Hospice (Figure 10) had a central lounge area for patients that was separated from offices and clinic rooms by a free-standing wall. The wall created a walkway in which staff members could move around the hospice area without disrupting the patients. The wall had a window in it however allowing staff members to observe patients. There was a separate dining room that was added to the building which was used as a meeting room when needed, but also a dining room for patients so they did not have to eat their meals from a tray. The lounge had a table next to where the activities took place, and both overlooked a large garden. I placed myself at the edge of the lounge area near the dining room to give me a view of both the lounge and dining room.

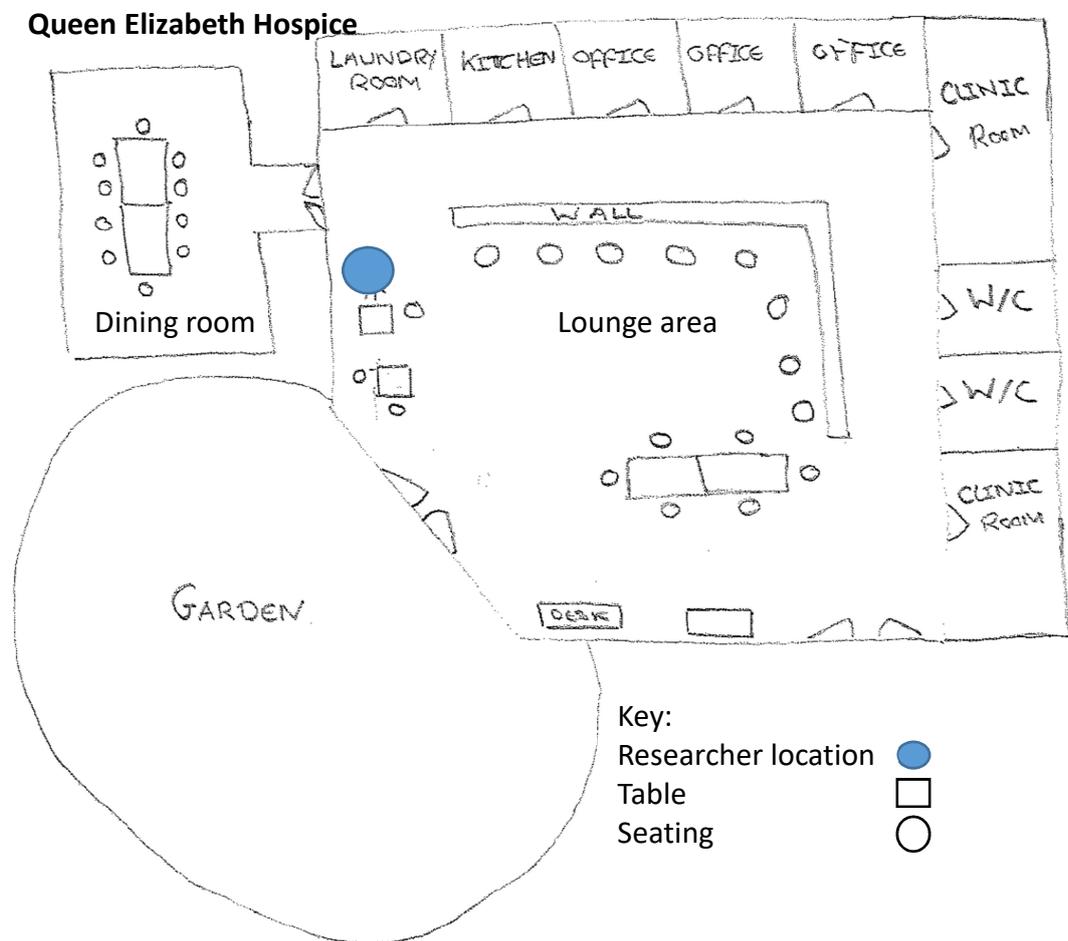
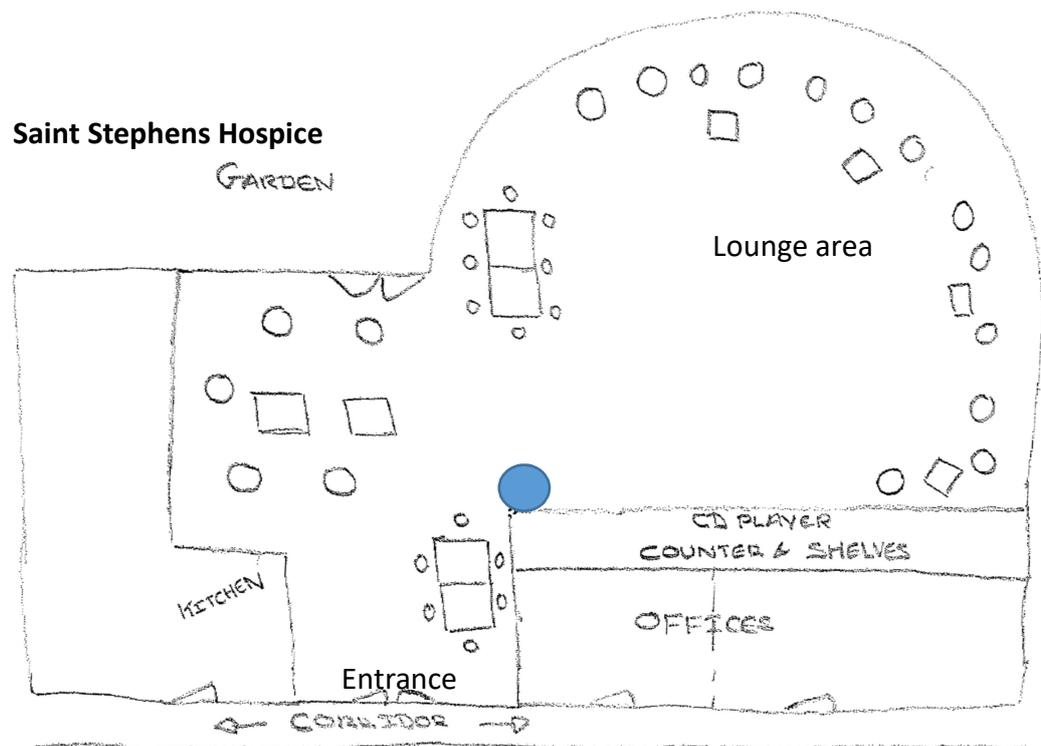


Figure 10: Diagram of Queen Elizabeth Hospice

Saint Stephens Hospice (Figure 11) had a large lounge area located off a main corridor through the building. The lounge had seating located around the edge of the room. This hospice did not have a dedicated dining room, but did have a table next to the seating area where patients ate meals. To the left of the seating area was a side area that provided a quieter area and was often used for one-to-one discussions or when the main lounge became too crowded. The main activities took place on a table near the entrance to the main lounge area. Although the main lounge area appeared to have a large open space, this was regularly filled with staff members and volunteers talking to patients who sat around the outside of the lounge area. I placed myself next to the activities table but still in the main lounge area giving me a view of the entire area. This enabled me to observe the main lounge as well as the activities table simultaneously, without requiring me to move around and intrude too much on the working environment.



- Key:
- Researcher location ●
  - Table □
  - Seating ○

Figure 11: Diagram of Saint Stephens Hospice

## 4.2 Observational results – Quality of Interaction Schedule (QUIS)

### 4.2.1 Descriptive characteristics of the data

#### 4.2.1.1 Participant interactions

Table 5 shows the interaction characteristics for the observational data. Interactions were considered to be any action between two or more individuals that can be either verbal or non-verbal, but all individuals involved must be aware and conscious of the interaction. There were 2115 observed interactions in total involving at least one resident or patient. There were 1113 recorded interactions in the care home settings and 1002 in the hospice settings. There were a total of 206 observational 'blocks', which resulted in 104 observation blocks in the care home setting and 102 in the hospice setting. A block was 15 minutes in duration with a 15 minute rest period between each block (Clark and Bowling 1990) totalling 26 hours of observation in the care home setting and 25.5 observation hours in the hospice setting. The mean number of interactions per observation block was 10.58 (SD=6.10) with the average number of interactions per block in the care home setting being 11.1 (SD=7.10) and 10.02 (SD=6.45) in the hospice setting.

Interaction Characteristics		Care Home	Hospice	Total	p value
Total number of observation blocks		104	102	206	-
Total number on interactions		1113	1002	2115	-
Mean (SD) number of interactions per block		11.1 (7.10)	10.02 (4.88)	10.58 (6.10)	0.20*
Mean (SD) duration of interaction in minutes		1.43 (2.28)	3.99 (6.45)	2.65 (4.91)	<0.001*
Interaction category n(%)	Positive social	831 (74.7)	777 (77.5)	1608 (76.0)	0.09 <sup>†</sup>
	Positive care	122 (11.0)	110 (11.0)	232 (11.0)	
	Neutral	156 (14.0)	114 (11.4)	270 (12.8)	
	Negative protective	2 (0.2)	1 (0.1)	3 (0.1)	
	Negative restrictive	2 (0.2)	0 (0)	2 (0.1)	
Dichotomised interaction category n(%)	Positive	953 (85.6)	887 (88.5)	1840 (87.0)	0.05 <sup>‡</sup>
	Negative	160 (14.4)	115 (11.5)	275 (13.0)	
Verbal or non-verbal n(%)	Verbal	1016 (91.3)	908 (90.6)	1924 (91.0)	0.59 <sup>‡</sup>
	Non-verbal	97 (8.7)	94 (9.4)	191 (9.0)	
Direction of interaction n(%)	Two-way	982 (88.2)	904 (90.2)	1886 (89.2)	0.14 <sup>‡</sup>
	One-way	131 (11.8)	98 (9.8)	229 (10.8)	

\*Independent t-test testing the difference between care home and hospice means

<sup>†</sup> Mann Whitney U test comparing the quality of interaction between care home and hospice care sectors

<sup>‡</sup> Chi Squared test comparing care home and hospice care sectors

*Table 5: Interaction characteristics of the observational data.*

#### 4.2.1.2 Duration of interaction

There was an overall mean duration of interaction of 2.65 minutes (SD=4.91). The average duration of interactions in minutes was longer in the hospice setting (mean=3.99, SD=6.45) than in the care home setting (mean=1.43, SD=2.28). Interactions in the hospice sector were significantly longer than interactions in the care home sector (mean difference=2.53,  $p<0.001$ )

#### 4.3.1.3 Interaction description

Table 6 shows interaction description for the content of the interactions that were observed throughout the study. When considering the study sites individually, and grouped by care sector, general conversation provided the most frequent description of interaction with 31% and 34% of interactions occurring in care homes and hospices respectively. The second most common category of interaction revolved around providing food and drink to residents and patients with 24% and 13% of interactions being contained in this category for care homes and hospices respectively, showing that meal times provide a key focus for interaction.

<b>Interaction description category</b>	<b>Sub-category</b>	<b>Care home</b>	<b>Hospice</b>
Activity	Activity	22 (2.0)	56 (5.6)
Care	Care	30 (2.7)	26 (2.6)
	Care – Comfort	8 (0.7)	8 (0.8)
	Care planning	5 (0.4)	13 (1.3)
	Mobility aid	68 (6.1)	41 (4.1)
Domestic roles	Clean and tidy	72 (6.5)	62 (6.2)
	Food/drink	264 (23.7)	126 (12.6)
Communicate	Communicate – activity	21 (1.9)	7 (0.7)
	Communicate – information	12 (1.1)	13 (1.3)
	Communicate – question	4 (0.4)	3 (0.3)
	Communicate - other	8 (0.7)	1 (0.1)
Conversation	Conversation – general	345 (31.0)	342 (34.1)
	Conversation – Activity	36 (3.2)	24 (2.4)
	Conversation during cleaning/tidying	5 (0.4)	22 (2.2)
	Conversation – food and drink	83 (7.5)	77 (7.7)
	Conversation with care aspect	67 (6.0)	73 (7.3)
Pleasantries	Brief greeting or goodbye	30 (2.7)	70 (7.0)
	Extended greeting or goodbye	21 (1.9)	30 (3.0)
Other	Other	12 (1.1)	8 (0.8)
Total		1113 (100)	1002 (100)

*Table 6: Frequencies n (%) of interaction category for each study site and the two care settings.*

#### 4.2.1.3 Interaction ratings

The majority of interactions in both care home and hospice settings were positive. Once dichotomised, 85.6% (n=953) and 88.5% (n=887) of interactions were positive in care homes and hospices respectively showing slightly more positive interactions occurring in hospices than in care homes in terms of percentage of total interactions in a given care setting. It was found that there were more negative interactions in care homes (n=160, 14.4%) than in hospices (n=115, 11.5%) when looking at the percentage of interactions in total ( $p=0.05$ ).

Overall across all four study sites, 76% (n=1608) of interactions were rated as positive social, 11% (n=232) were rated as positive care, 12.8% (n=270) were rated as neutral, and 0.1% of interactions were rated as negative protective (n=3) and negative restrictive (n=2). When broken down between interaction categories, 77.5% (n=777) of interactions in a hospice are positive social compared to 74.7% (n=831) in the care home setting. 11% of interactions were rated as positive care in care homes (n=122) and hospices (n=110). More interactions were rated as neutral in care homes (14%, n=156) than in hospices (11%, n=114). 0.2% (n=2) of interactions were rated as negative protective in the care home setting while 0.1% (n=1) received the same rating in the hospice setting. There were no negative restrictive interactions in the hospice setting while in the care home setting, 0.2% (n=2) of interactions received a negative restrictive rating.

#### 4.2.1.4 Verbal/non-verbal and direction of interactions

Table 5 shows that overall across all four study sites there were 91% (n=1924) verbal interactions observed and 9% (n=191) non-verbal interactions. Non-verbal interactions recorded in the qualitative field notes included interactions such as a staff member or volunteer putting a plate of food down without any verbal communication. The majority of interactions were verbal interactions with 91.3% (n=1016) of interactions in care homes and 90.6% (n=908) of interactions in hospices being verbal.

Across all four study sites, 89.2% (n=1886) of interactions observed were two-way in direction with only 10.8% (n=229) of interactions observed being one-way in direction. Examples from the qualitative observational log of two way interactions included participants having a conversation, whereas one way interactions include a staff member asking a resident a question who did not respond or show any indication they had heard, and the staff member leaving, or a staff member or volunteer putting food down in front of

a resident or patient and them not showing any indication that the staff member or volunteer has given them food until they left, possibly because they were conversing with another individual. The majority of interactions observed in all four settings were two-way interactions with 88.2% (n=982) of interactions in care homes and 90.2% (n=904) of interactions in hospices being two-way.

#### 4.2.1.5 Interaction participants

Table 7 shows who participated in the interactions that were observed in the care homes and the hospices. In the care home setting, staff members were involved in the largest proportion of interactions and initiated the most interactions with 739 interactions being initiated by staff members. The group of participants who initiated the second largest number of interactions were residents, initiating 179 interactions. In contrast, volunteers initiated the most interactions in the hospice setting, initiating 523 interactions compared to staff who initiated 209 interactions.

Care setting	Interaction Initiator	Participant					Total
		Staff	Resident/patient	Visitor	Volunteer	Group/other	
Care home	Interactions initiated by resident*	99	179	7	3	12	300
	Interactions not initiated by resident but involving a resident	739	-	20	54	-	992
Hospice	Interactions initiated by patient	41	126	7	42	33	249
	Interactions not initiated by patient but involving a patient	209	-	21	523	-	879

\*Initiated by resident involves resident/patient beginning the interaction. Interactions not initiated by the resident/patient means that interactions were initiated by another participant, but involved a resident or patient

Table 7: Who the interactions were initiated by, and who was involved in the interactions in care home and hospice care settings

Figure 12 shows the number of interactions for each main category of interaction by care home and by hospice settings. The charts highlight the differences in number of interactions around activities, conversations and ‘pleasantries’ with more of these interactions observed in the two hospices. In contrast, the care home sector has a higher number of domestic roles and communication of information interactions when compared to hospices.

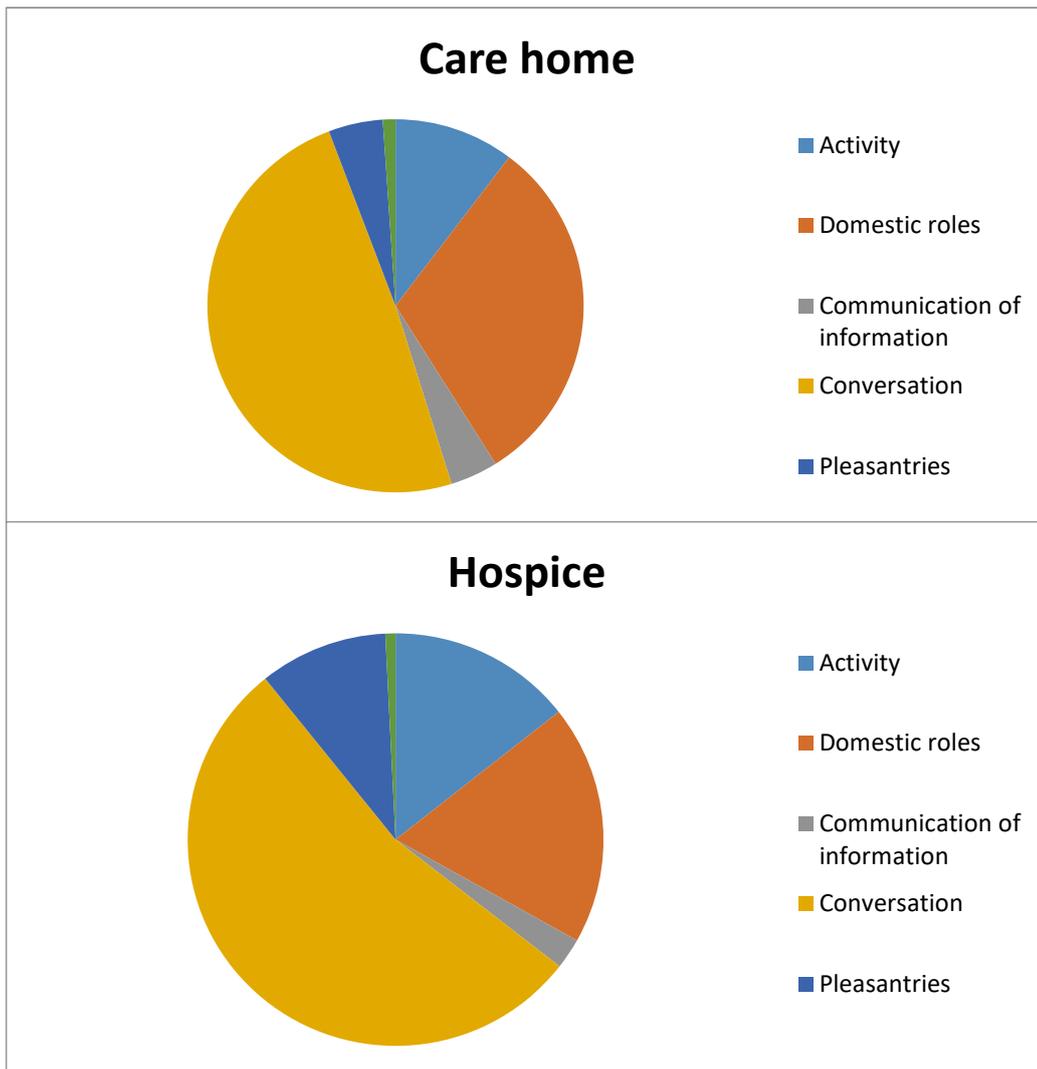


Figure 12: Pie charts showing the number of interactions per interaction category

#### 4.2.2 Summary

Table 5 shows that although there was no evidence of a difference between the number of interactions per observation block (mean difference=1.08,  $p=0.20$ ), there was a significant difference between the mean duration of interaction between care homes (1.43 minutes) and hospices (3.99 minutes). Hospices had longer interactions which might suggest a better

quality of interaction in hospices than in care homes. This is suggested by the significant difference (although only marginally) between the dichotomised interaction category of positive and negative interactions, with hospices having on average more positive interaction (88.5%) compared with care homes (85.6%) although this requires further statistical investigation.

### 4.2.3 Quality of interaction regression analysis

#### 4.2.3.1 Quality of interactions between care homes and hospices

The logistic regression analysis consisted of two models, Model A showing each predictive variable entered on its own and model B showing the predictive variables when other variables are controlled for. Table 8 shows that when each predictor variable is entered into the model without controlling for other covariates (model A), that residents and patients within the hospice settings are more likely to have positive interactions than the care home setting, although this difference has borderline statistical significance (OR=1.3, CI=1.002-1.68, p=0.05). However, when other covariates are controlled for (model B), then residents and patients were no more likely to have positive interactions within the care home setting than the hospice setting (OR=0.59, CI=0.30-1.17, p=0.13).

Predictor variables	Model A (Each predictive variable on its own) OR (95% CI) p value	Model B (Adjusted predictive variables) OR (95% CI) p value
Care home (vs Hospice)	1.30 (1.002-1.68) p=0.05	0.59 (0.30-1.17) p=0.13
One-way interaction (vs two-way interaction)	135.85 (88.18-209.29) p<0.001	7.30 (3.83-13.88) p<0.001
Non-Verbal interaction (vs verbal interaction)	529.47 (241.85-1159.14) p<0.001	41.40 (14.39-119.13) p<0.001
Duration of interaction (minutes)	93.004 (49.51-174.71) p<0.001	16.39 (8.37-32.12) p<0.001
Interaction initiated by:		
Staff member	1	1
Resident/patient	5.01 (3.10-8.09) p<0.001	1.13 (0.61-2.09) p=0.70
Visitor	* p=0.99	* p=0.99
Volunteer	0.86 (0.66-1.13) p=0.29	1.16 (0.55-2.44) p=0.70

\*Unable to calculate due to no visitor having an observable negative interaction

*Table 8: Logistic regression models showing the odds ratio (OR), p value and 95% CI of a positive interaction (positive care and positive social).*

Two-way interactions and verbal interactions were both strongly predictive of positive interactions. Model A shows that when not controlling for covariates, two-way interactions and verbal interactions have significantly higher odds of being positive in nature. When controlling for other covariates however (model B), these odds are reduced, but two-way interactions are still highly significant (OR=7.30, CI=3.83-13.88, p<0.001) as are verbal interactions (OR=41.40, CI=14.39-119.13, p<0.001).

The duration of an interaction is also a strong predictor of the quality of interaction with longer interactions being more likely to be positive in nature than shorter interactions. This result remains statistically significant when controlling for other covariates within the model (model B). With each additional minute the interaction lasted, the interaction had a significantly greater chance of being positive in nature (OR=16.39, CI=8.37-32.12, p<0.001).

There was no association between the quality of interaction and the type of person initiating it. When compared with staff members and not controlling for other covariates (model A), residents and patients who initiated interactions had a significantly higher odds that the interaction would be positive in nature (OR=5.01, CI=3.10-8.09, p<0.001). When

controlling for other covariates however (model B), this difference was not significant (OR=1.13, CI=0.61-2.09, p=0.70). There was no evidence that volunteers were more likely to have positive interactions than staff members (OR=1.16, CI=0.55-2.44, p=0.70) when other covariates had been controlled for in model B.

#### 4.2.3.2 Assumption of Linearity of Logit

The assumption of the linearity of logit for a continuous predictor variable was tested by examining the interaction effects between a continuous predictor variable and the natural log of the continuous predictor variable (Field 2009). A significant interaction effect means that the assumption is violated, however, when examining the interaction effects of continuous predictor variables (interaction duration) within this regression model, it was found to be not significant (p=0.80) so the assumption was not violated.

### 4.3 Findings from the Sheltered Care Environment Scale (SCES) questionnaire

#### 4.3.1 Descriptive characteristics of the data

The SCES questionnaire was used to measure the atmosphere of the study settings. Table 9 shows the number of SCES questionnaire responses and the type of participants who completed the questionnaire at each study site. A total of 25 questionnaires were left at each study site for completion or were handed to staff members, visitors and volunteers directly. Between 10 and 13 completed questionnaires were obtained from each site with 47 questionnaires being returned in total. Staff members within all care settings returned more questionnaires than other categories of participant. In the hospices, volunteers were more likely to be present hence a greater number of volunteer respondents were from this sector. Visitors were rarely seen in any of the care settings so provided the least number of responses, but visitor response numbers tended to be similar across all care settings.

<b>Study site</b>	<b>Staff member</b>	<b>Visitor</b>	<b>Volunteer</b>	<b>Total</b>
Manor Lodge	7	2	1	10
Harbour House	8	2	2	12
Queen Elizabeth Hospice	4	3	5	12
Saint Stephens Hospice	7	1	5	13
<b>Total</b>	26	8	13	47

*Table 9: Number of completed questionnaire, and total responses from each care setting by participant type*

#### 4.3.2 The atmosphere of the care sectors – Care Homes and Hospices

Table 10 shows the mean score for each subscale of the SCES questionnaire (cohesion, independence, self-disclosure, organisation, and comfort), and a total score for each study site, and for the care sector (i.e. care home or hospice) overall. Higher scores represent a more positive atmosphere. There was a tendency for the care homes to have lower means for each subscale compared to the hospices, and the care homes also had a lower overall atmosphere score than the hospice settings, suggesting a less positive atmosphere within the care homes.

Study site	Mean (SD) score for SCES subscales*					Total SCES score
	Cohesion	Independence	Self-disclosure	Organisation	Comfort	
<b>Manor Lodge (n=10)</b>	0.82 (0.22)	0.42 (0.19)	0.64 (0.15)	0.68 (0.23)	0.90 (0.10)	0.70 (0.09)
<b>Harbour House (n=12)</b>	0.75 (0.17)	0.43 (0.23)	0.62 (0.25)	0.85 (0.18)	0.75 (0.11)	0.68 (0.12)
<b>Care home total (n=22)</b>	0.78 (0.19)	0.42 (0.21)	0.63 (0.21)	0.77 (0.22)	0.82 (0.13)	0.69 (0.10)
<b>Queen Elizabeth Hospice (n=12)</b>	0.97 (0.07)	0.52 (0.16)	0.72 (0.20)	0.86 (0.11)	0.89 (0.13)	0.80 (0.07)
<b>Saint Stephens Hospice (n=13)</b>	0.95 (0.07)	0.68 (0.19)	0.70 (0.28)	0.84 (0.14)	0.82 (0.15)	0.80 (0.10)
<b>Hospice total (n=25)</b>	0.96 (0.07)	0.60 (0.19)	0.71 (0.24)	0.85 (0.12)	0.85 (0.14)	0.80 (0.08)

\* Higher scores correspond to more positive atmosphere

Table 10: Mean (Standard deviation) score and total score for each SCES subscale and care setting.

Table 11 indicates that the cohesion score was significantly different between care homes and hospices (mean difference = 0.18, 95% CI = -0.26 to -0.10,  $p < 0.001$ ). The independence score was also significantly different between care homes and hospices (mean difference = 0.17, 95% CI = -0.29 to -0.090,  $p = 0.006$ ). There was no significant difference between care homes and hospices for the self-disclosure, organisation and comfort scores although it should be noted that in all the subscales of the SCES questionnaire, the hospice has higher overall scores representing a more positive atmosphere in the hospice sector than the care home sector. The overall SCES score reported in Table 11 reports the combined scores of all the subscales of the SCES questionnaire. The overall score was found to be significant (mean difference = 0.11, 95% CI = -0.16 to -0.053,  $p < 0.001$ ).

Subscale	Care home*		Hospice		Mean difference (95%CI), p value
	n	Mean (SD)	n	Mean (SD)	
Cohesion Score	22	0.78 (0.19)	25	0.96 (0.071)	-0.18 (-0.26 to -0.10) <0.001
Independence score	21	0.42 (0.21)	24	0.60 (0.19)	-0.17 (-0.29 to -0.090) 0.006
Self-disclosure score	20	0.62 (0.21)	23	0.71 (0.24)	-0.081 (-0.22 to 0.059) 0.25
Organisation score	22	0.77 (0.22)	25	0.85 (0.12)	-0.074 (-0.18 to 0.034) 0.17
Comfort score	22	0.82 (0.13)	25	0.85 (0.14)	-0.036 (-0.12 to 0.044) 0.37
Overall SCES score	22	0.69 (0.10)	25	0.80 (0.017)	-0.11 (-0.16 to -0.053) <0.001

\* Lower scores correspond to worse levels of atmosphere, higher scores correspond to better levels of atmosphere

Table 11: Number and mean (standard deviation) for each subscale of the SCES questionnaire.

#### 4.3.2.1 Testing assumptions

The histograms produced to test the assumption of normality are located in Appendix XX. The histograms showed that the self-disclosure, independence and overall SCES scores are normally distributed; however the cohesion, organisation and comfort scores are not normally distributed. A variety of transformations such as the log and square root transformations were performed on the mean cohesion score data to produce a normal distribution, but no normal distribution was found from these transformations.

To test for the assumption of homogeneity of variance, box plots of the subscale scores were also produced (see Appendix XXI). The box plots, as well as Levene's test that was also examined show that the variances of the cohesion score and the organisation score are not distributed equally, so for these variables equal variances are not assumed. The Independence, self-disclosure, comfort and overall SCES scores all have equal variances assumed.

As some of the subscales violated the assumption of normality, non-parametric tests were conducted for each subscale of the SCES questionnaire as a sensitivity test. Analysis found that again, the cohesion score ( $p < 0.001$ ) and the independence score ( $p = 0.011$ ) remained statistically significantly different between care home and hospice care sectors. No significant difference was seen between the self-disclosure score ( $p = 0.11$ ), the organisation score ( $p = 0.50$ ) and the comfort score ( $p = 0.37$ ). The non-parametric tests found the same as the independent t-tests in that hospices had a significantly better cohesion and independence scores than care homes.

#### 4.4 Summary

The Quality of Interaction Schedule (QUIS) was used to gain a measure of the quality of interaction within the care sectors of care homes and hospices. The interactions were dichotomised into positive interactions and negative interactions and underwent a logistical regression analysis. There were 1113 recorded interactions in the care home setting and 1002 in the hospice setting. There were a total of 206 observational blocks, which resulted in 104 observation blocks in the care home setting and 102 in the hospice setting. In the care home setting, staff members were involved in the largest proportion of interactions and initiated the most interactions. In contrast, volunteers initiated the most interactions in the hospice setting showing significant presence within the hospice setting, as they initiated more interactions than staff members.

The analysis showed that there were no significant differences between care sector (care home or hospice) in terms of quality of interaction once other covariates had been controlled for. In addition, the quality of interaction did not depend on the type of person who initiated the interaction once covariates had been controlled for. The predictive covariates that strongly predicted a positive interaction included the direction of the interaction, whether the interaction was verbal, and the duration of the interaction.

A total of 47 SCES questionnaire responses were received and the mean score for each subscale showed that the hospice care settings scored higher than the care home settings showing a more positive atmosphere in hospices. Hospices had statistically better social climate scores for the cohesion and independence subscales, and the overall SCES score. This indicates that hospices had a more positive atmosphere than care homes. Although the hospice care settings had higher means than the care homes for the self-disclosure, organisation or comfort subscales, differences in these subscales were not statistically significantly different.

As some of the assumptions of the independent t-test could not be verified for all the variables in this small sample, a non-parametric Mann Whitney U test was conducted where the assumptions are more relaxed, giving a more robust, but less powerful test. The results of the non-parametric test verified the results of the independent t-test, showing that again there was a significant difference between cohesion and independence scores, but not the self-disclosure, organisation and comfort scores, with the hospice care sector having better levels of social climate, and therefore a better atmosphere than the care home sector.

# Chapter 5: Phase two – Interview findings

## 5.0 Introduction

This chapter presents the findings from the qualitative analysis of the interview data that aims to answer the third research question: What is the role that visitors and volunteers play in the life of those being cared for within the two care sectors? Additionally, a qualitative examination of social capital and the atmosphere of the care sectors is provided. Data from the qualitative log from phase one of the study was included to provide context to the findings and elaborate on extracts used from the interviews. Three key themes were identified from the interview data, enabling a better understanding of life in these care sectors and what the individuals in these settings bring and do for those who are being cared for. These themes were ‘integration’, ‘demarcation’, and ‘cohesion’.

## 5.1 Descriptive characteristics

A total of 39 interviews were conducted with residents, patients, staff members, visitors and volunteers across the four study sites. The number, gender and type of participants recruited at each study site are shown in Table 12. A total of 21 interviews were conducted in care homes and 18 in hospices. The mean duration of the interviews was 23 minutes (SD=9.9 minutes) with interviews being shorter for staff members due to the busy nature of their work.

Study site	Patient/Resident	Staff member	Visitor	Volunteer	Total
Manor Lodge	5	5	2	0	12
Harbour House	3	4	1	1	9
Queen Elizabeth Hospice	3	2	1	3	9
Saint Stephens Hospice	3	2	1	3	9
Male participants	6	1	0	1	8
Female participants	8	12	5	6	31
Total number of participants	14	13	5	7	39

Table 12: Number and type of participants for each study site split by male and female.

Of the participants, 31 were female (79%) and eight were male (21%) reflecting the higher female population in these care settings. When broken down by care sector there were 19 female participants and two male participants in the care home sector and 12 females and six males in the hospice care sector. There were more interviews conducted with residents and staff members in the care homes, compared with the hospice where most interviews were conducted with patients and volunteers.

The analysis produced three key themes: integration, demarcation and cohesion. The theme demarcation is split into two subthemes; professional demarcation and physical demarcation. Each theme is discussed in turn and supported by selective quotes taken directly from interview transcripts for illustrative purposes.

## 5.2 Integration

The theme 'Integration' encompassed the process of integrating the care settings with the resources, social engagement and social interaction that are available in the outside world in the community. This integration enabled the residents and patients within the care settings to have access to and experience the benefits of living in a community, such as a greater potential to develop wider social networks and social interaction, while within the care settings.

Visitors and volunteers were able to bring the world 'outside' into the care setting and integrate these two worlds. Visitors and volunteers provided a 'window' that enabled residents and patients to gain a glimpse of, and obtain information about, the outside world when they may be unable to access the outside world themselves. Care homes and hospices, by virtue of their purpose, can sometimes be seen to be closed, protected environments (Hämel 2016). This can create segregation between being inside the care setting and the wider community beyond the care setting. The process of Integration, provided by visitors and volunteers through 'bringing the outside in' enabled the development of a community feeling within the care setting.

*"I mean sometimes you talk about your own life to them because some of them are interested, you know, how are your grandchildren so you'll tell them, and you're bringing something from the outside in*

*as a volunteer, a bit different I think when you're working here, but being a volunteer I can bring my outside life in"*

Volunteer 1, Harbour House

Integrating the communities outside the care setting with those inside was evident across all four study care settings and was valued by all participant groups of resident/patient, staff member, visitor and volunteers. There were many examples of integration ranging from visitors taking residents and patients out of the care settings for the day to access the wider community, bringing services that were easily accessible in the community into the care settings such as a library, and bringing news about the local community and news from the world outside into the setting by visitors and volunteers interacting socially with residents and patients.

*"I've lived in [the local town] for quite a long time, so I know a fair number of people in the town, and I have quite a few visitors. They mostly come in the afternoon because they know I like working in the morning. I draw a lot so I like to do that in the morning, and then in the afternoon I feel that I can chat to whoever comes in. And I find out what's happening in the town and what's happening to the people that I've known for so many years, so all that's very good."*

Resident 4, Manor Lodge

Harbour House had access to a mobile public library that visited the care home on a regular basis to provide books for the residents. This service was not a voluntary service and received funding, but the funding was subsequently cut. This had detrimental effects for the residents as they felt that they were losing a connection to the wider community of the local town. It was also important for care home residents to be able to access the community by being able to physically leave the care home on trips and visits. If they were unable to leave the care home due to health constraints or disability, then they felt it was important that they still somehow had access to the outside services.

*"I don't know about other homes around here but I know they're all going to miss the public library a tremendous lot"*

Resident 2, Harbour House

Before coming into the care home, residents often engaged with the local communities through activities such as going to local shops and attending community events, activities

that were not always possible to continue with due to physical or cognitive limitations when in a care home. Consequently, the role of visitors became a vital way of bringing news and information about people and the local area to residents who found it difficult to leave the care home. Visitors provided the residents with a way to retain a feeling of connection with the community outside the care home. Visitors and volunteers brought to care home residents' information about their local community which they had once been a part of and enabled them, to some extent, to continue to be an active member of the community.

*“Well, they [visitors] bring me lots of news of what’s happening in [the town] and what’s happening to people that I know and that they know, and I always find that interesting.”*

Resident 4, Manor Lodge

Integration was also of great importance in the hospice settings. Many patients in the hospice setting were too ill to participate in the wider community any longer, despite being day care patients. The volunteers served as a means of keeping patients in touch with the ‘outside world’ through news, information about local developments and domestic stories, which in similar vein to the care home residents, enabled patients to still feel part of the local community. In a discussion about a recent visit to the hospice by a local football team, one volunteer referred to the roles of visitors and volunteers as such:

*“Yes it’s bringing the outside in which is always good and of course often people are too poorly to go to a football match but one gentleman we had who’s actually coming today is a [local] Town supporter”*

Volunteer 3, Saint Stephens Hospice

The volunteer recognised the benefit of the patients being able to access this aspect of the local community despite patients not being able to physically access the community themselves. The volunteer recognised that as patients were too ill to go to the football, it was beneficial for them to be able to still engage with the football team and the wider community by bringing that aspect of the community into the hospice.

The benefits of integrating the ‘outside’ within these two care sectors of hospice and care home were also recognised by staff members. Enabling the residents and patients to retain some form of access to communities was perceived as beneficial to those that are cared for

within the care settings. This was because it enabled the residents to maintain a sense of normality of living their life in the local community.

*“We actually encourage carers that have got babies, once they’ve left on maternity leave, to bring their babies in and bring their dogs in, you know, just a bit of normality”*

Manager 1, Manor Lodge

It became apparent from the data that limited integration with the outside community risked feelings of isolation and boredom. The crucial role visitors and volunteers played in helping to integrate the outside world within the care home or hospice care sectors was recognised and valued by the staff:

*“The more they see from the outside world and that lot because otherwise they just feel they’re locked away in a little -, I mean, obviously we have outings but this time of the year you can’t do anything, they can’t even get out in the garden and sit out in the garden can they, so this time of the year especially is more important to have the visitors, have the volunteers and everything else”*

Staff member 3, Manor Lodge

The exact number of volunteers the care settings had access to could not be obtained. In the care home settings the information was not recorded beyond obtaining a Disclosure and Barring Service (DBS) certificate due to the informal nature of the role. In the hospice settings volunteers worked in many different areas and it was not possible to view records from all the different areas. The number of volunteers was discussed during the interviews and it was found that the care homes had less than 10 volunteers each, while Saint Stephens Hospice had over 600 volunteers occupying various roles. It was very clear from the interviews, that hospices had a far greater number of volunteers than the care homes.

The hospice sector has a history of providing care financed by charitable income, and all hospice participants (staff, resident/patient, visitor and volunteer) appeared to be conscious of the charitable nature of the service they were providing or receiving. This could in part explain the increased volunteer presence in the volunteer settings, with volunteers undertaking roles that would in other settings be undertaken by paid members of staff. It was observed that the hospice settings attracted volunteers for a variety of roles

such as leading recreational activities. In contrast, in the care home setting activities were often undertaken by paid staff members such as activity co-ordinators, not volunteers.

*“I have learnt to do water colour painting while I have been here, well Caroline [volunteer] is the one that teaches things that, she has people doing things now sat around the table, and em, the more able ones do, the more able things you know some, you know, she encourages people to do things she does”*

Patient 2, Queen Elizabeth Hospice

*“Well, I don’t know if she’s a volunteer but there’s a lady called Ann that comes in and she deals with arts and crafts and she’s actually in the garden room now and she comes in every week. And then there’s another lady called Clare that comes in on Wednesdays and she does hairdressing. She was here this morning. She does the residents’ hair”*

Staff member 4, Manor Lodge

This quote from Manor Lodge demonstrates how a variety of people are brought in to provide activities and services for the residents but even the staff were unclear as to whether they were there in a voluntary or paid capacity. In fact, both of the people referred to were paid professionals who were employed by the care home to provide services such as recreational activities and hair dressing. In the care home, these services needed to be paid for to be brought into the care home, and were often what attracted day care residents to the care home. This was in contrast to the hospice setting where services were provided by volunteers free of charge. The larger presence of volunteers to provide free activities in the hospice suggests that hospices are more easily able to integrate the wider community with the community inside the care settings. All care settings need to provide adequate care and support regardless of the amount or original source of funding (charitable/statutory or private). In care homes there appeared to be less financial resource and less freedom in how the resources could be deployed on integrating the care home with the wider community. Integration with wider communities requires resources more apparent in hospices.

Saint Stephens’s Hospice was a charity funded hospice. The number of volunteers enabled the provision of services beyond traditional inpatient and day care services. Saint Stephens

was also able to run a programme that sent hospice volunteers into the community to support and engage with people in their own homes.

*“...there are over six hundred volunteers in the hospice because they do, they have the shops, they run the fundraising, you know you can't imagine what they don't do. There's 'hospice neighbours' who go and sit with people in their homes outside in the community, a huge amount.”*

Volunteer 3, Saint Stephens Hospice

This hospice was not only able to integrate the community with the hospice setting, but was able to integrate the hospice support within the wider community. The resources generated from voluntary networks that the hospice could draw on enabled them to be distributed around the community, providing help and support where it was needed. This in turn helped to integrate hospice support with the community so people were able to benefit from hospice contact and the benefits that brings, but from within their own home.

### 5.2.1 Theme summary

Integration was the process of integrating the care settings with the resources and social engagement and social interaction that are available in the local community. This integration enabled the residents and patients within the hospice and care home settings to access and experience the benefits of living in a community, such as social interaction and shared information about the community, while within the care settings. Volunteers and visitors were perceived to be key in achieving this integration of the 'inside' world with the wider (outside) community. Visitors such as relatives and friends, special visitors such as the local football team in the hospice, or volunteers were able to provide benefits to a wide range and number of residents and patients. An important difference between care homes and hospices was the number of volunteers to which the care settings had access. In care homes volunteers were rare requiring these organisations to fund positions that in hospices were filled by volunteers. Hospices tended to 'reach out' into the community more readily and were a more intrinsic part of a community historically, while care homes often operate independently of the community and the outside world must 'reach in' in the form of visitors.

The difference in the number of volunteers within care home compared with the hospice settings was evident and suggests that hospices have the potential for higher levels of social capital than care homes, evidenced by the increased presence of voluntary networks. Due in part to the abundance of volunteers, Saint Stephens's hospice was not only able to integrate the community with the hospice setting, but was able to integrate hospice support within the wider community. This suggests a much greater level of social capital within the hospice setting as it shows the community and hospice communities coming together for the mutual aim of providing palliative care to those that require it. It also shows that hospice and palliative care are services that have the potential to develop social capital (Horsfall, Noonan et al. 2012).

## 5.3 Demarcation

Demarcation represented the boundaries that were discussed during the interviews within both care home and hospice care sectors. Boundaries were considered at two levels: the boundaries between people in terms of their job role; and the boundaries and barriers that can hinder gaining access to the physical care setting. These boundaries could sometimes be 'blurred' within the care settings, meaning that not every aspect of the roles people have were distinct and separate from each other. For example, volunteers who provided a social role similar to a visitor, also provided a basic level of care as a staff member would do. These 'blurring of boundaries' or conversely, having very fixed boundaries were not always intentional, and sometimes evolved naturally within the care setting. Demarcation is sub-divided into two distinct sub-themes: professional and physical.

### 5.3.1 Professional demarcation

Professional demarcation referred to the boundaries between people and their roles within the care settings. Care homes had low levels of professional demarcation, meaning that roles and boundaries between people within the care setting were often 'blurred' with people taking on multiple roles and responsibilities. In contrast, hospices had very high levels of professional demarcation, whereby roles and responsibilities were distinct with fixed boundaries.

### 5.3.1.1 Low professional demarcation within the care home sector

A lack of professional demarcation between people who operate within the care home sector was apparent in both care home study sites. The care home setting was characterised by blurred boundaries between the people who work within these care settings. This was apparent from both interviews and from the observational qualitative log. An example of this was when an interview participant in a care home identified themselves as a visitor, but was referred to by staff as a volunteer, illustrating the blurred boundaries between roles. Despite identifying themselves as a visitor, they carried out tasks that could be considered the role of a volunteer such as making and fetching drinks for residents. This participant was also unable to differentiate between other visitors and volunteers within the care home. When asked if they were aware of any volunteers in the care home, the participant responded:

*“well I wouldn’t know which ones are which as I come in any day. I don’t know, there used to be one or two what needed you to hold cups of tea and all that, well I used to do that but I mean I aren’t a volunteer I just come in to see them ladies what I was sitting with, but if anybody needed help and I was here I used to hold the cup of tea, stir it up you know things like that”*

Visitor 1, Manor Lodge

This particular participant used to visit a close friend who resided in the care home but passed away several years ago. Being local to the area and part of the community they continued to visit other residents in the care home, following the death of the friend. The visitor often helped the care home and its residents by undertaking basic domestic roles such as stirring drinks for residents, getting drinks for residents and helping pass objects if the resident had mobility problems. While these seem like minor domestic roles that anyone could undertake, in the hospice sector these acts would be carried out by volunteers.

When the care home residents were asked about the presence and role of volunteers, the majority were unsure of whom they were. The few residents who thought they were aware of volunteers were often mistaken and the volunteer they were referring to was actually a staff member.

*“We have some volunteers come in to help do arts and crafts. We have a lady volunteer who comes in three days a week to do art*

*and crafts and also reminiscence and we have volunteers come in for that normally when people are on holiday from university”*

Resident 3, Manor Lodge

The ‘lady volunteer’ referred to in the quote above was a paid member of staff, not a volunteer. This reveals there was limited awareness of volunteers within the care setting as seen through low levels of professional demarcation. Interestingly, the quote above also illustrated the difference in voluntary work between care homes and hospices that was also observed in the qualitative log. In the hospice settings, volunteers tended to be older retired individuals who volunteered for long periods of time, in many cases over a number of years. Volunteers in care homes tended to be younger individuals who volunteered during holiday periods as a way to gain work experience to improve future job prospects.

A blurring of boundaries between staff members and volunteers worked in both directions, whereby, some staff members were considered to be volunteers, but also volunteers were also considered to be staff members.

*“There aren’t any volunteers in the art class. I know that, because I’m one of the main members of the art class. So I, there’s nobody there. The only person we have there is Mark the tutor who he comes, he lives in [the city], he comes in from [the city]. He I presume is paid, yes he’s paid.”*

Resident 3, Harbour House

In fact, the art tutor referred to by this resident was a volunteer who provided free art classes once a week on a voluntary basis. Although the art class was a popular activity, the voluntary job role of the art tutor was not discussed between the residents and the tutor despite residents having regular social contact with the art tutor. This might suggest that there is a lack of close relationships between the tutor and the residents, and that the relationship is merely a professional one. If the care home is considered a residents ‘home’, then it could be expected that the nature of the work someone does when entering the home would arise in conversation or be discussed in some way. This lack of professional demarcation shows that the voluntary role of the art tutor was not discussed and the relationship not developed as much as was observed in the hospice setting. Close relationships were formed within the hospice settings from similar activities between the patient and voluntary art tutor which were not as evident within the care home settings.

*“Jane [art tutor] is the one [volunteer] that has given me, yeah, you know, the most pleasure because she is the one that has actually taught me to water colour paint, you know there’s painting of mine hanging up in there and I have some at home as well, and she says they’re lovely and that but I don’t think there’s much to them but she does”*

Patient 2, Queen Elizabeth Hospice

These differences in the personal and professional relationships could arise from the difference in professional demarcation. If residents and patients within the care sectors are aware of the roles and responsibilities of volunteers and the social role that they have, then they may be more inclined to take advantage of that social role. It is possible residents may feel less burdensome engaging socially with volunteers than staff members who have a specific professional role to carry out.

#### 5.3.1.2 High professional demarcation within the hospice sector

In contrast to the care home sector, professional demarcation was evidenced within the hospice care sector where roles were much more clearly defined. Of the two care homes that took part in this study, one required their staff to wear uniforms, while the other didn’t, yet all hospice staff in both study sites wore uniforms. Staff members in care homes can sometimes wear name tags as a form of identification, but are not compulsory in every care home and were not used in the care homes in this study. Volunteers within the hospice settings distinguished themselves further through the use of name tags, badges showing significant years of voluntary service, and by wearing certain colour aprons to distinguish themselves from other staff groups. Volunteers were considered vital within the hospice settings. The crucial importance of volunteers for the every-day running of the hospice came through strongly in the interviews, as exemplified in the quote below:

*“They [volunteers] are really important actually because if we [the staff] weren’t here and we are behind the scenes doing things and there are no volunteers here the patients might feel quite unsupported”*

Staff member 2, Queen Elizabeth Hospice

*“Volunteers are really the backbone, the professionals, the nurses are doing the job, but the volunteers are just here and you know, they are looking after you and they are really helpful you know with a cup of tea or biscuit, and Anton is very funny, and another chap, I seen on Friday, he’s bloody mad he is [patient laughs]”*

Patient 3, Queen Elizabeth Hospice

The above quote shows that volunteers were considered a crucial part of the hospice setting by paid members of staff. Volunteers were provided with a handover each day like the staff members were, yet they were kept distinct from the staff by having their own separate handover specific to volunteers.

Volunteers considered their role to be unique, one that other people were not able to do as effectively. This suggests that they had a clear view of their role and function within the hospice setting, representing high levels of professional demarcation in the hospice settings.

*“Well I see my role as supporting the nursing staff, and we, the way I do that is by being able to spend time with the patients talking to them, where nurses are often doing the clinical stuff”*

Volunteer 2, Queen Elizabeth Hospice

*I think it’s nice that relatives come in and we, if no one is talking to them and we are not busy then we can chat and then see if medical staff is needed then politely get up and move away and let them do their job,*

Volunteer 1, Queen Elizabeth Hospice

The role of volunteers was often considered by all groups of participants in the hospice settings to be supporting the nursing staff. This was achieved through a variety of ways such as spending time with patients, engaging socially with them, while also providing basic domestic roles such as cleaning, making drinks and getting food. Supporting the patients and engaging with them socially enabled paid staff to perform their own roles more effectively, while the patients received important social benefits from the hospice. When discussing the number of volunteers within the hospice settings, volunteers gave responses that may be expected from staff members about issues that would affect a paid workforce.

For example volunteers discussed increased pressure if a volunteer is away, resulting in volunteers not able to function effectively in their specific role.

*“we [volunteers] are in a bit of dire straits if one of us is off, well when there was three or four that weren’t a problem but when there is two [volunteers] you know you are always emailing [to find extra volunteers to come in], not that you can’t cope but there is a difference between doing it [work needed] and not talking to the patients do you see what I mean, you can do it but you are not doing what you are meant to be here for as far as I am concerned”*

Volunteer 3, Queen Elizabeth Hospice

The above quote shows that while volunteers can be thought of as staff members in a hospice, in terms of needing sufficient numbers to operate effectively, they have a set role within the hospice setting that others are not able to do in their absence.

Hospice volunteers were treated like staff members in terms of receiving handovers and having dedicated roles, suggesting low levels of professional demarcation. But there were also clear boundaries around what volunteers can and cannot do showing high demarcation. These boundaries were set out for a variety of professional reasons such as health and safety, but also reinforced the difference in roles between people who work within the hospice sector.

*“Our volunteers have basic training but they’re not actually involved in manual handling things so, you know, if there are issues that we need to talk about, we address it there – specific needs of individuals and that sort of thing – and also we touch base with the volunteers; see if there’s anything they need to perhaps talk about or, you know, if there’s any problems they’re having and things that perhaps they don’t particularly want to be involved in that day for any particular reason.”*

Staff member 1, Saint Stephens Hospice

While demonstrating that there are set boundaries between the role of staff members and volunteers, the above quote also reinforces that close relationships are present within the hospice setting, not just between patients and other individuals within the care setting, but also between staff members and volunteers.

### 5.3.1.3 The effects of professional demarcation

Although a blurring of boundaries demonstrated by a lack of professional demarcation was not always a negative part of a care setting as seen in the care home, it has the potential to result in conflict if previously established boundaries become increasingly blurred. High professional demarcation, as identified in the hospice setting, has potential for creating conflict. The quote below highlights the frustration towards the hospice management felt by a hospice volunteer when their role changed due to an on-going technical fault. The fault meant that the volunteer undertook work that did not fall within their job role.

*“The politics what go on above your head do your nut in, like even with the bloody dish washer, that is been wrong for weeks and weeks and weeks and they said to him, well I said that’s another way to stand at the sink washing up and that isn’t my job”*

Volunteer 3, Queen Elizabeth Hospice

The role of volunteers was seen to be to support the staff members by engaging patients in social and other activities and undertaking basic domestic roles. Once the roles became blurred and volunteers began to see themselves more as staff members, it created tension between the volunteers and staff members. These tensions were also the result of forming close relationships with the patients.

*“There are sometimes issues in terms of them [volunteers] having been here a very long time some of them being very set in their ways, finding change very very difficult, and also sometimes you feel you have to justify your medical decisions to them as well because they get quite upset because they become so attached to the patients I guess”*

Staff member 2, Queen Elizabeth Hospice

*“I think as staff we try and sort of gear stuff, really, and not that we dictate to volunteers but actually it has to be led by staff and not led by volunteers. Although they do a lot of work, we’ve got to keep everything – it’s under our umbrella, really. So, actually, we do see volunteers and it’s like – there was an instance the other day and it was like, ‘Ooh! I’m going to have to say something’, and*

*that's awkward but it's fine. It's fine. You know, most of the time we work through that stuff."*

Staff member 1, Saint Stephens Hospice

*"now there is a lot of changes and I think the changes they, to them that is a job and I know that and that's the same is it is I suppose to us, but you can't help thinking sometimes some of the things are so petty you think who ever thought that one up?"*

Volunteer 3, Queen Elizabeth Hospice

Staff members sometimes felt that volunteers had lost some of the understanding of their role within the hospice. If the environment operated based on these set boundaries then conflict could arise when the boundaries were no longer as distinct as they once were. It then became the responsibility of the staff to reinforce the boundaries and ensure the roles set out for individuals are adhered to in order to prevent safeguarding issues arising and potential conflict.

Although negative interactions were rare in both care home and hospice care sectors, an example of a negative interaction was observed in phase one and explained in the qualitative log. The incident referred to a volunteer in the hospice having a discussion with a visitor about a care related topic about a patient while the hospice staff members were having a morning handover. Later when a volunteer informed a staff member about their discussion with the visitor, the staff member asked the volunteer to not do this again as it was not part of their role and it would be best if in future the volunteer asked a staff member to discuss the information with the visitor. There were clearly set boundaries, roles and responsibilities that, when broken, created conflict that needed to be actively managed. If conflict and tensions were not managed, then staff considered it could have a detrimental effect on the people who were cared for as well as work in the hospice such as other staff members and volunteers, as well as pose potential problems around safeguarding and confidentiality. This effect could have a detrimental impact on the atmosphere that the hospice intended to provide for the patients.

*"I know that some volunteers feel that...how can I put it? There's a 'them and us' culture. You know, there's staff and volunteers. And because of the confidentiality policies, some people feel they could be given more information. But, then again, it's confidential."*

Volunteer 2, Saint Stephens Hospice

*“I think perhaps some of the volunteers who’ve been here for quite a long time, they can get a little bit territorial, and this is their domain and you don’t – you know. So you have to guard against those sort of things, as well. We monitor, like, obviously confidentiality and that sort of thing, as well, because, you know, that’s important – that the volunteers keep confidences, because that can have a detrimental effect on a group, as well, if stuff is shared that should not be shared”*

Staff member 1, Saint Stephens Hospice

To a lesser extent this issue of conflict was seen in the care home setting. Within the care home setting, where there was not the same level of professional demarcation, tensions would not arise around individuals crossing the boundaries of their roles and responsibilities. Instead tensions revolved around the deployment of responsibility of volunteers.

*“Everybody seems to want to come the same day. And you know we have certain activities and they want to come. They don’t want to come on a normal day. A normal quiet day, then we don’t have anybody, when you could do with a pair of hands”*

Staff member 2, Harbour House

When there was a low level of professional demarcation such as in the care home, issues commented on in the interviews focused on how the resource of volunteers was deployed. It could mean that clear roles and responsibilities and high professional demarcation were able to ensure that volunteers undertook the roles that were required of them, ensuring that volunteers were able to be considered part of the workforce.

### 5.3.2 Summary of professional demarcation

Professional demarcation referred to the boundaries, roles and responsibilities of individuals who operate within the care sectors. Care homes were seen to have low levels of professional demarcation in that there were no clear boundaries between different groups working within the care home settings. All participants (resident, staff, visitor, and volunteer) found it difficult to know what the role of a person they saw was within the care home. Participants were often incorrect in their assumptions about that role, for example

recognising a staff member or volunteer and the role they had. In contrast, hospices appeared to have high levels of professional demarcation, in that there were very clear roles between different people within the care settings. Individuals were easily recognised as being a staff member, visitor or volunteer. More meaningful relationships were seen to form in the hospice settings. This may be in part due to having clear professional boundaries between those that work and operate in the care settings. Patients were more aware of who was there to interact with them in a social capacity, which could facilitate a more social and meaningful relationship that goes beyond the care of the patient.

Patients within the hospice setting were more aware of volunteers and more easily able to identify them. Patients were also more aware of a volunteer's social roles and responsibilities within the hospice setting. Patients who were more easily able to identify and engage with hospice network members (such as volunteers and staff members) whose purpose was to provide a social connection may receive benefits such as closer relationships.

If previously established boundaries become increasingly blurred, this has the potential to create conflict within the care settings. Once professional demarcation has been established, it has the potential to aid in the effective running of the care setting as long as the boundaries are maintained.

The potential for conflict to arise from high levels of professional demarcation may represent a negative aspect of social capital. A high level of social capital implies diverse social networks that allow information to flow between network members, such as hospice volunteers and staff members, to facilitate a mutual goal or aim (Coleman 1988). As more voluntary networks are created and interact with other professional networks, it provides more opportunity for differences of opinion to create conflict. This conflict can be detected by the people who work and are cared for in a care setting and has the potential to damage the atmosphere of the care setting.

### 5.3.3 Physical demarcation

Physical demarcation referred to the care settings' boundaries such as the walls and doors that increase or hinder physical access to the care setting. It was recorded in the observational log that care homes had locked doors and controlled entry and exit points, often due to necessity because of the number of residents with dementia present within

the care home sector. Yet hospices, in contrast, had automatic doors that were always unlocked with signs to direct and welcome potential visitors. The physical aspects of care home and hospice care settings controlled the flow of people through them, which could in turn provide a flow of information and increased social networks from an increase in volunteer and visitor numbers. A lack of such strict control around the care home and hospice boundaries allowed easier access for individuals outside the care settings to come inside, in the same way that having controlled barriers could hinder entry into the care setting.

While physical aspects of the care setting were seen to play a part in accessing the care settings, other more conceptual factors were also found to be linked to an individual's physical presence in the care setting. Conceptual factors were factors that could enable or inhibit physical access to the care setting, but were often subjective, personal views about the care setting itself. An example of conceptual factors that hindered people physically accessing the care settings were perceived difficulties associated with paperwork, and stigma attached to the care settings.

#### 5.3.3.1 Physical barriers to care setting entry

Entries relating to physical aspects of the care settings were recorded in the observational log, and highlighted during interviews. Although all care home and hospice care settings had open visiting hours with few visiting restrictions, it was noticed that care homes had controlled boundaries, in the context of physical demarcation. The care homes had entrances and exits that remained locked at all times, and a staff member was needed for residents or visitors to enter or leave. Care homes also had distinct and clearly defined communal areas, dining rooms and private areas, and also areas where residents were unable to go such as staff rooms. In contrast, hospices had lower levels of physical demarcation in that their doors were automatic and always unlocked allowing easy and quick access. The areas within the hospice were much more open with there being very few restrictions on where patients were unable to go.

As well as physical design aspects of the care settings, the location of the care settings also played a part in visitors and volunteers gaining access, particularly in the care homes. Visitors who did not live locally did not visit often. This could mean that residents in care homes could have less contact with visitors such as relatives. This in turn could lead to residents experiencing feelings of loneliness.

*“I think that some people will never have any visitors at all you see partly some of the older chaps come in after their wives have died and their children probably live miles away and don’t come that often well they can’t come that often, so I think that’s rather sad place really, I mean I’m lucky because my family all live locally”*

Resident 2, Harbour House

Physical distance was a recognised barrier to having visitors and played an important part in how residents viewed visiting in the care home in general. All participants acknowledged that visitors were an important aspect of life that residents should have. Yet many residents failed to have visitors because of lack of family, or their family lived a long distance away. As a consequence, many residents missed out on an important social aspect of living in a care home.

Increasing volunteer activity in the care settings may be a potential solution to an absence of visitors. In the two hospices volunteers were much more inclined to travel distances and spend more time engaged with and undertaking activities at the hospice they worked in. One of the hospices was developing a volunteer program to support hospice patients in their own homes covering an area of half a large rural county, suggesting distance was not an issue within the hospice settings.

Within the day hospice it was expected and encouraged that patients engaged with volunteers rather than visitors. One volunteer within the hospice, who had previously had ties to the hospice and had visited a patient there, provided an account in which the patient received visitors and spent more time with the visitors than engaging with hospice activities.

*“We have 2 or 3 friends, men, and they knew John was here on Fridays and they used to come here and see him and they used to go to the coffee bar and talk to him and I said to him [John] I said “John I don’t think that’s what this is all about, you’re here for relaxation and singing and you know, the friends that you have made here”*

Volunteer 2, Queen Elizabeth Hospice

The quote above comes from the context of the day hospice, where visitors are not turned away, but discouraged from visiting as one of the purposes of the day hospice is to provide

respite for family carers. The volunteer in the quote above, (who was a visitor at the time this narrative was set) was encouraging the patient to engage more with the new friends that he had made within the care setting. Since entering the care setting the patient had developed new social networks, and was also maintaining and still engaging with members of his older social networks. The strong community ties and the openness of the hospice setting helped this patient facilitate the development of new social networks, while still enabling the maintenance of older social networks. In contrast, residents in the care home, as discussed above, tended to have fewer opportunities for social interaction if family and friends lived some distance away. The issue of decreased social networks and interaction resulting in increased levels of loneliness could be overcome in part by the presence of volunteers within the care setting.

A further deterrent to gaining access to both care home settings which emerged in the interviews concerned the need for safeguarding and bureaucratic procedures such as obtaining a Disclosure and Barring Service (DBS) certificate. It was clear from the interviews that in order to attract more volunteers into the care home sector, application processes and funding issues around DBS required simplification.

*“I think the DBS, if that’s what it’s called, puts people off, because they have to pay for that and I think it’s £50, so that’s probably why, I mean, I had to pay for my own when I came here and that was two years ago and that was £50 then, so I think that’s probably what puts them off. I have had phone calls from volunteers, 18 year old boys, men, who want to come into the care sector to work and want a bit of experience, but they have to have so much vetting basically before they even come in the building”*

Volunteer 1, Harbour House

The issues of paperwork and financial cost were a considerable barrier to increasing a volunteer presence within the care home setting. These procedures, which are in place for safeguarding reasons, were considered another ‘doorway’ that potential volunteers have to go through before they can gain access to the care setting. Volunteers considered the process to becoming a volunteer in both care homes and hospices comparable to applying for a paid position.

*“Well, to explain it: you have to have an interview to become a volunteer”*

Volunteer 2, Saint Stephens Hospice

*“All of our volunteers have to be DBS checked. You know, we do a thorough recruitment procedure, so we get references for them”*

Staff member 3, Harbour House

It was felt in the care home settings that the arduous process to become a volunteer was a major barrier as to why people did not readily volunteer, yet the process is in many respects the same in the hospice setting which has an abundance of volunteers. It could be that the motivations for volunteering align much more with a hospice setting. Hospices appear to have stronger community ties and networks which allow their volunteers to overcome these barriers to physically gain entry to the care settings. It was suggested by some volunteers in the hospice settings that as well as community ties and barriers, it was the atmosphere that helped them overcome these barriers. Upon entry to the hospice, many prejudices about the environment were shown to be false. This openness and ability to overcome people’s preconceived ideas was a factor in having a prominent volunteer presence.

*“I mean coming into the hospice, a lot of people still have the idea that they’re here to die and that’s not what we’re about. We just want to make them – we don’t know what their problems are so we’re not here to talk about that, so we just talk generally about what goes on in their life and things like that”*

Volunteer 1, Saint Stephens Hospice

#### 5.3.3.1 Conceptual barriers to physically gaining entry to the care setting

As well as physical boundaries to the care settings, there were a number of more conceptual barriers that needed to be overcome such as the stigma that can be associated with care homes and hospices. This was recognised by staff members in both hospice and care home settings, as well as residents and patients. Stigma and prejudices about the care settings were felt to be particularly damaging to the reputation of the care home sector, and to what residents felt like inside the environment.

*"I think it's necessary to not be...oh...rather looking down on the residents as though they are people who don't know much about the area or about what's happening in the world outside"*

Resident 5, Manor Lodge

*"I still think there's this stigma around what life is like in a care home. And it puts people off wanting to come in, because I think they think that people are just going to be sitting there, you know, gaga, not being able to converse with them....I do think, you know, that there is this image that once people come into care homes, life finishes. And I'm trying desperately to change that view by inviting people in from the community, such as yourselves doing project work, just to see that there is a bit of life."*

Staff member 3, Harbour House

Participants from the care homes felt that the stigma attached to the care setting had a negative effect on the reputation of the home in the eyes of the outside community. This was a view also expressed within the hospice setting.

*"I have been quite surprised at professionals who've come who they – you know, I've said, 'Is it like you thought it would be?', and they've said, 'It's nothing like I thought it would be.' So obviously even professionals, there's a mental image out there that – you know, one professional said, 'Oh, I thought it was going to be sort of lots of rooms and people dying in all these rooms.' And it's like, actually, if a professional person thinks that, how does Joe Public feel?"*

Staff member 1, Saint Stephens Hospice

Participants were concerned about the effect that stigma was having within the community outside the care setting. Hospices were often viewed by the communities outside the care sector as places to go to die, while stigma in care homes was attached to the presence of dementia in the residents. It was felt that the stigma not only had a damaging effect on how people viewed the care settings, but also created a barrier to why people did not want to volunteer, or receive care in a care setting in the first place. This stigma contributed to high levels of demarcation as it enabled fixed boundaries to be placed around the care settings. Stigma helped create a boundary around the care settings which made people

such as volunteers not want to gain access to the care settings, despite the benefits such as integration and social interaction, which people entering the care setting could bring.

There was also a large amount of stigma around the illnesses that are present within the care settings. Hospices were viewed as a place to stay until you die, as reflected in the quote above, and the stigma around illness in care homes surrounded the level of dementia.

*“you know the other little snag is coming here and meeting quite a lot of people with dementia or wandering around looking lost it frightens quite a lot of people, so there’s quite a lot of people who don’t come, could come but don’t come, even some of my friends relations they say ‘oh well I don’t really like coming here’, you don’t like coming amongst a lot of people are rather lonely and miserable and crippled in one way or the other”*

Resident 2, Harbour House

People’s perception of what life in care homes was like, was also connected to their perception of dementia. This had a significant meaning for Harbour House. Harbour House had three separate wings, a ‘residential wing’, a ‘nursing wing’, and a ‘dementia wing’. The dementia wing was located in a different building to the other areas of the care home, and had its own issues around demarcation that kept it separate from the rest of Harbour House. Although few residents in the residential and nursing areas of Harbour House had dementia, participants felt that the care home was largely defined by the illness by people on the ‘outside’. While stigma is an issue for both care home and hospice care sectors, volunteers are able to overcome this issue more easily in the hospice sector. This could be because of the increased presence of dementia within the care home sector and the associated stigma attached to dementia which means people might more readily volunteer in a hospice than in a care home.

Many people within the care settings believed that to overcome the stigma attached to care homes and hospices, there needed to be a significant change in the way that the care sectors are viewed in the wider community. Participants in the hospice settings believed that to achieve this, the goals and aims of the hospice care sector needed to be made clearer.

*"I don't have visitors, they would be, they would have their own issues with coming to the hospice which so many people think of as the place you come to die. And it isn't. It's the place you come to learn how to live positively."*

Patient 3, Saint Stephens Hospice

One way in which both the care home and hospice care settings were trying to reduce the stigma around the care settings was by reducing the physical demarcation and making it easier for people outside the settings to come inside. One way that this was achieved was through the use of special events. These consisted of special activities, public holidays and celebrations such as Christmas, birthdays, and fetes. These events were seen as an opportunity to reduce the physical demarcation present within the care setting and to encourage volunteers, visitors and members of the community to enter the care setting. This also had the potential for promoting integration with the world inside the care settings with the world outside, as this resident suggested:

*"There's a woman coming in with the owls, she's got owls. She brings them in, because my friend's interested in owls. I'm waiting to see when it is they're coming, so that I can tell her, and she'll come. You see, if there's anything interesting, you just have to tell them and they can come and visit you, and sit with you"*

Resident 1, Harbour House

*"we had the autumn sale a fortnight ago and I mean they sold hell of a lot of stuff, I know my wife came in and I know other people's family came in so you know, that's something so they must have done very well because apparently they made lots of money"*

Patient 2, Queen Elizabeth Hospice

Special events and activities were often used as a way to entice people into the care home or hospice care settings that they would not normally visit. The events had the effect of reducing the demarcation, whether physical or conceptual, by allowing more people to enter the care setting. This in turn promoted social interaction and broadened the networks of the individuals who are cared for and work inside the care home and hospice care settings. Reducing the demarcation of the care settings and encouraging people from the outside world to come in also helped reduce the stigma attached to the settings.

*“I had never been in a hospice in my life, and when I came up to the front door, I thought, ‘Oh, dear, have I made a mistake? This is going to be so depressing.’ I walked in the door; all I could hear was laughter, people chatting.”*

Volunteer 2, Saint Stephens Hospice

One story from a care home manager highlighted the benefit of having special events within the care home. The local college was running a health and social care course and they wanted to undertake a project within the care home. The care home manager agreed as it was beneficial to the student’s education, but also provided the residents with some new people to talk to from a younger generation. The experience was well received by the care home residents and the students. It highlighted the stigma that people have around care homes, and how people from the outside community accessing the care home can help to reduce that stigma.

*“One of them [a student] said, when he came, I followed him up the stairs with his teacher, he didn’t know I was there actually, but he went, he said to his teacher ‘this isn’t nothing like I thought it was going to be, I really thought it was going to be smelly, just smell of old people, you know’ and I laughed, and he turned around and the teacher said ‘oh did you hear that?’ and I said ‘yeah, I did’ and I said ‘unfortunately that is the perception that people have got about care homes and if we can change that, to me that is going to be the best thing ever’”*

Staff member 3, Harbour House

#### 5.3.4 Summary of physical demarcation

Physical demarcation represented the physical boundaries of the care setting and the barriers that exist that can hinder access. While there were physical aspects such as paperwork that can discourage people from accessing the care setting, other factors that could block access to the care settings are more conceptual such as the perceived stigma associated with the care settings. High levels of physical demarcation were manifested by fixed boundaries, locked doorways, and high levels of stigma attached to the care setting. In contrast, low levels of physical demarcation included an open, easily accessible environment where barriers were absent or easily overcome. The advantage of low

physical demarcation was that it appeared to make it easier for individuals such as visitors and volunteers to access the care setting, and in turn for residents and patients to access the outside world. These reduced barriers made it easier to promote integration between the care setting and the world outside.

## 5.4 Cohesion

While cohesion is a subscale of the Sheltered Care Environment Scale (SCES), it was also seen to be a key theme within the qualitative work. The theme of cohesion described how members of the care setting work together as a whole team, a single unit to provide a mutual service, for a common goal. Although the care settings were made up of a diverse group of individuals, all care homes and hospices involved in the study provided a supportive and cohesive environment. This was not only represented by the atmosphere of the care settings, but also the way the care settings operated and were run from the different perspectives of the participants.

The care settings provided care and support to those that were cared for within the care settings, and also supported everyone that worked and visited the care settings. This resulted in the care settings being seen by participants as cohesive, defined as everyone working towards a common goal of providing care and support, and creating a positive, supportive environment.

*“the volunteers, they play a very crucial role in the whole set up of the whole thing you know, it’s every department, volunteers, staff, everything all pushing [in] the same direction”*

Patient 3, Queen Elizabeth Hospice

Although the patient in the hospice recognised that there were many groups of individuals who work within the care setting, they were all working together and *“pushing [in] the same direction”*. This gave a sense of a cohesive atmosphere to the patients within the care setting. This feeling was also voiced by those in the care home, but it was not as prominent an issue as in the hospices. This could be because of the absence of a multidisciplinary team that existed in the hospices. It would be expected that the staff members in a care home will all be working towards the same goal. However, care homes have fewer types of staff members and almost a complete absence of volunteers. This may result in a sense of

cohesion that is not as strong as in the hospice settings, because there are fewer groups of individuals such as volunteers that are available to 'push the same direction'

A variety of factors contributed to a cohesive environment. The care settings provided different types of support to residents and patients, as well as those that visited and worked in the care setting. The type of support identified ranged from helping with activities, helping ease the workload of other care givers, to providing emotional support.

*"Just help out generally, yeah basically you know, take people into the dining room if they need it, I help out sometimes serving lunches if they're a bit short staffed, I'll do lunches for them."*

Volunteer 1, Harbour House

By being able to perform basic domestic roles within the care home, the volunteer was able to support the staff and ease their workload. For example volunteers were able to bring food to the residents and in some instances, to have a brief social interaction with them while delivering the food. While this was perceived as positive within the care home, support of this nature was not felt necessary within the hospice settings because the number of volunteers meant that these domestic roles were solely the responsibility of the volunteers, freeing up staff members to do other work.

*"just a few simple three words 'how are you' you know without discussion the weather, just how are you, and I think that's what, those three words, to a relative or friend who is here, shows that someone is really caring about them because obviously so much of the time it is the patient that gets priority in everything"*

Volunteer 2, Queen Elizabeth Hospice

Much of the focus of the care and support that was provided within the care settings was directed towards the residents or patients, and often people who visited or worked within the care settings can be overlooked. The care settings provided a cohesive environment which involved providing support to everyone within the care setting, and not just residents or patients. Both care sectors can be emotional places to work, with narratives being told in both care homes and hospices about emotional events. The environment was seen to be more cohesive because people 'cared'

*"Everybody really gets on well with everybody. All the carers here care. Now that might sound like a silly thing to say, but there are a*

*lot of people out there doing that job who shouldn't be doing it. But everyone really cares and really gets into the job and it's a very emotional job, you know, like, every time we lose somebody or whatever, you know, we all get really, really upset, yeah."*

Staff member 3, Manor Lodge

The above quote arose as part of a discussion about volunteers and the atmosphere of the care home. The presence of volunteers contributed to the cohesive environment. Volunteers within the care settings acted as an additional resource to further support residents, but also support other staff members. In a story from a hospice volunteer about a member of staff who died within the hospice, the volunteer commented on how the event brought people together and how people supported each other through the difficult time within the hospice.

*"We had a memorial out here. And all the staff came outside and it was a lovely day and we played music and we talked about her and that sort of thing and that was – that was tough. It was tough. Everybody, I found it tough. It was, it was important and we felt, I felt – and I'm sure others did – that it was very important, that we were all together and there was great strength and support in that"*

Volunteer 3, Saint Stephens Hospice

The atmosphere of the care settings helped produce a cohesive environment. The atmosphere was described as "*relaxing*", "*warm*" and "*welcoming*" by many participants. It was a goal of care homes, but also of hospices to make a 'homely' atmosphere. Hospices tried to move away from the clinical setting and produce an environment that was considered more homely. Having a more positive atmosphere helped create a better working environment (Garrett and McDaniel 2001) which aided in creating a more cohesive environment within each care setting.

*"Obviously, from our point of view, we want things to sort of be as homely as we can, so – you know, to almost bring the home environment into a clinical setting, so we're trying to move away from clinical and make it more homely. Obviously they [volunteers] bring a lot of laughter. They bring a lot of conversation. Some of the ladies, they bring in flowers"*

Staff member 2, Saint Stephens Hospice

One of the advantages to having volunteers was that they were considered to make a more homely atmosphere and provided a sense of normality. This at first seems counter-intuitive as a typical home does not have volunteers, but it is what the volunteers brought to the care setting that made it homely. Volunteers who entered the care settings were able to bring social interaction, expand resident and patient social networks, and provide support to those within the care setting.

*“We’ve got to learn to live not just for ourselves, even if we live in our own little room here and I do that because that’s what I want to do. But you can’t just be on your own in the world and people who are down there with a lot of people, if they will realise that you know, they can contribute in a little way to other people’s happiness, they will find that they’ll live their life a bit happier as well. It’s a community feeling, why didn’t I say that? I needn’t have gone on like that. It’s a nice community feeling that’s what it is”*

Resident 3, Harbour House

The resident above was discussing the supportive environment and how everyone within the care home contributed to creating a sense of community and a cohesive environment within the care setting. Participants felt that having a sense of community within the care setting helped create a cohesive environment. This cohesion was experienced by all groups of participants (residents/patients, staff members, visitors and volunteers) and their differing perspectives on the care sectors.

It appeared easier to create a sense of community and a cohesive environment when there was a diverse mix of individuals within the care settings. Having an ample number of visitors and volunteers meant that broad social networks could be created. Regular contact and positive social interaction ensured that these networks and relationships with network members could be maintained and developed to provide mutual benefits. In this sense, hospices excelled as they had a large volume of volunteers and visitors all working towards the same goal of providing care and support to all individuals within the care setting. In contrast care homes had a comparative lack of volunteers which took away a form of support from the residents and staff members. This in turn put extra strain on staff. While still working towards mutual goals for the residents, this lack of support, diverse social networks and good quality relationships resulted in a less cohesive environment.

Despite a positive cohesive atmosphere being highlighted in all four study settings, examples of a perceived lack of cohesion were identified during interviews. A lack of cohesion was described by a participant as a lack of interaction and social engagement between residents of a care home.

*“You can sit with three people at your lunch table and nobody utters a word you don’t know if they’re all deaf or don’t want to talk or what or even if it’s your fault, you probably think it is your fault because you know you can’t go on making pointless conversation if nobody’s going to join in. I think that’s one of the difficulties here”*

Resident 2, Harbour House

There was an expectation among many staff members and volunteers that mealtimes were a focal point for social interaction. However, despite the residents sharing social spaces and mealtimes, meaningful connections between residents and patients, visitors, and volunteers were not formed without a sense of overall cohesion. A lack of social interaction could in part be the result of restricted social networks. In the care home there were a limited number of people for the residents to engage with socially, and the type of people rarely changed. This was not an issue that was present within the hospice sector. In the hospice sector, more diverse social networks were achieved by varied volunteers, visitors, and day care patients who could relate to other patients as they were in a similar situation. This lack of networking opportunity was felt by some residents within the care home sector.

*“if everybody had visitors, whether there was, you know sort of like a group of people who would come in and just visit. I don’t quite know whether there’s a volunteer’s society that would come in, something coming in, or gents could come in visit some people”*

Staff member 2, Harbour House

Care settings with volunteers and hospices were seen to have a more cohesive environment created by the diverse population within the hospice care setting. This facilitated cohesion between the patients and other groups of individuals. An increased number of visitors and volunteers improved the running of the care settings and improved the interaction, networks and support received by staff, patients and residents in a care home which created a cohesive environment, but these benefits provided additional

problems. A lack of cohesion within an environment that had visitors and volunteers came from a difficulty in maintaining role boundaries as seen in the professional demarcation theme. While cohesion could be seen from the residents and patient's perspective, there appeared to be less cohesion from the perspective of the staff and volunteer members of the care settings as a result of a lack of professional demarcation.

*"Sometimes I think perhaps some of the volunteers who've been here for quite a long time, they can get a little bit territorial, and this is their domain and you don't – you know, so you have to guard against those sorts of things"*

Staff member 1, Saint Stephens Hospice

Differences between staff members and volunteer's opinions and views created problems which reduced the cohesiveness of the care setting. These professional boundaries needed to be maintained to ensure a cohesive and supportive environment, and to ensure everyone within the care setting is working towards the same mutual goals.

#### 5.4.1 Theme summary

Cohesion was the unity of the care setting and the people within the care setting working towards a mutual goal of providing care and support to any people who may need it. This support was not limited to staff providing support to residents and patients, but everyone within the environment supporting each other to create a cohesive care environment. Visitors and volunteers provide a crucial role in creating the cohesive environment by providing wider social network opportunities that can provide support to those within the care setting. This can in turn create a homely, supportive and cohesive environment as people are able to draw on these networks for support. Although a care setting such as a care home with few or no visitors and volunteers is not necessarily creating a fragmented atmosphere, or a lack of cohesion, visitors and volunteers are able to enhance the cohesiveness of the environment.

## 5.5 Summary of the key themes and relationships between the themes

Integration was seen to be a process of integrating the care settings with the resources and social engagement and interaction that are available in the outside world in the community, and enabling residents and patients to access these benefits. This theme links with the demarcation theme, in that having reduced physical demarcation allows for individuals such as visitors and volunteers to enter the care setting more easily and provide better integration between the care setting inside with the community outside. This could explain the differences observed between care homes and hospices regarding why care homes appeared to lack social capital when compared to hospices that have an abundance of volunteers and access to more social resources. Hospices were seen to have lower physical demarcation overall which resulted in a higher level of integration with the community. This integration contributes to the feeling of a cohesive environment within the care settings.

Another contributing factor to cohesion was the professional demarcation theme. Professional demarcation refers to the boundaries, roles and responsibilities of individuals who are cared for and work within the care settings. Although cohesion does not depend entirely on the level of professional boundaries that are placed within the care settings, it could contribute to it. For example once high levels of professional demarcation were achieved, they needed to be maintained to preserve the cohesive environment. If the boundaries between staff and volunteers broke down, began to overlap with each other, and are not managed appropriately, it had negative effects on the cohesiveness of the environment by creating tensions between volunteers and staff members.

The figure below (Figure 13) shows a diagrammatic representation of the three key themes in relation to each other and the care sectors providing an overview of the themes. There are groups of people such as visitors, volunteers and staff members who regularly enter and work within care home and hospice care settings. These groups are required to overcome challenges concerned with gaining 'access' to the care settings, and maintain 'boundaries' when in the care setting. These challenges are represented by the barriers discussed in the demarcation theme. If people manage to overcome these demarcation challenges, they have a role in facilitating the integration of the world outside within the care setting inside. This was achieved through expanding the social networks of the residents and patients within the care sectors, and increasing positive social interaction

with network members. This in turn aided the creation of a cohesive environment which can be experienced by and benefit those who work, visit or are cared for within the care settings.

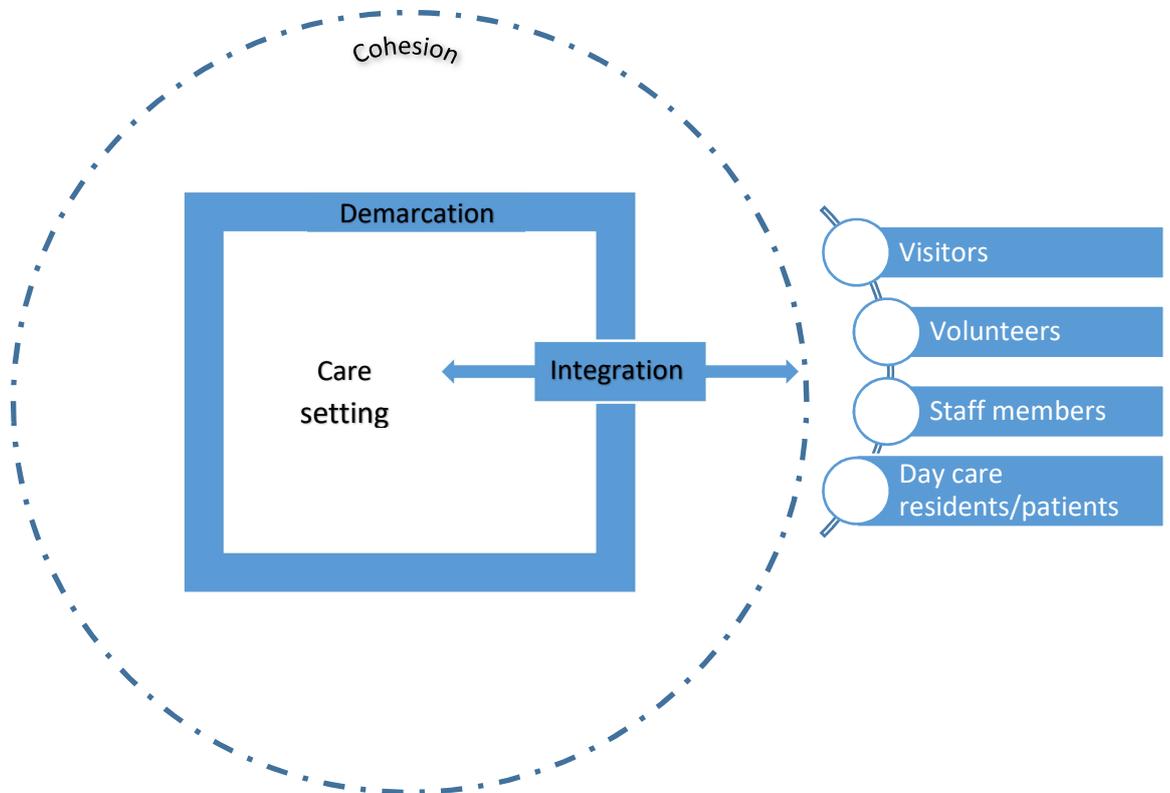


Figure 13: Diagram representing the three key themes in relation to each other and the care environment.

# Chapter 6: Discussion

## 6.0 Introduction

This chapter presents a discussion of the study findings in relation to the research questions and in the context of the existing literature. The chapter then presents a conceptual framework based on the qualitative and quantitative findings of the study as a whole. The chapter outlines the methodological strengths and limitations of the study and implications for policy, practice, and future research.

## 6.1 The study aims and questions

The aim of the study was to gain an understanding of the relationship between social capital and atmosphere, and the quality of interaction present in care homes and hospices. The study also aimed to examine the role that visitors and volunteers have in the life of those that are cared for in care homes and hospices. The study used a mixed methods approach to answer the following research questions:

1. What is the relationship between the social capital of older residents/patients and the atmosphere of the setting in which they are cared?
2. Are the quality and quantity of interactions between staff and those being cared for different between the two care sectors, care home and hospice?
3. What role do visitors and volunteers play in the life of those being cared for within the two care sectors?

## 6.2 The findings in relation to the research questions

### 6.2.1 What is the relationship between the social capital of older residents/patients and the atmosphere of the setting in which they are cared?

The present study builds on previous work by examining links between structural social capital and the atmosphere of a care setting, while also examining these concepts in different types of care settings for older people. The atmosphere of a care setting has been shown to be important for people who are cared for and those that work within different care settings (Lemke and Moos 1987, Timko and Moos 1991, Garrett and McDaniel 2001,

Tu vesson, Wann-Hansson et al. 2011). Social capital has also been extensively researched in many contexts including a health care and public health context (Moore and Kawachi 2017). Findings from the present study suggest that the two concepts are linked. Both concepts appear to be important in relation to the care of older adults (Holahan and Moos 1982, Muckenhuber, Stronegger et al. 2012) but no research to date has explored a potential link. This study showed that care settings with higher levels of social capital, such as diverse social networks, have beneficial effects for people who are cared for, work and visit the care settings, including an improved positive atmosphere.

Because of the complexity of the concept, there is great variation in how social capital has been measured (Devine and Roberts 2003, Van Deth 2003). The study presented in this thesis utilised quantitative observation and questionnaires, and qualitative interviews as a way of examining social capital and its relationship with atmosphere in care homes and hospices. A direct comparison of the findings of this study with those of other studies is problematic due to the different methods employed in other studies. The findings of the present study, however, supports other research that has shown that social capital is important for older adults (Muckenhuber, Stronegger et al. 2012) including the benefits of maintaining strong community ties (Eilers, Lucey et al. 2007).

While the study cannot answer the first research question quantitatively, the mixed methods approach provided an insight into social capital and the atmosphere of the care sectors of care home and hospice. It would appear that higher levels of social capital are positively correlated to a more positive atmosphere within a care setting.

Social capital is a contested concept that is difficult to be measured directly given its multidimensional nature. Social capital in this study was defined as a resource created by the presence of social networks that use social interactions to create and maintain these networks. Individuals are then able to draw upon these networks to create a sense of trust, social norms and reciprocity, to facilitate mutual benefit and action within a social structure. This study measured the quality of interactions among network members such as staff members, residents/patients, visitors and volunteers, within the two care sectors as a proxy measure of structural social capital. The observations also provided an idea of who the main network members are among the residents and patients within the care sectors, such as volunteers in hospices, or staff members in care homes.

The key difference that set hospices apart from care homes was more diverse network members shown by the abundance of volunteers. In the care homes, volunteer interactions

were rare compared to the hospice setting, and staff members were involved in the largest proportion of interactions and initiated the most interactions. This suggests that residents' main form of social network and interaction comes from members of staff. In contrast, volunteers initiated the most interactions in the hospices highlighting the importance of their presence in the hospice setting, as they initiated with patients more interactions than staff members. Hospices host a more diverse network of people compared with care homes, with volunteers playing a key role in the patient's lives. Voluntary social networks are an important concept in Putnam's version of social capital (Putnam 1995) suggesting that hospices and their abundance of volunteers offer a higher level of social capital and stronger community ties than care homes.

There was also evidence of hospices and care homes providing mutual benefit and action, in terms of carrying out social and care tasks to achieve goals within the care settings. From the qualitative data, volunteers saw their main role as interacting with and supporting the residents and patients which in turn helped to support the care staff. Hospice participants such as patients, staff members and volunteers were all able to come together to support each other to create a caring and supportive environment and a sense of cohesion. This sense of cohesion was maintained with positive social interaction in both care homes and hospices.

Findings from the present study suggested that hospices had a more positive atmosphere than the care home sector, as shown by the SCES measure of atmosphere. In this study, hospices scored higher on the SCES questionnaire than care homes, with a significant difference being seen in the overall SCES measure of atmosphere. This suggests that the two hospices in this study had a more positive atmosphere than observed in the two care homes. Social capital and the atmosphere of a care setting appeared to be related, although this was not directly tested quantitatively in this study. However, there is evidence from the qualitative data to support this contention, as the cohesiveness and positive atmosphere of the care homes, but particularly the hospices were linked to having a greater flow of people from the local community. Diverse social networks including volunteers and visitors interacting positively with residents and patients contributed to a sense that social capital was in greater supply in a hospice setting. This in turn could lead to a more supportive environment and more positive atmosphere.

The SCES questionnaire was developed by Lemke and Moos (1987) as a method to measure the atmosphere of different care facilities. Lemke and Moos (1987) developed the tool and

provided normative data based on their study of a sample of 244 older people care facilities including residential homes, nursing homes and older people’s apartments located in the USA. Table 13 below reports the normative data of the SCES questionnaire along with the mean scores reported in the present study. The normative scores presented by Lemke and Moos (1987) are comparable with both the care home and hospice scores reported in the present study, despite the small sample that was used. This suggests the SCES is a reliable tool to use to assess the atmosphere of a residential care setting, as well as the hospice setting. Another study (Mitchell and Kemp 2000) reported lower mean scores than the normative data for the SCES subscales (cohesion and independence) used in their study. The difference in scores in Mitchell and Kemp (2000) study when compared to the present study and Lemke and Moos (1987) could be due to a difference in care facility. Mitchell and Kemp (2000) used the SCES tool in assisted living facilities. While this term does include residential care facilities, assisted living facilities cover a broad range of residential care facilities. This can include different types of care facility such as living apartments, retirement communities, or nursing homes. The difference in facility type could explain the difference in mean SCES scores between their study and the normative data. However, lower scores between care homes and hospices were not noticed in the present study, which could suggest that the tool is a valid method to measure the atmosphere of a hospice setting, and that hospices have a better atmosphere than care homes.

<b>SCES subscale</b>	<b>Normative data reported by staff (n=366) members of residential care facilities provided by Lemke and Moos (1987)</b>	<b>Mean care home SCES scores from the present study (n=22)</b>	<b>Mean hospice SCES scores from the present study (n=25)</b>
Cohesion	0.74	0.78	0.96
Independence	0.55	0.42	0.60
Self-disclosure	0.60	0.62	0.71
Organisation	0.73	0.77	0.85
Comfort	0.86	0.82	0.85

*Table 13: Mean normative SCES scores from residential care facilities with mean SCES scores from care homes and hospices from the present study. Scores range from 0 to 1 with a higher mean score representing a more positive atmosphere*

Some evidence suggests that quality of life improved upon entry into hospice care (Cohen, Boston et al. 2001). Atmosphere measured using the SCES had the strongest correlations with care home resident quality of life compared to other variables such as health status, social involvement, and facility characteristics (Mitchell and Kemp 2000). In the present study, hospice respondents reported a more positive atmosphere compared to care homes. While quality of life was not examined in the present study, it could suggest that quality of life in hospice patients is higher than that of care home residents, in part due to a more positive and supportive atmosphere. A more positive atmosphere may not only predict quality of life of residents and patients, but also provide benefits to staff members and volunteers in care homes and hospices. A positive atmosphere and a more supportive workplace has been found to be negatively associated with lower levels of staff burnout (Garrett and McDaniel 2001). A more positive atmosphere is likely to be one that may be more supportive for the volunteers working there. This may also be a factor as to why hospices are more able to attract and retain volunteers, more so than care home sectors. As volunteers are an unpaid workforce (Addington-Hall and Karlsen 2005) it may be the case that they value a supportive and positive work environment, more so than financial gain, to want to work within a particular setting.

As well as access to a more positive atmosphere, other motivations for volunteering were recorded in the qualitative log and commented on during the interviews. It was noticed that volunteers in care homes tended to be younger, motivated to gain experience to pursue career goals, while hospice volunteers tended to be older and retired. This has been noted in other research (Planalp and Trost 2009) who report that older volunteers have stronger social motivations for volunteering in a hospice setting. Planalp and Trost (2009) conclude that volunteer coordinators in hospice and palliative care settings should consider these motivations when accessing and building social networks around volunteering. An awareness of these motivations may aid volunteer coordinators in recruiting and retaining volunteers into these types of care settings. These social motivations for volunteering and a better understanding of these motivations in developing social networks in the hospice setting may contribute to the cohesive environment that was found in the hospices in the present study, more so than the care homes.

## 6.2.2 Are the quality and quantity of interactions between staff and those being cared for different between the two care sectors?

Two-way interactions, verbal interactions, and a longer duration of the interaction were predictive of the quality of the interaction that took place in both care homes and hospices. Residents and patients who initiated the interactions themselves had higher odds of a positive interaction than when other people initiated the interaction. A possible explanation for this finding is that residents and patients have a higher desire for social contact than other individuals who initiated interactions whose main motivations may be care orientated, as may be the case with staff members. While there were no statistically significant differences between the quality or number of interactions in care homes and hospices, there was a difference in the type of people who were involved in interactions with residents and patients. Staff members provided the most interactions within the care home sector and volunteers provided the most interactions within the hospice sector.

The QUIS tool has been developed in the care home setting, and widely used in other more clinical health care settings. As a result, it is likely that the QUIS tool is sensitive enough to detect differences in the quality of interaction between the care home and hospice settings, although no significant difference was found. The findings of the present study could suggest that there is little difference in social care provided within these two care settings, and that social interaction is important within both care homes and hospices. This could lend weight to the idea that a hospice model of social care is already being implemented within the care home setting, and that a 'blurring of lines' between care home and hospice care is occurring in the UK. It could also suggest that a social model of care as implemented in a day hospice could readily be adapted and implemented into care homes that may not have a more positive level of interaction as they have the potential to achieve.

In both care home and hospice settings, interactions that involved some significant level of care, such as helping attend to personal hygiene or medical discussions and therapies, were conducted in private spaces such as bedrooms or treatment rooms and were not observed. In hospices there are likely to be more medical discussions and therapies that take place; these interactions can often be longer in duration than other interactions. As these interactions also took place in private spaces and were not observed, these types of interactions could not account for the difference in interaction duration between care home and hospice. Instead, it is likely the resident/patient to staff/volunteer ratio accounts

for the difference in duration of interaction as there was a higher ratio of volunteers and staff to patients in a hospice than there were to residents in a care home.

The hospices compared with the care homes, were notably populated by a greater variety of individuals, such as members of a multi-disciplinary medical team and hospice volunteers. This diversity in the hospice care setting population provided more opportunities for patients to engage with people socially who they may not normally have encountered outside of the care setting. Bridging social capital (Putnam 2001) refers to relationships between different social groups and networks that are outward looking of a group that includes people across many diverse social boundaries. This increased opportunity for bridging social capital was seen to be lacking within the care home setting. Care homes were limited in the variety of individuals who reside and work within the setting with the main groups being residents and staff members. Care home residents are more likely to come from similar socio-economic backgrounds due the relative financial cost of living in a particular care home. This is less likely to be the case in a hospice where care is typically provided free to all, funded by the state or a charity. As patients and residents in the study were only observed if they were over the age of 65 years, some patients in the hospice had to be excluded from the study but it is evidence of a wider age range than likely to be observed in a care home.

Although there was no difference between the quality of interaction between care homes and hospices, quality of interaction is important in the care of older people (Drageset 2004, Ellis 2010, Drageset, Kirkevold et al. 2011). A diverse population alone within the care setting will not create a more positive atmosphere or higher levels of social capital. The variety of networks must be created and maintained through positive social interaction. This was seen within the care home settings as although the population diversity was narrow when compared to hospices, care homes did have a large number of visitors. The visitors might have increased the size of the social networks of residents within the care home, but a lack of interaction between visitors and residents observed from the QUIS findings showed that this was not the case. In the hospice setting, interview participants reported that visitors were rare. Yet there were a similar number of interactions involving visitors and patients in the hospice sector as there was within the care home sector. This suggests that it is the combination of a variety of groups within a social network and meaningful positive interactions that helped create social capital and a positive atmosphere for those cared for in both hospice and care home settings. It has also been shown in a review by Lee, Woo et al. (2002) that improved social networks both inside a care home

setting and outside had a significant impact on psychological wellbeing. Entry into the care home was often associated with loss of privacy and control over activities of daily living which lead to feelings of a devalued self (Lee, Woo et al. 2002). Conversely, improved social networks were seen as a way to improve these feelings of a devalued self through meaningful social interaction. Volunteers may be a way to create more diverse social networks upon entry into the care home setting, and improve psychological wellbeing, as may be the case when a patient enters the hospice setting.

There has been work that has highlighted the benefits of palliative care within a care home setting (Baer and Hanson 2000, Beyer, Bitschnau et al. 2011, Beyer and Pissarek 2015, Meier 2015, Miller, Lima et al. 2015). The study presented in this thesis provided evidence that social capital such as diverse social networks and volunteer presence is abundant in the hospice sector shown by the number of volunteer interactions, and can be created and utilised by those in the hospice. The study also provided evidence that social capital can also be created within the care home sector to provide benefits such as diverse networks and social interaction to the residents in a care home setting. A number of benefits appeared to accrue from an increased social capital, represented by an increased volunteer presence. These benefits included higher levels of integration with the community, as seen in other studies (Hämel 2016), more diverse social networks and a more cohesive environment by providing support to both residents/patients, visitors and staff members. These benefits were experienced more so in the hospice sector than the care homes sector but the benefits were still recognised within the care home setting. By implementing the hospice philosophy on the social aspects of care such as community engagement and volunteering within the care home sector as well as palliative care aspects (Meier 2015, Miller 2015), then this may improve the care home setting by improving levels of social capital and in turn the positive atmosphere of the care settings.

### 6.2.3 What is the role that visitors and volunteers play in the life of those being cared for within the two care sectors?

Visitors and volunteers are common place within the care home and hospice sectors respectively. Previous literature (Addington-Hall and Karlsen 2005) has shown that volunteers in a hospice setting are considered vital and as important as staff members. Analysis of the qualitative data in the present study found that visitors and volunteers provided a number of important roles that can increase the level of available social capital

in these settings. This can improve the atmosphere of the care settings by providing a more cohesive environment and increasing the level of integration between the world outside the care setting with the life inside these settings.

Volunteers and visitors were key to integrating the inside world with the wider (outside) community. Visitors such as relatives and friends were able to provide benefits to single residents or patients while special visitors such as the football team in the hospice or volunteers were able to provide benefits such as increased opportunities for social interaction to a wider range and number of residents and patients.

Consistent with previous literature (Sévigny, Dumont et al. 2009), the present study found that visitors and volunteers had a number of barriers to overcome to gain access to the care settings. Once within the care setting there can sometimes be strict roles that visitors and volunteers adhere to which can become blurred. These boundaries were evident to all participant groups (resident/patient, visitor, volunteer and staff member) within the study. Issues concerned with gaining physical access to the care settings such as paperwork and perceived stigma need to be overcome for integration between care setting and the outside world. Negative aspects of having an increased social capital within a care setting included conflict, (Nelson, Pratt et al. 1995, Sévigny, Dumont et al. 2009) which had the potential to occur once established boundaries between staff and volunteers began to overlap. These boundaries needed to be renegotiated in order for the benefits of social capital, such as integration and cohesion, to take effect.

The qualitative analysis showed that cohesion was an important concept within the care settings. Social cohesion has been defined as the absence of latent social conflict and the presence of strong social bonds (Berkman, Kawachi et al. 2014). Cohesion is an important component of social capital (Moore and Kawachi 2017) and atmosphere (Moos, Gauvain et al. 1979, Moos and Lemke 1996) in understanding how people in communities can function together effectively. In the present study, the presence of volunteers and visitors working together with the residents/patients and staff played a significant part in contributing to a supportive and caring atmosphere. Something that could affect the cohesion of the setting that was apparent in the interview data was professional demarcation, where already established boundaries and roles between staff members and other participant groups such as volunteers then became blurred and overlapped. The tensions that result from these blurred boundaries between the overlapping responsibilities of volunteers, family members and staff members were observed in a palliative home care setting by Sévigny,

Dumont et al. (2009). Sévigny, Dumont et al. (2009) suggested that these conflicts are present in volunteering itself rather than the type of care setting.

Conflict between volunteer groups and volunteer and staff member groups may be a natural occurrence of volunteering itself, which could explain why the issues were apparent in hospice settings, but less so in care home settings that took part in the present study where there were fewer volunteers. Payne (2002) provided evidence that differences in perspectives can cause tension between hospice volunteers and volunteer co-ordinators for bereavement services which can affect how the services provided by volunteers are planned and implemented. The hospices in the present study had an abundance of volunteers, and issues around professional demarcation and blurred boundaries between volunteers were apparent as reported in other hospice settings by Sévigny, Dumont et al. (2009). Although visitors and volunteers are an integral part of hospice communities they can also be seen by some patients as intrusive (Cooper, Gray et al. 2008, Claxton-Oldfield and Marrison-Shaw 2013). While care homes also had volunteers, they were fewer in number than the hospices, and conflict was not as apparent. The lack of conflict could be because of a lack of volunteers, but also because the boundaries between staff and volunteers were not as established to begin with. Having clearly defined boundaries and roles as seen in the hospice settings does not create conflict, but rather the conflict is the result of when these pre-established boundaries begin to blur and overlap. This conflict perhaps represents the negative aspect of social capital. An abundance of social capital implies diverse social networks that allow information to flow between network members, such as hospice volunteers and staff members, to facilitate a mutual goal or aim (Coleman 1988). As more voluntary networks are created and interact with other professional networks, it provides more opportunity for social networks to overlap and differences of opinion to create conflict. This conflict can be detected by the people who work and are cared for in a care setting and has the potential to damage the atmosphere of the care setting.

Two of the main barriers reported by volunteer coordinators were that patients receiving palliative home care and their families did not want more people coming in and out of the patient's home as it would provide extra burden to the patients and their families. Patients and their families did not want to hear the terms "hospice" or "palliative care" because of perceived stigma attached to these terms (Claxton-Oldfield and Marrison-Shaw 2013). Barriers such as stigma, particularly surrounding dementia, may present a possible explanation as to why care homes had few visitor interactions and lower numbers of

volunteers. Despite interview data showing that there was an abundance of visitors in care homes, care homes had few social interactions recorded in the observational data. While visitors can overcome the perceived stigma around the level of dementia of a care home to visit their relative, it may prevent them from interacting with other residents. This was not an issue that was apparent in the hospice observations where it was reported in the interviews that there were few visitors, yet had comparable observed interactions to the care homes.

From the interview data, demarcation, the physical barriers to the care settings, played a role in the extent to which integration between the world inside the care setting and the world outside occurred. This finding is supported by other research that found that care homes often either strive for integration with the local community or conversely create a 'sheltered zone' for their residents, away from the community (Hämel 2016). This difference in the way care homes choose to operate suggests a large variation in care home culture that is often determined by the care home managers. Yet the decisions about engagement and integration with the wider (outside) community have been shown in this study to have important effects on the people who are cared for within the care settings in the form of social networks that residents and patients can create.

Care homes have different perspectives on how involved a community should be and either include community integration in their care home ethos, or provide a 'safe zone' for residents away from the community (Hämel 2016). Conversely, the hospices in this study, supported by the findings of other published studies (Sévigny, Dumont et al. 2009), appeared to be more open to promoting community integration and reducing the barriers between the community and the care setting as shown by volunteer recruitment and fundraising. Indeed, Sévigny, Dumont et al. (2009) suggest this has become a necessity for hospices as community engagement and the principle of volunteerism is essential for the hospice and palliative care movement to function effectively. Community engagement provides not only opportunity to develop a volunteer workforce, but also attract funds which for many hospices as non-profit charity organisations is essential.

Once visitors and volunteers overcome the issues surrounding gaining access to the care settings and the blurred boundaries that can arise in the care settings, they can bring benefits to those inside the care setting. Benefits can include an increased flow of information into the care setting and broader social networks for those that work or are cared for in the care settings. These benefits, when combined with positive social

interaction to develop and maintain the social connections, can provide an increased social capital and a more positive atmosphere within the care sectors.

### 6.3 Conceptual Framework

Figure 14 shows a conceptual framework based on the combined results of phases one and two of this study. The conceptual framework is a diagrammatic representation of both the qualitative and quantitative findings of this thesis. The framework shows that interaction between those who enter the care settings and those already inside the care setting is key to providing a cohesive environment and integration between the community outside and life inside the care setting. This does not provide justification as to why quality of interaction was examined within this study, but rather shows the finding that quality of interaction was needed in order to facilitate the benefits of having people access the care setting such as integration and cohesion.

The framework highlights the key people from the community outside the care homes and hospices that can enter the care settings and the importance of good quality interactions. These groups of people, accompanied by a high quality of interaction can provide benefit to those that are cared for and work within the care settings. These benefits include integration between the community outside and life inside the care settings, and help provide and maintain a cohesive environment.

What the qualitative and quantitative findings show is that there are a variety of people who enter the care sectors from the outside community. The main categories of individuals who enter the care settings were visitors, volunteers, staff members and day residents/patients. These groups of people can have meaningful positive contact and interactions with permanent residents/patients which facilitates integration of the care settings with the world outside. The role of visitors and volunteers in the care settings, once combined with positive social interaction helped create a cohesive environment. The benefits of integration and cohesion however, could only be experienced and felt once visitors and volunteers were able to overcome the barriers to gaining access to the care settings, such as perceived stigma attached to the care sectors. Once established, the boundaries between the participant groups such as volunteer and visitor needed to be maintained in order to sustain an integrated community and a cohesive environment.

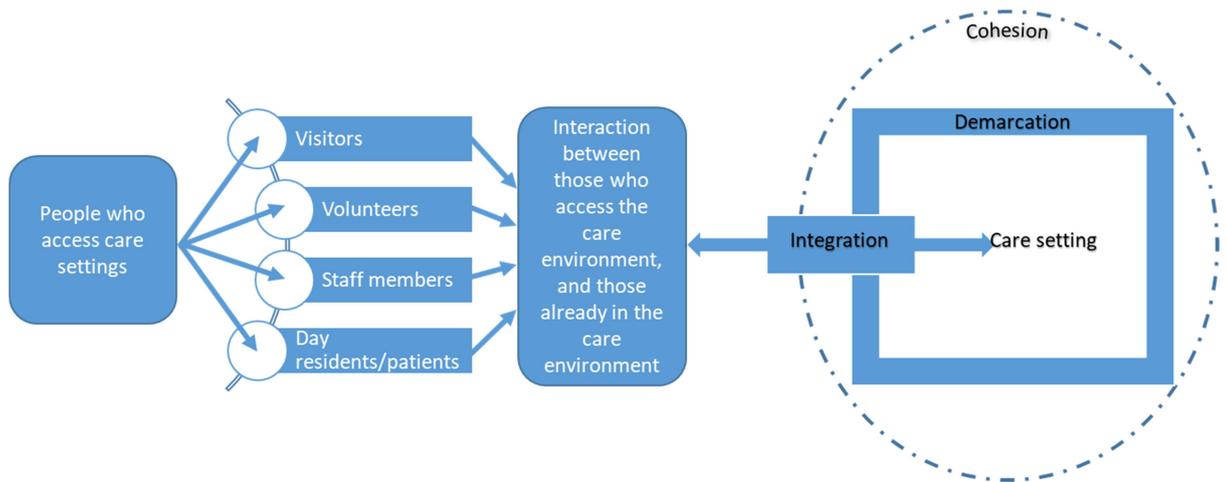


Figure 14: Conceptual Framework based on the data gathered throughout the study

## 6.4 Strengths of the research

The strengths of the study include the use of mixed methods to gain insights into the concepts of social capital and atmosphere in two different care sectors; in-depth observations of organisations that often go under-researched; and time spent within the care settings prior to data collection to aid in the design of the study. These strengths meant that the study was able to obtain meaningful conclusions about the social capital and atmosphere of the care settings that are based on both qualitative interview and quantitative observational and questionnaire data.

To gain a comprehensive view of life inside the care homes and hospices used in this study from a social capital perspective, a mixed methods approach was used. Social capital is a complex concept that has proven difficult to define and measure (Paldam 2000, Portes 2000, Fulkerson and Thompson 2008). This mixed methods approach enabled structural social capital to be examined from multiple perspectives to provide a more comprehensive view of this contested concept. The quantitative data provided an examination of who the main social network members were of the residents and patients in care homes and hospices, and how these networks were maintained using social interactions. This provided a proxy measure of structural social capital in a way that has not been used previously. The quantitative data also allowed a quantitative examination of the atmosphere of the care settings. This allowed discussion around, and conclusions to be drawn, about the relationship between social capital and atmosphere. The qualitative data allowed social interactions to be put into context, giving deeper meaning to the quantitative observations.

The qualitative data also allowed a more in-depth examination of the care setting atmosphere beyond using the SCES questionnaire alone, and provided an in-depth examination of the role that visitors and volunteers have in these different care settings. When examined concurrently, the quantitative and qualitative data provided a greater understanding of social capital in these two care settings than either methodology could provide alone.

The use of mixed methods allowed the collection of a range of data to address the research questions. Observations have been considered an important way to gain a view of life inside care facilities for older people (Clark and Bowling 1990). The observational phase of the study allowed the collection of both qualitative and quantitative observation, allowing the quantitative observations to be put into context by the qualitative observations. The observational tool (Dean, Proudfoot et al. 1993) allowed a large number of social interactions to be observed.

There is a diverse population of individuals within the care settings, such as staff members, residents/patients, visitors, and volunteers. A relatively large number of interviews needed to be conducted to ensure all target participants were represented within the data. It was decided 40 interviews would be conducted allowing 10 interviews to be undertaken at each of the four study sites, with participants coming from each of the four target groups of visitor, volunteer, staff member and resident/patient. During the study, a total of 39 interviews were conducted. While qualitative research is not generalizable in a probabilistic sense, the findings were broadly transferable between care settings and participant groups. Codes and themes were comparable between the care home and hospice care settings, and across the participant groups. The transferability between care setting and participant group ensures comparisons can be drawn from the two care sectors (Houghton, Casey et al. 2013).

I undertook forty hours of voluntary work within one of the study sites, and spent seven hours at each of the other three study sites prior to data collection. This enabled me to gain a comprehensive understanding of the care settings before data collection, providing the opportunity to hold informal discussions with staff members and residents/patients about the research. The purpose of the voluntary work was to ensure the study was designed with the care settings in mind so the research would have minimal impact on the everyday running of the care homes and hospices. The voluntary work also ensured the study's relevance to the day to day practice within each care setting.

It was anticipated that by spending time in each of the care settings prior to data collection and engaging with people about the research the Hawthorne effect (Diaper 1990) might be minimised. The Hawthorne or observer effect is the alteration of a participant's behaviour due to their awareness of being observed. While the Hawthorne effect is often a limitation of observational research, the time spent within the care settings prior to data collection might have helped reduce the effect. For the study to remain ethical, participants were made aware of the observational aspect of the study. Other techniques such as covert observations were not considered appropriate for the settings and participant observation would not allow the collection of the type of data required for the QUIS observational tool. By spending time in the care settings prior to data collection, it allowed the participants to become used to my presence within the care settings.

## 6.5 Limitations of the research

In this study, the day hospice as opposed to inpatient hospice setting was compared to care home settings. This was for a number of pragmatic reasons. It became apparent through the voluntary work undertaken before commencing the study that the nature of hospice care is changing and day care facilities are becoming the primary source of hospice care. Inpatient hospice centres are most commonly used only at the very end of a patient's life. In-patient hospice care would not have been comparable to care home care, and in addition would have raised ethical issues about conducting research with people at the very end of life. It was noticed during the voluntary work, in the fieldwork notes and commented on throughout the course of the research, that all of the resources and benefits such as access to services and volunteers were the same within the inpatient hospice as the day centre hospice areas. The key difference was that day hospice patients attended the hospice, usually on a weekly basis, and spent the rest of the time in their own home, while inpatients were confined to the hospice ward. Patients that attended the day hospice could be considered to be 'visitors' to the hospice setting, while residents in a care home live in the care home as if it was their own home. The day hospice is comparable to care home life as many care homes, including the homes that took part in the present study, accepted and cared for day care service users. The care homes provided day care service users the same level of care and access to care home facilities as full time residents, and day care service users in the care homes were included in the present study in the same way day care patients in a hospice were. The care home communal areas also had

similar physical design and layout to the day hospices communal areas, as seen in the diagrams of the care settings in chapter 4, suggesting that the different care settings were designed in a similar way.

There were a number of limitations that require consideration when interpreting the study findings. The QUIS observation tool recorded the quality of interactions based on five categories. For the analysis, the five categories were dichotomised into two broader categories representing positive and negative interactions. This meant that some information was lost in the analysis. Dichotomising the quality of interaction into two broader categories was appropriate, however, as within these care settings not all interactions could involve a social element, for example emergencies. By combining the positive social and positive care interaction categories it was possible to ensure all positive interactions were recorded, while not scoring positive care interactions lower due to an emergency situation where providing care was the primary focus of the interaction. As there were few observable negative interactions, combining the negative categories with the neutral category enabled there to be more observations in that category ensuring a large enough sample of negative interactions for the analysis to be viable (King and Zeng 2001). By dichotomising the outcome variable, it allowed logistic regression analysis to be used as it has in other clinical settings where the QUIS tool has been utilised (Barker, Griffiths et al. 2016). Regression analysis enabled comparisons of the care home and hospice care settings to be made and also shows what covariates help make an interaction positive.

In the conduct of the study a number of limitations with the research tools and design of the study were noted. While the study aimed to explore the atmosphere of the care settings, this is a difficult concept to measure directly as it is described as the 'feel' or 'personality' of a place when an individual enters the environment (Lemke and Moos 1987, Lemke and Moos 1990, Moos and Lemke 1996). This makes the concept highly subjective and personal to an individual. There were also a small number of responses (n=22 in care homes and n=25 in hospices) obtained from the care settings which means that caution should be used when interpreting the results, although a non-parametric test was also used to test whether findings still held when statistical assumptions were relaxed. Fewer questionnaire responses were received than originally planned. This was not a limitation of the questionnaire, but rather a flawed assumption that there would be a larger population within the care settings from which a sample could be drawn.

To assess the atmosphere of the care settings the SCES was given to staff members, volunteers and visitors, but not residents or patients. While the questionnaire was designed to be given to participants who work in the care settings (Lemke and Moos 1987), residents/patients are likely to have a different perspective of what the atmosphere is like in the care settings. It is also reported that proxy measures of resident satisfaction with care services are not always accurate (Gasquet, Dehé et al. 2003). It was felt that as the residents were already providing data in the form of observations that the SCES should be administered to the staff members instead of residents to reduce the burden on the residents.

The SCES was originally designed for residential care facilities and has not been used within the hospice sector before. While there are measures of the atmosphere that may have been better suited to the hospice settings, such as the ward atmosphere scale (Friis 1986, Røssberg and Friis 2003), these would have been less suitable for care home use. It was felt that hospice settings were more comparable to care home settings in terms of the atmosphere. A hospice setting tries to create a less clinical and more homely atmosphere in the same way as a care home. This means that the SCES questionnaire for measuring the atmosphere is more applicable to a hospice care setting than a measure designed for a clinical setting would be for a care home setting. A possible solution to this might have been to use a different type of measure such as an organisational climate measure (Norbergh, Hellzen et al. 2002). The organisational climate includes aspects that could be related to the positive social atmosphere of a care setting. For example organisational climate includes aspects around the 'liveliness' of the environment, 'conflicts' within the environment and 'freedom' within the environment (Norbergh, Hellzen et al. 2002). It also measures 'trust', the participant's emotional confidence in the relationships within the care setting that would also have been relevant to cognitive social capital (Mitchell and Bossert 2007, Forsman, Nyqvist et al. 2012). This measure could perhaps have been more suitable for both care sectors, but would not have provided an examination of the atmosphere, only organisation of the settings which would be expected to differ based on the nature of the care sectors.

There were a number of limitations regarding the QUIS observational tool. The tool itself enabled the classifying of interactions based on their quality and content. What the tool was unable to distinguish was if a resident or patient that was involved with the interaction had a cognitive impairment such as dementia. It was not possible to determine if the quality or quantity of interactions differed between residents with and residents without

cognitive impairment. What the tool did allow for was notes to be added to the observations about interactions that involved a participant who had dementia, but this could not be controlled for within the analysis. It would be possible to modify the tool to allow the participant categories (resident/patient, staff member, visitor and volunteer) to be broken down into more specific groups (for example with/without cognitive impairment). This could be useful as it may be the case that negative interactions occur more in residents with a cognitive impairment than residents without a cognitive impairment. Residents with cognitive impairment may be more likely to do things that warrant an interaction that restricts their freedom such as wanting to leave the care setting or eating food that has been on the floor. However, mental capacity is often fluctuating, and cognitive impairment is not binary. Care home residents may vary in their level of impairment on a day to day basis and it was not possible to assess residents for capacity during each day of observation due to the potential number of residents being observed who could enter the communal areas.

The modification of breaking down participant categories could also be applied to the staff member category to distinguish between different types of staff members for example, senior care staff, nursing staff and activity co-ordinators. While this change could provide more accurate data, it could also make the task of recording observations more challenging as it would require the observer to have more information about the participants. It could also prove difficult to achieve when observing a busy care setting where multiple interactions are on-going simultaneously.

A final limitation of the QUIS observation tool within the present study was the issue of recording the duration of interactions. While interaction duration was recorded as accurately as possible using a stopwatch, it proved difficult to record the duration of multiple interactions that were on-going simultaneously. A solution to this would be to use an electronic device to record multiple observations simultaneously that allows the observer to indicate the precise moment when they observe each interaction to begin and when it ends.

Despite a variety of participant groups being included in the qualitative interview phase of the study, residents and patients who lacked mental capacity were excluded from the interviews. This was due to ethical concerns around obtaining consent and the need to obtain accurate data about who the visitors and volunteers were within the care home or hospice. However, participants who lacked capacity were still included in the observational

aspect of the study. Residents and patients who lack capacity due to cognitive impairment may have difficulty in distinguishing volunteers from staff members and other groups of individuals who work and visit the care settings. Although there were pragmatic reasons for people who lacked capacity to be excluded from the interviews, this does have implications for the findings of the study. It is unclear from the present study if people who lacked capacity had access to more diverse networks, different quality of interactions or higher levels of social capital. It is also unclear if people who lacked capacity experience the atmosphere of the setting differently from those that had capacity, or if they benefitted from higher social capital and more positive atmosphere. This limitation would need to be addressed in future work examining social capital in populations who lack mental capacity due to cognitive impairment.

An unavoidable limitation of the interviews was that their duration was shorter than originally intended. It was initially intended for interviews to be around 30 minutes, but in practice the mean duration was 23 minutes, with staff members providing the shortest interviews. This was unavoidable due to the busy nature of the care settings. Many of the staff interviews were interrupted as it was difficult for the staff to dedicate a significant proportion of their time to the interviews so they were shortened to accommodate their work needs. This has implications for the research in that staff members may have been under represented within the data as less time was spent interviewing staff members than other groups of participants such as residents and patients. Despite this, an adequate proportion of the interviews came from staff members and theme saturation did occur. Saturation was achieved as no new codes or themes emerged in the data. Findings were similar between staff member participants as ideas, codes and themes occurred in different staff interviews from different care settings.

The duration of the interviews was also restricted due to ethical concerns from a local ethics committee for a hospice study site. It was felt by this committee that an interview of an average of 30 minutes in length would be too intensive for patients to manage. Thirty minutes was suggested by the committee as the maximum time allowed for an interview and not the average. This lowered the duration of participant interviews within the hospice setting as interviews were shortened. Although similar concerns arose about interview duration within care homes, interestingly care home residents provided the longest interviews. This could mean that hospice patients are underrepresented within the data while care home residents are overrepresented, as more time was spent interviewing care home residents than hospice patients. Despite the difference in interview duration, theme

saturation did occur. Codes and themes were recurrent between residents in the care home settings, and patients in the hospice settings.

Volunteers took part in more interviews in the hospice setting than the care home setting. This is a result of the greater presence of volunteers in hospices than care homes. It was observed in the number of interactions, discussed in the interviews and recorded in the qualitative log, that the two hospices in this study had many more volunteers than the two care homes. Care homes that had a high volunteer presence could have been chosen to be approached to take part in the study to provide balance in volunteer numbers between care homes and hospices. However, this would have meant that the care homes involved in the study would not have been representative of care homes in general.

## 6.6 Implications for policy and practice

Evidence from the present study suggests a number of changes that could be made to improve the care of older people, particularly within the care home sector. An open environment such as one that encourages integration between the care setting and the local community, with a mixture of individuals such as volunteers and day care service users was seen to have a positive effect on the atmosphere of the care settings. This was in addition to the quality of interaction being positive enough between residents/patients and other participant groups such as staff members and volunteers to develop and maintain meaningful social networks and relationships.

Care settings could have a more open environment by having an increased number of day care service users. This would increase the number of new individuals that the permanent resident and patients could interact with. In the care home setting, more day care service users can provide a new person for permanent residents to interact with. These day care service users may be in similar circumstances in terms of the level of care needed, but the day care service users may come from different backgrounds, which can provide different opportunities for social interaction. Interacting with people from different background was seen to broaden social networks. Day care service users could also vary from day to day which would also create broader social networks as there would be a wider variety of people within the care setting on a daily basis and increase the opportunity for social interaction. There are issues around funding day care places in care homes. In hospices, patients attended day care services before their illness progressed to a point that they

required full time medical attention, requiring them to become inpatients. In some cases for potential care home residents, once funding is secured, the funding could be used for day care services prior to the resident moving full time into the care home. This would increase the number of day care service users and ease the transition between living independently and moving into the care home. It may also lengthen the amount of time that a resident is able to live independently in the community before entering the care home as a full time resident. There has been recent work (Di Bona, Kennedy et al. 2017) that has aimed to facilitate a more diverse mix of people that care home residents can interact with by bringing school children into a dementia care home setting. The initiative increased children's awareness of dementia, while also engaging residents with dementia in social activities. This study provides evidence that a more diverse population inside the care home environment can prove beneficial for residents, as well as those that access the care home setting. A more diverse community provided by day care residents and children within a care home setting however poses certain risks such as increased opportunity for infectious diseases to enter and spread within the care home setting. This could pose a particular issue in a care home for older people who are likely to be more susceptible to infections. In order to counteract the potential for infectious diseases to spread, it may be necessary to adhere to stricter hygiene procedures such as increased hand washing in a way that avoids the risk of reducing the 'homeliness' that care homes often strive to create.

A wider variety of residents, such as day care service users could strengthen bonding and bridging social capital for the residents. In the hospice sector, varied day care patients can have the added benefit of providing emotional support to other day care patients managing their life limiting illness. This extra support provided by patients may improve the cohesion of the care setting. Increasing the day care service users within the care home sector however, provides its own challenges due to the limited resources available. While the day care service users would receive funding or fund themselves to pay for the care they receive, they would still require staff support and time from the care setting. This would potentially place extra burden on the staff members. To manage this issue, an increased voluntary presence would help provide the extra support that the staff members would require. The diverse networks provided by the volunteers would also provide benefits such as improved cohesion in the care settings and more opportunities for social interaction. Some evidence suggests that volunteers contribute to improving health care services while decreasing the economic challenges associated with maintaining an improved service (Abraham, Arrington et al. 1996).

Although residents who plan entry into a care home with their family and care professionals ease the transition into care (Lee, Woo et al. 2002), many residents who enter a care home do so in a crisis situation. Pressure felt by the resident entering a care home in a short period of time and the need to make decisions quickly can lead to the resident concealing their own needs with regard to the care home placement (Davies and Nolan 2004). Although day care services are not possible to ease the transition into care for those who enter under a crisis situation, if they enter a care home that has a large number of day service users they may be able to increase their social network size which can result in residents feeling increased levels of support (Cheng 2009). In addition to increased feelings of support, a larger social network size created by an increased presence of day care service users has the potential to maintain a higher level of cognitive functioning in individuals at the later stages of Alzheimer's disease (Bennett, Schneider et al. 2006). This suggests a potential for day care service users to be able to improve the lives of residents with cognitive impairment as well as those without cognitive impairment.

While an increased number of day care service users has the potential to increase the social network size of residents, the limited time they spend in a care setting may inhibit close relationships forming between day care residents with other residents and staff members. This potential issue however is not something that was seen in the day centre hospice users within the present study. Hospice and care home day centre users in this study spent one day per week at the care setting. While this lack of time at the care setting may suggest a lack of opportunity to form close relationships, many of the participants commented on the close relationships they felt, and the support that they received from them which contributed to the feeling of cohesion felt within the care settings. The findings from the present study suggest that for day care residents and patients, it is the quality of interaction that enables the formation of close relationships which can lead to a feeling of a cohesive atmosphere felt within the care settings.

In the care homes, despite there being a number of visitors, there were few recorded interactions involving visitors. In the interviews, it was found that visitors tended to go to the bedrooms or private areas to see their relative or friend. While privacy is a necessity within the care home sector, more effort could be made to encourage interactions between visitors and residents to broaden the social networks of the residents. For example, more special events and social gatherings could be organised such as summer fetes and parties, and regular visitors invited to the events, as they are in the hospice sector. If the purpose of the visit is to encourage interaction and not spend time within the

private spaces, then this could facilitate a higher level of positive interaction among residents. Although visitors were not thought to have as much of a regular presence within the day care centre of the hospices, they still had a strong presence at special events such as Christmas parties and fund-raising events where network opportunities were available. This would again have challenges with being implemented within a care setting due to the lack of resources available within the care settings, and often within the care home sector, the need to maintain a profit margin.

While volunteers are common place within the hospice sector (Addington-Hall and Karlsen 2005, Addington-Hall and Karlsen 2005) they have a lesser presence within the care home sector, despite the benefits of volunteering still being recognised. Care homes could implement a similar process of volunteer recruitment to increase volunteer numbers as exists within the hospice sector. This again may be difficult to implement within a care home given the limited resources available and the need to maintain a profit margin. Yet once achieved, the benefits of volunteers could potentially negate the cost of initial recruitment. Political parties have suggested that volunteering and community involvement are methods to help improve society as a whole, and encourage volunteering and community involvement in civil service staff (Conservative Party 2010). Volunteers could be introduced into a care home setting though a culture change that may need to occur to increase the popularity of volunteering within the care home settings.

Organisational culture may be a way to monitor and change the culture of a care home setting to increase the popularity of volunteering within the care home setting.

Organisational culture is a contested concept with many definitions, but can be seen as a social construct based on normative beliefs and values and is expressed in terms of behaviour and attitudes (Scott, Mannion et al. 2003). There are many ways to measure organisational culture (Scott, Mannion et al. 2003) and it has been found that organisational culture can be strengthened within older peoples care settings (Etherton-Beer, Venturato et al. 2013). Some research has found that barriers to changing the organisational culture of a care setting are excluding staff members from culture change activities, and a high turnover of staff. Enablers to culture change include resident and family participation and empowerment at the facility level as opposed to the corporate level, meaning facilities are more able to make and implement decisions locally as opposed to the corporation (Scalzi, Evans et al. 2006). Scalzi, Evans et al. (2006) conclude that it is beneficial to include all levels of staff, residents, and the community in culture change

activities. This could include improving community engagement and changing the culture towards care homes to gain more volunteers within the care home settings.

Aside from a culture change to increase volunteering within a care home, there are a number of challenges that need to be overcome. Financial burden is a consideration faced not only by care home residents, but also for volunteers as they are required to pay for a Disclosure and Barring Service (DBS) certificate to ensure they are suitable to work with vulnerable adults. The qualitative findings of the present study highlighted that the DBS certificate was a significant barrier to gaining access to the care settings faced by volunteers that needed to be overcome, as discussed within the demarcation theme of the qualitative findings in section 5.3.3.1. The acquisition of a DBS certificate however proved less of a barrier within the hospice setting than in the care home setting. As volunteers from both care home and hospice settings within this study were required to pay for their own DBS certificate, it is unlikely the financial cost that hinders volunteers within a care home setting more than a hospice setting. Instead, volunteers may prefer to work in a hospice rather than a care home due to the charitable nature of a hospice compared to the for-profit ownership of care homes (Scourfield 2007).

As hospice volunteer motives have been shown to be altruistic in nature or for a desire of social contact (Stelzer and Lang 2016), these motives may align more with a hospice ethos than a care home. There is evidence to suggest that care home volunteers do not receive a sense appreciation or emotional connection, particularly when interacting with residents with dementia (Funk and Roger 2017). It could be that volunteers do not form such close relationships with residents in care homes as is possible in hospice settings, due to the presence of cognitive impairment. This could in turn limit the number of volunteers within a care home setting. Stigma surrounding care homes and people with dementia was highlighted within the study as a barrier to gaining access to the care settings. Stigma has also been highlighted in other work about perceptions of stigma relating to dementia and the role of reciprocity (Gove, Small et al. 2017). By reducing this stigma through the use of special events such as summer fetes as discussed previously, it may be possible to change volunteer perceptions of life inside the care home, and increase volunteer numbers. Combatting this stigma could not only increase volunteering within a care home, but also improve resident social inclusion through increased interaction and communication, enhancing their potential to reciprocate social contact (Gove, Small et al. 2017). If residents with dementia are more able to reciprocate communication and participate more actively

in the care home society, then care home volunteers may have more chances of having their needs of emotional closeness met (Stelzer and Lang 2016).

The implications for practice are intended as a way of building social capital and in turn improving the atmosphere of the care settings, despite the link between the atmosphere of a care setting and its social capital needing further investigation. The link between social capital and its effects on mental and physical health are unclear, and the ambiguity of the relationship has been previously noted (Coll-Planas, Nyqvist et al. 2016). A systematic review of social capital interventions by Coll-Planas, Nyqvist et al. (2016) found that there is a lack of evidence and diversity among trials with results of social capital interventions showing mixed benefits for outcomes such as quality of life, wellbeing and self-perceived health. Yet the authors concluded that there is some evidence that for certain populations and outcomes, interventions could be effective. Some high quality trials, assessed by using the Cochrane risk of bias tool (Higgins, Altman et al. 2011), showed a favourable impact of social capital on overall mental and physical health, mortality, and the use of health-related resources (Coll-Planas, Nyqvist et al. 2016). This shows interventions designed to improve social capital could have merit when implemented within a care sector for older people.

## 6.7 Implications for future research

The findings from this study point to several avenues for future research. Due to the complexity of the concept, the present study examined only a small aspect of social capital. The methods used have provided an overview of the concept in the form of social interaction and networks, and the role of network members such as visitors and volunteers within two different care sectors. The study showed ways in which social capital can provide benefit to the care of older adults. Although the methods used have met the study aims, social capital has previously been examined primarily through the use of surveys (Van Deth 2003). The complexity and difficult nature of measuring social capital mean that comparisons between and across studies are challenging. There is a need for multi-method strategies to strengthen empirical evidence of social capital and its many different forms and types (Van Deth 2003). The variety of methods that this study used was able to examine social capital from different perspectives and was able to gain an understanding of social capital in the context of care settings for older people. This study highlights the possibility that these methods are a valid way to further investigate the social capital of older people within different types of care sector.

There is a lack of empirical evidence that explores social capitals types and dimensions in relation to older people's health (Coll-Planas, Nyqvist et al. 2016). Findings are mixed and sometimes contradictory with some studies showing a positive association between social capital and some aspects of health (Poortinga 2006, Norstrand, Glicksman et al. 2012), while others found no associations (Wahl, Bergland et al. 2010, Holt, Schulz et al. 2012). One explanation for these contradictory findings is the diversity of definitions and measurement methods of social capital used (Paldam 2000).

People with dementia make up a large proportion of care home residents (Matthews and Denning 2002). There is some evidence that people with cognitive impairment caused by dementia may lack certain aspects of cognitive social capital such as reciprocity (Gove, Small et al. 2017). As dementia has a high prevalence within a care home setting this relationship warrants further investigation. The findings from the present study provide a basis of examining social capital with a focus on residents with dementia. Observational methods are a way to gather valuable and reliable data from people who may lack capacity due to dementia (Brooker and Surr 2006), and this study has shown that observations are a novel method to gain an understanding of social capital.

The present study could be used to generate research ideas relating to social capital and older people's access to palliative care services as the direction of the relationship is not yet known. For example, it is not clear if social capital led to better access to palliative care, or access to palliative care resulted in a greater abundance of social capital. Patients in the hospice sector had better access to a wider variety of health care services. There were more diverse staff networks and multidisciplinary staff teams within the hospice setting, compared to the care home setting. It was not clear though if social capital caused the patients to have better access to the hospice service, or if having a life-limiting illness can cause an increase in social capital at the end of life as some research suggests (Horsfall, Noonan et al. 2012). Further research is warranted in order to determine the direction of the relationship between social capital and access to health services. Although some longitudinal evidence taken over a 7 year period has shown that generalised trust is an independent predictor of self-rated health (Giordano, Bjork et al. 2012), there is also a need for better defined concepts and measurement around social capital to enable conclusions to be drawn which are underpinned by empirical evidence.

In England and Wales, 81.5% of the population live in urban areas and 18.5% live in rural areas, however, residents in rural areas often have a higher age profile than those in urban

areas (Office of National Statistics 2011). Evidence has shown that older people with advanced diseases in rural areas have an increased sense of isolation and dependence on others (Duggleby, Penz et al. 2011). This evidence suggests that social capital can play an important role in a rural setting. Traditionally rural areas are seen to have higher levels of social capital as lower population density encourages connections between residents and higher levels of trust, although some evidence has found that bonding social capital is higher in rural areas, but bridging social capital is marginally greater in urban areas (Sørensen 2016). This difference could be due to the greater diversity of people present in urban areas for reasons such as immigration or socioeconomic status. Other work has shown that there are rural and urban differences in terms of social capital, with mental health being positively associated with social capital in rural and urban areas, while physical health was positively associated with social capital in only urban areas (Ziersch, Baum et al. 2009).

Hospices may have better bridging social capital due to their location within mostly urban areas (Sørensen 2016) and links with hospitals, while care homes can often have rural or urban locations. Rural locations were found in the findings of this study to increase demarcation by making it more difficult for visitors and volunteers to access the care settings, particularly in care homes. The number of volunteers in the care setting could also be affected by a rural or urban location, and the number and quality of interactions in turn affected by people having difficulty in accessing the care setting. A study exploring the relationship between rural and urban care settings may improve understanding of older people's social capital and the atmosphere of a care setting.

This study provided an overview of the people who access and interact with residents and patients within the care home and hospice care sectors. Further work should aim at providing a more comprehensive examination of the social structures within the care settings as a proxy measure of social capital, for example through the use of social network analysis. Social network analysis can provide an overview of the size and strength of social networks of individuals and some research has suggested that it can be used to examine social capital (Leonard, Horsfall et al. 2013, Moore and Kawachi 2017). Social network analysis has been used as a method to examine interaction patterns and support networks of individuals in a diverse range of health care settings including primary care practices, hospices and care homes (Scott, Tallia et al. 2005, Bergman and Haley 2009, Abbott, Bettger et al. 2013). As this study shows that hospices have broader social networks due to

an increased presence of day patients and volunteers, social network analysis could be used to formally examine this.

This study observed that the presence of volunteers and the quality of interactions they provide play a crucial role in the care of patients within the hospice sector. They provide many benefits such as improved cohesion and integration with the outside world. These benefits are also felt within care homes although volunteers were in shorter supply. This suggests that care homes may benefit from an increased volunteer presence in the same way that hospices do. This could be directly examined in future research by seeing if the presence of volunteers in a care home has benefits to the residents in terms of social interaction or quality of life. An intervention study in the form of a cluster randomised controlled trial (RCT) could test this hypothesis. Other outcome measures could examine any other benefits that residents may experience from a volunteer presence such as increased social networks measured through social network analysis or improved quality of life within the care home.

While this suggested study has the potential to provide useful results that may benefit those who receive care within a care home, there are many challenges associated with such a study. One of the main challenges would be recruitment. Care home participation within research is often lacking, particularly for residents with dementia (Davies, Goodman et al. 2014). It may also prove difficult to recruit volunteers to a care home considering the difference in motivations between the for profit nature of many care homes and the altruistic motivations of volunteers (Stelzer and Lang 2016). Another potential problem with a study of this type could be that of attrition of the care homes themselves, the staff within the care homes and also the residents. Care homes can often have a high turnover of staff (Donoghue 2010) which in itself is associated with decreased quality of care within a nursing home setting (Castle and Engberg 2005). Robust outcome measures to assess change in social capital have yet to be fully developed or tested. This could be in part due to the variety of definitions of social capital. This could cause problems for RCTs as trials require pre-determined and focused outcome measures. Attempting to examine social capital as a whole through the use of too many outcome measures could create issues in interpreting the findings associated with the multiplicity of analysis (Schulz, Altman et al. 2010). Care homes are also intended to be residents' homes. There would be ethical issues concerned with the intervention of bringing volunteers into the residents' homes. Some residents may not be open to the idea of more people entering the care home. These

ethical issues would need to be considered in order to maintain the rights and privacy of the residents of the care home.

Larger care homes that are operated by a national organisation are becoming more common. It has been found that small converted properties and privately managed care homes were more likely to close down despite these types of care home having a better social environment (Darton 2004). A positive atmosphere is an important factor in choosing a care home to reside in (Netten, Darton et al. 2002). Social capital appears to be linked to the atmosphere of a care setting in that settings with higher social capital as seen in the hospices also have a more positive atmosphere. Future research is needed to investigate this link further. Interventions aimed at improving social capital for older adults in health care settings are lacking although there does appear to be a potential for social capital interventions to have benefit on the health of older adults (Coll-Planas, Nyqvist et al. 2016). While there is work that uses health outcome measures in social capital intervention studies, (Coll-Planas, Nyqvist et al. 2016), the present study suggests that the atmosphere of a care setting may be a viable outcome measure for social capital interventions. This would test the association between social capital and the atmosphere of a care setting further than the present study, while also examining other benefits of social capital that have not yet been explored within older people's care settings.

Care home design may be able to influence the development of social capital and facilitate a positive atmosphere of a care setting. Environments that are considered homely rather than institutional benefit both residents as well as staff members within a care home setting. Evidence has found that care homes whose design is focused on safety can create a risk-averse environment which sometimes acts against resident quality of life (Parker, Barnes et al. 2004). The study also found that better staff morale was associated with non-institutional environments for residents rather than facilities for staff. It was noted from the diagrams produced within the qualitative log (shown in section 4.1) that both within the care home and hospice care settings, the communal areas were laid out in a similar way which aimed to be homely and promote interaction. There was often a large communal living space with chairs arranged in a way that encouraged interaction, which in turn could help promote social capital through increased network opportunities. Research produced in Norway (Hauge and Kristin 2008) found that while care homes aim to make the environment more like home with a communal living area, residents had reduced opportunity for privacy. Residents perceived themselves as having forced relationships if they were unable to move between communal and private spaces. It was only the

healthiest and most mobile residents that were able to withdraw to private spaces where they were able to control who they spent their time with (Hauge and Kristin 2008).

The environment within the hospice sector has also been shown to have an effect on the social wellbeing of patients. Using ethnography, Rigby, Milligan et al. (2014) found that older people tended to remain within the privacy of their rooms. When patients did make use of communal areas it was most often the garden that was used rather than living areas as it provided patients at the end of their life with feelings of being close to nature. A balance between the need for supervision and independence is needed and person centred ways of working within the environment can help improve the social wellbeing of older people in care (Rigby, Milligan et al. 2014). There is a potential link between building design and the atmosphere of a care setting, and it has been noted that small care homes with a homely environment are more likely to close down due to no longer being financially viable (Darton 2004). Future work could examine the link between the building design and the social capital of a care setting more closely to better understand how the concepts are related. This has the potential to improve the atmosphere of a care setting and to promote the quality of life of residents and patients who are cared for within them.

## 6.8 Reflection

Throughout this research project, there were times that caused me to question my role as a researcher, and the nature of this particular research project. During the data collection process and while I attended the care settings, I witnessed many interactions. Many I recorded as part of the data collection process, but others were made informally outside of structured observation periods but during my time in the care settings. Many of these informal interactions embodied what I considered good aspects of care, for example, a care assistant telling jokes to a particular resident that evoked positive reactions from the resident. The care assistant would be aware of the jocular relationship she had with a particular resident and use playful language, which, at one level might be thought of as 'non-professional'. If she saw that I was present while engaging with the resident in this way, the carer immediately stopped the interaction and felt that she had to justify why she was acting a certain way. The carer would explain that she would not interact this way with other residents, and that she was just trying to reciprocate the conversation in the same manner as was expected by the resident. In my view, I could see little wrong with the interaction. The interaction was clearly appreciated by the resident who was laughing and

enjoying the jokes, and often was the one to initiate the conversation. It made me believe that she knew the resident well and was engaging with him in his preferred manner. If I were in the resident's position, interacting in my preferred manner and having joyful interactions would make me feel at home. Observing such interactions made me question the effect I was having in the care settings. Behaviour changing under observation is well documented and reported widely and known as the Hawthorne effect (Diaper 1990). In order to reduce the effect my presence would have in the care settings, and to help build a rapport with the people who live, work, and visit the care settings, I undertook several hours voluntary work at each study site. Despite this preparatory work I began to worry that my presence in the care home was restricting the interactions that the residents preferred. I reassured the carer many times that I was not there to report on her behaviour or interactions but she still repeatedly justified her interactions. I reflected on my presence in the care setting and wondered if a different approach would have made the staff of the care home more comfortable. An ethnographic approach would have enabled me to spend more time working closely with the staff, so they would not see me as an "outsider" observing them and as a result, not feel the need to change or justify their behaviour as much.

Prior to data collection, I applied to a national ethical committee for ethical approval. One of the outcomes of this process was that I was unable to collect certain types of data from the care settings that took part in the research, such as how long the staff, residents and patients lived in or attended the care homes and hospices. The ethics committee thought this data was too personal and inappropriate to ask within a hospice setting given the nature of the service the hospice provides. This meant that I was unable to collect some demographic data that I had originally intended to collect. I had originally accepted this comment from the ethics committee without question in order to receive ethical approval. Upon reflection and having completed the study, I regret that I did not challenge the ethical committee on this point. Throughout the research process when talking to potential participants about the study, participants openly mentioned to me how long they had been receiving care at that particular care setting. I felt that this was interesting as often within the day centre of the hospice, attendance was much longer than the inpatient ward, and sometimes longer than residents remained within the care home. I would have liked to include more detail about this within the findings of the thesis, and feel that I may have felt more satisfied by the completion of the study if I had challenged the ethical committee more about what data I intended to collect, whether it changed the outcome or not. I think

by doing this PhD, my confidence has increased so that in future I will be more able to articulate and justify why I designed a study the way I did.

There are other observational tools that were considered for use within this study such as Dementia Care Mapping (DCM). DCM was developed as a clinical tool and is often used as a way that can help evaluate components of the quality of care for people with dementia. DCM achieves this by giving a voice to the behaviours of people with dementia who might have difficulty expressing their experience. Following a period of DCM the observer will feedback to staff their observations and a joint discussion will help inform changes to care relating to the observed residents (Kitwood and Bredin 1997). In more recent years, DCM has gained popularity as a research tool that has shown potential to be able to rate the subjective experience of the person with dementia (Sloane, Brooker et al. 2007). DCM allows the reporting and recording of behaviours, as well as the recording of the residents ill-being or well-being that are recorded by an observer over given time periods. These behaviour category codes are reviewed and validated with each version of DCM (Brooker and Surr 2006). On reflection, DCM could have been used as the observation tool used within this study. It may have provided a proxy measure of social capital as it would allow detailed recording of participants' actions and interactions over a given time period. It also had the potential to highlight any potential benefits of interaction based on their observed wellbeing score. However, DCM was developed as a way to develop person centred care for people with dementia and DCM's use has been shown to improve staff members' attention to monitoring and attending to a resident's wellbeing (Chenoweth and Jeon 2007). I am not sure I would have chosen DCM over the quality of interaction schedule. DCM is becoming more widely used as an outcome measure and research tool (Chenoweth and Jeon 2007, Sloane, Brooker et al. 2007), but it was not the intention or purpose of this study to change practice in any way which DCM is often used for. The quality of interaction schedule was designed and developed for a care setting in order to assess interactions, not to develop practice in any way. This study aimed to observe the care settings current environments in order to gain an understanding of their level of social capital. DCM was also designed specifically as an observational tool for use in dementia care, yet the focus of this study was not dementia, but older people in general. Because of this I was concerned about the validity of DCM as a measure in observing residents without dementia, but also patients in a hospice setting, many of whom do not have any form of dementia. The quality of interaction scale was both designed for use within a care home setting for all residents,

not only those with dementia, but has also been validated in a medical care setting such as hospitals, so I chose it as the more appropriate measure to use within this study.

## 6.9 Conclusion

This study set out to examine social life within the care sectors of care homes and hospices using a mixed method approach to gain a comprehensive understanding of the care settings from a social capital perspective. The findings showed that while the quality of interaction does not differ between care sectors, there were a larger number of interactions with volunteers in the hospice. The presence of volunteers and the large number of interactions they have with patients suggests a more diverse network of individuals in the hospice sector than the care home sector. The hospice sector also had more positive atmosphere than the care home settings. It was found that volunteers and visitors provide several benefits such as creating a cohesive environment, and providing integration between the world inside the care setting with the world outside. The findings of the present study suggest that social capital is linked to the atmosphere of the care settings with higher levels of social capital resulting in a more positive atmosphere and a more cohesive care environment. Improving the structural social capital of older people within the care settings by providing more diverse social networks of volunteers and day care service users could result in a better atmosphere within the care setting. There are negative aspects of social capital, such as the tensions that can emerge if pre-established boundaries between groups of people such as volunteers and staff members begin to blur, and social and professional network groups begin to overlap. These blurring boundaries need to be renegotiated in order to create a more positive atmosphere that can be experienced and benefited by all people who live, work and visit the care sectors.

# References

- Abbott, K. M., J. P. Bettger, K. Hampton and H.-P. Kohler (2012). "Exploring the use of social network analysis to measure social integration among older adults in assisted living." Family & community health **35**(4): 322-333.
- Abbott, K. M., J. P. Bettger, K. N. Hampton and H.-P. Kohler (2013). "The feasibility of measuring social networks among older adults in assisted living and dementia special care units." Dementia: 1471301213494524.
- Abraham, I. L., D. T. Arrington and L. I. Wasserbauer (1996). "Using elderly volunteers to care for the elderly: opportunities for nursing." Nursing Economics **14**(4): 232-239.
- Addington-Hall, J. and A. O'Callaghan (2009). "A comparison of the quality of care provided to cancer patients in the UK in the last three months of life in in-patient hospices compared with hospitals, from the perspective of bereaved relatives: results from a survey using the VOICES questionnaire." Palliative Medicine **23**(3): 190-197.
- Addington-Hall, J. M. and S. Karlsen (2005). "A national survey of health professionals and volunteers working in voluntary hospice services in the UK. I. Attitudes to current issues affecting hospices and palliative care." Palliative medicine **19**(1): 40-48.
- Addington-Hall, J. M. and S. Karlsen (2005). "A national survey of health professionals and volunteers working in voluntary hospices in the UK. II. Staff and volunteers' experiences of working in hospices." Palliative medicine **19**(1): 49-57.
- Adler, P. S. and S.-W. Kwon (2002). "Social capital: Prospects for a new concept." Academy of management review **27**(1): 17-40.
- Age-UK. (2013). "Later Life in the United Kingdom, December 2013." Retrieved 17/01/2014, from [http://www.ageuk.org.uk/Documents/EN-GB/Factsheets/Later\\_Life\\_UK\\_factsheet.pdf?dtrk=true](http://www.ageuk.org.uk/Documents/EN-GB/Factsheets/Later_Life_UK_factsheet.pdf?dtrk=true).
- Altman, D. G. and J. M. Bland (1995). "Statistics notes: the normal distribution." Bmj **310**(6975): 298.
- Amieva, H., R. Stoykova, F. Matharan, C. Helmer, T. C. Antonucci and J.-F. Dartigues (2010). "What aspects of social network are protective for dementia? Not the quantity but the quality of social interactions is protective up to 15 years later." Psychosomatic medicine **72**(9): 905-911.
- Andrew, M. K. (2005). "Social capital, health, and care home residence among older adults: a secondary analysis of the Health Survey for England 2000." European Journal of Ageing **2**(2): 137-148.
- Baer, W. M. and L. C. Hanson (2000). "Families' perception of the added value of hospice in the nursing home." Journal of the American Geriatrics Society **48**(8): 879-882.

Bagley, H., L. Cordingley, A. Burns, C. G. Mozley, C. Sutcliffe, D. Challis and P. Huxley (2000). "Recognition of depression by staff in nursing and residential homes." Journal of Clinical Nursing **9**(3): 445-450.

Baker, R., D. Angus, E. R. Smith-Conway, K. S. Baker, C. Gallois, A. Smith, J. Wiles and H. J. Chenery (2015). "Visualising conversations between care home staff and residents with dementia." Ageing and Society **35**(02): 270-297.

Barker, H. R., P. Griffiths, I. Mesa-Eguiagaray, R. Pickering, L. Gould and J. Bridges (2016). "Quantity and quality of interaction between staff and older patients in UK hospital wards: A descriptive study." International Journal of Nursing Studies **62**: 100-107.

Bennett, D. A., J. A. Schneider, Y. Tang, S. E. Arnold and R. S. Wilson (2006). "The effect of social networks on the relation between Alzheimer's disease pathology and level of cognitive function in old people: a longitudinal cohort study." The Lancet Neurology **5**(5): 406-412.

Bercovitch, M. (2007). "The loneliness experience of the dying and of those who care for them." Palliative and Supportive Care **5**: 153-159.

Bergman, E. J. and W. E. Haley (2009). "Depressive symptoms, social network, and bereavement service utilization and preferences among spouses of former hospice patients." Journal of palliative medicine **12**(2): 170-176.

Berkman, L. F., I. Kawachi and M. M. Glymour (2014). Social epidemiology, Oxford University Press.

Beyer, S., K. Bitschnau, L. Pelttari and P. A. (2011). "Hospice and Palliative Care in nursing homes." Retrieved 03/07/2014, from <http://interlinks.euro.centre.org/model/example/HospiceAndPalliativeCareInNursingHomes>.

Beyer, S. and A. H. Pissarek (2015). "Integrating hospice and palliative care in Austrian nursing homes." European Journal of Palliative Care **22**(6): 282-284 283p.

Bourdieu, P. (1986). The Forms of Capital. New York, Greenwald Press.

Bowling, A. (1991). "Social support and social networks: their relationship to the successful and unsuccessful survival of elderly people in the community. An analysis of concepts and a review of the evidence." Family Practice **8**(1): 68-83.

Bowman, C., J. Whistler and M. Ellerby (2004). "A national census of care home residents." Age and Ageing **33**(6): 561-566.

Braun, V. and V. Clarke (2006). "Using thematic analysis in psychology." Qualitative research in psychology **3**(2): 77-101.

Briggs, D. (2010). "Notes on the end of life: the social interactions between patients, carers and professionals." Quality in Ageing and Older Adults **11**(2): 35-46.

- Brooker, D. J. and C. Surr (2006). "Dementia Care Mapping (DCM): initial validation of DCM 8 in UK field trials." International journal of geriatric psychiatry **21**(11): 1018-1025.
- Brown, L. and T. Walter (2013). "Towards a social model of end-of-life care." British Journal of Social Work: bct087.
- Bryman, A. (2012). Social research methods, Oxford university press.
- Buchanan, R. J., M. Choi, S. Wang and C. Huang (2002). "Analyses of nursing home residents in hospice care using the minimum data set." Palliative medicine **16**(6): 465-480.
- Caperchione, C., W. Lauder, G. S. Kolt, M. J. Duncan and W. K. Mummery (2008). "Associations between social capital and health status in an Australian population." Psychol Health Med **13**(4): 471-482.
- Care Home Selection. (2017). "What is the difference between council owned care homes and privately owned care homes?" Retrieved 24/07/2017, from <http://www.carehomedselection.co.uk/factsheets/difference-council-owned-care-homes-privately-owned-care-homes/>.
- Carpiac-Claver, M. L. and L. Levy-Storms (2007). "In a manner of speaking: communication between nurse aides and older adults in long-term care settings." Health communication **22**(1): 59-67.
- Castle, N. G. and J. Engberg (2005). "Staff turnover and quality of care in nursing homes." Medical care **43**(6): 616-626.
- Cattell, V. (2001). "Poor people, poor places, and poor health: the mediating role of social networks and social capital." Social science & medicine **52**(10): 1501-1516.
- Cheng, S.-T. (2009). "The social networks of nursing-home residents in Hong Kong." Ageing & Society **29**(2): 163-178.
- Chenoweth, L. and Y.-H. Jeon (2007). "Determining the efficacy of dementia care mapping as an outcome measure and a process for change: a pilot study." Aging and Mental Health **11**(3): 237-245.
- Chenoweth, L., M. T. King, Y.-H. Jeon, H. Brodaty, J. Stein-Parbury, R. Norman, M. Haas and G. Luscombe (2009). "Caring for Aged Dementia Care Resident Study (CADRES) of person-centred care, dementia-care mapping, and usual care in dementia: a cluster-randomised trial." The Lancet Neurology **8**(4): 317-325.
- Clark, P. and A. Bowling (1990). "Quality of everyday life in long stay institutions for the elderly. An observational study of long stay hospital and nursing home care." Social Science & Medicine **30**(11): 1201-1210.
- Claxton-Oldfield, S. and H. Marrison-Shaw (2013). "Perceived barriers and enablers to referrals to community-based hospice palliative care volunteer programs in Canada." American Journal of Hospice and Palliative Medicine: 1049909113504482.

- Cohen, S. R., P. Boston, B. M. Mount and P. Porterfield (2001). "Changes in quality of life following admission to palliative care units." Palliative medicine **15**(5): 363-371.
- Coleman, J. S. (1988). "Social capital in the creation of human capital." American journal of sociology: S95-S120.
- Coll-Planas, L., F. Nyqvist, T. Puig, G. Urrútia, I. Solà and R. Monteserín (2016). "Social capital interventions targeting older people and their impact on health: a systematic review." Journal of Epidemiology and Community Health.
- Conservative Party (2010). Building a Big Society. London: Conservative Party.
- Cooper, L., H. Gray, J. Adam, D. Brown, P. McLaughlin and J. Watson (2008). "Open all hours: a qualitative exploration of open visiting in a hospice." International journal of palliative nursing **14**(7).
- Creswell, J. W. and V. L. P. Clark (2007). Designing and conducting mixed methods research.
- Darton, R. A. (2004). "What types of home are closing? The characteristics of homes which closed between 1996 and 2001." Health & social care in the community **12**(3): 254-264.
- Davies, S. and M. Nolan (2004). "'Making the move': relatives' experiences of the transition to a care home." Health & social care in the community **12**(6): 517-526.
- Davies, S. L., C. Goodman, J. Manthorpe, A. Smith, N. Carrick and S. Iliffe (2014). "Enabling research in care homes: an evaluation of a national network of research ready care homes." BMC medical research methodology **14**(1): 47.
- Dean, R., R. Proudfoot and J. Lindesay (1993). "The quality of interactions schedule (QUIS): development, reliability and use in the evaluation of two domus units." International Journal of Geriatric Psychiatry **8**(10): 819-826.
- Department of Health. (2015). "Prime Minister's Challenge on Dementia 2020." Retrieved 16/11/2017.
- Devine, F. and J. M. Roberts (2003). "Alternative approaches to researching social capital: a comment on van Deth's measuring social capital."
- Dewing, J. (2008). "Process consent and research with older persons living with dementia." Research Ethics Review **4**(2): 59-64.
- Di Bona, L., S. Kennedy and G. Mountain (2017). "Adopt a care home: an intergenerational initiative bringing children into care homes." Dementia. Submitted for publication.
- Diaper, G. (1990). "The Hawthorne effect: A fresh examination." Educational Studies **16**(3): 261-267.
- Donoghue, C. (2010). "Nursing home staff turnover and retention: An analysis of national level data." Journal of Applied Gerontology **29**(1): 89-106.
- Drageset, J. (2004). "The importance of activities of daily living and social contact for loneliness: a survey among residents in nursing homes." Scandinavian Journal of Caring Sciences **18**(1): 65-71.

Drageset, J., M. Kirkevold and B. Espehaug (2011). "Loneliness and social support among nursing home residents without cognitive impairment: a questionnaire survey." International Journal of Nursing Studies **48**(5): 611-619.

Duffy, B., J. R. Oyebode and J. Allen (2009). "Burnout among care staff for older adults with dementia: The role of reciprocity, self-efficacy and organizational factors." Dementia **8**(4): 515-541.

Duggleby, W. D., K. Penz, B. Leipert, D. M. Wilson, D. Goodridge and A. Williams (2011). "I am part of the community but... The changing context of rural living for persons with advanced cancer and their families." Rural and remote health **11**(3).

Durkin, D. W., M. S. Shotwell and S. F. Simmons (2014). "The impact of family visitation on feeding assistance quality in nursing homes." Journal of Applied Gerontology **33**(5): 586-602.

Dykstra, P. A., T. G. Van Tilburg and J. de Jong Gierveld (2005). "Changes in Older Adult Loneliness Results From a Seven-Year Longitudinal Study." Research on aging **27**(6): 725-747.

Edvardsson, D., D. Fetherstonhaugh and R. Nay (2010). "Promoting a continuation of self and normality: person-centred care as described by people with dementia, their family members and aged care staff." Journal of clinical nursing **19**(17-18): 2611-2618.

Edvardsson, J. D., P. O. Sandman and B. H. Rasmussen (2005). "Sensing an atmosphere of ease: a tentative theory of supportive care settings." Scandinavian Journal of Caring Sciences **19**(4): 344-353.

Eilers, M. K., P. A. Lucey and S. S. Stein (2007). "Promoting social capital for the elderly." Nursing economic\$ **25**(5): 304.

Elliott, A. C. and W. A. Woodward (2007). Statistical analysis quick reference guidebook: With SPSS examples, Sage.

Ellis, J. M. (2010). "Psychological transition into a residential care facility: older people's experiences." Journal of advanced nursing **66**(5): 1159-1168.

Etherton-Ber, C., L. Venturato and B. Horner (2013). "Organisational Culture in Residential Aged Care Facilities: A Cross-Sectional Observational Study." PloS one **8**(3): e58002.

Farmer, T., K. Robinson, S. J. Elliott and J. Eyles (2006). "Developing and implementing a triangulation protocol for qualitative health research." Qualitative health research **16**(3): 377-394.

Field, A. (2009). Discovering statistics using SPSS, Sage publications.

Field, J. (2008). Social Capital. Abingdon, Oxon, Routledge.

Fielding, N. G. and J. L. Fielding (1986). "Linking data: Qualitative and quantitative methods in Social Research." Beverly Hills: Sage.

Forsman, A., F. Nyqvist, I. Schierenbeck, Y. Gustafson and K. Wahlbeck (2012). "Structural and cognitive social capital and depression among older adults in two Nordic regions." *Aging & Mental Health* **16**(6): 771-779.

Fossey, J., S. Masson, J. Stafford, V. Lawrence, A. Corbett and C. Ballard (2014). "The disconnect between evidence and practice: a systematic review of person-centred interventions and training manuals for care home staff working with people with dementia." *International journal of geriatric psychiatry* **29**(8): 797-807.

Friis, S. (1986). "Characteristics of a good ward atmosphere." *Acta Psychiatrica Scandinavica* **74**(5): 469-473.

Froggatt, K. A. (2001). "Palliative care and nursing homes: where next?" *Palliative medicine* **15**(1): 42-48.

Fulkerson, G. M. and G. H. Thompson (2008). "The Evolution of a Contested Concept: A Meta-Analysis of Social Capital Definitions and Trends (1988-2006)\*." *Sociological Inquiry* **78**(4): 536-557.

Funk, L. M. and K. S. Roger (2017). "Implications of the Shifting Landscape of Residential Care for Volunteers' Lived Experiences and Role Involvement." *Ageing International* **42**(1): 44-61.

Garrett, D. K. and A. M. McDaniel (2001). "A new look at nurse burnout: the effects of environmental uncertainty and social climate." *Journal of Nursing Administration* **31**(2): 91-96.

Gasquet, I., S. Dehé, P. Gaudebout and B. Falissard (2003). "Regular visitors are not good substitutes for assessment of elderly patient satisfaction with nursing home care and services." *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences* **58**(11): M1036-M1041.

Gates, M. F. (1991). "Transcultural comparison of hospital and hospice as caring environments for dying patients." *Journal of Transcultural Nursing* **2**(2): 3-15.

Ghasemi, A. and S. Zahediasl (2012). "Normality tests for statistical analysis: a guide for non-statisticians." *International journal of endocrinology and metabolism* **10**(2): 486-489.

Giordano, G. N., J. Bjork and M. Lindstrom (2012). "Social capital and self-rated health--a study of temporal (causal) relationships." *Soc Sci Med* **75**(2): 340-348.

Gove, D., N. Small, M. Downs and M. Vernooij-Dassen (2017). "General practitioners' perceptions of the stigma of dementia and the role of reciprocity." *Dementia* **16**(7): 948-964.

Grande, G. E., J. M. Addington-Hall and C. J. Todd (1998). "Place of death and access to home care services: are certain patient groups at a disadvantage?" *Social science & medicine* **47**(5): 565-579.

Gray, H., J. Adam, D. Brown, P. McLaughlin, V. Hill and L. Wilson (2011). "Visiting all hours: a focus group study on staff's views of open visiting in a hospice." International journal of palliative nursing **17**(11).

Guba, E. G. and Y. S. Lincoln (1994). "Competing paradigms in qualitative research." Handbook of qualitative research **2**(163-194): 105.

Hall, M. A., B. Zheng, E. Dugan, F. Camacho, K. E. Kidd, A. Mishra and R. Balkrishnan (2002). "Measuring patients' trust in their primary care providers." Medical care research and review **59**(3): 293-318.

Hall, S., D. Opio, R. H. Dodd and I. J. Higginson (2011). "Assessing quality-of-life in older people in care homes." Age and ageing **40**(4): 507-512.

Hämel, K. (2016). "Making nursing homes more community-oriented: insights from an exploratory study in Germany." Ageing and Society **36**(04): 673-693.

Hancock, G. A., B. Woods, D. Challis and M. Orrell (2006). "The needs of older people with dementia in residential care." International Journal of Geriatric Psychiatry **21**(1): 43-49.

Harden, A. (2010). "Mixed-methods systematic reviews: integrating quantitative and qualitative findings." Focus **2010**(25): 1-8.

Harpham, T., M. J. De Silva and T. Tuan (2006). "Maternal social capital and child health in Vietnam." J Epidemiol Community Health **60**(10): 865-871.

Hauge, S. and H. Kristin (2008). "The nursing home as a home: a field study of residents' daily life in the common living rooms." J Clin Nurs **17**(4): 460-467.

Health, D. o. (2005). Mental Capacity Act. London, HMSO.

Healthcare Improvement Scotland. (2011). "Quality of Interaction Schedule, Observation Tool (2011) Inspecting acute care for older people." Retrieved 12/01/2015, from [http://www.healthcareimprovementscotland.org/our\\_work/inspecting\\_and\\_regulating\\_care/nhs\\_hospitals\\_and\\_services/care\\_of\\_older\\_people/procedures\\_and\\_tools/observation\\_tool.aspx](http://www.healthcareimprovementscotland.org/our_work/inspecting_and_regulating_care/nhs_hospitals_and_services/care_of_older_people/procedures_and_tools/observation_tool.aspx).

Helliwell, J. F. and R. D. Putnam (1995). "Economic growth and social capital in Italy." Eastern Economic Journal **21**(3): 295-307.

Higgins, J. P., D. G. Altman, P. C. Gøtzsche, P. Jüni, D. Moher, A. D. Oxman, J. Savović, K. F. Schulz, L. Weeks and J. A. Sterne (2011). "The Cochrane Collaboration's tool for assessing risk of bias in randomised trials." Bmj **343**: d5928.

Higginson, I., J. Hearn, K. Myers and A. Naysmith (2000). "Palliative day care: what do services do?" Palliative medicine **14**(4): 277-286.

Holahan, C. J. and R. H. Moos (1982). "Social support and adjustment: Predictive benefits of social climate indices." American Journal of Community Psychology **10**(4): 403-415.

- Holt, C. L., E. Schulz, B. R. Williams, E. M. Clark and M. Q. Wang (2012). "Social, Religious and Spiritual Capital and Physical/Emotional Functioning in a National Sample of African Americans." Journal of Community & Applied Social Psychology **22**(4): 346-362.
- Horsfall, D., K. Noonan and R. Leonard (2012). "Bringing our dying home: How caring for someone at end of life builds social capital and develops compassionate communities." Health Sociology Review **21**(4): 373-382.
- Houghton, C., D. Casey, D. Shaw and K. Murphy (2013). "Rigour in qualitative case-study research." Nurse researcher **20**(4): 12-17.
- Hunt, M. R. (2009). "Strengths and challenges in the use of interpretive description: reflections arising from a study of the moral experience of health professionals in humanitarian work." Qualitative health research **19**(9): 1284-1292.
- Iida, H. and R. G. Rozier (2013). "Mother-perceived social capital and children's oral health and use of dental care in the United States." Am J Public Health **103**(3): 480-487.
- Jacob, S. A. and S. P. Furgerson (2012). "Writing interview protocols and conducting interviews: Tips for students new to the field of qualitative research." The Qualitative Report **17**(42): 1-10.
- Johnson, R. B. and A. J. Onwuegbuzie (2004). "Mixed methods research: A research paradigm whose time has come." Educational researcher **33**(7): 14-26.
- Johnson, R. B., A. J. Onwuegbuzie and L. A. Turner (2007). "Toward a definition of mixed methods research." Journal of mixed methods research **1**(2): 112-133.
- Kash, B. A., N. G. Castle and C. D. Phillips (2007). "Nursing home spending, staffing, and turnover." Health care management review **32**(3): 253-262.
- Kennett, C. and M. Payne (2005). "Understanding why palliative care patients' like day care'and'getting out'." Journal of palliative care **21**(4): 292.
- Kennett, C. E. (2000). "Participation in a creative arts project can foster hope in a hospice day centre." Palliative medicine **14**(5): 419-425.
- Kernohan, W. G., F. Hasson, P. Hutchinson and B. Cochrane (2006). "Patient satisfaction with hospice day care." Supportive care in cancer **14**(5): 462-468.
- Killett, A., D. Burns, F. Kelly, D. Brooker, A. Bowes, J. La Fontaine, I. Latham, M. Wilson and M. O'NEILL (2016). "Digging deep: how organisational culture affects care home residents' experiences." Ageing & Society **36**(1): 160-188.
- Kinash, S. (2006). "Paradigms, methodology & methods." Bond University: Australia. Retrieved October 5: 2011.
- King, G. and L. Zeng (2001). "Logistic regression in rare events data." Political analysis: 137-163.

- Kirkley, C., C. Bamford, M. Poole, H. Arksey, J. Hughes and J. Bond (2011). "The impact of organisational culture on the delivery of person-centred care in services providing respite care and short breaks for people with dementia." Health & social care in the community **19**(4): 438-448.
- Kitwood, T. and K. Bredin (1997). Evaluating dementia care the DCM method, Bradford, England: Bradford Dementia Research Group, Bradford University.
- Knight, C., S. A. Haslam and C. Haslam (2010). "In home or at home? How collective decision making in a new care facility enhances social interaction and wellbeing amongst older adults." Ageing and Society **30**(08): 1393-1418.
- Knight, T. and D. Mellor (2007). "Social inclusion of older adults in care: Is it just a question of providing activities?" International journal of qualitative studies on health and well-being **2**(2): 76-85.
- Lee, D. T., J. Woo and A. E. Mackenzie (2002). "A review of older people's experiences with residential care placement." Journal of Advanced Nursing **37**(1): 19-27.
- Lemke, S. and R. H. Moos (1987). "Measuring the social climate of congregate residences for older people: Sheltered Care Environment Scale." Psychology and Aging **2**(1): 20.
- Lemke, S. and R. H. Moos (1990). "Validity of the Sheltered Care Environment Scale: conceptual and methodological issues." Psychology and Aging **5**(4): 569-571.
- Leonard, R., D. Horsfall and K. Noonan (2013). "Identifying changes in the support networks of end-of-life carers using social network analysis." BMJ supportive & palliative care: bmjspcare-2012-000257.
- Leow, M. Q., M.-F. Chan and S. W. Chan (2014). "Predictors of change in quality of life of family caregivers of patients near the end of life with advanced cancer." Cancer nursing **37**(5): 391-400.
- Lewis, J. M., M. DiGiacomo, D. C. Currow and P. M. Davidson (2014). "Social capital in a lower socioeconomic palliative care population: a qualitative investigation of individual, community and civic networks and relations." BMC palliative care **13**(1): 1.
- Lewis, J. M., M. DiGiacomo, T. Lockett, P. M. Davidson and D. C. Currow (2013). "A social capital framework for palliative care: supporting health and well-being for people with life-limiting illness and their carers through social relations and networks." Journal of pain and symptom management **45**(1): 92-103.
- Lewis, M. J. (2007). Medicine and care of the dying: A modern history, Oxford University Press, USA.
- Li, S. and J. Delva (2012). "Social capital and smoking among Asian American men: an exploratory study." Am J Public Health **102** Suppl 2: S212-221.
- Lievesley, N., G. Crosby, C. Bowman and E. Midwinter (2011). The changing role of care homes. Centre for Policy on Ageing.

- Lin, N. (2002). Social capital: A theory of social structure and action, Cambridge university press.
- Lin, N., K. S. Cook and R. S. Burt (2001). Social capital: Theory and research, Transaction Publishers.
- Maccabee, J. (1994). "The effect of transfer from a palliative care unit to nursing homes—are patients' and relatives' needs met?" Palliative medicine **8**(3): 211-214.
- Matthews, F. E. and T. Denning (2002). "Prevalence of dementia in institutional care." The Lancet **360**(9328): 225-226.
- McAllister, C. L. and M. A. Silverman (1999). "Community formation and community roles among persons with Alzheimer's disease: a comparative study of experiences in a residential Alzheimer's facility and a traditional nursing home." Qualitative Health Research **9**(1): 65-85.
- McDougall, F., F. Matthews, K. Kvaal, M. Dewey and C. Brayne (2007). "Prevalence and symptomatology of depression in older people living in institutions in England and Wales." Age and Ageing **36**(5): 562-568.
- Meier, D. (2015). "Tomorrow's nursing homes must integrate palliative care." Retrieved 01/12/2015, from <http://www.mcknights.com/guest-columns/diane-e-meier-md-facp/article/391683/>.
- Meier, D. E. (2011). "Increased access to palliative care and hospice services: opportunities to improve value in health care." Milbank Quarterly **89**(3): 343-380.
- Miller, S. C. (2015). "Hospice and Palliative Care in Nursing Homes: Challenges and Opportunities for Enhanced Access." Rhode Island medical journal (2013) **98**(4): 26-29.
- Miller, S. C., J. C. Lima and S. A. Thompson (2015). "End-of-life care in nursing homes with greater versus less palliative care knowledge and practice." Journal of palliative medicine **18**(6): 527-534.
- Mitchell, A. D. and T. J. Bossert (2007). "Measuring dimensions of social capital: evidence from surveys in poor communities in Nicaragua." Soc Sci Med **64**(1): 50-63.
- Mitchell, J. M. and B. J. Kemp (2000). "Quality of Life in Assisted Living Homes A Multidimensional Analysis." The Journals of Gerontology Series B: Psychological Sciences and Social Sciences **55**(2): P117-P127.
- Modie-Moroka, T. (2009). "Does level of social capital predict perceived health in a community?—a study of adult residents of low-income areas of Francistown, Botswana." Journal of health, population, and nutrition **27**(4): 462.
- Moniz-Cook, E., R. Woods and E. Gardiner (2000). "Staff factors associated with perception of behaviour as 'challenging' in residential and nursing homes." Aging & Mental Health **4**(1): 48-55.

- Moore, D. C. and B. Hanratty (2013). "Out of sight, out of mind? a review of data available on the health of care home residents in longitudinal and nationally representative cross-sectional studies in the UK and Ireland." Age Ageing **42**(6): 798-803.
- Moore, S. and I. Kawachi (2017). "Twenty years of social capital and health research: a glossary." Journal of Epidemiology and Community Health: jech-2016-208313.
- Moos, R. H. (1974). Evaluating treatment environments: A social ecological approach. New York, Wiley.
- Moos, R. H. (1997). Evaluating treatment environments: The quality of psychiatric and substance abuse programs. New Brunswick, NJ, Transaction Publishers.
- Moos, R. H., M. Gauvain, S. Lemke, W. Max and B. Mehren (1979). "Assessing the social environments of sheltered care settings." The Gerontologist **19**(1): 74-82.
- Moos, R. H. and S. Lemke (1996). Evaluating residential facilities: The multiphasic environmental assessment procedure, Sage Publications, Inc.
- Moran-Ellis, J., V. D. Alexander, A. Cronin, M. Dickinson, J. Fielding, J. Sleney and H. Thomas (2006). "Triangulation and integration: processes, claims and implications." Qualitative research **6**(1): 45-59.
- Morgan, D. L. (2007). "Paradigms lost and pragmatism regained methodological implications of combining qualitative and quantitative methods." Journal of mixed methods research **1**(1): 48-76.
- Muckenhuber, J., W. J. Stronegger and W. Freidl (2012). "Social capital affects the health of older people more strongly than that of younger people." Ageing and Society **33**(05): 853-870.
- Nelson, H. W., C. C. Pratt, C. E. Carpenter and K. L. Walter (1995). "Factors affecting volunteer long-term care ombudsman organizational commitment and burnout." Nonprofit and Voluntary Sector Quarterly **24**(3): 213-233.
- Netten, A., R. Darton and L. A. Curtis (2002). Self-Funded Admissions to Care Homes. Funded/commissioned by: Department for Work and Pensions, Research Report No. 159, Personal Social Services Research Unit.
- Neuman, W. L. (2005). Social research methods: Quantitative and qualitative approaches, Allyn and Bacon Boston.
- NHPCO (2015). "Figures: Hospice Care in America." Alexandria, VA: National Hospice and Palliative Care Organization: 10-11.
- NHS. (2012). "End of Life Care - Hospice Care." Retrieved 03/07/2014, from <http://www.nhs.uk/Planners/end-of-life-care/Pages/hospice-care.aspx>.
- Nihtilä, E. and P. Martikainen (2007). "Household income and other socio-economic determinants of long-term institutional care among older adults in Finland." Population studies **61**(3): 299-314.

Norbergh, K. G., O. Hellzen, P. O. SANDMAN and K. Asplun (2002). "The relationship between organizational climate and the content of daily life for people with dementia living in a group-dwelling." Journal of clinical nursing **11**(2): 237-246.

Norstrand, J. A., A. Glicksman, J. Lubben and M. Kleban (2012). "The Role of the Social Environment on Physical and Mental Health of Older Adults." Journal of Housing For the Elderly **26**(1-3): 290-307.

O' Cathain, A., E. Murphy and J. Nicholl (2010). "Three techniques for integrating data in mixed methods studies." BMJ **341**: c4587.

Office for National Statistics. (2008). "National Population Projections 2008." Retrieved 04/08/2014.

Office for National Statistics. (2012). "Deaths registered in England and Wales, 2012." Retrieved 27/06/2014, from <http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-325289>.

Office for National Statistics. (2013). "Characteristics of Older People - What does the 2011 Census tell us about the oldest old living in England and Wales? ." Retrieved 27/06/2014, from [http://www.ons.gov.uk/ons/dcp171776\\_342117.pdf](http://www.ons.gov.uk/ons/dcp171776_342117.pdf).

Office of National Statistics (2011). "Census Analysis-Comparing Rural and Urban Areas of England and Wales." London: Office for National Statistics pp. Report.

Oksanen, T., M. Kivimaki, I. Kawachi, S. V. Subramanian, S. Takao, E. Suzuki, A. Kouvonen, J. Pentti, P. Salo, M. Virtanen and J. Vahtera (2011). "Workplace social capital and all-cause mortality: a prospective cohort study of 28,043 public-sector employees in Finland." Am J Public Health **101**(9): 1742-1748.

Paldam, M. (2000). "Social capital: one or many? Definition and measurement." Journal of economic surveys **14**(5): 629-653.

Pallant, J. (2013). "SPSS survival manual: A step by step guide to data analysis using IBM SPSS." Maidenhead: McGraw-Hill.

Parker, C., S. Barnes, K. McKee, K. Morgan, J. Torrington and P. Tregenza (2004). "Quality of life and building design in residential and nursing homes for older people." Ageing and Society **24**(6): 941-962.

Payne, M. (2006). "Social objectives in cancer care: the example of palliative day care." European journal of cancer care **15**(5): 440-447.

Payne, S. (2002). "Dilemmas in the use of volunteers to provide hospice bereavement support: evidence from New Zealand." Mortality **7**(2): 139-154.

Petrovic-Poljak, A. and C. Konnert (2013). "Sense of community in long-term care: the views of family caregivers of elderly military veterans." International Psychogeriatrics **25**(03): 390-402.

- Planalp, S. and M. Trost (2009). "Motivations of hospice volunteers." American Journal of Hospice and Palliative Medicine.
- Poortinga, W. (2006). "Social relations or social capital? Individual and community health effects of bonding social capital." Soc Sci Med **63**(1): 255-270.
- Portes, A. (2000). The two meanings of social capital. Sociological forum, Springer.
- Putnam, R. (1993). "Making democracy work: civic traditions in modern Italy." Princeton University Press.
- Putnam, R. D. (1995). "Bowling alone: America's declining social capital." Journal of democracy **6**(1): 65-78.
- Putnam, R. D. (2001). Bowling alone: The collapse and revival of American community, Simon and Schuster.
- Rasmussen, B. H. (1998). "How patients spend their time in a hospice and in an oncological unit." Journal of advanced nursing **28**(4): 818-828.
- Rigby, J., C. Milligan and S. Payne (2014). "How does the environment of a UK hospice impact on the social wellbeing of older inpatients?: an ethnographic study." Palliative Medicine **28**(6): 788-788.
- Robards, J., M. Evandrou, J. Falkingham and A. Vlachantoni (2014). "Mortality at older ages and moves in residential and sheltered housing: evidence from the UK." Journal of epidemiology and community health: jech-2013-203097.
- Rokach, A., R. Matalon, A. SaFarov and M. Bercovitch (2007). "The dying, those who care for them, and how they cope with loneliness." American Journal of Hospice and Palliative Medicine **24**(5): 399-407.
- Rokach, A., R. Matalon, A. Safarov and M. Bercovitch (2007). "The loneliness experience of the dying and of those who care for them." Palliative & supportive care **5**(2): 153-159.
- Rosenberg, J. P., D. Horsfall, R. Leonard and K. Noonan (2015). "Informal caring networks for people at end of life: building social capital in Australian communities." Health Sociology Review **24**(1): 29-37.
- Røssberg, J. and S. Friis (2003). "A suggested revision of the Ward Atmosphere Scale." Acta Psychiatrica Scandinavica **108**(5): 374-380.
- Rosser, M. and L. King (2003). "Transition experiences of qualified nurses moving into hospice nursing." Journal of advanced nursing **43**(2): 206-215.
- Russell, H. and P. E. Foreman (2002). "Maintaining a relationship with a family member in a nursing home: The role of visitor." Journal of Family Studies **8**(2): 147-164.
- Sackley, C., T. Hoppitt, S. Levin and K. Cardoso (2006). "Observations of activity levels and social interaction in a residential care setting." International Journal of Therapy and Rehabilitation **13**(8): 370-373.

Scalzi, C. C., L. K. Evans, A. Barstow and K. Hostvedt (2006). "Barriers and enablers to changing organizational culture in nursing homes." Nursing administration quarterly **30**(4): 368-372.

Schulman-Green, D., R. McCorkle, L. Curry, E. Cherlin, R. Johnson-Hurzeler and E. Bradley (2004). "At the crossroads: making the transition to hospice." Palliative & supportive care **2**(04): 351-360.

Schulz, K. F., D. G. Altman and D. Moher (2010). "CONSORT 2010 statement: updated guidelines for reporting parallel group randomised trials." BMC medicine **8**(1): 18.

Schwartz, C. E. and M. A. Sprangers (2000). Adaptation to changing health: Response shift in quality-of-life research, American Psychological Association.

Scott, J., A. Tallia, J. C. Crosson, A. J. Orzano, C. Stroebel, B. DiCicco-Bloom, D. O'Malley, E. Shaw and B. Crabtree (2005). "Social network analysis as an analytic tool for interaction patterns in primary care practices." The Annals of Family Medicine **3**(5): 443-448.

Scott, L. O., J. M. Law, D. P. Brodeur, C. A. Salerno, A. Thomas and S. C. McMillan (2014). "Relationship with God, Loneliness, Anger and Symptom Distress in Patients with Cancer Who are Near the End of Life." Journal of hospice and palliative nursing: JHPN: the official journal of the Hospice and Palliative Nurses Association **16**(8): 482.

Scott, T., R. Mannion, H. Davies and M. Marshall (2003). "The quantitative measurement of organizational culture in health care: a review of the available instruments." Health services research **38**(3): 923-945.

Scott, T., R. Mannion, M. Marshall and H. Davies (2003). "Does organisational culture influence health care performance? A review of the evidence." Journal of Health Services Research & Policy **8**(2): 105-117.

Scourfield, P. (2007). "Are there reasons to be worried about the 'caretization' of residential care?" Critical Social Policy **27**(2): 155-180.

Sévigny, A., S. Dumont, S. R. Cohen and A. Frappier (2009). "Helping them live until they die: volunteer practices in palliative home care." Nonprofit and voluntary sector quarterly.

Shaw, K. L., C. Clifford, K. Thomas and H. Meehan (2010). "Improving end-of-life care: a critical review of the Gold Standards Framework in primary care." Palliative Medicine **24**(3): 317-329.

Shelton, R. C., L. H. McNeill, E. Puleo, K. Y. Wolin, K. M. Emmons and G. G. Bennett (2011). "The association between social factors and physical activity among low-income adults living in public housing." Am J Public Health **101**(11): 2102-2110.

Siisainen, M. (2003). "Two concepts of social capital: Bourdieu vs. Putnam." International Journal of Contemporary Sociology **40**(2): 183-204.

Sloane, P. D., D. Brooker, L. Cohen, C. Douglass, P. Edelman, B. R. Fulton, S. Jarrott, R. Kasayka, D. Kuhn, J. S. Preisser, C. S. Williams and S. Zimmerman (2007). "Dementia care mapping as a research tool." Int J Geriatr Psychiatry **22**(6): 580-589.

Sloane, P. D., S. Zimmerman, L. Hanson, C. M. Mitchell, C. Riedel-Leo and V. Custis-Buie (2003). "End-of-Life Care in Assisted Living and Related Residential Care Settings: Comparison with Nursing Homes." Journal of the American Geriatrics Society **51**(11): 1587-1594.

Sørensen, J. F. (2016). "Rural–urban differences in bonding and bridging social capital." Regional Studies **50**(3): 391-410.

South West Public Health Observatory (2010). Deaths in Older Adults in England. National End of Life Care Intelligence Network.

Statistics, L. (2013). "Binomial Logistic Regression using SPSS Statistics." Retrieved 16/11/2016, 2016, from <https://statistics.laerd.com/spss-tutorials/binomial-logistic-regression-using-spss-statistics.php>.

Stelzer, E.-M. and F. R. Lang (2016). "Motivations of German hospice volunteers: how do they compare to nonhospice volunteers and US hospice volunteers?" American Journal of Hospice and Palliative Medicine® **33**(2): 154-163.

Stevenson, D. G., H. A. Huskamp, D. C. Grabowski and N. L. Keating (2007). "Differences in hospice care between home and institutional settings." Journal of palliative medicine **10**(5): 1040-1047.

Tang, W.-R., L. S. Aaronson and S. A. Forbes (2004). "Quality of life in hospice patients with terminal illness." Western Journal of Nursing Research **26**(1): 113-128.

Taylor, J., J. Sims and T. P. Haines (2014). "'I accept it [staff assistance]; no choice': an ethnographic study of residents' attitudes towards mobility within nursing homes." International journal of older people nursing **9**(4): 258-268.

Teddlie, C. and A. Tashakkori (2009). Foundations of mixed methods research: Integrating quantitative and qualitative approaches in the social and behavioral sciences, Sage Publications Inc.

Teno, J. M., B. R. Clarridge, V. Casey, L. C. Welch, T. Wetle, R. Shield and V. Mor (2004). "Family perspectives on end-of-life care at the last place of care." Jama **291**(1): 88-93.

Thomas, J. E., B. O'Connell and C. J. Gaskin (2013). "Residents' perceptions and experiences of social interaction and participation in leisure activities in residential aged care." Contemporary Nurse **45**(2): 244-245.

Thomas, R. (2001). "Patients' perceptions of visiting: a phenomenological study in a specialist palliative care unit." Palliative medicine **15**(6): 499-504.

Thorne, S. (2016). Interpretive description: Qualitative research for applied practice, Routledge.

Thorne, S., S. R. Kirkham and J. MacDonald-Emes (1997). "Focus on qualitative methods. Interpretive description: a noncategorical qualitative alternative for developing nursing knowledge." Research in nursing & health **20**(2): 169-177.

Timko, C. and R. H. Moos (1991). "A typology of social climates in group residential facilities for older people." Journal of Gerontology **46**(3): S160-S169.

Townsend, P. (1964). The last refuge, Routledge and Kegan Paul London.

Turesson, H., C. Wann-Hansson and M. Eklund (2011). "The ward atmosphere important for the psychosocial work environment of nursing staff in psychiatric in-patient care." BMC nursing **10**(1): 12.

Van Deth, J. W. (2003). "Measuring social capital: orthodoxies and continuing controversies." International Journal of Social Research Methodology **6**(1): 79-92.

Victor, C. R. and A. Bowling (2012). "A longitudinal analysis of loneliness among older people in Great Britain." The Journal of Psychology **146**(3): 313-331.

Wahl, A., A. Bergland and B. Loyland (2010). "Is social capital associated with coping, self-esteem, health and quality of life in long-term social assistance recipients?" Scand J Caring Sci **24**(4): 808-816.

Waldrop, D. P. and E. S. Rinfrette (2009). "Making the transition to hospice: exploring hospice professionals' perspectives." Death studies **33**(6): 557-580.

Ward, R., A. A. Vass, N. Aggarwal, C. Garfield and B. Cybyk (2008). "A different story: exploring patterns of communication in residential dementia care." Ageing and society **28**(05): 629-651.

Watson Campbell, R. (2015). "Being discharged from hospice alive: The lived experience of patients and families." Journal of palliative medicine **18**(6): 495-499.

Webb, E. J., D. T. Campbell, R. D. Schwartz and L. Sechrest (1966). Unobtrusive measures: Nonreactive research in the social sciences, Rand McNally Chicago.

Wigan & Leigh Hospice. (2011). "The hospice movement." Retrieved 13/01/2018, 2018, from <http://www.wlh.org.uk/about/hospice-facts/the-hospice-movement>.

Wilson, S. A. (1997). "The transition to nursing home life: A comparison of planned and unplanned admissions." Journal of Advanced Nursing **26**(5): 864-871.

Wowchuk, S. M., S. McClement and J. Bond Jr (2007). "The challenge of providing palliative care in the nursing home." International Journal of Palliative Nursing **13**(7): 345-350.

Ziersch, A. M., F. Baum, I. G. Darmawan, A. M. Kavanagh and R. J. Bentley (2009). "Social capital and health in rural and urban communities in South Australia." Aust N Z J Public Health **33**(1): 7-16.

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## Appendix I

### Quality of Interaction Schedule (QUIS) observation tool

Example interaction

Time approx. start and end	Interaction description	Code: PS, PC, N, NP, NR	Verbal/non -verbal	Instigated by, 1 way/2 way/group (Arrow) Between	Event/comments
1.5 minutes	greeting	ps	v	Volunteer ↔ patient	Greeting when entering the room

#### **CODE:**

PC – Positive care – interactions relating to the care needs of the resident/patient, e.g. explaining or reassuring why something needs to be done.

PS – Positive social – interactions that are social in nature, not to do with any care needs of the resident/patient, e.g. general chat about weather, starting conversation.

N – Neutral – brief indifferent interactions not meeting any other criteria, e.g. putting a plate of food down in front of a resident/patient without any other contact

NP – Negative protective – providing care, keeping safe removing from danger in a restrictive way, e.g. taking food from someone that has been on the floor

NR – negative restrictive – interactions that restrict or oppose freedom of action, e.g. moving or examining people without warning or explanation

Interaction = [Instigated by which participant], → one way: ↔ two way [between, other participant to interaction]

## Appendix II

### Sheltered Care Environment Scale (SCES)

#### Sheltered Care Environment Scale Questionnaire

Name of care setting: \_\_\_\_\_

Gender? (Circle as appropriate)            Male            Female

Are you a staff member, visitor or volunteer? \_\_\_\_\_

Today's Date: \_\_\_\_\_

#### **Instructions:**

There are 45 questions on this questionnaire. They are statements about the place in which you work or visit. Based on your experience here, please answer these questions Yes or No. Ask yourself which answer is generally true.

Circle yes if you think the statement is true or mostly true of this place.

Circle no if you think the statement is false or mostly false of this place.

Please be sure to answer every question.

Thank you for taking the time to complete this questionnaire. Once complete, please return it to the researcher in person, leave it in the designated collection box, or return it to the researcher via the prepaid envelope provided.

### Question

1. Do residents get lots of individual attention?	Yes	No
2. Do staff members spend a lot of time with residents?	Yes	No
3. Do staff members sometimes talk down to residents?	Yes	No
4. Are there a lot of social activities?	Yes	No
5. Do a lot of residents just seem to be passing time here?	Yes	No
6. Are requests made by residents usually taken care of right away?	Yes	No
7. Do staff members sometimes criticise residents over minor things?	Yes	No
8. Do residents tend to keep to themselves here?	Yes	No
9. Are the discussions very interesting?	Yes	No
10. Do residents usually depend on staff to set up activities for them?	Yes	No
11. Do residents usually wait for staff to suggest an idea for an activity?	Yes	No
12. Are residents taught how to deal with practical problems?	Yes	No
13. Are many new skills taught here?	Yes	No
14. Are residents learning to do more things on their own?	Yes	No
15. Are residents strongly encouraged to make their own decisions?	Yes	No
16. Do residents sometimes take charge of activities?	Yes	No
17. Do residents care more about the past than the future?	Yes	No
18. Are some of the resident's activities really challenging?	Yes	No
19. Are residents careful about what they say to each other?	Yes	No
20. Are personal problems openly talked about?	Yes	No
21. Do residents tend to hide their feelings from one another?	Yes	No
22. Do residents talk a lot about their fears?	Yes	No
23. Is it hard to tell how residents are feeling?	Yes	No
24. Do residents talk a lot about their past dreams and ambitions?	Yes	No
25. Do residents ever talk about illness and death?	Yes	No
26. Do residents talk about their money problems?	Yes	No
27. Do residents keep their personal problems to themselves?	Yes	No
28. Do residents always know when staff will be around?	Yes	No
29. Are activities for residents carefully planned?	Yes	No
30. Do some residents look messy?	Yes	No

31. Do things always seem to be changing around here?	Yes	No
32. Do residents know what will happen to them if they break a rule?	Yes	No
33. Is there a lot of confusion here at times?	Yes	No
34. Is this place very well organised?	Yes	No
35. Are things sometimes unclear around here?	Yes	No
36. Are people always changing their minds around here?	Yes	No
37. Is the furniture here comfortable and homey?	Yes	No
38. Is it ever cold and drafty here	Yes	No
39. Can residents have privacy whenever they want	Yes	No
40. Does this place seem crowded?	Yes	No
41. Is it sometimes very noisy here?	Yes	No
42. Does it ever smell bad here?	Yes	No
43. Is it ever hot and stuffy in here?	Yes	No
44. Is the lighting very good here?	Yes	No
45. Do the colours and decorations make this a warm and cheerful place?	Yes	No

## Appendix III

### Letter of approach – care home manager



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## Letter of Approach

### Care home manager

**Title of Project:** The relationship between the social life of older people and the atmosphere of different care settings.

**Researcher:** Michael Woodward

You are being invited to take part in a study that will look at the social life and interaction of older people in care homes, and to see if this has any relationship with the atmosphere of the care home. To help you consider whether or not to take part, some information has been provided about what participation will involve for you and this care home. I would like to conduct a study that uses observations of the communal areas of the care home, and conduct interviews with residents or patients, staff, volunteers and visitors, and to obtain questionnaire responses with the visitors and staff of the care home.

Social networks and interactions are important factors in residents' lives in care homes. The atmosphere of a care home is often described as the 'feel' or 'personality' you get for a place when you enter it, for example a place may feel 'homely' or 'institutionalised'. The study aims to look at these concepts by using observations, interviews and questionnaires in 2 care homes to see how the social life and atmosphere are related, and to see how visitors and volunteers affect these concepts.

You have been invited to take part as a manager of a care home. It is entirely up to you if you want to permit the research to be conducted at this site. If you decide to take

part, I will take observations from communal areas of the care home and look at things such as interactions of people and who the interactions are with. If convenient, I would be happy to attend a general meeting with staff and the residents, or at specific staff and resident meetings to make them aware of the research and what it will involve. I will provide posters and leaflets about the research to hand out at the meeting if needed, and to put around the care home to remind and inform people about the research.

The observations will be in 15 minute blocks followed by a 15 minute rest period, and will be spread out over different times over several days. These will be arranged with you prior to any observations taking place. I would also like to give a questionnaire to staff members and visitors and volunteers of the care home. This questionnaire will measure the atmosphere of the care home and should take no more than 10 minutes to complete and requires only yes/no answers. The researcher would also like to conduct a total of around 10 interviews with residents, staff members, visitors and volunteers. These interviews will last approximately 30 minutes at a time and private place convenient to the interviewee. They will be audio recorded and shall discuss the role of volunteers and visitors in the care home. Participants of the questionnaire and interviews will be approached individually by the researcher, and if possible with a member of staff to introduce the researcher, and given their own information sheets to decide if they would like to take part. Everything that is observed or reported in interviews will remain completely confidential unless the researcher observes, or is told in interview some information that indicates someone is at risk of harm. This would be discussed with the person involved before telling anyone else. It is estimated that the research will last approximately 4 weeks at this care home, depending on how quickly the target number of interviews and questionnaire responses can be obtained.

If participants do not wish to take part in the observations, questionnaires or interviews they just have to let you or me know and they will be excluded from any data collection. This information will be communicated to the potential participants at the meeting at the start of the research, and on the posters and leaflets that will be provided. It will be made clear to all participants that if they decide to not take part or withdraw from the study then it will in no way affect their receipt or any services or employment.

Thank you for taking the time to read this information. If you have any questions or concerns, or would like more information, then please feel free to contact myself, at the email address provided at the top of the information page. This research is being

undertaken as part of a PhD under the supervision of Professor Antony Arthur, Email: [antony.arthur@uea.ac.uk](mailto:antony.arthur@uea.ac.uk), and Professor Francine Cheater, Email: [f.cheater@uea.ac.uk](mailto:f.cheater@uea.ac.uk).

Should you wish to make a complaint about the research, you can contact Professor Fiona Poland, an independent person to the research who has agreed to manage any complaints that are received. Her contact details are below. These contact details will be available in all participant information sheets for anyone who wishes to make a complaint.

Professor Fiona Poland  
Email: [f.poland@uea.ac.uk](mailto:f.poland@uea.ac.uk)  
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Thank you for your time.  
Yours sincerely  
Michael Woodward

## Appendix IV

### Letter of approach – hospice manager



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## Letter of Approach

### Hospice manager

**Title of Project:** The relationship between the social life of older people and the atmosphere of different care settings.

**Researcher:** Michael Woodward

You are being invited to take part in a study that will look at the social life and interaction of older people in hospices, and to see if this has any relationship with the atmosphere of the hospice. To help you consider whether or not to take part, some information has been provided about what participation will involve for you and this hospice. I would like to conduct a study that uses observations of the communal areas of the hospice, and conduct interviews with residents or patients, staff, volunteers and visitors, and to obtain questionnaire responses with the visitors and staff of the hospice.

Social networks and interactions are important factors in patients' lives in hospice. The atmosphere of a hospice is often described as the 'feel' or 'personality' you get for a place when you enter it, for example a place may feel 'homely' or 'institutionalised'. The study aims to look at these concepts by using observations, interviews and questionnaires in 2 hospice to see how the social life and atmosphere are related, and to see how visitors and volunteers affect these concepts.

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Thank you for your time.

Yours sincerely

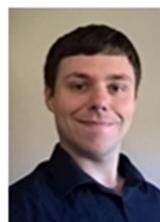
Michael Woodward



**The relationship between the social life of older people and the atmosphere of different care settings.**

**What the study is about?**

This study will look at the social life of older people and atmosphere or 'feel' of the care home.



**Researcher:**  
Michael Woodward

**What the study involves?**

The study will involve observations, questionnaires and interviews.

A researcher will be taking **observations** in communal areas of this care home. Notes will be taken but no one will be identified.

The study will also involve a **questionnaire** for staff, visitors and volunteers, and the researcher would also like to conduct **interviews** with residents, staff, visitors and volunteers.

If you would like to volunteer for any part of the study, just ask the researcher, Michael. Equally if you do not wish to take part, just inform the researcher either in person or at the contact details provided below.

**All individuals in communal areas will be included in observations.** If you are not happy at any point to be observed then let the researcher or manager know and you will not be included in any observations. You are free to withdraw at any time without giving reason.

The researcher is **not** judging staff in any way, they are only trying to capture an accurate representation of what life is like in a care home and how people interact with each other.

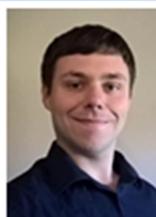
If you have any questions, comments or concerns about the research then please speak to Michael either in person, or via email at [m.woodward@uea.ac.uk](mailto:m.woodward@uea.ac.uk), or if they are not available then contact can be made via the care manager [site specific details to be added later]



## The relationship between the social life of older people and the atmosphere of different care settings.

### What the study is about?

This study will look at the social life of older people and atmosphere or 'feel' of the hospice



Researcher:  
Michael Woodward

### What the study involves?

The study will involve observations, questionnaires and interviews.

A researcher will be taking **observations** in communal areas of this hospice. Notes will be taken but no one will be identified.

The study will also involve a **questionnaire** for staff, visitors and volunteers, and the researcher would also like to conduct **interviews** with residents, staff, visitors and volunteers.

If you would like to volunteer for any part of the study, just ask the researcher, Michael. Equally if you do not wish to take part, just inform the researcher either in person or at the contact details provided below.

**All individuals in communal areas will be included in observations.** If you are not happy at any point to be observed then let the researcher or manager know and you will not be included in any observations. You are free to withdraw at any time without giving reason.

The researcher is **not** judging staff in any way, they are only trying to capture an accurate representation of what life is like in a hospice and how people interact with each other.

If you have any questions, comments or concerns about the research then please speak to Michael either in person, or via email at [m.woodward@uea.ac.uk](mailto:m.woodward@uea.ac.uk), or if they are not available then contact can be made via the care manager

## Appendix VII

### Leaflet – Care home

Version 3. Date: 20/07/15

#### **What will happen to the data that the study collects?**

The data will be kept confidential and analysed by the researcher. The findings of the data will be written up in a PhD thesis and for publication in scientific journals.

#### **Who has reviewed the study to make sure it is safe?**

All materials and procedures for the research have been reviewed by the Social Care Research Ethics Committee to make sure they are safe for all the participants.

#### **Who to talk to about problems or concerns with the observations?**

If you have any problems or concerns, please talk to Michael if he is on site or at the contact details provided. If the problem with the research is urgent and then please contact the manager or a senior member of staff.

Complaints can be made to Professor Fiona Poland at: Email: [f.poland@uea.ac.uk](mailto:f.poland@uea.ac.uk),  
Tel: 01603 593630  
Fiona Poland  
University of East Anglia  
Queens Building 2.12  
Norwich  
Norfolk  
NR4 7TJ

#### **About the researcher**

This research project is part of a PhD doctoral degree being undertaken at the University of East Anglia supervised by Professor Antony Arthur, [antony.arthur@uea.ac.uk](mailto:antony.arthur@uea.ac.uk) and Professor Francine Cheater, [f.cheater@uea.ac.uk](mailto:f.cheater@uea.ac.uk). It is intended that the study will be written up in the form of a PhD thesis and the findings will be published in scientific peer reviewed journals.

If you would like any information then please contact Michael in person, or at the details below:

Michael Woodward  
Email: [m.woodward@uea.ac.uk](mailto:m.woodward@uea.ac.uk)  
Web: <https://www.uea.ac.uk/health-sciences/people/profile/m-woodward>  
Phone: 07920793486

Michael Woodward  
University of East Anglia  
Edith Cavell Building 1.27  
School of Health Sciences  
Norwich Research Park  
Norwich  
Norfolk  
NR4 7TJ

*Thank you for taking the time to read this leaflet. Any expression of interest you have about the research does not commit you to take part.*

Document C\_Leaflet care home



**THE RELATIONSHIP BETWEEN  
THE SOCIAL LIFE OF OLDER  
PEOPLE AND THE  
ATMOSPHERE OF DIFFERENT  
CARE SETTINGS.**

**Researcher: Michael Woodward  
University of East Anglia**



### What the study is about

The research project is looking at the social life of older people in different types of care, and its relationship with the 'atmosphere' of the care home.

### What the study involves at this care home?

The study will involve observations of communal areas within the care home, a questionnaire that can be completed by staff members, visitors and volunteers, and interviews with staff members, visitors, volunteers and residents of the care home.

The researcher, Michael, will be present within the care home. Michael will first take observations from communal areas of the care home. The study is not looking to judge or assess anyone within the care home, they are only there to look at who the residents of the care home interact with and how. Michael will under no circumstances take observations from private places such as bedrooms. Observations will take place in 15 minute blocks for a few hours during the morning and afternoon for around 1 week and will be arranged with the care manager.

Michael will also ask some staff, visitors and volunteers to complete a questionnaire. The questionnaire is

designed to measure the atmosphere of a care home. The questionnaire should take 10 minutes to complete and only requires yes/no answers. More information is provided to you if you decide to complete the questionnaire.

Michael is also conducting interviews. If you take part in an interview, you will be given an information sheet. If you would like to be interviewed you will be asked to sign a consent form. The interview will look at the experiences of visitors and volunteers within the care home and the role that they play in the lives of the residents living in the care home.

### What the research means for you

You do not have to do anything if you do not want to. Michael will take observations from all people (unless they request not to be included) in communal areas at pre-arranged times. Michael may approach you and ask you if you would like to take part in the questionnaires and interviews.

If you would not like to be included in the observations, or approached about any of the other part of the research, then just inform Michael and you will not be included in the research.

If however, you would like to take part in the research then you can just ask Michael if he is present and he can organise this for you, or you can contact him by telephone or email.

if you have any questions, please speak to Michael it the details provided on this leaflet  
Not taking part or withdrawing from the research will in no way have an effect on receipt of any services or employment.

### Your details will remain confidential

During the observations, if any information is taken that can lead to someone being identified, it will be removed from all observation notes and all information will remain confidential. If you take part in the questionnaire, again, no identifying information will be taken. A more detailed information sheet will be provided to you should you agree to complete the questionnaire.

If you take part in the interviews, a more detailed information sheet will be provided giving more details, but again any information you provide will remain confidential. No one will be able to be identified in any way from any data or in any reports that come from this research.

Everything I observe or you say/report is confidential unless you tell us something that indicates you or someone else is at risk of harm. I would discuss this with you before telling anyone else. All data will be kept securely for 10 years as required by university policy.

### What will happen to the data that the study collects?

The data will be kept confidential and analysed by the researcher. The findings of the data will be written up in a PhD thesis and for publication in scientific journals.

### Who has reviewed the study to make sure it is safe?

All materials and procedures for the research have been reviewed by the Social Care Research Ethics Committee to make sure they are safe for all the participants.

### Who to talk to about problems or concerns with the observations?

If you have any problems or concerns, please talk to Michael if he is on site or at the contact details provided. If the problem with the research is urgent and then please contact the manager or a senior member of staff.

Complaints can be made to Professor Fiona Poland at: Email: [f.poland@uea.ac.uk](mailto:f.poland@uea.ac.uk),  
Tel: 01603 593630  
Fiona Poland  
University of East Anglia  
Queens Building 2.12  
Norwich  
Norfolk  
NR4 7TJ

### About the researcher

This research project is part of a PhD doctoral degree being undertaken at the University of East Anglia supervised by Professor Antony Arthur, [antony.arthur@uea.ac.uk](mailto:antony.arthur@uea.ac.uk) and Professor Francine Cheater, [f.cheater@uea.ac.uk](mailto:f.cheater@uea.ac.uk). It is intended that the study will be written up in the form of a PhD thesis and the findings will be published in scientific peer reviewed journals.

If you would like any information then please contact Michael in person, or at the details below:

Michael Woodward  
Email: [m.woodward@uea.ac.uk](mailto:m.woodward@uea.ac.uk)  
Web: <https://www.uea.ac.uk/health-sciences/people/profile/m-woodward>  
Phone: 07920793486

Michael Woodward  
University of East Anglia  
Edith Cavell Building 1.27  
School of Health Sciences  
Norwich Research Park  
Norwich  
Norfolk  
NR4 7TJ

*Thank you for taking the time to read this leaflet. Any expression of interest you have about the research does not commit you to take part.*



**THE RELATIONSHIP BETWEEN THE SOCIAL LIFE OF OLDER PEOPLE AND THE ATMOSPHERE OF DIFFERENT CARE SETTINGS.**

**Researcher: Michael Woodward**  
University of East Anglia



### What the study is about

The research project is looking at the social life of older people in different types of care, and its relationship with the 'atmosphere' of the hospice.

### What the study involves at this hospice?

The study will involve observations of communal areas within the hospice, a questionnaire that can be completed by staff members, visitors and volunteers, and interviews with staff members, visitors, volunteers and patients of the hospice.

The researcher, Michael, will be present within the hospice. Michael will first take observations from communal areas of the hospice. The study is not looking to judge or assess anyone within the hospice, they are only there to look at who the patients of the hospice interact with and how. Michael will under no circumstances take observations from private places.

Observations will take place in 15 minute blocks for a few hours during the morning and afternoon for around 1 week and will be arranged with the care manager.

Michael will also ask some staff, visitors and volunteers to complete a questionnaire. The questionnaire is

designed to measure the atmosphere of a hospice. The questionnaire should take 10 minutes to complete and only requires yes/no answers. More information is provided to you if you decide to complete the questionnaire.

Michael is also conducting interviews. If you take part in interviews you will be given an information sheet. If you would like to be interviewed you will be asked to sign a consent form. The interview will look at the experiences of visitors and volunteers within the hospice and the role that they play in the lives of the patients in the hospice.

### What the research means for you

You do not have to do anything if you do not want to. Michael will take observations from all people (unless they request not to be included) in communal areas at pre-arranged times. Michael may approach you and ask you if you would like to take part in the questionnaires and interviews.

If you would not like to be included in the observations, or approached about any of the other part of the research, then just inform Michael and you will not be included in the research.

If however, you would like to take part in the research then you can just ask Michael if he is present and he can organise this for you, or you can contact them by telephone or email.

If you have any questions, please speak to Michael if the details provided on this leaflet. Not taking part or withdrawing from the research will in no way have an effect on receipt of any services or employment.

### Your details will remain confidential

During the observations, if any information is taken that can lead to someone being identified, it will be removed from all observation notes and all information will remain confidential. If you take part in the questionnaire, again, no identifying information will be taken. A more detailed information sheet will be provided to you should you agree to complete the questionnaire.

If you take part in the interviews, a more detailed information sheet will be provided giving more details, but again any information you provide will remain confidential. No one will be able to be identified in any way from any data or in any reports that come from this research.

Everything I observe or you say/report is confidential unless you tell us something that indicates you or someone else is at risk of harm. I would discuss this with you before telling anyone else. All data will be kept securely for 10 years as required by university policy.

## Appendix IX

### Letter to consultee

[Care setting headed paper with contact details]

Dear [Name of potential consultee]

[Name of care setting] is working in partnership with Michael Woodard, a researcher at the University of East Anglia (UEA) on a study of the relationship between the social life of older people and the atmosphere of different care settings.

As part of this research, Michael will be undertaking observations of people located in the **communal areas** of the care home to look at things such as social interactions and who the interactions are with. All observations will remain anonymous and no identifying information will be recorded. Observations will be taken throughout the morning and afternoon periods for around 1 week, and these times will be arranged with the care manager first. Everything observed is confidential unless the researcher witnesses something that indicates someone is at risk of harm. We would discuss this with you before telling anyone else.

An important part of this research is the ethical considerations of everyone involved. It is important that only people who are willing and happy to be included in these observations are included. Anyone who does not want to be included in the research just has to let a member of the care staff or the researcher know and they will not be involved in any of the research, this will in no way effect the services that they receive here.

You are being approached as you are someone who may be willing to act as a consultee for [name of resident/patient to be added] who lack the capacity to decide whether they wish to participate in this research, who is currently being cared for here. The role of acting as a consultee is entirely optional and you do not have to act as a consultee, and [name of resident/patient] does not have to take part in the study. If you do not act as the consultee this will have no effect on any services that are being provided to any resident.

The role of a consultee is to provide advice about what you feel may have been the wishes of the resident with regard to taking part in this research project. You are not being asked to consent on behalf of the person who lacks capacity, but you are being asked to try and set aside any personal views you may have about the research and consider only the past and present views of the person who lacks capacity with regard to this study. At any stage you can advise the researcher that the person who lacks capacity would not want to be included in the study and the researcher will respect that advice. If a resident has fluctuating capacity, and loses capacity during the course of the research observations, then they will continue to be included in the study unless you as the consultee advise otherwise, or the resident shows any signs of discomfort with the research, in which case they would be removed from the study immediately.

If you agree to act as a consultee for the resident, then you are asked to sign the consultee declaration form provided at the end of this letter and return it to us at the address provided, or to [name of care setting], and give advice to the researcher about what you feel the wishes of the resident who lacks capacity may have been with regard to participating in this research. To do this, please fill out the form and return it to either the researcher at the contact details provided or the care provider. Please be aware however, that if you are a nominated consultee, such as a paid carer or staff member as there are no relatives or friends able to act as a personal consultee, then you cannot be a participant in other part of the research, and will not be included in any observations, or asked to complete the questionnaire or take part in the interview.

It is important to note that only observations in communal areas of the care home will take place, and no one will be identified at any stage. If the resident shows any signs of discomfort with the research or the researcher at any stage, then the research will stop and they will be excluded from any of the observations taking place from that point on. They will be reminded of the research every time Michael comes to conduct the research and if they ever show any indication that they do not want to take part then they won't be included. I have included an information leaflet about the research that is available around [care setting name] to provide more information about the research. If you have any questions or would like to discuss the research then you can either contact myself or the researcher, Michael, via the details located on the information leaflet. Residents who lack capacity will not be included in the questionnaire or the interview parts of the research, only the observations within the communal areas.

If you have any complaints about the research, there is a person who is independent to the research who would be willing to deal with the complaint. The contact details are:

Professor Fiona Poland  
Email: [f.poland@uea.ac.uk](mailto:f.poland@uea.ac.uk)  
Tel: 01603 59**3630**  
Address:  
Professor Fiona Poland  
University of East Anglia  
Queens Building 2.12  
Norwich Research Park  
Norwich  
Norfolk  
NR4 7TJ

Thank you for taking the time to read this information.

Yours sincerely

[Care manager name]

[Signed by care manager]



## Consultee Declaration Form

**Title of Project:** The relationship between the social life of older people and the atmosphere of different care settings.

**Researcher:** Michael Woodward

**Email address:** [M.Woodward@uea.ac.uk](mailto:M.Woodward@uea.ac.uk). Telephone number: 07920793486

Please initial each box

1. I confirm that I have read and understand the consultee information sheet (Version 3: 20/07/2015) for the above study.
  
2. I have had the opportunity to consider the information, ask questions about my role as a consultee and have these answered satisfactorily.
  
3. I understand that my participation in acting as a consultee is voluntary and that I am free to withdraw change my mind at any time without giving any reason without any receipt of services being affected for anyone involved.
  
4. I understand that I am being asked my advice about what I think the person who I am acting as a consultee for would want with regard to the research, and am not basing my advice on my own personal views.
  
5. I understand that everything observed is confidential unless the researcher witnesses something that indicates someone is at risk of harm.

---

Name of acting consultee

---

Date

---

Signature

Name of person who I am willing to act as a consultee

for \_\_\_\_\_

I think \_\_\_\_\_ would like to take part in this study (please circle below)

**Yes**

**No**

If you would like to discuss the research or the consultee information further, please contact Michael Woodward, the researcher for the study.

## Appendix XI

### Ethical approval letter



Social Care REC  
Ground Floor  
Skipton House  
80 London Road  
London  
SE1 6LH

Telephone: 0207 972 2568

21 July 2015

Mr Michael J T Woodward  
PhD Student  
University of East Anglia  
Edith Cavell Building 1.27  
School of Nursing Sciences  
Norwich Research Park  
Norwich  
NR4 7TJ

Dear Mr Woodward

**Study title:** The relationship between social capital and the social climate of a care environment for older people: A comparative study in two care sectors  
**REC reference:** 15/IEC08/0035  
**Protocol number:** N/A  
**IRAS project ID:** 173394

Thank you for your letter of 20 July 2015. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 16 July 2015

#### Documents received

The documents received were as follows:

Document	Version	Date
Copies of advertisement materials for research participants [Leaflet]	3	20 July 2015
Copies of advertisement materials for research participants [Leaflet - Hospice]	3	20 July 2015
Covering letter on headed paper [Cover letter]	3	20 July 2015
IRAS Checklist XML [Checklist_20072015]		20 July 2015
Other [Letter of notification to consultee of participants who lack capacity]	3	20 July 2015
Participant information sheet (PIS) [PIS - interview, resident_patient]	3	20 July 2015
Participant information sheet (PIS) [PIS - Interview, staff, visitor, volunteer]	3	20 July 2015

A Research Ethics Committee established by the Health Research Authority

Participant information sheet (PIS) [PIS - Interview, staff, visitor, volunteer, Hospice]	3	20 July 2015
Participant information sheet (PIS) [PIS - interview, patient hospice]	3	20 July 2015

### Approved documents

The final list of approved documentation for the study is therefore as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of advertisement materials for research participants [Poster]	2	01 July 2015
Copies of advertisement materials for research participants [Poster - Hospice]	2	01 July 2015
Copies of advertisement materials for research participants [Leaflet]	3	20 July 2015
Copies of advertisement materials for research participants [Leaflet - Hospice]	3	20 July 2015
Covering letter on headed paper [Cover letter]	1	13 May 2015
Covering letter on headed paper [Cover letter]	2	09 July 2015
Covering letter on headed paper [Cover letter]	3	20 July 2015
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Letter from sponsor and proof of indemnity]	1	14 May 2015
Interview schedules or topic guides for participants [Interview Schedule]	1	11 May 2015
IRAS Checklist XML [Checklist_15052015]		15 May 2015
IRAS Checklist XML [Checklist_09072015]		09 July 2015
IRAS Checklist XML [Checklist_20072015]		20 July 2015
Letters of invitation to participant [Letter of approach to care setting manager]	2	02 July 2015
Letters of invitation to participant [Letter of approach, Hospice manager]	2	02 July 2015
Other [Supervisor CV]	1	12 May 2015
Other [Consultee declaration form]	1	07 July 2015
Other [Letter of notification to consultee of participants who lack capacity]	3	20 July 2015
Participant consent form [Consent form, Interview]	1	11 May 2015
Participant information sheet (PIS) [PIS - Questionnaire]	2	02 July 2015
Participant information sheet (PIS) [PIS - Questionnaire Hospice]	2	02 July 2015
Participant information sheet (PIS) [PIS - Interview, staff, visitor, volunteer]	3	20 July 2015
Participant information sheet (PIS) [PIS - Interview, staff, visitor, volunteer, Hospice]	3	20 July 2015
Participant information sheet (PIS) [PIS - interview, resident_patient]	3	20 July 2015
Participant information sheet (PIS) [PIS - interview, patient hospice]	3	20 July 2015
REC Application Form [SC_Form_15052015]		15 May 2015
Referee's report or other scientific critique report [Transfer Panel confirmation letter]	1	17 November 2014
Research protocol or project proposal [Protocol]	1	11 May 2015
Summary CV for Chief Investigator (CI) [Chief Investigator CV]	1	10 May 2015

Summary, synopsis or diagram (flowchart) of protocol in non technical language [Diagram of study design]	1	11 May 2015
Validated questionnaire [Sheltered Care Environment Scale (SCES) questionnaire]	2	30 June 2015

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

<b>15/IEC08/0035</b>	<b>Please quote this number on all correspondence</b>
----------------------	---

Yours sincerely



**Barbara Cuddon**  
**REC Manager**

E-mail: nrescommittee.social-care@nhs.net

Copy to: Mrs Yvonne Kirkham  
Mrs Gosia Majsak-Newman, Norfolk and Suffolk Primary and Community Care  
Research Office

## Participant Information Sheet

### Questionnaire

**Title of Project:** The relationship between the social life of older people and the atmosphere of different care settings.

**Researcher:** Michael Woodward

**Email address:** [M.Woodward@uea.ac.uk](mailto:M.Woodward@uea.ac.uk)

You are being invited to take part in a study that will look at the social life and interaction of older people in care homes and to see if this has any relationship with the atmosphere of the care homes. We are asking you to complete a questionnaire that should take no more than 10 minutes and only requires yes and no answers. Your help with this study is greatly appreciated.

The questionnaire will look at the 'atmosphere' of the care home, and will be used get a picture of what life is like in different types of care. If you would like to take part then please complete the questionnaire provided. It is your decision if you would like to take part and entirely voluntary. All your answers will be kept confidential, and it should take no more than 10 minutes to complete the questionnaire.

If you complete the questionnaire, then you can return it by giving it to the researcher, Michael, in person, leaving it in the designated box to collect the questionnaires or you can post it to the address below with the envelope provided.

If you would like more information about the questionnaire or the study in general, then please speak to the researcher, Michael, and he will be more than happy to answer any

questions you may have. Either contact him in person on site, or via the contact information below.

Everything that you say or report is confidential unless you tell us something that indicates you or someone else is at risk of harm. We would discuss this with you first before telling anyone else. If you do not complete the questionnaire then there will be no effect on any receipt of services or employment for yourself or anyone else. If you would wish to make a complaint about the research then contact details of a person who is independent to the researcher are provided below. All answers will be anonymised in any report produced by the study.

**Researcher contact details:**

Michael Woodward  
University of East Anglia  
Edith Cavell Building 1.27  
School of Nursing Sciences  
Norwich Research Park  
Norwich NR4 7TJ  
Email: [M.Woodward@uea.ac.uk](mailto:M.Woodward@uea.ac.uk)  
Tel: 07920793486

**Contact information in case of a complaint:**

Professor Fiona Poland  
University of East Anglia  
Queens Building 2.12  
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Email: [f.poland@uea.ac.uk](mailto:f.poland@uea.ac.uk)  
Tel: 01603 593630

## Participant Information Sheet

### Questionnaire

**Title of Project:** The relationship between the social life of older people and the atmosphere of different care settings.

**Researcher:** Michael Woodward

**Email address:** [M.Woodward@uea.ac.uk](mailto:M.Woodward@uea.ac.uk)

You are being invited to take part in a study that will look at the social life and interaction of older people in hospices and to see if this has any relationship with the atmosphere of the hospice. We are asking you to complete a questionnaire that should take no more than 10 minutes and only requires yes and no answers. Your help with this study is greatly appreciated.

The questionnaire will look at the 'atmosphere' of the hospice, and will be used get a picture of what life is like in different types of care. If you would like to take part then please complete the questionnaire provided. It is your decision if you would like to take part and entirely voluntary. All your answers will be kept confidential, and it should take no more than 10 minutes to complete the questionnaire.

If you complete the questionnaire, then you can return it by giving it to the researcher, Michael, in person, leaving it in the designated box to collect the questionnaires or you can post it to the address below with the envelope provided.

If you would like more information about the questionnaire or the study in general, then please speak to the researcher, Michael, and he will be more than happy to answer any questions you may have. Either contact him in person on site, or via the contact information below.

Everything that you say or report is confidential unless you tell us something that indicates you or someone else is at risk of harm. We would discuss this with you first before telling anyone else. If you do not complete the questionnaire then there will be no effect on any receipt of services or employment for yourself or anyone else. If you would wish to make a complaint about the research then contact details of a person who is independent to the researcher are provided below. All answers will be anonymised in any report produced by the study.

**Researcher contact details:**

Michael Woodward  
University of East Anglia  
Edith Cavell Building 1.27  
School of Nursing Sciences  
Norwich Research Park  
Norwich NR4 7TJ  
Email: [M.Woodward@uea.ac.uk](mailto:M.Woodward@uea.ac.uk)  
Tel: 07920793486

**Contact information in case of a complaint:**

Professor Fiona Poland  
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Norwich  
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Tel: 01603 593630

## Appendix XIV

### Interview Schedule

#### **Participant interview schedule for use with residents/patients, staff members, visitors and volunteers**

*Wording/phrasing of questions will change depending on the type of participant that is being interviewed*

**“Thank you for agreeing to take part in this interview. Can I just check that you have read and understood the information sheet and the signed consent form that was provided?”**

*If unable to sign a consent form ask them to provide verbal consent by saying their name and that they consent to the interview.*

**“In order to accurately capture the content of the interview I would like to record it. Are you happy for me to record the interview?”**

*Remind the participant that everything they say including names will be confidential and left out of any reports the study produces.*

**“The first few questions I would like to ask are about any volunteers who work here.”**

- First of all, can you tell me whether volunteers often visit/work here?
- Could you tell me about the volunteers that you get here? Such as how many and how often they come?
- Can you tell me about how much contact you have with volunteers and what that involves?
- What do they do around here?
  - Around the care environment?

- For the residents/patients
- Can you tell me about a scenario in which a volunteer does something around the care environment that you liked, or found particularly helpful?
- What do you like most about having volunteers here
- ..... And what don't you like, if anything, about having volunteers around here?
- 
- What do you think volunteers bring to the 'atmosphere' or 'feel' of the place (hospice or care home) and why that is?
- Can you think of an example of how they contribute to the social life of this place?

**The next set of questions are about the visitors who come here**

*If necessary explain to the participant that visitors can include family members, health professionals, anyone that can come to the place for a short time to see someone or do a particular job who does not work here*

- Can you tell me about the visitors that you get here?
- In general, from your perspective, what are the most common groups of visitors come here
  - Such as health professionals, family or relatives, social workers etc.
- Do you have a lot of contact with the visitors and what does the contact involve?
  - Prompt about residents going out with visitors if they do at all
- Can you tell me a bit about what they do around here when they come and where do they spend most of their time?
  - Around the care environment?
  - For the residents/patients
- Can you describe or tell me about what a particular visit from a visitor would involve?
  - For a health care professional
  - and a relative/family member
- What do you like most about having visitors come here?
  - Or if no or few visitors, would you like them to come and why?
- ..... And what don't you like about having visitors around here?
- Why do you think they come here?
- Can you tell me what you think visitors bring to the 'atmosphere' or 'feel' of the care environment and why that is?

**We are coming towards the end of the interview now, and the last few questions that I would like to ask are about the atmosphere here [care home or hospice] or the general feel the place**

- Overall how do you find the general atmosphere here?
  - What contributes to that feeling towards the atmosphere
- Are there any particular people or things that happen around here that change the atmosphere that you have noticed?
- Can you describe what changes or influences the atmosphere around here for the better and for the worse?
- Tell me about how much influence you think visitors and volunteers have over the atmosphere of the care environment.
- Overall, do you think that more people, such as visitors and volunteers would be a positive thing, or a negative thing to this place and why?

Are there any other points or issues that you would like to discuss, either something new or adding to what we have talked about today?

Thank participants for the time they have given to participate in the research.

**Participant Information Sheet**  
**Interview**



**Title of Project:** The relationship between the social life of older people and the atmosphere of different care settings.

**Researcher:** Michael Woodward

**Email address:** [M.Woodward@uea.ac.uk](mailto:M.Woodward@uea.ac.uk)

You are being invited to take part in an interview to talk about visitors and volunteers that come into the care home. If you would like, you can have the information in this sheet read to you by the researcher or a member of staff if you do not want to read it all. The purpose of the interview is to discuss the social life and interactions of older people in care homes with regard to visitors and volunteers, and to see if this has any relationship with the atmosphere of the care home.

To help you consider whether or not to take part, please read the information provided to help understand why the research is being conducted and what your role in it is.

### Why have I been invited to take part?

We are interested in what you think as a resident about what role visitors and volunteers have in the life of residents in this care home and what they bring to the atmosphere of the care home.

### Do I have to take part?

No, it is entirely up to you if you want to take part in the interview, it is completely voluntary.

### What do I have to do if I take part?

If you decide to take part, all you have to do is sign the consent form to show that you are willing to take part. The researcher will interview you in a private room. If you give permission, he will record the interview with a voice recorder. The interview will be transcribed and all details such as names will be left out of the transcription. The interviewer will then ask you about visitors and volunteers in the care home and what you think they do for the lives of the residents. The discussion will also talk about the atmosphere of the care home and what you think the visitors and volunteers bring to the atmosphere of this care home. The interview should take around 30 minutes.

### What are the possible risks and disadvantages of taking part?

It is possible that people may feel uncomfortable talking to the researcher, to try and minimise this feeling no sensitive topic will be discussed in the interviews, but if you would not like to answer a specific question or talk about a specific topic then you do not have to.

### What are the possible benefits of taking part?

Although there are no direct benefits to you, you taking part is greatly appreciated and will help us understand what life is like in care homes. The results of the study may help contribute to improving the atmosphere and social life of care homes and improve the wellbeing of the residents that use these types of facilities in the future.

### Will all my information be kept confidential?

Yes. All information you give such as names and locations will remain completely confidential. No information that can lead to anyone being identified will be used in any report or publication that this study produces. Everything you say or report during the interview is confidential unless you tell us something that indicates you or someone else is at risk of harm. We would discuss this with you before telling anyone else.

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about the research. The contact details can be found at the end of this information sheet.

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**Researcher contact details:**

Michael Woodward

University of East Anglia

Edith Cavell Building 1.27

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Norwich Research Park

Norwich NR4 7TJ

Email: [M.Woodward@uea.ac.uk](mailto:M.Woodward@uea.ac.uk)

Phone: 07920793486

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Norwich

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NR4 7TJ

Email: [f.poland@uea.ac.uk](mailto:f.poland@uea.ac.uk)

Tel: 01603 59**3630**

## Participant Information Sheet

### Interview

**Title of Project:** The relationship between the social life of older people and the atmosphere of different care settings.

**Researcher:** Michael Woodward

**Email address:** [M.Woodward@uea.ac.uk](mailto:M.Woodward@uea.ac.uk)

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To help you consider whether or not to take part, please read the information provided to help understand why the research is being conducted and what your role in it is.

### Why have I been invited to take part?

We are interested in what you think as a patient about what role visitors and volunteers have in the life of patients in this hospice and what they bring to the atmosphere of the hospice.

### Do I have to take part?

No, it is entirely up to you if you want to take part in the interview, it is completely voluntary.

### What do I have to do if I take part?

If you decide to take part, all you have to do is sign the consent form to show that you are willing to take part. The researcher will interview you in a private room. If you give permission, he will record the interview with a voice recorder. The interview will be transcribed and all details such as names will be left out of the transcription. The interviewer will then ask you about visitors and volunteers in the hospice and what you think they do for the lives of the patients. The discussion will also talk about the atmosphere of the hospice and what you think the visitors and volunteers bring to the atmosphere of this hospice. The interview should take around 30 minutes.

### What are the possible risks and disadvantages of taking part?

It is possible that people may feel uncomfortable talking to the researcher, to try and minimise this feeling no sensitive topic will be discussed in the interviews, but if you would not like to answer a specific question or talk about a specific topic then you do not have to.

### What are the possible benefits of taking part?

Although there are no direct benefits to you, you taking part is greatly appreciated and will help us understand what life is like in this hospice. The results of the study may help contribute to improving the atmosphere and social life of hospices and improve the wellbeing of the patients that use these types of facilities in the future.

### Will all my information be kept confidential?

Yes. All information you give such as names and locations will remain completely confidential. No information that can lead to anyone being identified will be used in any report or publication that this study produces. Everything you say or report during the interview is confidential unless you tell us something that indicates you or someone else is at risk of harm. We would discuss this with you before telling anyone else.

What if I do not want to be interviewed or stop the interview early?

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**Researcher contact details:**

Michael Woodward

University of East Anglia

Edith Cavell Building 1.27

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Norwich Research Park

Norwich NR4 7TJ

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Email: [f.poland@uea.ac.uk](mailto:f.poland@uea.ac.uk)

Tel: 01603 593630

## Participant Information Sheet



### Interview in care homes

**Title of Project:** The relationship between the social life of older people and the atmosphere of different care settings.

**Researcher:** Michael Woodward

**Email address:** [M.Woodward@uea.ac.uk](mailto:M.Woodward@uea.ac.uk)

You are being invited to take part in an interview that will look at the social life and interaction of older people in care homes with regard to visitors and volunteers, and to see if this has any relationship with the atmosphere of the care home. To help you consider whether or not to take part, please read the information provided in this information sheet to help you understand why the research is taking place and what your role in the research would be. We are asking you to take part in an interview to talk about visitors and volunteers that come into the care home.

### What is the purpose of the study?

Social life and interaction is an important part of care home life. Visitors and volunteers are a large part of the social life of older people in care homes. The atmosphere of a care home is often described as the 'feel' or 'personality' you get for a place when you enter it, for example a place may feel 'homely' or 'institutionalised'. The interview aims to look at what role visitors and volunteers have in the life of older people in care homes and to see if the role differs between different types of care.

## Why have I been invited to take part?

You have been invited to take part in this interview as you have had contact and/or are aware of the visitors and volunteers that come into the care home. We are interested in what you think about what role they play for residents in this care home.

## Do I have to take part?

No, it is entirely up to you if you want to take part in the interview, it is completely voluntary.

## What do I have to do if I take part?

If you chose to take part, all you have to do is sign the consent form to show that you are willing to be interviewed by the researcher about the role of visitors and volunteers and the social life within the care home. The researcher will interview you in a private room. With your permission the researcher will record the interview with a voice recorder so it can be transcribed after the interview but details such as names will be removed from the transcript. The interview should take around 30 minutes.

## What are the possible risks and disadvantages of taking part?

It is possible that people may feel uncomfortable talking to the researcher, to try and minimise this feeling no sensitive topic will be discussed in the interviews, but if you would not like to answer a specific question or talk about a specific topic then you do not have to.

## What are the possible benefits of taking part?

Although there are no direct benefits to you, you taking part in the interview is greatly appreciated and shall help us to understand what life is like in care homes. The results of the study may help contribute to improving the atmosphere of care homes and improve the wellbeing of the residents that use these types of care homes in the future.

## Will all my information be kept confidential?

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produces. Everything you say or report is confidential unless you tell us something that indicates you or someone else is at risk of harm. We would discuss this with you before telling anyone else.

### What if I do not want to be interviewed or stop the interview early?

It is completely optional and voluntary if you want to take part in the interview or not. If you do not want to take part then that is fine and there will be no negative consequences. It will have no effect on any services provided to the residents or employment of anyone at this care home. If you wish, you can also stop the interview at any time and do not have to give a reason why. You can also take a break during the interview and it can be continued after the break

### What if there is a problem and I wish to make a complaint or leave the study?

In the unlikely event of a problem occurring, you can talk to the researcher. The researcher shall try to answer any questions or solve any problems that you have with the research. If you wish to leave the study and not have your interview used then contact should be made with the researcher either in person or via the e-mail address at the beginning and end of this information sheet. The data provided before leaving the study will still be used. If you do not want any data you have provided to be used, just let the researcher know and all data will be destroyed. Alternatively you can make a complaint to Professor Fiona Poland, a person who is independent to this research. Her contact details are provided at the end of this information sheet.

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## Further information and contact details

If you have any further questions, please feel free to talk to the researcher who will answer any other questions you have. Thank you for taking the time to read this information sheet. If you would like a summary of the findings at the end of the study, you are more than welcome to these. Just make the researcher aware that you would like a summary of the findings and you will be provided with a copy once the study is over. Once again, thank you for your time.

### **Researcher contact details:**

Michael Woodward  
University of East Anglia  
Edith Cavell Building 1.27  
School of Nursing Sciences  
Norwich Research Park  
Norwich NR4 7TJ  
Email: [M.Woodward@uea.ac.uk](mailto:M.Woodward@uea.ac.uk)  
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Norfolk  
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Tel: 01603 593630

## Participant Information Sheet

### Interview Hospices

**Title of Project:** The relationship between the social life of older people and the atmosphere of different care settings.

**Researcher:** Michael Woodward

**Email address:** [M.Woodward@uea.ac.uk](mailto:M.Woodward@uea.ac.uk)

You are being invited to take part in an interview that will look at the social life and interaction of older people in hospices with regard to visitors and volunteers, and to see if this has any relationship with the atmosphere of the hospice. To help you consider whether or not to take part, please read the information provided in this information sheet to help you understand why the research is taking place and what your role in the research would be. We are asking you to take part in an interview to talk about visitors and volunteers that come into the hospice.

### What is the purpose of the study?

Social life and interaction is an important part of hospice life. Visitors and volunteers are a large part of the social life of older people in hospice. The atmosphere of a hospice is often described as the 'feel' or 'personality' you get for a place when you enter it, for example a place may feel 'homely' or 'institutionalised'. The interview aims to look at what role visitors and volunteers have in the life of older people in hospice and to see if the role differs between different types of care.

## Why have I been invited to take part?

You have been invited to take part in this interview as you have had contact and/or are aware of the visitors and volunteers that come into the hospice. We are interested in what you think about what role they play for patients in this hospice.

## Do I have to take part?

No, it is entirely up to you if you want to take part in the interview, it is completely voluntary.

## What do I have to do if I take part?

If you chose to take part, all you have to do is sign the consent form to show that you are willing to be interviewed by the researcher about the role of visitors and volunteers and the social life within the hospice. The researcher will interview you in a private room. With your permission the researcher will record the interview with a voice recorder so it can be transcribed after the interview but details such as names will be removed from the transcript. The interview should take around 30 minutes.

## What are the possible risks and disadvantages of taking part?

It is possible that people may feel uncomfortable talking to the researcher, to try and minimise this feeling no sensitive topic will be discussed in the interviews, but if you would not like to answer a specific question or talk about a specific topic then you do not have to.

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Although there are no direct benefits to you, you taking part in the interview is greatly appreciated and shall help us to understand what life is like in hospice. The results of the study may help contribute to improving the atmosphere of hospice and improve the wellbeing of the patients that use these types of hospice in the future.

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### What if I do not want to be interviewed or stop the interview early?

It is completely optional and voluntary if you want to take part in the interview or not. If you do not want to take part then that is fine and there will be no negative consequences. It will have no effect on any services provided to the patients or employment of anyone at this hospice. If you wish, you can also stop the interview at any time and do not have to give a reason why. You can also take a break during the interview and it can be continued after the break

### What if there is a problem and I wish to make a complaint or leave the study?

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Tel: 01603 593630



## Consent Form

### Interview

**Title of Project:** The relationship between the social life of older people and the atmosphere of different care settings.

**Researcher:** Michael Woodward

**Email address:** [M.Woodward@uea.ac.uk](mailto:M.Woodward@uea.ac.uk)

Please initial each box

1. I confirm that I have read and understand the information sheet (Version 3: 20/07/15) for the above study.
2. I have had the opportunity to consider the information, ask questions and have these answered satisfactorily.
3. I understand that my participation is voluntary and that I am free to withdraw from the interview at any time without giving any reason.
4. I understand that no identifying information taken from the interviews will be used in any report or publication that the study may produce.
5. I understand that the interview will be recorded and agree to take part in the interview.

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

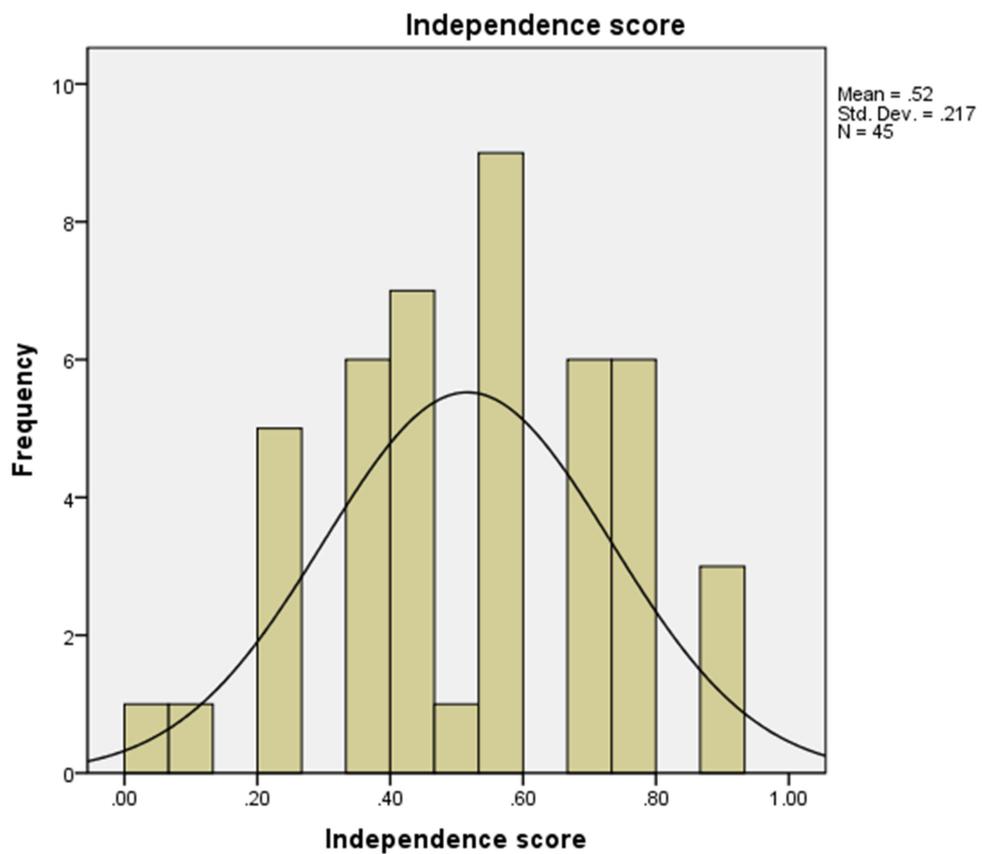
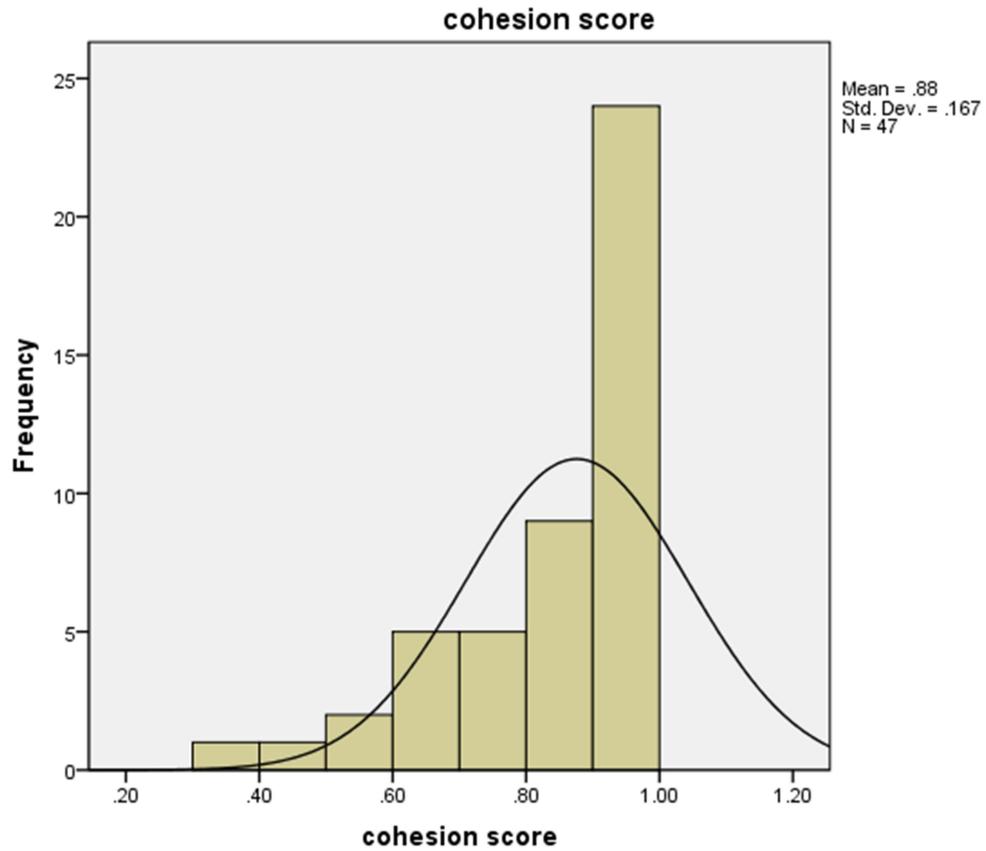
\_\_\_\_\_  
Name of Researcher

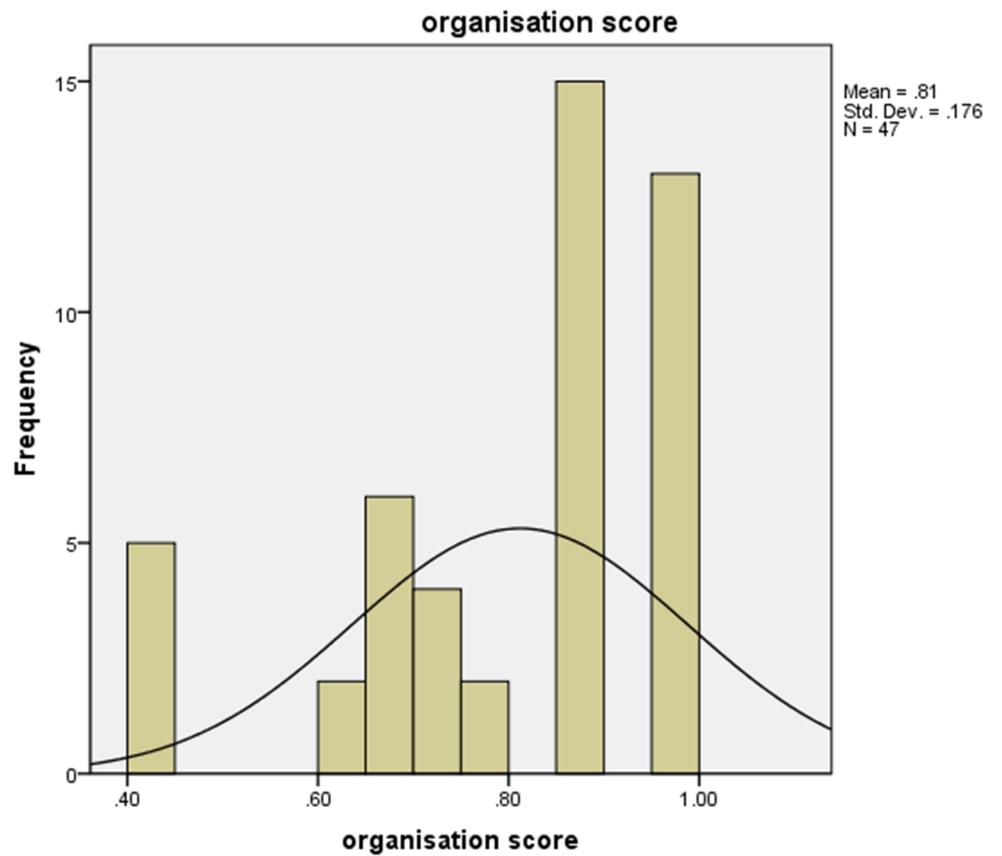
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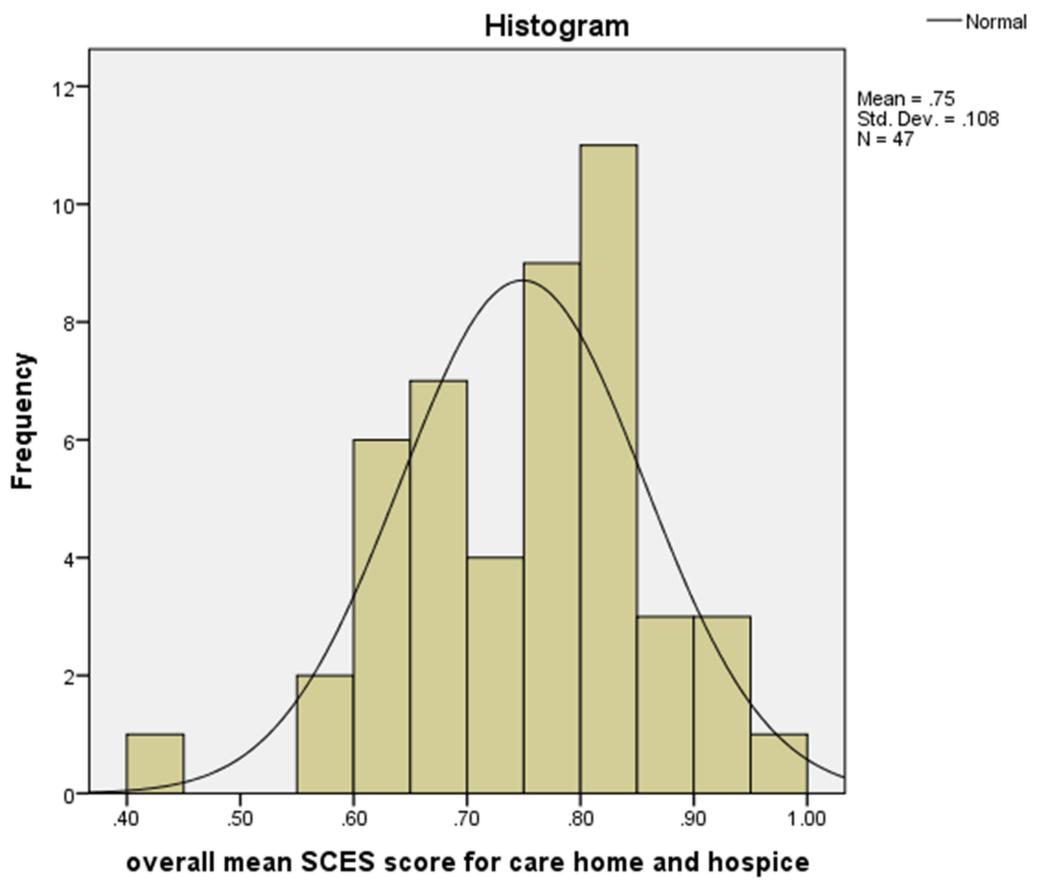
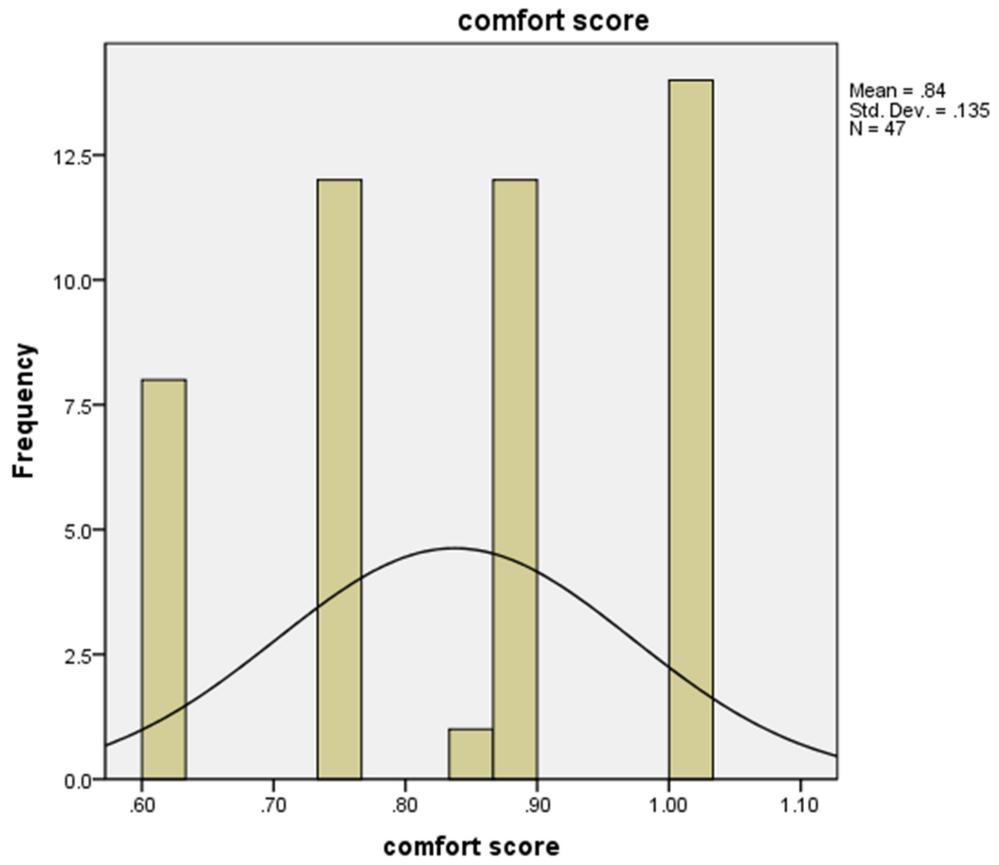
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Signature

## Appendix XX

Sheltered Care Environment Scale results – assumptions for normality

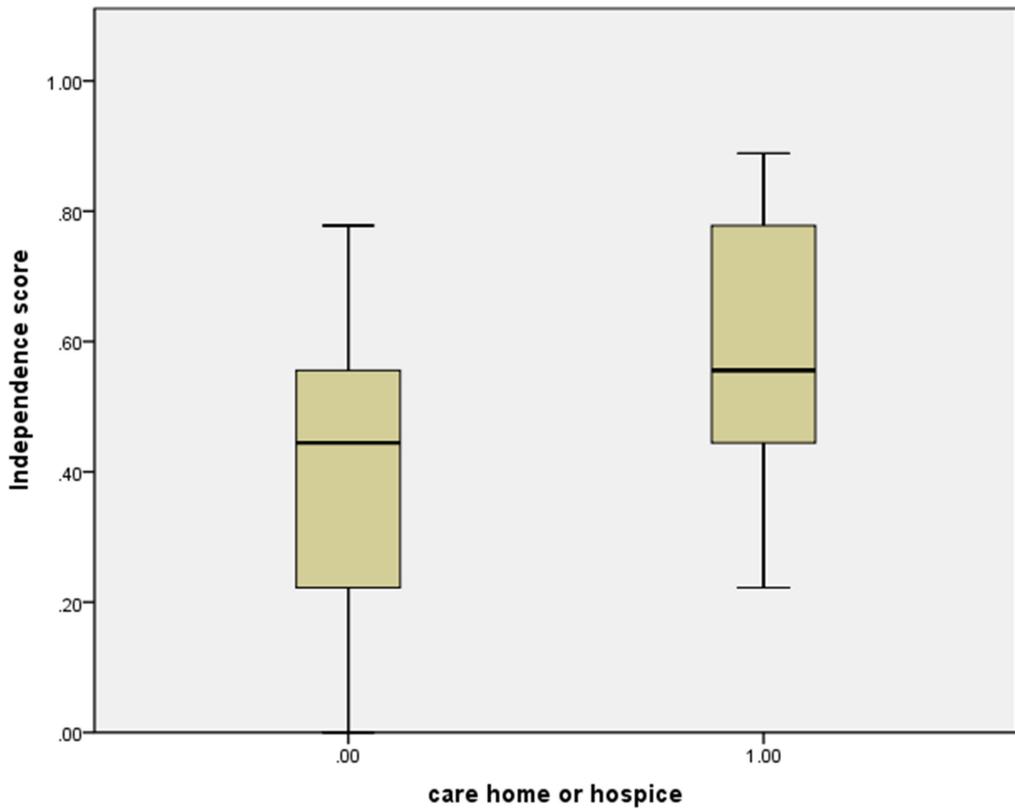
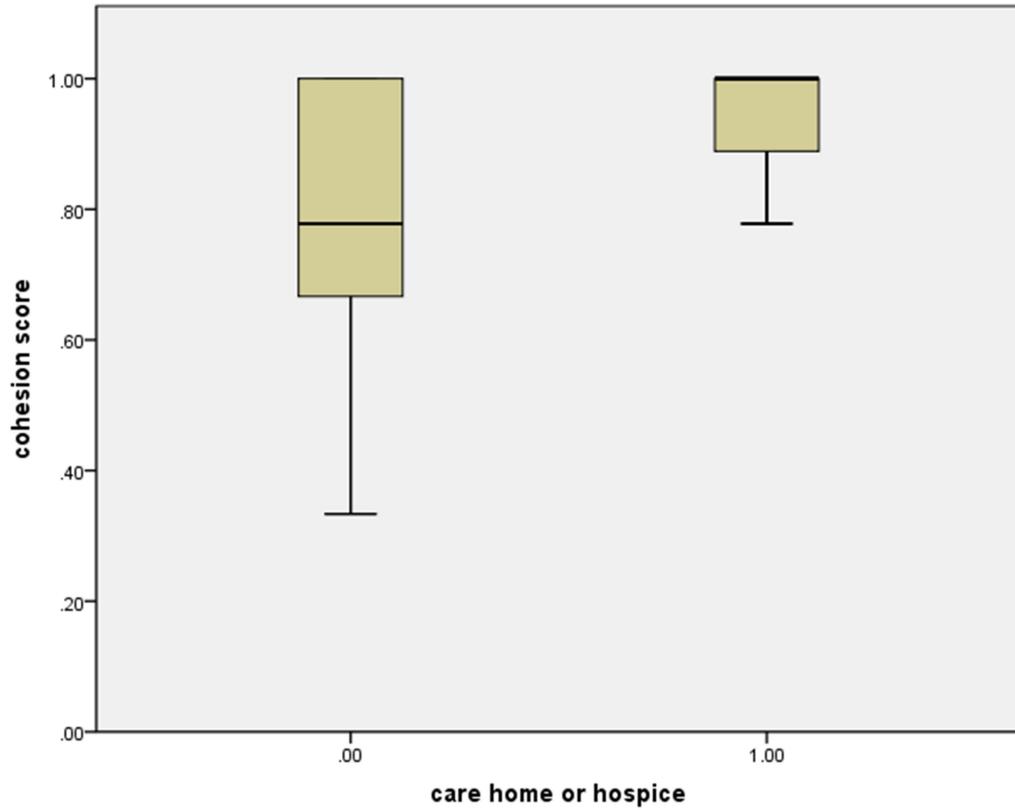


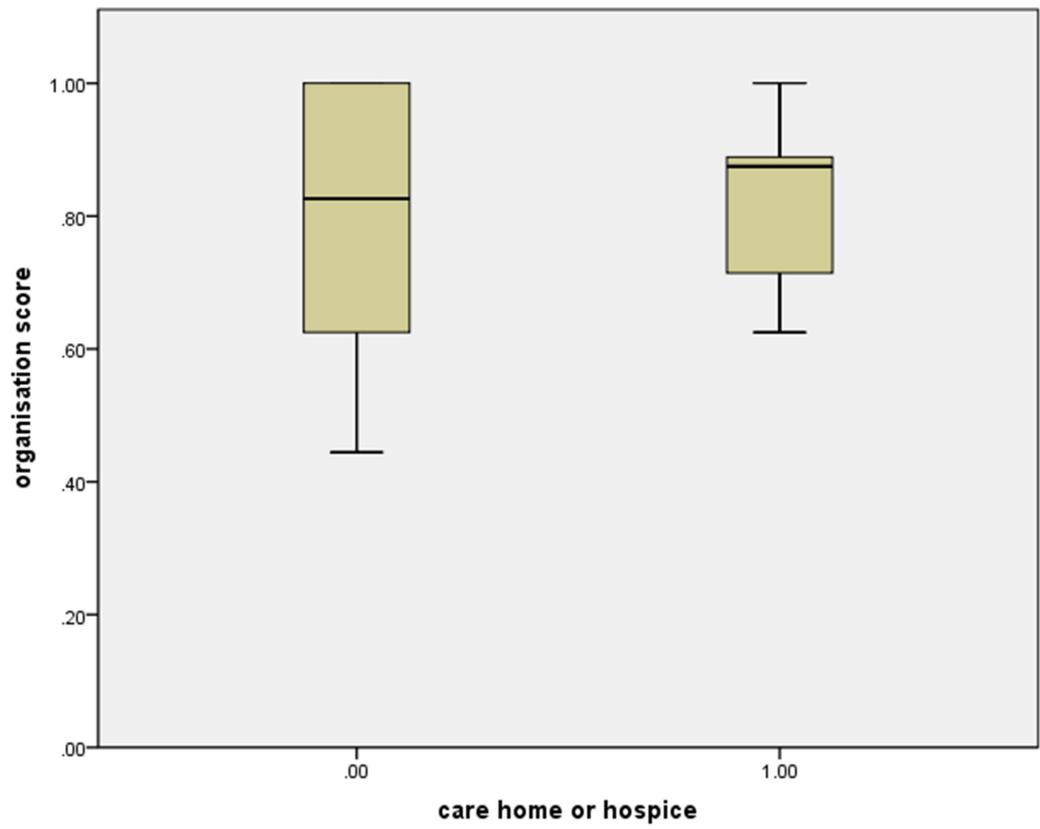
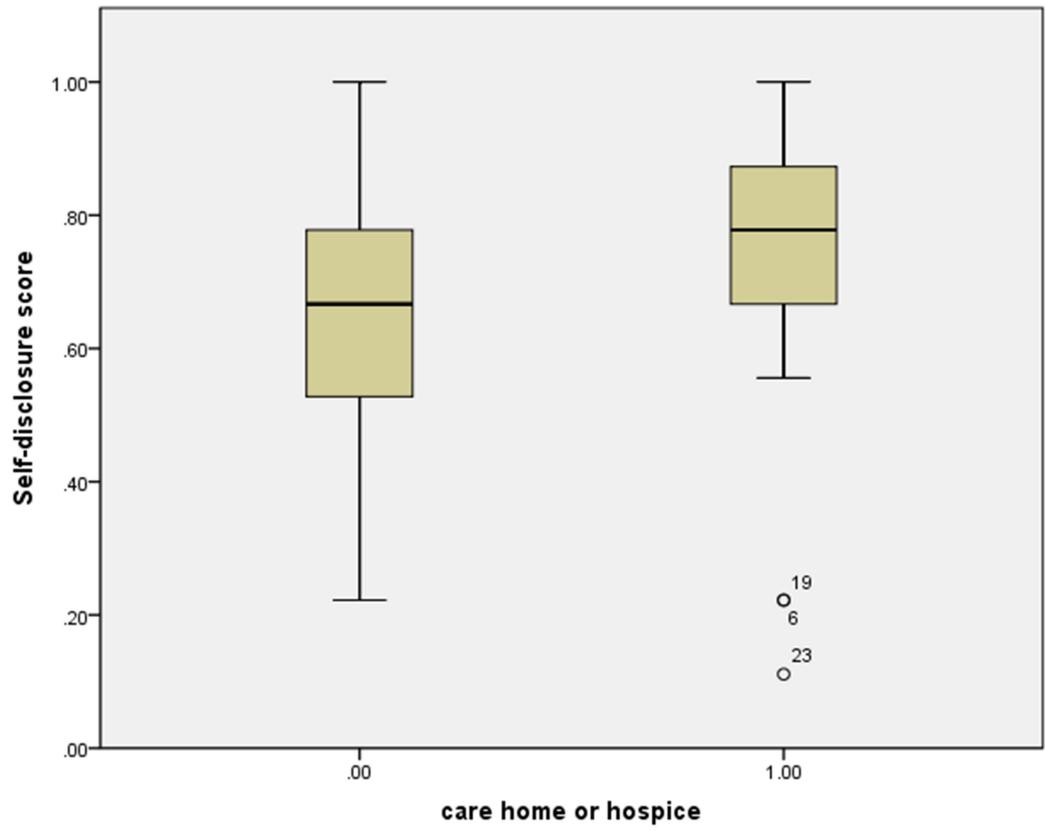


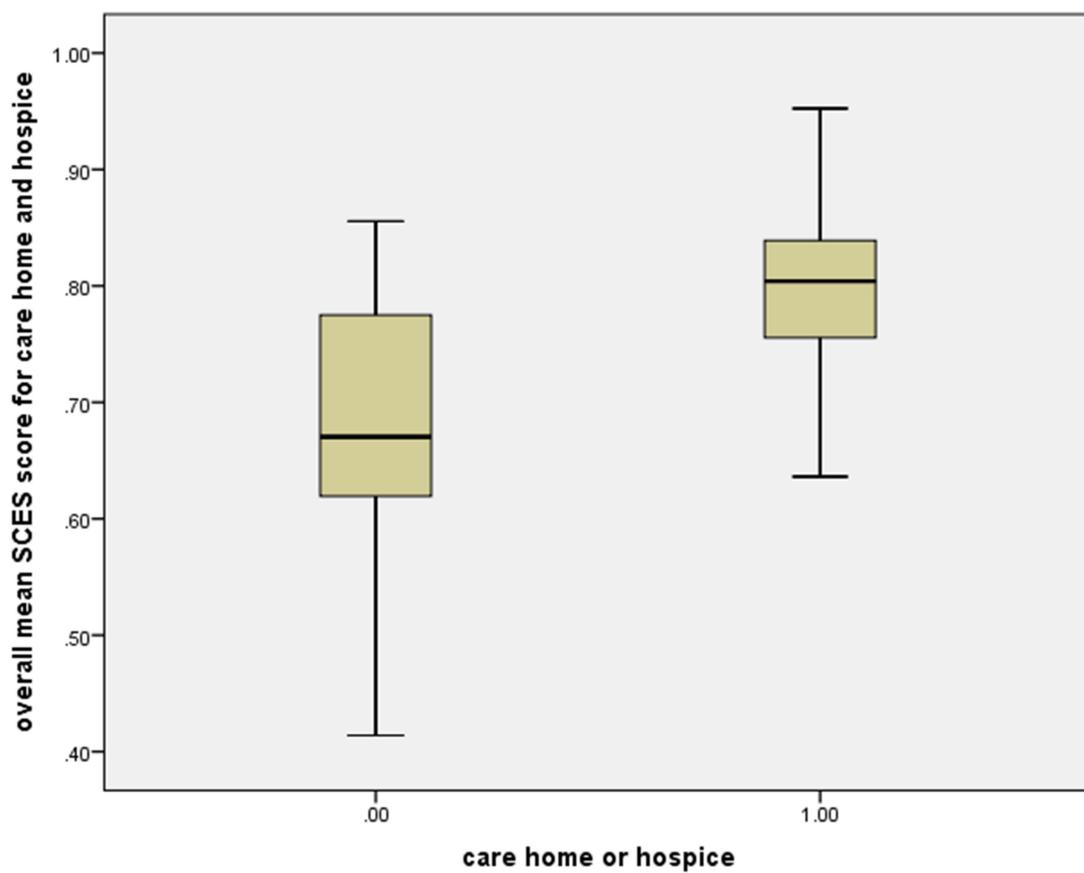
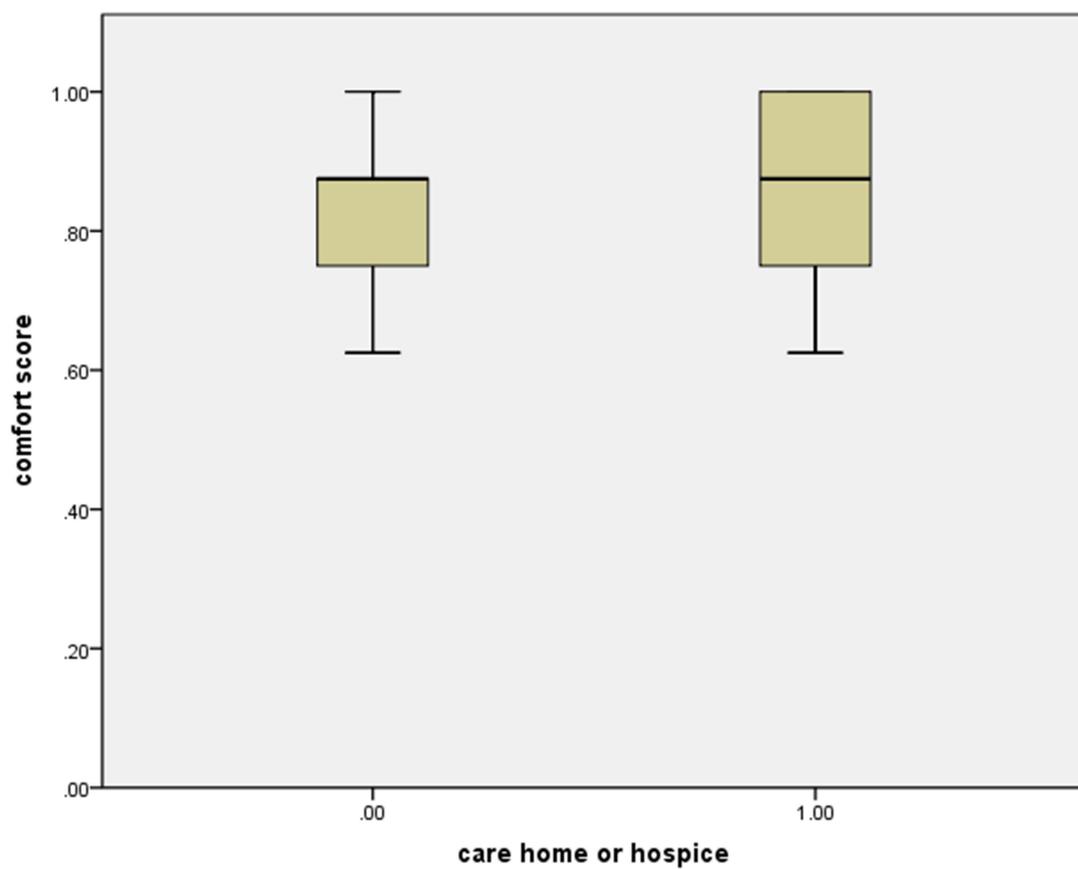


## Appendix XXI

Sheltered Care Environment Scale – assumptions for homogeneity of variance







## Appendix XXII

Coded transcript produced in NVivo 11.



*[Transcriber's note: the quality of the recording meant that the interviewer was difficult to hear at times.]*

**Interviewer**  
So the first section is about volunteers, and so, from your perspective, kind of how many volunteers do you see when you come in here and how many do you work with in the day centre?

**Respondent**  
I work with three volunteers in the day centre, but there's other volunteers that take part. There's a volunteer physio, who's a qualified physio, but she's a volunteer.

**Interviewer**  
Does volunteer work. Oh, wow.

**Respondent**  
Yeah.

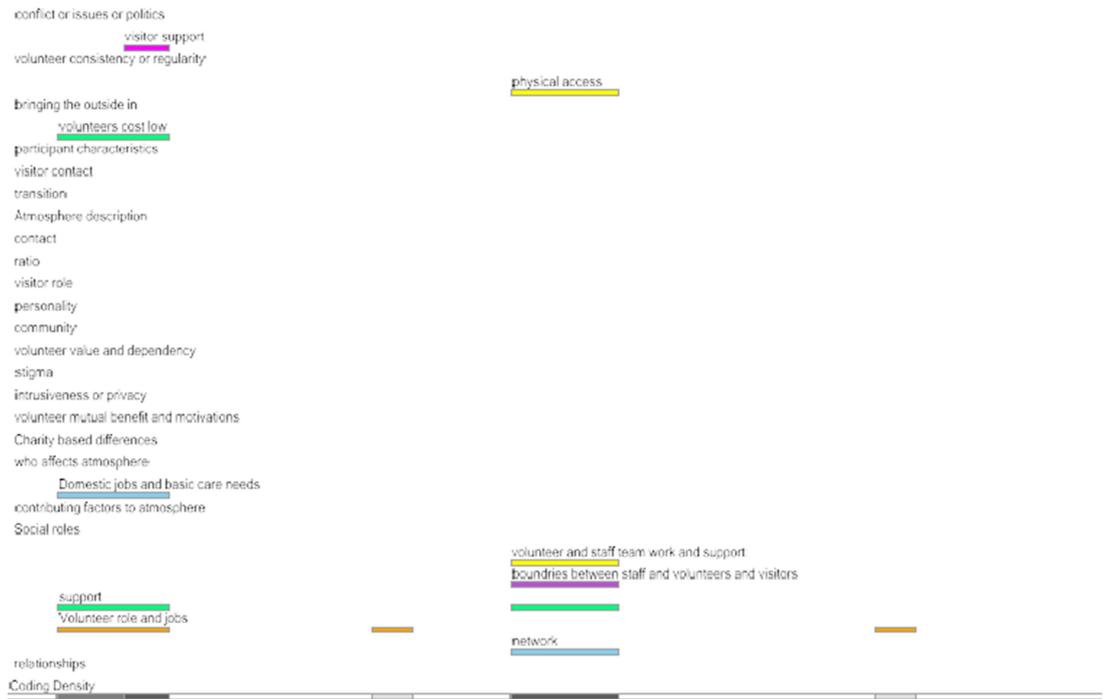
**Interviewer**  
That's quite good.

**Respondent**  
And obviously you – throughout the hospice you meet other volunteers in different roles.

**Interviewer**  
Yeah. And so they do a lot, then – lots of different roles.

**Respondent**  
There's a whole variety within the hospice. There is people like myself who come in just to help and socialise with the patients. As I said, there's a physio there. You have volunteers on the ward. In the offices you have a number of volunteers. The lady you meet at the desk when you come in is a volunteer.

**Interviewer**  
Oh, right.



**Respondent**

Yeah. I also come into contact with – we've got a small army of volunteer drivers, who transport patients from home to here and back, or maybe to hospital appointments or whatever, and one of the volunteers who is a volunteer driver, Tim, him and I co-facilitate a men's support group, which is for men who are terminally ill or they care for their loved one or they're bereaved. So we meet for a couple of hours every two weeks, it is. And that's been going for about two years, now. So Tim helps there, and then there's another chap, David, who he acts as a kind of stand-in. If Tim or I are ill or can't come, he comes. But he's started to come every second meeting now, so that he's in touch and gets to know the actual participants.

**Interviewer**

That's good.

**Respondent**

And even in the kitchen you've got volunteers.

**Interviewer**

Wow, so they really are everywhere, then.

**Respondent**

Yeah. And my wife, she's got advanced multiple sclerosis, so she's virtually paralysed from the waist down. But, despite that – she's in an electric wheelchair and can do very little physical, but she comes in every second Monday onto the ward in the evening and (she's done the counselling course here) she goes and counsels – chats to the patients in the ward.

**Interviewer**

That's really good.

**Respondent**

And she also sits on – what do they call it? Users Advisory Committee. She sits on that, as well.

**Interviewer**

Oh, wow, so....

**Respondent**

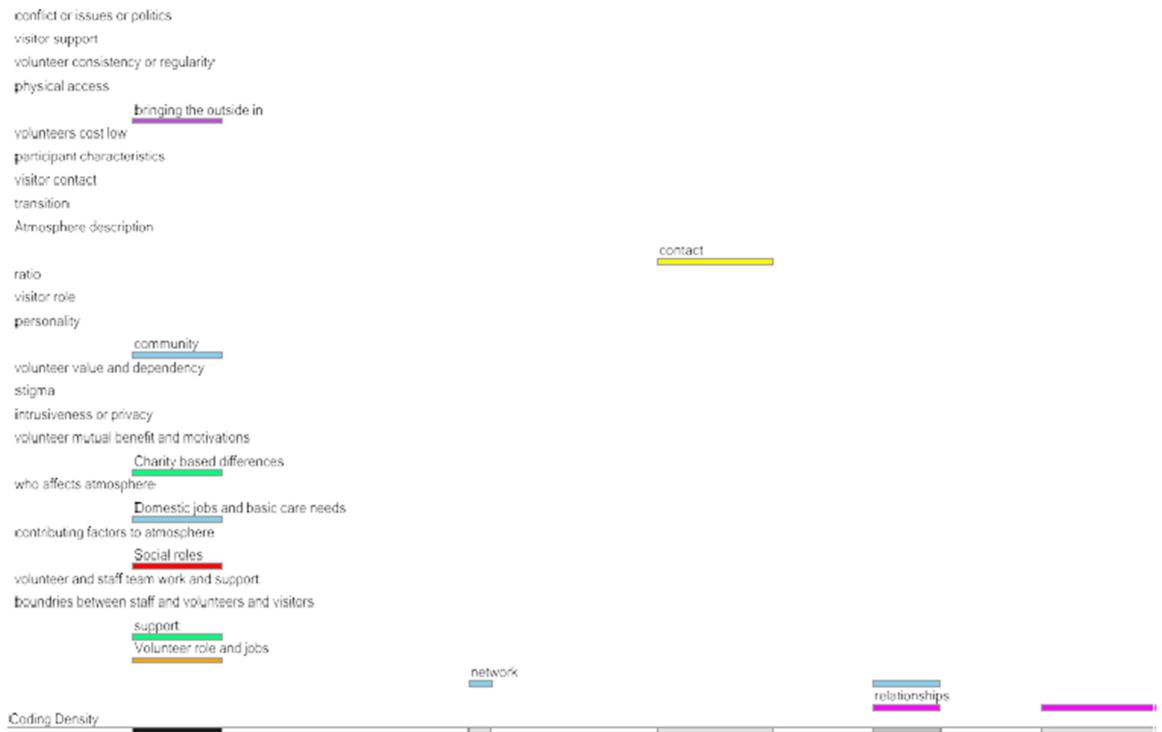
So there's a huge variety. The gardens are maintained by volunteers.

**Interviewer**

So they take part in just about everything, then.

**Respondent**

And, of course, outside the hospice you've got the Hospice Visitors. Do you know about that?



**Interviewer**

No.

**Respondent**

Again, it's a large group of volunteers who go into people's homes and they'll either take them out, just socialise with them and chat or maybe do a little bit of gardening or whatever for a couple of hours every week.

**Interviewer**

That's fantastic.

**Respondent**

Yeah. And they're all volunteers.

**Interviewer**

Oh, wow.

**Respondent**

My wife has one lady who comes to her, because my wife's on the books here as a patient, also, and that's been going for about three years. And I drive a wheelchair-accessible vehicle with a ramp, and the lady that visits my wife, very often I'll drive my wife in here, on a Wednesday, she'll take my wife out in the car and they go shopping and spend a bloody fortune, excuse my language.

**Interviewer**

Fine. That's always the way, isn't it? Typical. That's what my wife's like – goes shopping. So do you have a lot of contact, then, with all the other volunteers? Do you see them a lot?

**Respondent**

I mainly see them on a Wednesday or when I come in to run my men's group.

**Interviewer**

Yeah.

**Respondent**

Howard, the chap with the little dog, he's become a friend, so on occasions he comes round to our house for tea with his wife.

**Interviewer**

Oh, that's nice.

**Respondent**

And, yeah, there's one or two of them that, you know, we're not friend-friends but we socialise on occasions.



**Interviewer**  
That's good. So what do you like most, then, about having volunteers around you or being a volunteer?

**Respondent**  
Being a volunteer?

**Interviewer**  
Yeah. What do you like most?

**Respondent**  
Well, to explain it: you have to have an interview to become a volunteer, and I had never been in a hospice in my life, and when I came up to the front door, I thought, 'Oh, dear, have I made a mistake? This is going to be so depressing.' I walked in the door; all I could hear was laughter. People chatting. And I've been doing it for five and a half years, now, and I did it basically because I wanted to help. I've got a background in social work...nursing...and that...I actually do it for selfish reasons now because I get so much out of it. Much more than I give.

**Interviewer**  
So very rewarding.

**Respondent**  
And it is very rewarding, and it's very sad at times. Because of the nature of the place, people become very ill and they die, and you can't help but get attached to people, especially with people – I've known some patients for a number of years now.

**Interviewer**  
Yeah, got quite good relationships, I imagine. Yeah.

**Respondent**  
And one thing that I have often thought is – as I said, I've got a background in social work and nursing and I think now – I think, 'I wish I'd done this years ago.' And then I have to say to myself, 'No, you weren't ready for it.' Because it's totally different from anything else I've ever done.

**Interviewer**  
Yeah, I can imagine. [0:07:58] kind of prepare yourself for coming in, with all the nature of the place and things, so....

**Respondent**  
Yes.

**Interviewer**  
So....

**Respondent**

And it's a joy to see – lots of people who are terminally ill have a very isolated life, and it's a joy to see them come in here and they're quite withdrawn, and within about two or three weeks, they're chatting away and laughing.

**Interviewer**  
That's nice, yeah.

**Respondent**  
Very often they take each other's phone numbers and, you know, become friends.

**Interviewer**  
Oh, and build up relationship then with each other, as well.

**Respondent**  
Mm.

**Interviewer**  
That's good. So is there anything you don't like about being a volunteer or the volunteers do around here? Can't think of anything?

**Respondent**  
Um. [Pause] I know that some volunteers feel that...how can I put it? There's a 'them and us' culture. You know, there's staff and volunteers. And because of the confidentiality policies, some people feel they could be given more information. But, then again, it's confidential.

**Interviewer**  
Yeah.

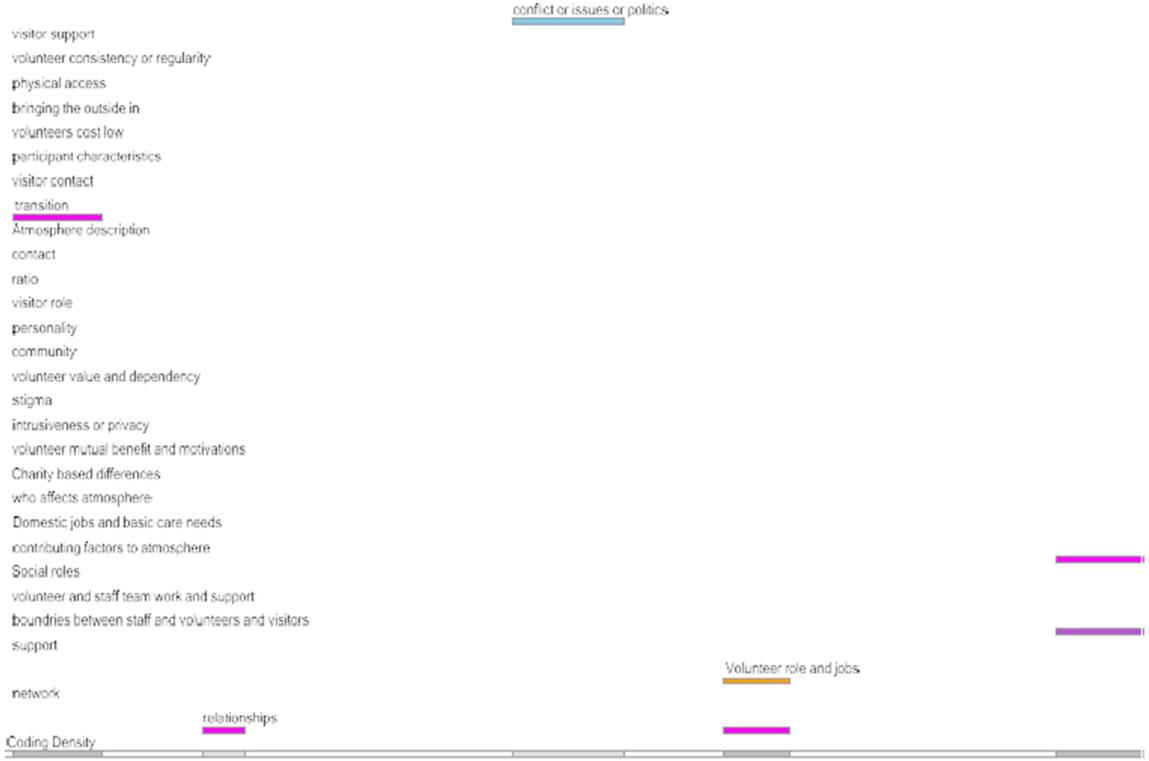
**Respondent**  
And most of the things that I learn about people's lives, they themselves tell me. They tell me what their illness is, how they cope with home, or relationships at the moment, etcetera.

**Interviewer**  
That's nice, then. Yeah, if they can be quite open and talk to you about things.

**Respondent**  
Oh, yeah.

**Interviewer**  
That's good. Well, what do you think volunteers bring to the atmosphere of the place and why? What do they do for it?

**Respondent**  
I think because we're not employed, we don't have to work within strict guidelines.



conflict or issues or politics				
visitor support				
volunteer consistency or regularity				
physical access				
bringing the outside in				
volunteers cost low				
participant characteristics				
visitor contact				
transition				
Atmosphere description				
contact				
ratio				
visitor role				
personality				
community				
volunteer value and dependency				
stigma				
intrusiveness or privacy				
volunteer mutual benefit and motivations				
Charity based differences				
who affects atmosphere				
Domestic jobs and basic care needs				
contributing factors to atmosphere				
Social roles				
boundaries between staff and volunteers and visitors				volunteer and staff team work and support
support				
Volunteer role and jobs				
network				
relationships				
Coding Density				

**Interviewer**  
Yeah.

**Respondent**  
So we can be ourselves. Laugh and joke with people or sit and counsel them when they're very sad and down. So I think we bring an air of informality and... because we don't have a title like 'nurse' or 'doctor' or whatever, people, I find, are more open.

**Interviewer**  
That's good, then, yeah. Build up a better relationship.

**Respondent**  
Yeah.

**Interviewer**  
That's nice. So can you think of an example, then, of how volunteers contribute to, like, the social life of the place? Like, running quizzes and things like that? Do they – so the social life—?

**Respondent**  
Well, you'll hear a dreadful quiz in the next half hour.

**Interviewer**  
[Laughing]

**Respondent**  
That Malcolm, who's a volunteer. He's also a trustee, and he's the only trustee I've ever met who works at the coal face. You'll find him (probably just finished now) washing dishes in there. And he does all manner of things in the hospice.

**Interviewer**  
Yeah, so it's – the volunteers have quite a big impact on the social life of patients while they're here.

**Respondent**  
Yeah. Yeah. I think we also, to a certain extent, free the staff to do other things.

**Interviewer**  
Yeah.

**Respondent**  
Cause one of the policies [0:12:11] here is that there should always be a volunteer or a member of staff in the room all the time. So if they have to attend a meeting or they have to attend to something clinical, the volunteers can take over. And I think especially in the last year, the management changed the contracts of the staff so they could actually – do more than one job. They could perhaps work in the ward and then go out into the community, or they

conflict or issues or politics  
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 personality  
  
 volunteer value and dependency  
 stigma  
 intrusiveness or privacy  
 volunteer mutual benefit and motivations  
 Charity based differences  
 who affects atmosphere  
 Domestic jobs and basic care needs  
 contributing factors to atmosphere  
 Social roles  
 volunteer and staff team work and support  
 boundaries between staff and volunteers and visitors  
 support  
 Volunteer role and jobs

visitor role  
 community

network  
 relationships

Coding Density

can go down to the new centre in [Haberhill - 0:13:06] and do something down there. So they're not restricted to just one ward. So it does free them.

**Interviewer**

Yeah. Have a bit of flexibility.

**Respondent**

Yeah.

**Interviewer**

Yeah, that's good. The next few questions are about - 'cause it's - that can be basically anyone who's not a volunteer or employed in the hospice. It can be family members, it can be... like if people come in for charity events. Like someone told me there was a football team here a while ago.

**Respondent**

Yeah, Ipswich.

**Interviewer**

Yeah. So are there a lot of visitors here, then? Like, do people get a lot of visitors, like, coming in and out?

**Respondent**

Um. [Pause] From outside of the hospice, not a lot. Not, at least, in the day centre. You have people who, perhaps, are doing their nursing course, who come and do a day in each department, but as far as visiting's concerned, no, we don't have a lot of visitors come round. Sometimes people are shown round. Prospective clients, or perhaps someone who's involved in the community - say a vicar or something like that - will come round.

**Interviewer**

Right.

**Respondent**

And of course we've got our own chaplains, who are in and out all the time and they do a wonderful job, and very often, unfortunately, they've got to know people but people die, and they very often conduct funerals and hold memorial services actually within the hospice.

**Interviewer**

Yeah. Well, yeah, they'd build up a relationship, as well, with....

**Respondent**

Yeah.

**Interviewer**

That's good. So what would you say is the most common people who visit, then? If you can think of one. Would it be family members or just external people?

**Respondent**



**A mixture.**

**Interviewer**  
Yeah. That's good.

**Respondent**  
When you say 'visitors', very often... a family member will drive a patient into, say, the day centre, and pick them up, and they tend to stop and have a cup of tea and a chat, and you get to know them, as well, which I think is quite important.

**Interviewer**  
Yes.

**Respondent**  
But, apart from people being shown round and people like the football club that came, I don't think we have a lot. One of the big parts with social life of patients is on Mondays, and they have a drop-in session. People come and they have coffee and tea and they are quite a few volunteers do that. And some volunteers, you know, do counselling and all sorts of things.

**Interviewer**  
So they kind of help out every way, then.

**Respondent**  
Yeah. There's several hundred volunteers.

**Interviewer**  
Yeah. Somebody said there were around—

**Respondent**  
You know, in the shops, for instance – charity shops.

**Interviewer**  
That's good, then. So... when visitors come in, then, and any groups, do you have a lot of contact with them or is it just kind of you see them in passing?

**Respondent**  
I tend to – I'm terrible in my way. If someone wanders in, I'll go and introduce myself, say, 'Come on in and sit down and have a chat to the patients and have a cup of tea.' I almost drag them in.

[Laughter]

**Interviewer**  
That's good, I suppose, in a way, yeah.

**Respondent**  
Yeah.

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Charity based differences

Domestic jobs and basic care needs

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volunteer and staff team work and support  
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who affects atmosphere

contributing factors to atmosphere

**Interviewer**

Yeah, nice. I suppose that makes it kind of like nice and friendly and welcoming.

**Respondent**

Yeah. Mm. And especially if relatives are coming to look round with a view to their family member coming, you've already made that contact. And they can say to the their relative that's going to come in, 'I met this idiot called John. You'll like him.'

[Laughter]

**Interviewer**

Well, yeah, kind of build up that relationship before they even come.

**Respondent**

Yeah.

**Interviewer**

That's really good. So when visitors come, do you think they bring anything to the atmosphere?

**Respondent**

Well, if it's a group like, say, the Ipswich Football Club, obviously that's quite an occasion for some of the residents – not 'residents', some of the patients, especially those who are unfortunate enough to support the team.

**Interviewer**

Oh, yeah. [0:18:39] Ipswich Football Club, yeah.

**Respondent**

But patients love to see people coming in.

**Interviewer**

Yeah.

**Respondent**

And especially if they stay and sit down and have a chat and a cup of tea.

**Interviewer**

Yeah. Somebody else to talk to, I suppose.

**Respondent**

Mm.

**Interviewer**

Yeah. That's good. The last few questions, then, are just about kind of the atmosphere in general. So how would you describe the atmosphere?



**Respondent**

Uplifting. Very supportive. As I said before, you watch patients come in and, in a very short space of time, they become themselves and they come out of their shell. So I would say it's quite a easy-going atmosphere. It's supportive. And the patients care about each other. There's one man in here at the moment who's having a bad day, and several other patients have said that they're worried about him, asking him if he's OK.

**Interviewer**

So, yeah, do you think anything can happen that changes the atmosphere or is it pretty stable?

**Respondent**

What do you mean?

**Interviewer**

Can anything make it better or worse, that you've seen, or does it stay the same all the time – the atmosphere?

**Respondent**

Well, obviously people only come for six-week sessions, and then there's a break, and then they may come back for another few sessions, so it's an ever-changing collection/clientele, all with their different personalities. So it does change, according to the people that are coming. One of the good things about here is you've got staff who have been long serving in the day centre, and the volunteers that we have here at the moment on a Wednesday have been here for several years, so we've become a team, and I think that's very important.

**Interviewer**

Yeah.

**Respondent**

And I think... you need to become a team and you all know each other's roles and....

**Interviewer**

Work together for [0:21:49].

**Respondent**

Everyone knows what to do and they know each other.

**Interviewer**

Yeah, that's good. Do you think, then, volunteers and visitors, when they come, have a lot of influence over the atmosphere, then?

**Respondent**

Yeah. Yeah. I think so. Things that do alter the atmosphere obviously is things like deaths. You know, we have a patient who – I've seen a couple of patients who actually would die while they're here, and that's very upsetting for everyone.

**Interviewer**  
Yeah. I can imagine, yeah. So who would you say would have the biggest influence over the atmosphere? Would it be volunteers or staff members or the patients themselves or...?

**Respondent**  
I'm not trying to dodge that question, but I see a combination.

**Interviewer**  
Yeah, that's fine. That's a perfect answer. Yeah. So it takes kind of everybody to make it what it is.

**Respondent**  
Mm.

**Interviewer**  
Yeah. That's really good. And, overall, do you think more volunteers/more visitors would be a good thing or a bad thing, or is it about right?

**Respondent**  
I think it's OK. I think we've got a good balance at the moment.

**Interviewer**  
Yeah. That's good. Kind of...imagine if there was any more it would get kind of crowded and busy and....

**Respondent**  
Yeah, and I think if there's too many staff or volunteers in a room like this, you know, people feel overcrowded and, you know, sometimes you can give too much care. Someone's just wanting to relax and read the paper or something, and then people are constantly coming up and saying, 'Would you like your feet up? Want a glass of water? Blah, blah, blah, blah, blah.' And they think, 'Just go away and leave me in peace!'

**Interviewer**  
Yeah. [0:23:54] peace and quiet. Yeah.

**Respondent**  
Mm.

**Interviewer**  
That's really interesting. I think that's it for what I've got to say.

**Respondent**  
That it?

**Interviewer**  
Yeah. Is there anything else you want to say like the atmosphere or volunteers or anything?

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Charity based differences  
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Domestic jobs and basic care needs  
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Social roles  
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**Respondent**

No, I think we've covered it all, really.

**Interviewer**

Yeah. It's very nice. There's always something going on. There's always activities and things.

**Respondent**

Mm, and for me as a volunteer, every time I come into this hospice, my mood comes up. It's a beautiful place to work. I wouldn't call it 'work', really. It's a beautiful place to be part of, and I've met some wonderful people. And one thing that always strikes me is we have people who have been captains of industry – I mean patients; others who have been humble labourers or just mums or whatever, and what happens is, people drop the mask. They cease to become a business magnate and they become themselves, and a very common thing, especially from people who have been very successful in their lives and now they're terminally ill, is they say, 'John, the only thing that matters in this life is love. The rest is rubbish.'

**Interviewer**

That's nice, yeah.

**Respondent**

And that's a wonderful teaching.

**Interviewer**

Yeah. That's really good. Thank you very much.

**Respondent**

That it? Do you want a cup of tea or anything?

**END OF RECORDING**

## Appendix XXIII

Concept maps of themes produced in NVivo 11.

